DISABILITY AND CITIZENSHIP:
AN EMANCIPATORY STUDY OF PROFESSIONALS' ATTITUDES TO DISABLED PEOPLE.

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by

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ABSTRACT

The research described in this thesis had two main aims. First, to examine the concept of citizenship and to develop it in relation to the experiences of disabled people. Secondly, and of equal importance, to test an emancipatory methodology within an academic doctoral context. The empirical work supporting the first aim consisted of 30 interviews with 'professionals' to assess their attitudes towards disabled people. The analysis of these interviews showed how professionals' views were linked to concepts of citizenship, specifically those of moral rights, attitudes, difference, consumerism and risk.

The emancipatory model within which the research was conducted involved an Advisory Group of disabled people who contributed to the planning and guiding of the research and the analysis of the data. A significant part of the thesis discusses the ethical and methodological issues of 'ownership' of the research in terms of the tension between the writer of the thesis gaining an academic qualification (PhD) and the use of emancipatory methods in research. It also shows how the development of the concepts relating to citizenship arising from the analytical process was influenced by the input of the Advisory Group. One additional outcome of carrying out research in this paradigm was the production of an accessible report, with suggested points for action, to provide a product of relevance to those who took part in the research (see appendix). The conclusions to the thesis assess the extent to which the methodology was of an emancipatory nature and propose a development of the citizenship model.

INTRODUCTION

This thesis examines the concept of citizenship in relation to the experiences of disabled people. Much of it is written in the first person (eg. 'I' did this...'I' found that...). This creates a more informal style than is used in much academic writing although this form is frequently used in feminist research (such as Lather, 1987, Ribbens, 1990). However, by writing mainly in the first person, I am following a deliberate path of action that reflects the emancipatory model of the research. The emancipatory methodology used (which is described in more detail in chapter 2) focuses on the need to make research more relevant and meaningful to those it attempts to study and to recognise the role of the researcher in the process (Oliver, 1992). Hence, it is also a recognition of being part of a 'political' struggle of the self-empowerment of traditionally oppressed groups of people. By writing in a more personalised style, my aim is to be a narrator of the 'story' of the disabled people in this study and to acknowledge the reflexive nature of the research process. Within the thesis the speech of the Advisory Group of disabled people will be put in italics to distinguish it from other quotes. The Advisory Group had an important voice in the methodological process and the analysis and I would like to emphasise that voice in the written word.

Agreement over preferred and accepted terminology in relation to disability changes over time and in relation to different contexts. The present study began in 1995 and was finally completed in 2002, during which time, there were differences of opinion within the disabled community and differences between the academic community and the non-academic community as to what terminology to use. Throughout the thesis I will use both the term ‘disabled people’ and ‘people with disabilities’. Within academic literature (Oliver, 1990) the term ‘disabled people’ is usually used, partly to accentuate the political nature of disability as an identity. However, it has also been argued (particularly among people with learning difficulties) that the term ‘people with disabilities’ should be used to emphasise that disabled people are people first (Northfield, 2001). Within the present study, the Advisory Group of disabled people , who were active participants in the research process, expressed their acceptance of both terms, thus both terms were used.

Biographical Background

This thesis describes a research project which looked at disability and citizenship using an emancipatory methodology. The research was specifically asking welfare professionals and retail/ leisure managers the extent to which they perceived disabled people as citizens. The focus of enquiry for the research emerged from an experiential, a professional and a policy starting point. The reflexive requirement of the emancipatory paradigm suggests such biographical data (or 'intellectual autobiography' as Stanley and Wise, 1993, p. 177-178 call it) should be outlined.

My own journey into research around disability issues began in 1993 when I worked for 3 months as a 'personal assistant' to a disabled student (whom I shall call 'Sally') as part of an Independent Living Scheme in the South of England. My shifts involved spending 48 hours at a time with Sally, helping her with personal and household tasks and driving for her. This experience gave me an enormous insight into her world, and therefore, a greater understanding of issues facing disabled people.

I came to understand that, clearly, her choices were limited by the system created and structured by a non-disabled majority. As a wheelchair user, she could only access one particular bank because it was the only one with a low enough cash machine. She could not use public transport. She would often eat at McDonalds because it had accessible toilets. She would often be ignored by shop assistants who, frequently, would talk to Sally's non-disabled friends rather than her. She had the humiliation of being asked very intimate, personal questions about her daily activities as part of a Disability Living Allowance assessment. She couldn't use certain shops because the only access was via a step.

This experience became instrumental in my choice of subsequent career as a social worker since I had been particularly struck by both the physical and attitudinal barriers faced by Sally in her daily life.

Following this experience, I trained as a social worker specialising in Community Care and disability. I then worked as a specialist social worker in disability in a Social Services department, followed by further jobs in the Voluntary Sector, working with both people having either a physical impairment or a learning difficulty. The nature of the work I pursued tended to focus on promoting rights and independence for disabled people (eg. training schemes/ work experience and advocacy work with disabled people). I also worked as a voluntary advisor on the management committee of an organisation run by and for disabled people. My most recent post as development worker at Hull Council for Voluntary Service, focuses on influencing policy-makers to take into account the views of the Voluntary and Community sector. Although this is a sideways move from working with disabled people, the focus of the job is still around rights and independence for those perceived as experiencing a relative lack of power.

In 1995, I began this PhD in Social Policy on a part-time basis in conjunction with part-time, paid work with disabled people. The Disability Discrimination Act (1995) had recently become law and its implementation was to be staged over a number of years. The disabled people with whom I had contact both as a professional and on a personal level tended to be apprehensive about the potential effectiveness of the Disability Discrimination Act. Their experiences had generally been on the receiving end of oppressive practices and negative attitudes, particularly from professional workers in the welfare professions (eg. social workers/ doctors/ nurses) and they did not feel that the new legislation would be particularly effective in changing attitudes and practices. Before 1995, there had been no legislation in the UK that focused on the discrimination of disabled people, and experiences of discrimination were widespread (Barnes, 1991), with no opportunity for legally fighting against such actions. Previous legislation (eg. the Chronically Sick and Disabled Person's Act (1970); Disabled Persons (Employment) Act (1958); Disabled Persons (Services, Consultation and Representation) Act (1986)) had focused mainly on the *provision of services* to people with impairments within a medical model which emphasised being 'looked after'.

It was within this context, therefore, that my focus of enquiry for the PhD research centred around disability and citizenship. Citizenship was a useful theoretical framework from which to explore the notion of rights and had been used by Lister (1997) in reference to women. My personal involvement in the disability community had given me an insight into the experiences of disabled people; my professional practice as a social worker, and later as a development worker in the Voluntary Sector, gave me an understanding of some of the structures and professional attitudes inherent in the services provided for disabled people; and the introduction of the Disability Discrimination Act in 1995 gave me a springboard for using it as a heuristic device on which to base a research project. I had considered the literature around disability, both in my social work training (my MA/ DipSW dissertation focused on An Empowerment Approach to Disability and Community Care) and my professional practice and I had become aware of the differences between the medical and social models of disability. My experiences and observation at the time indicated that politically active disabled people in the disability movement strove to focus on the social model, where environmental and attitudinal factors were seen as a crucial factor in the oppression of disabled people (Oliver, 1990), while many professionals in the 'welfare' services continued to apply a medical model of disability, where disabled people were seen as passive recipients of services and where their impairment was regarded as a personal 'problem' (Borsay, 1986).

My experience, training and professional practice in 1995, therefore, combined to recognise the tensions inherent in the power dynamics between disabled people and professionals. I was keen to explore this further within a structured research project. However, my concern was to validate the lived experiences of disabled people within the process, rather than to impose my own values and knowledge as a non-disabled person. Within this research, therefore, my use of an Advisory Group of disabled people was an essential and necessary part of the methodological process. By conducting the research in this way, I was attempting to address power imbalances between disabled people and non-disabled people; professionals and service users; researchers and the researched; and between lived experiences and theoretical knowledge. This created tensions within the academic setting of achieving a PhD in terms of ownership of the research. The methodology chapter constitutes a large and comprehensive part of this thesis because I have described the process and some of the ethical issues which became apparent during the research. I have also discussed the tensions between working with disabled people as co-researchers and achieving and 'owning' a PhD.

The research involved setting up and facilitating an Advisory Group of disabled people which guided and informed the research and which was involved in the process of the analysis of the data. It also involved undertaking 30 interviews with 'professionals', asking them about their attitudes to, and understanding of, disabled people and disability issues. The Advisory Group recommended potential professionals to interview and drew up the interview schedule. The interview questions were based around discussions of citizenship rights and the Disability Discrimination Act (1995). The Advisory Group also provided a preliminary analysis of the data and worked with me to develop and produce an 'accessible report'.

The members of the Advisory Group were recruited from disability agencies in the university city, whilst the interviews with professionals were undertaken outside the city in order to maintain confidentiality. Many of the individuals in the Advisory Group were known to me on either a personal or professional level. Having had a background as an ally in the disability movement, I felt that the relationships that I had already built up were helpful in enabling me to work in a positive way with disabled people. The methodology chapter will describe in greater detail the preparation, practicalities and process of working with the Advisory Group.

Although I experienced some difficulties in balancing the work, time and commitment required for undertaking PhD research with the demands of a social work based career, I feel that there have been advantages to undertaking research in this context. I have found that, within my professional practice in both Social Services and the Voluntary Sector, I have been able to use the theoretical knowledge concerning disability and citizenship in my practice: my professional practice continues, therefore, to be developed from a theoretical base. Furthermore, the research process has reinforced and developed social work skills in facilitating groups, carrying out interviews, and working with service users in an empowering way. It has added a constructive critical awareness of professional practice and helped me to develop an academic rigour towards my professional work.

In addition, my professional practice has influenced and enhanced my experience and understanding of the research process in that the research was not undertaken in an academic vacuum initiated purely through past research and literature: my personal and professional practice gave me a greater understanding of the lived experience of disabled people and of the importance of addressing power imbalances within the research community. My awareness of some of the issues arising from the interaction between disabled people and professionals helped me to focus the research at an early stage.

I feel that the experience of undertaking a PhD, of using an emancipatory methodology, and of my understanding and development of citizenship theories, continues to inform my present practice as a development worker in the Voluntary Sector. My present practice in the Voluntary Sector also continues to influence the context and priorities within which I undertake research.

Outline of chapters.

Chapter 1. Literature Review: Citizenship and Disability

In Chapter One, the literature review, I shall address first some of the literature around the Social Model of Disability (Oliver, 1990), and then move the focus to citizenship, particularly on Marshall's (1950) definition of citizenship and then consider further developments in citizenship theory. Marshall's (1950) tripartite model of citizenship was based on the elements of civil, political and social rights and also focused on the obligations of the state to protect and provide for those rights. This model was primarily relevant for the development of a discussion of rights in terms of *class* and Marshall describes how the 'upper' classes achieved rights first, followed by the 'middle' classes and finally the 'working' classes. However, it can be seen that, by focusing on *class*, Marshall did not recognise the exclusion of other marginalised groups from citizenship rights. In Chapter One, I shall review the literature on women and citizenship (Lister, 1997) and then the literature around disabled people and citizenship (Oliver, 1990). As a result I shall suggest that within the literature, disabled people are often seen to be excluded from full citizenship status in terms of access, attitudes and employment.

By drawing on the example of women and of disabled people, I shall show how theories of citizenship have developed from the rights based model of Marshall (1950) to encompass elements of exclusion, participation and membership.

The focus on citizenship will be used as both a theoretical and a methodological basis for the research. That is, the methodology will adopt an inclusive and participatory approach indicative of a comprehensive view of citizenship. This will therefore develop the existing debates on citizenship in relation to disabled people.

Chapter 2. Methodology: An emancipatory Approach

The research also has an exploratory methodological dimension that considers issues of power between the researcher and the researched. In Chapter Two, the Methodology chapter, I shall outline the salient features of an emancipatory research model and then will draw heavily on an example of emancipatory research by Tozer and Thornton (1995) who used an Advisory Group of *older people* to participate, guide and develop their research into Community Care issues. I shall also consider other research examples such as Kirby (1999), and Maguire (1993) who have used different styles of, what can be described as, 'emancipatory methods'. The methodology chapter will describe the present study, which involved setting up an Advisory Group of disabled people who were co-researchers in the research process rather than merely subjects. The role of the Advisory Group was to be active participants in the process, acting as a focus group for debate, contributing to the development of the research questions and sample design, providing the viewpoints of disabled people, analysing the interviews with the professionals, and guiding and controlling the research process. In the methodology chapter, I shall also describe the process of undertaking thirty interviews with professionals in which the interviewees were asked questions whose aim was to explore the extent to which disabled people were perceived as citizens. The interviews focused on issues relating to the Disability Discrimination Act (1995) which were defined by the Advisory Group and the interviews were then discussed and analysed by the Advisory Group in conjunction with myself. The interviews were undertaken outside the university city in order to maintain confidentiality. That is, if they were undertaken locally the members of the Advisory Group may have known some of the interviewees, and vice versa. When the interviews were transcribed they were also anonymised to further address confidentiality issues. The Advisory Group also contributed their own experiences and opinions, which were used to illuminate the concepts generated in the analysis of the interviews.

The research is sited in a social model of disability (which will be described in Chapter One) and the methodology chapter describes how disabled people have been active participants rather than passive recipients in this doctoral research. The issue of the relative position of power of the researcher is also addressed. I have described the tensions within the methodological process of working in an emancipatory way. These tensions were mainly around the issue of ownership of the research and the products of the research (eg. the accessible report and the PhD thesis). I also show the stages where, and extent to which, the Advisory Group were involved.

Chapter Two also describes the process of *analysis* in the research. In a similar way to the data gathering process, the Advisory Group played a crucial role in the analysis. The Advisory Group's contribution added extra elements to the analysis and provided an additional 'lens' through which the data could be viewed. The analysis process involved the following stages:

a) The Advisory Group undertook a preliminary analysis of the interviews (raw data) in discussion with myself. This led to the production of the accessible report, which included practical and policy recommendations.

b) I undertook a further systematic analysis of the interviews, drawing out theoretical concepts.

c) I analysed the transcripts of the Advisory Group meetings, drawing out the participants' experiences and opinions. These were used as an experiential synthesis to confirm the relevance of the emerging theoretical concepts to the lived experiences of disabled people.

d) I showed how the concepts of moral rights, attitudes, difference, consumer and risk were generated by the analysis process.

This process is outlined in each analytic chapter (Chapters Three, Four, and Five). These three chapters develop emerging concepts and themes relating to citizenship which arose from the interviews with professionals/ managers, but presents them within the context of the discourses in which they are most frequently found.

Chapter 3: Academic discourse

Chapter Three shows how the academic discourse of citizenship rights could be developed by the findings of this research. It shows how the data resonated with existing dimensions in the citizenship literature (as outlined in Chapter One) but also describes how the element of 'moral' rights , which emerged from the data, could be added to such writings.

The Advisory Group defined 'moral' rights as rights to respect, privacy, dignity and being treated fairly. This definition of rights develops Marshall's (1950) model of citizenship where rights were classified in terms of civil, political and social rights. The experiential synthesis (that is, the synthesis of the interview data with the experiences/ opinions of the disabled people in the Advisory Group) also showed that the element of 'moral' rights resonated with the lived experiences of disabled people. In this way, it could be seen as an important element affecting the citizenship status of disabled people.

Chapter Three also shows how this study has expanded the concept of exclusion to include visibility, barriers and consultation. This development of existing themes in the 'academic discourse' reinforces and expands the concept of citizenship to include elements of particular relevance to disabled people.

Chapter 4: Advisory Group discourse.

Chapter Four focuses both on the concept of attitudes and the concept of difference which emerged from the analysis of the data. I refer to this as the Advisory Group discourse since it develops the priorities of the Advisory Group, pinpointed in Chapter Two (Methodology). Chapter Four shows how the concept of attitudes could be added to the debates around citizenship and also how this research applies the concept of 'difference' specifically to disabled people. It further discusses how a 'model of difference' could influence understanding of difference as a *valued* identity. In addition, it shows how the influence of the Advisory Group within the research in terms of refocusing the interviews from citizenship onto attitudes, played a part in developing this previously underworked dimension within the writings on citizenship.

Chapter 5: Professionals' discourse.

Chapter Five discusses the concept of the consumer and that of risk, both of which were generated by the data. These concepts are referred to as the professionals' discourse since the interview data of the professionals revealed the extent to which disabled people were viewed strongly as potential consumers in the markets in which the professional served. It was noted that, in particular, professionals in the retail/ leisure industries (eg. managers of supermarkets, restaurants, art galleries and cinemas) placed a high importance on disabled people as potential customers. However, it was seen that the participation of disabled people beyond that of consumer (for example as employee) could be hindered by the notion of 'risk'. Although the concept of consumer and of risk arose mainly from the further systematic analysis of the interview data by myself (rather than from the Advisory Group's preliminary analysis), the experiential data from the Advisory Group showed that the issues of consumer and risk were also relevant to disabled people in their daily lives. This chapter also shows how the Advisory Group's influence in the methodological process around the choice of interviewees was instrumental in causing data to be collected in which such new concepts became transparent.

Chapter 6: Conclusion.

The Conclusion discusses the development of citizenship theory in the light of the research findings to assess the extent to which disabled people are perceived as citizens. In it, I show how the social model of disability can be developed into a social model of difference and how this has been useful in terms of consolidating the focus on attitudes into a framework of citizenship theory. I have suggested that the significance of this research has been in the connections made between citizenship and disabled people. These connections have been neglected in much of the previous literature.

In the conclusion chapter I also show how the different concepts that were generated can be embodied within a development of citizenship theory. The following diagram, which will be discussed in more detail in Chapter Six, illustrates how work on citizenship can be further developed in the light of this research:

Figure 1: Developing Citizenship

Academic discourse

Citizenship

[development of traditional model]

- Rights- adding moral rights
- Exclusion- adding:
  - visibility
  - barriers
  - consultation
- Obligations of state

[literature]

Advisory Group discourse

Attitudes

['New' concept]

Including:

- Lack of awareness
- Language
- Experience affecting attitudes
- Changing attitudes
- Medical model of disability
- Sympathy
- Disability a 'problem'

Professionals' discourse

Consumer

['New' concept]

- Consumer vs. Employee
- Cost vs. Benefit
- Equal Opportunities
- Providing for the majority

Difference	Risk
['New concept']	[New concept]
Including:	Including:
- Difference	- Health and Safety
- Equality	- Safety of others
- Social Model of Disability	- Protection

From the analysis of the data, therefore, I draw the conclusion that disabled people experience negative attitudes due to other people's perception of them as 'different' and also that disabled people are often seen as consumers in the market, but not as potential employees because of the perception of 'risk' which they pose.

Following on from this, I shall offer a critique of Marshall (1950), by discussing his focus on rights, showing how this study has added to Marshall's theory by exploring and developing dimensions of rights and exclusion. I shall also argue that although Marshall reflected academic developments in the 1950s, citizenship theories have now developed to encompass issues of exclusion around marginalised groups. As a result, I shall suggest that the outcomes of this study provide a way of developing citizenship theories, by incorporating concepts of moral rights, attitudes, difference, consumerism and risk. I shall go on to suggest that citizenship can be seen as an *ideal* to strive for, and also, theoretically, a continuum accommodating different individuals and groups at differing stages of its development. I shall also argue that the ideal notion of citizenship is a society in which there is a valuing of difference and a celebration of diversity within an infrastructure of accepted rights and responsibilities.

Following this, I shall go on to discuss the extent to which the doctoral research was successful in carrying out an emancipatory methodology, showing how there are different levels of participation in such research and how elements of advocacy and consultation are an important part of the process. In discussing the elements of 'added value', which were generated by carrying out the research in this way, I reflect on the tensions within an academic context of undertaking such research. I argue that the method was successful as an evaluative process and that it can pave the way, as a learning experience, for further research.

Finally, the conclusion shows how this study has implications within the present policy landscape and within professional practice. I remind the reader of the recommendations of the Advisory Group (quoted from the accessible report) on promoting training for employees, of having disabled people as employees, of consulting with disabled people, and of challenging attitudes (see appendix for accessible report)), for in this way, the Advisory Group were suggesting that a reassessment of professionals' attitudes could help to benefit the promotion of equal citizenship for disabled people. I therefore reflect on, and review, the outcomes of the research through the Advisory Group lens and, finally highlight their priorities and analysis of the data.

The Conclusion of the thesis, therefore suggests that the exclusion of disabled people as active and equal citizens is affected by moral rights, attitudes, the perception of 'difference', consumerism and risk. I also argue that these concepts need to be added to the citizenship literature. Finally, I show how a focus on these concepts contributes to the development of a discussion of disablism.

CHAPTER 1: LITERATURE REVIEW
CITIZENSHIP AND DISABILITY

Since the present study focused on research related to disabled people and took as its starting point the Social Model of disability, the literature review will firstly discuss the differences between the Social Model and the Medical Model of disability. Following on from this, the main body of the literature review will consider theories of Citizenship. It will be divided into three sections: first, citizenship, the individual and rights, second citizenship, the state and its obligations, and third a section on citizenship and exclusion. In each section, the relevant concepts will be related to disabled people.

The Social and Medical Model of Disability

This research used the Social Model of disability as a start point for developing citizenship theory and for testing the emancipatory paradigm of research. The Social Model of disability which focuses on disabling barriers in the environment contrasts with the Medical Model of disability which focuses on the disabling barriers of an individual's impairment. The first section of this chapter will look at definitions of both the Medical and Social Models of disability and will address the issue of disability in relation to writings on Citizenship.

The Medical Model of disability

The concept of disability can be seen to be relative rather than absolute as definitions have altered and been reassessed throughout history and within and among different societies (Drake 1999). In terms of the historical context, in Britain, for example, before the Industrial Revolution, people with impairments could generally be accommodated into working roles, but with the onset of machinery, certain standardised ways of working emerged, which often resulted in the exclusion of people with impairments from the workforce. For example:

> ...[the] increase in the speed of factory work, the enforced discipline, the time-keeping and the production norms, all these were a highly unfavourable change from the slower, more self-determined methods of work into which many handicapped [*sic*] people have been integrated. (Ryan and Thomas, 1980, p. 101).

During and after the Industrial Revolution the emphasis could be seen to be very much on a person's *unproductivity* and thus their *inabilities*. This reinforced an ideology of *dependency* for people with impairments: since people with impairments faced the possibility of exclusion from the workforce, they had to rely on others for an income and for resources (eg. Oliver, 1996).

Definitions of disability, therefore, can be seen to be constructions of society (Albrecht and Levy, 1981) and are therefore often dependent on economic factors, attitudes, political definitions and media representations.

An approach adopted in the 1960s and 1970s was to see disability as 'inability' and a three-fold classification of the term was adopted (Based on the World Health Organisation (WHO) definitions):

> a) impairment- lacking all or part of a limb, or having a defective limb, organ or mechanism of the body.
> b) disability- the loss or reduction of functional ability.
> c) handicap- the disadvantage or restriction of activity caused by disability.
> (Harris, 1971)

This classification also talks about a 'continuum' of disability ranging from very severe to very slight and defines disability in relation to what is seen as 'the norm' in terms of function or ability. Although the World Health Organisation has recently reassessed and redefined its definition in the light of pressure from the disability movement (eg. Oliver, 1990), it can be seen that these classifications were the basis on which many assumptions relating to disability were made. They were also very much focused on a medical, or 'functional', definition of disability.

In this way, definitions of disability were focused on the physical 'dysfunction' of the body and individualised the problem to the person. The World Health Organisation classification has since been referred to as the 'Medical Model of Disability' (eg. Oliver, 1993). The Medical Model relates to the way in which a disabled person was often seen as a *victim* of their impairment and their disability was seen as a 'personal tragedy' in need of pity and compensation where,

> ...sharp distinctions are drawn between different types of impairment and their causes are sought exclusively within the individual: thus mental and physical handicaps [*sic*] are construed as mere biological differences... (Borsay, 1986, p. 180).

The Medical Model sees the disabled person in terms of an individual who is 'sick' or impaired, and who, as a result of their impairment, has a need to be 'cared for' and dependent on other people. Within this view, there is no reference to a shared economic, social and political dependency: the focus is on the *functional* limitation of the impaired individual and thus their lack of participation in society. It is an approach that proposes that professionals 'know best' about a person's condition and the management of that condition and assumes therefore the individual can benefit from the knowledge and skill of such professionals (Oliver 1990). However, this approach offers an individualised attitude and does not address wider issues of oppression experienced by disabled people. Furthermore, under this model, any barriers in the environment which are experienced by people with impairments, such as physical access to buildings transport, and education and also the barrier of attitudes, are not addressed as an issue.

The Medical Model can be seen to avoid issues of rights and Citizenship in its wider context since it proposes that the disabled person is *dysfunctional* and therefore not able to participate in society. It also gives no sense of commitment by the state to advocate on behalf of disabled people: it only requires that the state provide 'medical', or 'caring' services to alleviate the 'problem' of the impairment.

The Social Model of disability.

In contrast to the Medical Model, the Social Model of disability moves away from an individual focus and focuses more on society and the oppression inherent in it through barriers which maintain and perpetuate a large element of dependency for people with impairments ie. disabled people are seen as collective victims of an uncaring, unknowing society, rather than victims of circumstance (Oliver, 1993). The Social Model of disability recognises the stigmatising, discriminatory nature of the structure of society and the position of powerlessness (eg. Holdsworth, 1991) created in a society where a dominant, able-bodied class holds the power and therefore create structures which do not allow for people who are not non-disabled. Disability is therefore seen to be,

> ...imposed by a society which expects all its members to conform to the yardstick of able-bodied normality and builds physical and social environments which penalise any 'misfits' (Borsay, 1986, p. 183)

The Social Model is concerned with seeing the oppression of disabled people as a civil rights issue rather than simply a medical or social problem for individuals and believes that the only way to achieve equality is by removing the disabling structures in society through anti-discrimination legislation (eg., CORAD, 1982) on similar lines to legislation concerned with race and gender. The Disability Discrimination Act (1995) can be seen as an initial attempt to address issues of oppression and provides some rights, particularly in terms of employment and access to goods and services.

It can be argued that a Social Model of disability can initiate a more empowering approach to professional practice since it highlights the traditional dependency-creating bureaucratic paternalism of a medical-based model and, in challenging this, aspires to put power into the hands of the consumers. It also suggests that self-empowerment may be a collective way forward for the wider group of disabled people (Oliver, 1990).

Many authors (Crow, 1996, French, 1993) now acknowledge the need for a recognition of the individuality of personal physical experiences of disability within a societal context, which thus argues for a synthesis of the two models. Although the Social Model of disability more successfully describes the individual and collective experiences of oppression, it can be suggested that both models merely explain a denial of equal rights for disabled people. Within the Medical Model, citizenship cannot be achieved because of problems with the individual. It suggests that if the disabled person can become non-disabled through medical intervention then they can experience full citizenship rights. The Social Model serves to be equally negative in that a disabled person is denied citizenship by the barriers inherent in society. The empirical inadequacy of the Social Model, therefore, is that, although it describes existing barriers, it does not, of itself, campaign for change. However, adopting the social model of disability has been a useful vehicle for disabled people who have collectively been involved in campaigning for *environmental* and *attitudinal* change. The collective political action of disabled people has highlighted the need to address issues of rights for disabled people. It is the area of citizenship rights to which I now turn.

Citizenship and Rights: T.H. Marshall.

Citizenship is an elusive concept. (Blackburn, 1993, p. 99)

Definitions of Citizenship, like definitions of disability, are relative rather than absolute as citizenship is also a concept that varies according to its historical and geographical context. Citizenship, as a contemporary theme in politics and social science can be seen to have been a recently resurrected concept, which was originally conceived in the 1950s by T.H. Marshall. Marshall's focus centred around civil, political and social rights and was seen in the historical context of 'class' development. More recent writers, eg. Barbalet (1988), Darhendorf (1996), Giddens (1982), Bulmer and Rees (1996) Bryson and Lister (1994), Oliver (1990) and others have sought to widen the concept of Citizenship and have introduced issues such as exclusion, membership, obligations, market economy, and other rights. They have also recognised that the class dimension is not the only factor in the development of achieving rights. Oliver (1990) and Lister (1997,) for example, pinpoint *disabled people* and *women* respectively as traditionally having fewer rights in society than non-disabled people and men. More recent researchers are addressing Citizenship in terms of the other 'excluded' groups of people, such as gay and lesbian people (eg. Anndermahr, 1992, Snyder, 1992), older people (eg. Arber and Ginn, 1991) and children (eg. Evans, 1993, Turner, 1986, 1993).

This research has taken the issue of Citizenship as a theoretical base for both its methodology (eg. aiming for emancipation, participation and inclusion) and its substantive analysis (attitudes, difference, consumerism and risk). The remainder of the literature review will consider theories of Citizenship, which focus particularly on the three dimensions of rights, obligations of the state and exclusion. These dimensions are important since they are frequently given a position of authority in the literature. Although the study of citizenship in Britain has been 'much subject to intellectual fashion' (Bulmer and Rees, 1996), Marshall (1950), who described and developed these elements, can be seen to have given a comprehensive outline on which to build.

Rights

First, the literature around the issue of 'Rights' as a focus for Citizenship will be discussed.

> Citizenship can readily be described as participation in or membership of a community. (Barbalet, 1988, p. 2)

Although T.H. Marshall can be seen to be one of the founders resurrecting Citizenship in terms of sociological theory, it was in fact in existence as a concept before this time. Historically, for example, Aristotle considered Citizenship in relation to those in power ie. Citizenship was bestowed upon those who had a position of power whereas slaves and working men and women were not seen as citizens in ancient Greek civilisation. Added to this, Citizenship generally implied the achievement of wealth, which, in more recent periods, has related to the factor of 'class'.

> Citizenship can be characterised as both a status and a set of rights. (Barbalet, 1988, p. 15).

In terms of status, Marx (1843) considered Citizenship as a status to be gained and he suggested that the law could play a small part in achieving that status. He proposed that the gaining of equal Citizenship status for all went hand-in-hand with a 'playing out' of the class system, possibly in terms of a social revolution. In the twentieth century, the development of Citizenship was seen as relevant, particularly with the advancement of social class. Marshall saw Citizenship, initially as a status attached to full membership of a community:

> Citizenship is a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what the rights and duties shall be, but societies in which Citizenship is a developing institution create an image of an ideal Citizenship

> against which achievements can be measured and towards which aspiration can be directed. (Marshall, 1950, p. 29)

It can thus be seen that the status of 'citizen' was an ideal to be gained. The ideal can be seen as both an inspiration and a yardstick with which to measure differing levels of citizenship.

Marshall (1963) focused mainly on citizenship in terms of rights and in terms of obligations of the state. He defined citizenship in terms of civil rights, political rights, and social rights, as outlined below:

> 1. The <u>civil</u> element is composed of the rights necessary for individual freedom- liberty of the person, freedom of speech, thought and faith, the right to own property and to conclude valid contracts and the right to justice...
> 2. By the <u>political</u> element I mean the right to participate in an exercise of political power, as a member of a body invested with political authority or as an elector of such a body...
> 3. By the <u>social</u> element I mean the whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilised being according to the standards prevailing in the society. The institutions most closely connected with it are the educational system and the social services... (Marshall, 1963, p. 74)

He suggests that these rights were achieved by British society in a chronological order ie. the 18th century saw an enactment of civil rights, the 19th century saw the achievement of political rights and finally social rights were achieved in the 20th century with the presence of the welfare state, education and the health service. In terms of class, he saw the 'upper class' as achieving Citizenship rights first followed by the 'middle classes' and then the 'working classes'. He suggested that class conflict, in general, was directly related to the expression of struggle for Citizenship rights.

The following diagram (my interpretation), I feel summarises Marshall's position:

Figure 2: Achieving Citizenship

Civil Rights
'Ruling class' initially.
[citizens are *subject* to the law and equal before the law]

Political rights.
'Middle class' wanting to influence ruling class.
[citizens are able to feed their interests *into* the law.

Social rights.
'working class' wanting entitlements to services etc. that the middle class already had.
[citizens can afford to *defend* themselves in court of law.]

The following discussion will relate the elements of civil, political and social rights to the examples of women and of disabled people. In this way, it will highlight the relationship between citizenship and disabled people that sets the basis for the present study.

Civil rights

In terms of civil rights, women's achievements in this area, could be seen to come later than those of the working classes. Within the nineteenth century, for example, it was recognised that the gendered role of women reduced their rights as citizens:

> There remain no legal slaves, except the mistress of every house. (Mill, 1989, p. 5)

Lister (1997) criticises Marshall because citizenship was presented as gender - neutral and Marshall's model disguised gender divisions. For example, historically, women were denied the formal status of rights of citizens as were slaves in Ancient Greece, and in the nineteenth century, western married women were not independent individuals in law. Presently, in many developing countries women are still seen as legal minors, and even up until the early 20th century, within the UK, women were denied the vote, free education, employment and independence, particularly if they were married, although eventually the Sex Discrimination Act (1975) addressed some of these issues (eg. Lister, 1997). Lister suggests that,

> The historical legacy has been to contribute to an image of women as incapable of true Citizenship. (Lister, 1997, P. 66)

She criticises Marshall's model of Citizenship for being *linear* because he implies that rights in Britain were achieved in a certain order in relation to the class structure. She suggests that this description of the process of citizenship did not recognise the struggle of *oppressed groups* to achieve citizenship at different times;

> In post-colonial societies women typically won the vote at the same time as men, although it does not follow that they thereby became equal political citizens with them. (Lister, 1997, p.68)

In terms of Citizenship, women *have* gained civil rights in law. However, it is also the case that the state has fewer obligations to intervene in aspects of family life than 'public' life, so women have less *protection* in the law since a large proportion of women have established themselves within a role focusing on children and family. There are, however, some forms of legal protection in terms of domestic abuse and in terms of child protection.

Arguably, the journey of disabled people to achieving civil rights parallels that of women in that it was not linear, ie. rights were not gained in the same order, or at the same time, as non-disabled people. In Britain, for example, legislation has only recently been created to protect disabled people from discrimination (the Disability Discrimination Act, 1995). Bryson and Lister, (1994) suggest that disabled people are often denied the rights that non-disabled people have but that there are ways in which this can be rectified:

> To be disabled in Britain is to be denied the fundamental rights of Citizenship to such an extent that most disabled people are denied their basic human rights... It is possible to remove all the barriers to Citizenship that disabled people face. (Bryson and Lister, 1995, p.5)

Oliver (1996) argues that, theoretically, disabled people have civil rights in terms of property rights, rights to freedom of thought, speech, religious practice, assembly and association. However, these rights can be seen to be hindered by *access* issues. Furthermore, up until 1995 (before the Disability Discrimination Act) disabled people were denied rights against *discrimination*. The Disability Discrimination Act (1995) can be seen to go some way to addressing the issue of civil rights but has limitations in terms of difficulties in *enforcing* owners of buildings to make them accessible and also in the lack of commitment to making transport accessible. Since 'civil rights' includes a person's freedom to access their environment, the element of the issue of access largely affects a disabled person's ability to achieve civil rights.

The extent of denial of civil rights to disabled people is eloquently described by Anne Begg (1995), a disabled MP, who talks about her experiences of disability and how they affected her daily life:

> ... Imagine a world where there was a barrier across the door of most shops on the high street which read, "Sorry, no women beyond this point" ....or a world where every time you go out, be it to a pub, restaurant, shopping or wherever, you then find that there are no toilets for you, or that the ones they have constructed for you are full of furniture....or a world where the only way you can travel on some British Rail trains is in the guard's van, while you're not

> allowed on most buses or the London Underground at all simply because you happen to be black...or where a cinema which has just allowed a drunk man to enter with a fag hanging out of his mouth, turns round and says "you can't come in here because you've got bright red hair and you're a fire hazard.....If such social apartheid occurred to you just because you were male or female or black, there would, quite rightly, be a public outcry. The gross unfairness of such treatment is so clear. Yet all of the above, and much more, has happened to me at some time in my life. And my crime? I use a wheelchair to get around. (p. 3)

It can be seen that, rather than promoting civil rights in law, the focus of laws relating to disability has been more around the provision of goods and services. Buck (1993) argues that:

> UK legal protection for the disabled has been based largely on a public administration model. (p. 191)

He also suggests that disabled people are largely powerless in this process.

In terms of civil rights, the Disability Discrimination Act (1995) differs from both the Sex Discrimination Act (1975) and the Race Relations Act (1976) in that it does not address *indirect* discrimination. Although it attempts to remove some of the barriers such as access to employment, for example, it does not seek to remove any of the *institutional* barriers experienced by disabled people. Gooding (1996) cites the example of a disabled person being excluded from opening a bank account because they cannot produce a driving license, for example. This constitutes indirect discrimination because the individual's reason for not having a driving license could be related to their impairment and this would be so for many other people with impairments. The Americans with Disabilities Act (1990), which is more sweeping in its aims, does use the concept of direct and indirect discrimination but also includes the need to actively dismantle the environmental barriers faced by disabled people. In this way, it addresses the issue of *civil* rights for disabled people to a greater extent than the Disability Discrimination Act (1995).

The Americans with Disabilities Act (1990) had an influence on the development of the Disability Discrimination Act (1995). The Americans with Disabilities Act (1990) outlined provision for rights in employment, public services, private sector services, transport and housing. However, in the UK there were objections to developing these rights due to the issue of cost:

> The arguments against such laws in the UK are usually based on objections to the potential cost or on the perceived failures of sex and race discrimination law. (Buck, 1993, p. 194)

Arguably, however, the issue of cost doesn't recognise the *benefits* brought about, for example, by having disabled people in employment and not claiming welfare benefits. Furthermore, in developing the case for civil rights legislation Buck argues that Acts like the Disability Discrimination Act can be instrumental in changing attitudes:

> ...they have (literally) incalculable effects on the community in terms of the formulation of attitudes towards the disabled. (Buck, p. 194)

The Americans with Disabilities Act (1990) has accorded extensive rights to disabled people in the USA in relation to public and private sector employment; public services and transport; education, recreation and leisure; telecommunications; and in terms of the redress available where employers or service providers fail to comply with the law. The legislation was adopted within the context of a wider civil rights strategic direction in the United States of America. In contrast, disability legislation in the UK (including the Disability Discrimination Act, 1995) has developed in a rather haphazard fashion with no specific enduring aims or commitment to the citizenship of disabled people. Its,

> ...contemporary profile represents a mixture of strong elements of state welfare, the encouragement of private provision, but, as yet, only very limited aspects of a 'rights-based' approach. (Drake, 1999)

Disabled people in Britain can be seen to be excluded to an extent from full civil rights. This is primarily to do with the inadequacy of present legislation which does not seem to address wider civil rights aspects or indirect discrimination and seems less effective than UK Acts related to race and gender or the Americans with Disabilities Act (1990).

It can be seen that:

> It is time for more powerful legal measures to attempt to strike a sensible balance between a duty to "accommodate" the needs of the disabled and the reasonable needs of employers and others in order to enable the disabled citizen to achieve the fullest possible participation and integration in society (Buck, 1993, p. 195).

The idea of a 'range' of Citizenship rights as a continuum is a useful way to expand Marshall's model. Buck suggests that:

> The claims from disabled persons to have a proper place in the *range* [my italics] of Citizenship rights have been neglected for too long. (p. 195).

This quotation suggests that Citizenship is about participation and integration which can be seen as elements of the dimension of 'exclusion', rather than 'accommodating' a person's 'extra' needs. This will be discussed further in the section on 'exclusion'.

I will show in Chapter Two how I adopted an emancipatory methodology for this study. I suggest in Chapter Two that, by using this methodology, I addressed aspects of inclusion, integration and participation. That is, participatory tools were used (an Advisory Group of disabled people) and I was inclusive/ integrative in my selection criteria when recruiting members of the Advisory Group. I feel that the process used in this study (which will be discussed further in Chapter Two) shows that there are links between participation, integration and inclusion and that these all contribute to a focus on citizenship. In this way, the present study sought to include disabled people as equal participants, thus exemplifying Buck's (1993) standpoint to 'give disabled people a proper place' (p. 195). Not only, then, do concepts of citizenship suggest aspects of inclusion, participation and integration, but this viewpoint can be widened to address issues around disabled people as participants in research processes.

In terms of civil rights, therefore, the position of women and the position of disabled people with regard to citizenship, reflects changing attitudes, expectations and stereotypes. It can be seen that although there is some legislation to address the rights of women and the rights of disabled people, arguably, there are barriers to achieving those rights that are still apparent today. In this way, it can be seen that Marshall's *linear* model has neglected the situation of 'oppressed groups', some of whom achieved rights much later than non-oppressed groups.

Political rights

Following on from the last section, I would like to discuss the elements of *political* rights as an aspect of citizenship, with particular reference to women and to disabled people. To reiterate Marshall's definition, political rights can be defined as the right to,

> ...participate in an exercise of political power, as a member of a body invested with political authority or as an elector of such a body... (Marshall, 1963, p. 74).

Blackburn (1993) argues that political rights include participation in political life, including the right to participate in rule-making institutions and the right not to be treated unfairly. Bryson and Lister (1994) consider political rights to be in terms of access to rights and participation in politics. These authors suggest that politics in the UK, in general, is dominated by middle class white (and non-disabled) men. In this way, there is less expectation that women will participate in political gatherings and in general, because of 'domestic' stereotyping, and the fact that their access to the time, contacts and knowledge required to operate in such areas has been restricted. This consequently means that their views and needs have not been represented in politics to the same extent as have those of men and that change is usually influenced by a non-female majority. They also argue that in order for women to have full civil, political and social rights, social policies need to promote change in terms of more effective, enforceable anti-discrimination legislation, employment, welfare benefits and wider access to political participation.

Political rights have also played a large part in the disabled community. Arguably, the 'lack' of political rights due to barriers in society has been a contemporary issue of concern within the disability movement in recent years. Although the majority of disabled people have a legal right to vote, it has been shown in research (eg. Ward, 1997, MIND 1990) that some disabled people are not listed on the electoral role. This may be particularly so for some who live, or who have lived, in residential care and also for those considered to be not of the ability to understand (Many people with a learning disability or a mental health problem have been included in this category and therefore *excluded* as citizens.). It is also sometimes difficult for disabled people to join political parties because meetings can be held in inaccessible buildings, information is not usually available in accessible formats and campaigning can be difficult, again due to access problems.

Finkelstein (1993) uses the phrase 'socially dead' when describing the lack of presence of disabled people from all major areas of social life, including political life. The voice and concerns of disabled people have thus been absent in the political arena although disabled people formally, and technically, have political rights. In addition, disabled people have also not been encouraged or been given the opportunity to speak in the political arena because their bodies and minds can sometimes be assumed to be incomplete and their inabilities are stressed more than their abilities or their right to participate (Barton, 1993). Disabled people are seen to be excluded because of their *difference* which is seen in negative terms as a 'problem'.

As a result, apart from a small number of high profile individuals, for example David Blunkett MP, now Home Secretary, few disabled people have been active in politics and often have difficulty in exercising their political rights. Furthermore, it can be suggested that political rights are not only manifest in political activity:

> Part of the challenge of liberation movements has been to widen the concept of the political: to suggest that personal, domestic and social relations are as political as voting and democratic representation. (Shakespeare, 1993, p. 259).

In this, Shakespeare is suggesting that the concept of 'political' results in 'inclusion' in its fullest sense. In recent years, particularly in the campaign for civil rights legislation prior to the Disability Discrimination Act (1995), disabled people have collectively used Direct Action as a political force. In this way, although there are barriers to political rights for disabled people, it can be seen that disabled people are now more visible in the political arena in the UK.

Social rights

The final element of Marshall's (1950) model, that is, social rights, will now be discussed. Barbalet (1988) suggests that rights are important in social analysis because they structure social relationships and also that people struggle to achieve or defend their rights. Macpherson (1985) makes the distinction between civil rights and social rights by suggesting that civil rights are about being *against* the state and social rights are about being *by* the state, that is, the state should *provide* social rights but should not act *against* an individual's freedoms:

> For persons to act as citizens there must be freedoms the state cannot invade and therefore actions which the state cannot perform; for persons to consume as citizens the state must provide, and is therefore obliged to perform certain specific actions. (Macpherson, 1985, p. 23).

In the nineteenth and twentieth centuries there was a general improvement in civil/ political rights, but not for disabled people. The Mental Deficiency Act (1913), for example, gave Local Authorities power to place 'mental defectives' in institutions (with the written advice of two doctors). This has been referred to as the '...nadir of the civil rights of people with learning difficulties.' (Walmsley, 1991, p. 222). Although the 20th Century, according to Marshall, saw the emergence of *social* rights, this did not encompass disabled people. English Poor Laws (which were an early attempt to provide support to those not able to look after themselves) referred to the 'impotent poor' and consequently, poor relief appeared to require the surrender of civil/political rights:

> In practice, much modern analysis of disability draws heavily upon the way in which the bureaucracy and professionals administering large public (and voluntary sector) programmes of assistance for the disabled force the disabled to conform with certain stereotypical expectations of the wider community: docility, limited capacity, gratitude. (Buck, 1993, p. 181)

In this way, although there was some provision for people with impairments in terms of social assistance, this provision also served to reinforce stereotypes and attitudes relating to disability inherent in society.

In terms of Social rights, disabled people today are given access to services provided by the local authority such as day centres, residential care, welfare benefits, health facilities and an adequate schooling. However, a large percentage of disabled people can be seen to be living in poverty because of the necessity to live on welfare benefits, of having little choice or control over their activities of daily living (eg. being dependent on the timetables of carers for their support needs), of not being able to access many of the facilities enjoyed by non-disabled people, of having little say in the way some services are run, and, often not having the opportunity of an education equitable to that of a non-disabled person. It can also be seen (eg. Lonsdale, 1986) that there is a very high percentage of unemployment among disabled people and in this way, disabled people's ability to access choice and control is reduced. The main denial of social rights arises from a combination of problems, poverty and low expectations about what a disabled person wants or needs (eg. Disability Alliance, 1988).
The problem of Social rights for disabled people, therefore, emerges from the lack of inclusion in society and the difficulties associated with being unable to access the same services and facilities as other citizens:

> ... social rights to use the same facilities as everyone else are not accorded to disabled people, whether these be rights to move around the built environment, to travel on transport systems which claim to be public or to have access to public information of all kinds, because usually it is only produced in spoken or written English. (Oliver, 1996, p. 48)

Taylor (1989) advocates for Citizenship anchored on *need* rather than *rights*, that is, need can be seen as dynamic and differentiated; rights universal and abstract. However, Lister (1997) suggests that,

> ...in the UK it is argued that a shift of emphasis from the rights to the needs of disabled people has opened the way for the professional domination of welfare provision and a retreat from active to passive citizenship. (p. 86)

This implies that disabled people's social rights are to be considered within a framework of state obligations . This will be discussed further in the next section. However, it is useful here to also consider social rights within the context of Community Care policies as this is an area where they are frequently made transparent for disabled people.

M. Barnes suggests that the key features of Citizenship in relation to Community Care are:

1. A development of the notion of social rights. (referring to the foundation of welfare state; social justice and obligations; and access to resources.)
2. A consideration of the role which procedural rights may play in securing access to welfare and fair treatment by public services (e.g. the right to receive a written statement of the results of assessment of needs, the need for: information; advice, advocacy and representation; access; promptness; handling of individual cases; redress through appeals and complaints (Doyle and Harding, 1992, p. 74)

> 3. Arguments for an extension of civil rights to groups not already protected by anti-discrimination legislation (latterly, disabled people; future protection may include gay and lesbian people for example)
> 4. The gendered nature of much earlier thinking about 'the citizen' and the development of notions of Citizenship which include, rather than exclude, women
> 5. The notion of Citizenship not only as a status, but as a practice. This refers to the ability of nominal citizens to participate within civic, social and economic life. (M. Barnes, 1997, p. 39)

I would argue that in terms of Community Care, social rights relate to issues of entitlement. Plant (1992) argues that all citizens should be entitled to these rights:

> Civil and political rights are not dependent on living a virtuous life; nor does one have to be a member of the deserving poor to qualify for social rights. (p. 60).

However, in terms of Community Care, entitlements are often assumed against a list of criteria. Although people do not have to be a member of the 'deserving poor' they do generally need to fulfil specific criteria within Community Care policies in order to justify the best use of resources. The argument against social rights being automatic is that there are limited resources and also that if individuals have to contribute to the provision of resources e.g. taxation, then providing for the social rights of others is a restriction on their right to spend their income in a way they choose. The argument is that there has to be a 'professional judgement' on the balance of provision of services compared with individual need. A recent solution has been the provision of Direct Payment schemes in which people with impairments have a right to receive a service but can spend their financial entitlement in the way they choose.

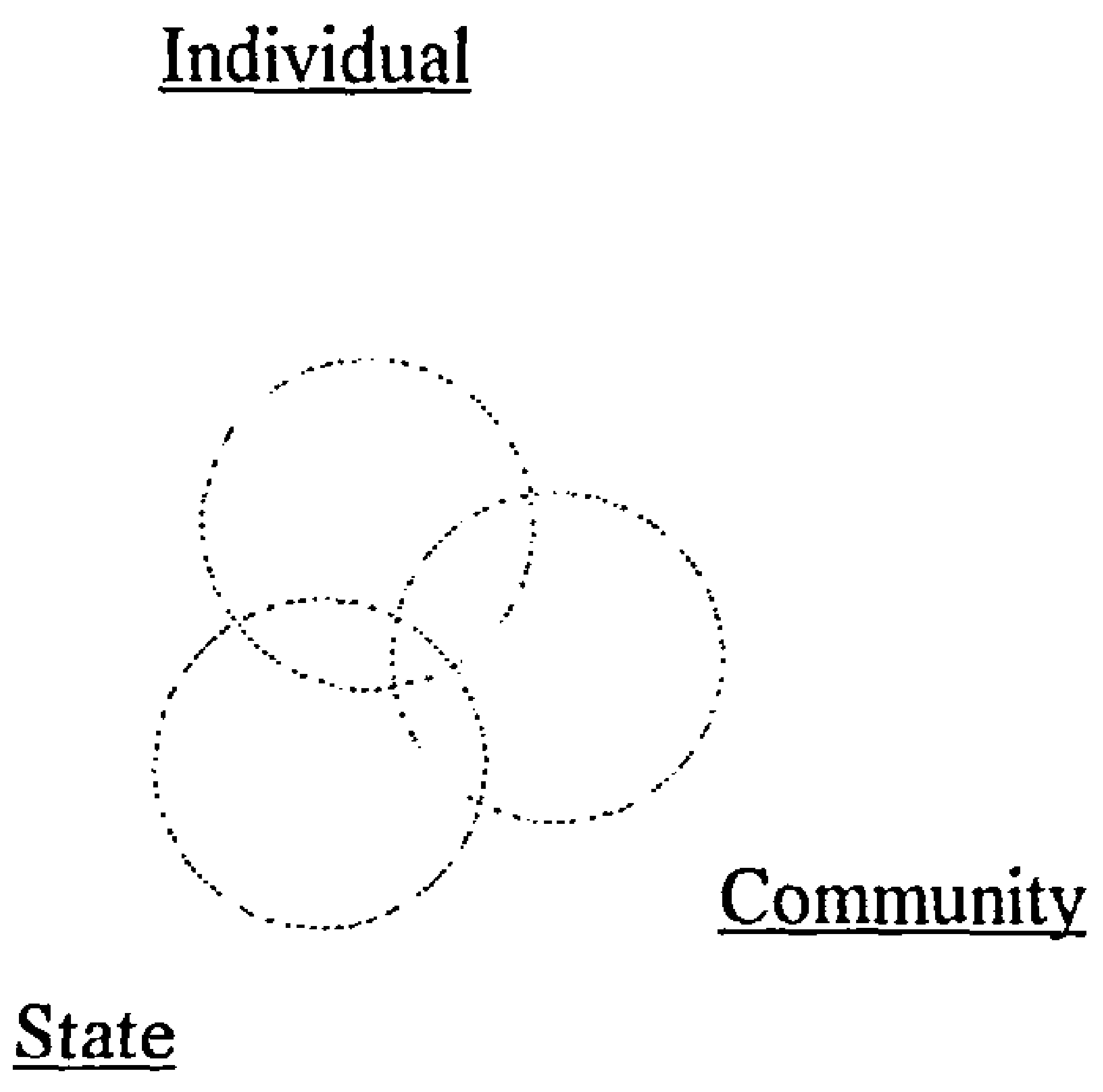
Social rights, therefore, are an element of citizenship for disabled people. However, the achievement of social rights for disabled people is not sequential as Marshall argued since all rights for oppressed groups have tended to be granted as a result of struggle and negotiation. It can be seen that Marshall was writing of a male, non-disabled society and may not have considered the position of women or that of disabled people.

To review Marshall's tripartite analysis of citizenship, then, Bryson and Lister (1994) suggest that his theory is too simplistic. From their feminist viewpoint, he does not seem to consider the position of women since his overriding focus is on class. He thus fails to look at issues related to the family and areas of traditional gender domination such as employment. He likewise neglects disability. In general, he fails to recognise individual differences within society (as exemplified by women and disabled people) and this becomes problematic when he discusses the obligations of the state to its citizens, to which I now turn.

Citizenship and Obligations of state.

Marshall's (1950) focus on citizenship rights highlights the status and needs of the individual within the state. Another element of Marshall's theory of citizenship is the role and obligations of the state, that is the granting, and maintaining of citizenship rights by the state. Marshall refers to Citizenship as the interconnections, obligations and entitlements between the state, the community and the individual. In this way, he suggests that in order for citizens to access their citizenship rights, the state needs to be accountable in granting those rights and in helping individuals to achieve citizenship status. In developing Marshall's standpoint, I would interpret this in terms of the individual having an obligation to herself/ himself, the community having an obligation to provide for its own needs and the state having an obligation to enforce laws that ensure a person's rights. The following diagram indicates this:

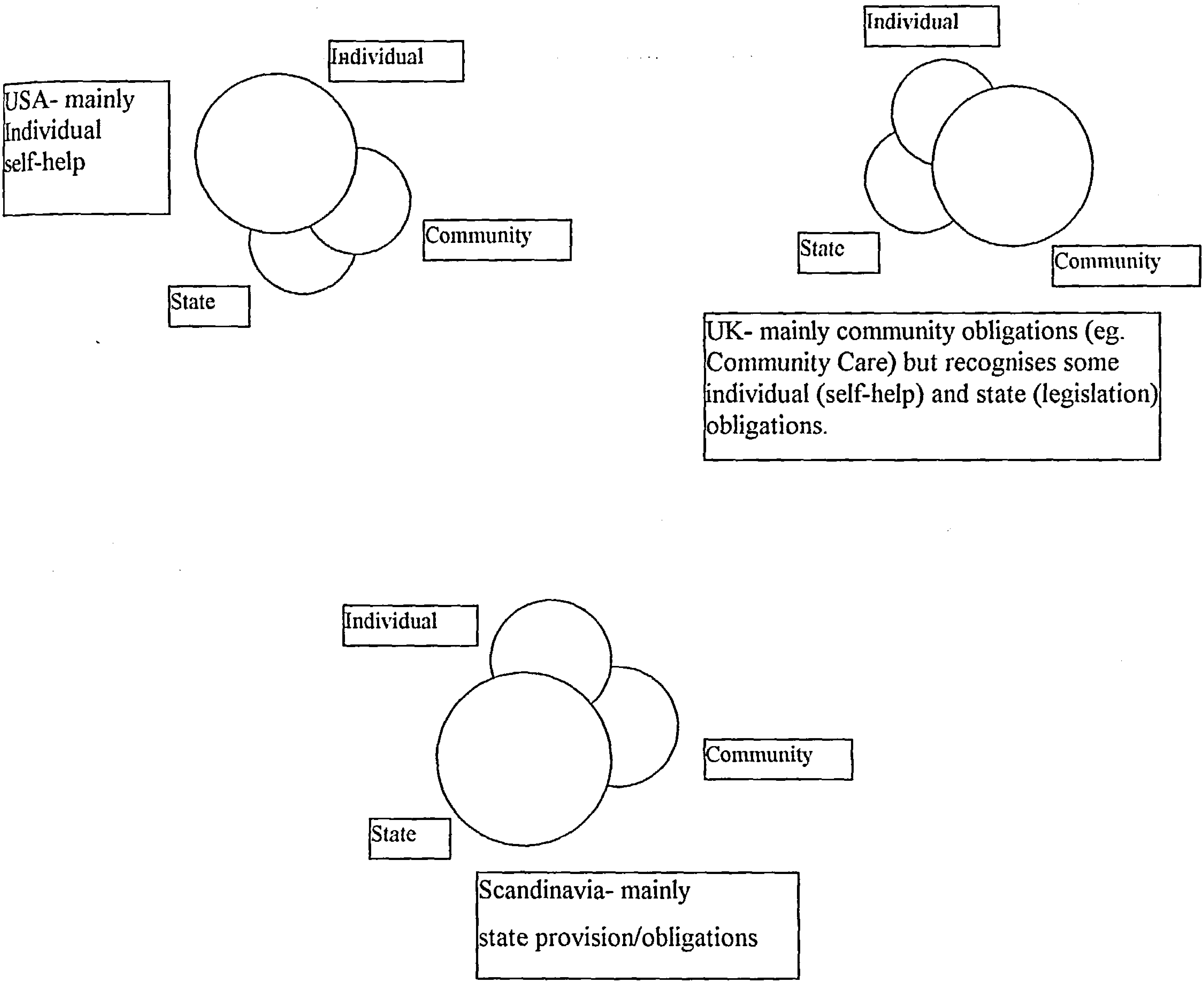
Figure 3: Obligations of citizenship



This diagram implies that the obligations of the individual, community and state are interrelated. It could be argued that an equal balance of all three constitutes the basis for a full balance of Citizenship rights ie. without the individual helping themselves for example (eg. collective/self-empowerment), rights of access to community facilities are unjustified and having civil rights in a court of law needs to be combined with a community's obligation to be accountable to itself and the individuals within it in order for those rights to work within society.

Rees (1996) shows the differences of emphasis of state obligations within various countries. He suggests that Scandinavia, for example puts great weight on state provision and obligations. Conversely, the USA emphasises individuality and self-help. Finally, he suggests the UK is somewhere between the two. Linking Rees' viewpoint with the previous discussion, I would suggest that this can be diagrammatically summarised in the following way:

Figure 4: Obligations of citizenship- different models



The diagram shows that different countries prioritise differing responsibilities within a citizenship paradigm. The extent to which the state plays a role in terms of obligations depends very much on the political and historical background. Barbalet (1988) comments that the dilemma is around the state being both dependent on support from the social classes and groups, and at the same time influential over its subjects. He argues that when the state experiences pressure for change from political groups it has three options, that is, ignore it, give in to it, or repress it. The choice, he suggests, is dependent on the consequences in terms of the state's continuing ability to rule and is also dependent on the balance of social forces and the state's security. He calls the interaction between the state and the individual a 'struggle':

> In any event, it is crucial to accept that no matter how intense the struggle for Citizenship rights, it is the state which ultimately grants them, and it may choose to do so even in the absence of such a struggle. (Barbalet, p. 110)

In this way, therefore, the state has a large amount of power in terms of citizenship. Thus, when talking about the rights of citizenship, the obligations of the state need to be addressed as an important factor.

Another obligation of the state in terms of citizenship is that of entitlements. Entitlements that are granted by the state as an obligation can be seen to equate with the element of 'social rights' in Marshall's model. By implication, therefore, the state needs to provide services and resources, particularly to those who are disadvantaged or vulnerable in some way and cannot purchase services as an individual. In Britain, therefore, obligations of the state can refer to the provision of welfare and resources within a welfare state (Barbalet, 1988, p. 77-79).

I shall first discuss the obligations of the state in relation to the provision of services and then look specifically at the obligations of the state in relation to disabled people.

Initially, I shall address the issue of welfare provision, as an element of social rights, within the context of the perceived needs and wants of the individual as a citizen. Marshall's view is that the process of Citizenship is a force that softened the class struggle and social divisions and that the Welfare state had the effect of incorporating social rights into the *status* of Citizenship.

Much of Marshall's standpoint originates from his focus on class as the key aspect of the gaining of citizenship rights. As described earlier in this chapter, he suggested that the 'ruling class' achieved rights first, followed by the middle class and then the working class. He saw the provision of social rights, particularly in reference to 'entitlements' as being a way in which the working classes could increase their membership in, and participation of, the society in which they lived. Within the present study, I have suggested, as a result of the analysis of the data, that there are other aspects, not just class, that affect a person's ability to gain citizenship rights. Chapters 3, 4 and 5, for example show how the findings of this study identify moral rights, attitudes, difference, consumerism and risk as all affecting citizenship.

Within the present study, class struggle was not identified as an underlying issue in relation to the citizenship of disabled people. In Chapter Six, my critique of Marshall further demonstrates that his focus on class was in fact too narrow, but can be explained by considering his work within the historical context in which it was written. Also in Chapter Six, I go on to discuss the concept of disablism and how it relates to issues of multiple oppression (Vernon and Swain, 2002). In this way, I suggest that class, along with other factors, such as gender, race, disability, all add to experiences of oppression. It must be acknowledged that there may still be aspects of class that effect the status of citizenship in today's society, particularly in relation to entitlements to welfare benefits and services. However, within the present study, the development of other issues was seen as more prominent and pertinent to disabled people.

Marshall considered that welfare provision (within the structure of 'social rights') was granted later than civil rights and political rights. In this way, it can be suggested that welfare rights evolved in a logical way from other rights. In contrast to this viewpoint, however, it can also be suggested that welfare rights arose out of an element of *need*. If rights are seen in terms of needs then there also has to be an awareness of 'wants' as different to 'needs':

> There is a conflict in Citizenship theory between the liberal demand for want satisfaction and the welfarist imperative that objective needs must be met. (Barry, (1990) p. 50)

Barry argues that it is difficult to have an objective measure of needs because, in reality, assessment of needs are judged in terms of priorities and consensus and therefore may not be considered objective.

Having defined an individual's needs, the state is seen to have an obligation to provide resources to its citizens to meet those needs. Barry *(ibid)* defines three reasons for providing resources (e.g. welfare) for Citizens:

i) resources need to be provided, otherwise social disintegration /alienation will result;
ii) resources need to be provided because citizens have a right to resources;
iii) resources need to be provided because citizens demand to be treated equally.

I shall address the relevant strengths of each point in turn to consider the obligations of the state in providing resources.

i) Resources need to be provided, otherwise social disintegration /alienation will result.

Although it would seem reasonable to suggest that disadvantaged citizens should get their needs met by the state, there is actually no convincing evidence that receiving welfare produces the 'good citizen'. In other words, it can be seen as an ideal but individuals are not 'moralised' by the existence, and receipt, of welfare. In this way, the argument is not strong in terms of receiving state provision of resources.

ii) Resources need to be provided because citizens have a right to resources.

It can be suggested that:

> ...just as my well-being is harmed by aggressive action, it is undermined by lack of resources. (Barry, 1990, p. 54)

In this way, Barry is suggesting that the right to resources is related to *safety* and *belonging*. Added to this, it can be argued that, the obligations of the state in terms of provision of resources implies that there is a commitment to the good of the *whole* as a community, ie. individuals are members of a community and have an obligation to that community beyond themselves as individuals. However, by following through the argument of resources as a right, the implementation of the provision of resources can be problematic:

> The serious problem is surely that the attribution of welfare rights to individuals in the presence of scarcity throws up insoluble distributional problems. (*op cit*, p. 57-8).

Plant (1990) reiterates this viewpoint by inferring that a 'right' to resources is often dependent on the degree of resources available and, furthermore, that this usually requires a judgement on the part of a professional to justify the use of resources:

> The basic reason why liberals do not believe in the extension of the idea of rights to the social and economic field is the fact of scarcity. There can be no enforceable right to scarce resources. (p. 22)

He goes on to suggest that while the rights to freedom of action should not be dependent on scarce resources,

> Social and economic rights, however, are paradigmatically rights to resources. (p. 23)

and in order to decide on the criteria for using resources, a judgement needs to take place. The argument he is putting forward is that the state obligation for providing resources to individuals as a right is 'diluted' by the rationing of resources. He is thus challenging the notion that provision of resources by the state is actually a 'right':

> ..how the resources are allocated will have to be judged not against the enforceable claims of the right holder, but against some conception of the most effective use of resources, effectiveness being judged in terms of welfare and utility. However, if rights routinely have to give way to considerations of utility, in what sense are they rights? (p. 23)

iii) resources need to be provided because citizens demand to be treated equally.

The assumption that resources are provided because citizens demand to be treated equally, moves the focus of the Citizenship debate towards the elements of equality and participation: that is, citizens assume a right to take an equal part in the society in which they live. However, there is often inequality in the distribution of resources to citizens which suggests an unequal and unjust system. It can therefore be seen that, in a capitalist society, the structure of market forces , as a system, could be seen as unjust because resources cannot be provided equally to all citizens. However, although the system may be considered to be unjust, the ideal of providing resources equally does not necessarily have to be an argument *against* the market system:

> Marshall's concept of Citizenship would certainly not exclude a role for the market; only those dysfunctional elements within it that attenuated full Citizenship would come under critical scrutiny. (Barry, 1990, p. 59).

However, even in a society where, despite market forces, all citizens were treated equally, it would not always follow that services would be *consumed* equally: a whole range of factors come in to play, such as, income, access to higher education, and tax relief on mortgage interest. Barry (1990) suggests that if citizenship is related to the demand to be treated equally, then the state often plays a 'nannying' role in order to distribute resources equally (p. 58-59). In this discussion, it has been pointed out that there is a dichotomy between providing for all citizens equally, and living in a capitalist society that encourages market forces. However, Barry is saying that there is a role for the state in obligations but that the individual also needs to govern his/ her own life to an extent:

> Citizenship is not undermined by the penetration of social life by the market; nor is it enhanced by transferring to the state the individual's responsibility for the government of many aspects of his own life. (p. 76)

The discussion of the obligations of the state can be developed by relating it to the concept of 'community'. In general, 'community' is often seen as an identity of people through common ties of language and culture rather than entitlements to rights. However, in developing the previous discussion around market forces, community also focuses on the element of participation:

> Nowadays, the argument is part of the 'civic humanist' or 'republican' ideal that understands a society as more than a collection of anonymous individuals held together by abstract rules of law: it is a community of active, participating citizens. (Barry, 1990, p. 52)

Following on from this, Citizenship can be seen as a *formal* concept centring around the rights and obligations of being a member of a community. However, it can be seen that the element of 'membership' often implies an element of 'exclusivity':

> At a first glance Citizenship refers to a certain kind of exclusivity: someone is a citizen of a country because he [*sic*] has certain legal protections and entitlements that do not apply to outsiders. (Barry, 1990, p. 45).

In terms of 'obligations of the state', therefore, it seems to be the case that the obligations are given to those that are the exclusive *members* of the community it serves and not to others. Since membership is often related to geography and nationality, then the obligations of the state to its members are generally fairly well defined. Yet, a lack of clarity can arise for those individuals who do not have clear membership (for example, asylum seekers and immigrants and those defined as 'incompetent').

In general, however, the concept of 'the community' is seen to be an *ideal* for which to aim. Lister (1997) argues that communities can create a sense of mutual interdependence in which there is inclusivity as well as exclusivity :

> An appeal to community asserts a public interest beyond individual self-interest in recognition of the fact that people are social creatures who live in a condition of mutual interdependence. (p. 83).

In this way, she is arguing for the pluralist politics of community and the idea of heterogeneity. However, she does recognise that 'community' can also oppress those deemed 'different' since inclusiveness can imply sameness. She suggests that 'community' could, ideally, be a moveable construct which, ultimately, could encourage diversity:

> Instead of obscuring diversity, division and difference, this conception would place them centre stage and would be seen as 'multiple and open' rather than 'fixed and eternal'...(Lister, 1997), p. 84

It can therefore be seen that Citizenship rights and community as an ideal can have differing and sometimes conflicting standpoints because the rights of an individual could conflict with the ability to access membership of a community. Marshall emphasised the notion of 'membership' of a community. He suggested that:

> Citizenship is a status bestowed on those who are full members of a community. (Marshall, 1950, p. 84)

In this way, he is suggesting that the community can play a crucial role in the development of citizenship status.

I shall now move on to address issues around the obligations of the state in relation to disabled people as a specific group. This will first involve a brief historical discussion of the provision of services to disabled people and then a more specific discussion on the obligations of the state to disabled people in relation to a framework of citizenship.

Obligations of the state and disabled people

Buck (1993) suggests that the origin of state obligations to disabled people in the UK begins with the deserving/undeserving hierarchy of the Poor Law, ie. those that were unable to look after themselves, or provide for themselves, were given very basic state help in return for work. English Poor Laws based their criteria on a definition of the "impotent poor", a definition that could be seen as oppressive, patronising, and excluding disabled people from participating fully in the community. English Poor Laws were the forerunner of later provision of welfare services such as social services, health care, and education. In terms of protecting people with impairments, therefore, institutions such as residential and nursing homes, and institutional day care were all designed to protect them from harm and to protect the community from having to be responsible for the 'impotent poor' as a visible unit. Barbalet (1988) suggests that in the mid-nineteenth century there was no distinct legal protection for people with impairments: often they were reliant on family support or charity.

Following on from this, in the late nineteenth century, provisions were put in place for deaf and blind children to be educated, and this was later extended to people with learning difficulties (then referred to as the "mentally handicapped"). After the First World War provision for disabled people shifted its focus to ex-servicemen, and then towards the end of the Second World War the 1944 Disabled Persons (Employment) Act was put in place as an attempt to retrain disabled people to address a shortage of non-disabled employees (Drake, 1999). Under this legislation, employers with twenty or more employees were required to employ 3 per cent of registered disabled people on their workforce. Post-war provision brought social security benefits for disabled people and this was followed by a range of welfare benefits over the subsequent years, for example, Attendance Allowance, Mobility Allowance, Invalidity Pension, Severe Disablement Allowance, Disability Living Allowance and Disability Working Allowance. Hence, historically, in terms of provision of income for disabled people, there has not been a coherent state framework. The provision has been affected by political and social situations:

> Despite some demands from the Social Security Advisory Committee for more cohesion designing an appropriate benefit structure for the disabled, it would appear that, at least for the foreseeable future, an *ad hoc* approach to benefits for the disabled [sic] continues. (Buck, 1993, p. 185)

In terms of services, the Chronically Sick and Disabled Person's Act (1970) puts a duty on the Local Authority to identify the number of disabled people in their area and provide a range of services to meet their needs, for example, aids and adaptations in the home.

Although the position of disabled people as citizens has improved, Oliver (1996) states that the state has actually *failed* to serve disabled people in the following three distinct ways: the costs of the welfare state are too high and therefore there is a need to cut spending; the provision of welfare encourages dependency; and services are dominated by, and serve the interests of, (non-disabled) professionals.
He suggests that present government strategy to address these issues should encompass Community Care policies, a "market" approach and the rhetoric of empowerment and citizens charters. However, Oliver takes the view that:

> ... while it [the government] may want a market in social welfare, it does not want a market where users have any power. (p. 55).

He considers that the present Citizenship model is one in which individuals (in this case, disabled people) have services and rights but no power with which to exercise choice and control and equality. Oliver and Barnes reinforce this by suggesting that a welfare state that causes people to be passive recipients, rather than active participants, further undermines an individual's access to full Citizenship. (Oliver and Barnes, 1993).

In terms of Citizenship, therefore, the obligation of the *state*, for disabled people should be seen in terms of providing enforceable, effective legislation and relevant services. Following on from this, in relation to disabled people, it can be seen that the obligation of the *community* should be to work within an inclusive framework; and the obligations of the *individual* disabled person should be to work towards self-help and collective empowerment. Marshall's focus on class seems to bear little relevance to disabled people but the position of disabled people, historically, has gradually improved in terms of Citizenship:

> Whilst there is no room for complacency and the struggle for empowerment and participatory Citizenship with all the rightful entitlements is going to be difficult and costly, it is important to keep an historical perspective on these issues and to recognise what has been achieved in a relatively short period of time. (Barton, 1993, p. 244).

Historically, therefore, in terms of obligations of the state, disabled people have been able to access services and resources defined for them as an *entitlement* right in legislation. In this way, the state has been able to provide some of the 'social rights' of disabled people.

It has been suggested that in order to access entitlements and social rights an individual needs to have membership of a community. It is to the aspect of membership that I now turn, as part of a wider debate on inclusion/ exclusion.

Citizenship and Exclusion

It has already been suggested that citizenship encompasses an element of *membership of a community*. In terms of the 'obligations of the state', discussion has focused around defining the inclusive and exclusive nature of membership in terms of oppressed groups and provision of services. It has been shown that it is only those individuals who are defined as 'members' ie. those who are citizens of the state who are eligible for state provision. The next section will address the aspect of 'exclusion' in relation to citizenship, in more detail and it will look at the examples of exclusion in relation to women and disabled people. It will also discuss the concept of participation and will then re-visit the idea of 'membership'.

Citizenship:

> ... operates simultaneously as a mechanism of both inclusion and exclusion. (Lister, 1997, p. 4.) .

This viewpoint has also been raised by Dahrendorf (1996) who considers that people use Citizenship in two ways: firstly by talking about a wider philosophical concept of *rights* and secondly the political concept of *membership*. In this way, he accepts Marshall's theories around civil and political rights but adds another dimension, that of 'membership' of a community. Furthermore, 'membership', as previously discussed, implies inclusion and exclusion. Rees (1996) develops this by arguing that the concept of Citizenship is seen as an *internal* Citizenship rather than *external* Citizenship. He cites the example of immigrants, who are not considered members of a state and are not deemed as full citizens and therefore, they are seen to be excluded from the internal citizenship of society in terms of rights. However, the status of immigrants within the state is complex, since they have some basic rights in terms of protection and provision of services and human rights under legislation such as the Human Rights Act, 1998. Their citizenship status, therefore, relates more to their legal membership of a nation and their identity within that nation. Therefore, they can be considered to be partial citizens in this sense.

Dahrendorf points out that another category of people who are seen to only have partial citizenship rights and are thus excluded from other citizenship rights are children. Children are not considered full citizens but they achieve full citizenship status when they become adults. In the same way, I would argue, it is often suggested that disabled people can *become* full citizens if they are made non-disabled through treatment, physiotherapy or surgery. However, although I would suggest that disabled people could be referred to as partial citizens in terms of their membership of society and their access to aspects of society, their 'partial' citizenship status is different to the 'partial' citizenship status of immigrants and children. In terms of immigrants and children, their status is defined in legal terms with reference to age (for children) and nationhood (for immigrants). The status of disabled people, on the other hand, is not defined in law in this way. As I will show in the findings of this study, their lack of membership, and thus their partial citizenship status, is related more to the denial of aspects of rights (such as access to the environment, transport, and employment) and in terms of attitudes towards them rather than legal status.

It can be suggested that, often, Citizenship is related to the obligations of the 'powerful' to the 'powerless' (ie. the 'state' to the individual; the non-disabled person to the disabled person). I would suggest that a person can have Citizenship rights in Marshall's terms but may not be an equal citizen because they have a relative lack of position of *power*. This can be seen, for example, in the relative lack of MPs in parliament from minority groups, such as women, ethnic minorities, and disabled people: they have rights legally, but their lack of representation in politics means that their views and needs are not being addressed. Exclusion, therefore, is also related to power (Lister, 1997).

The exclusion/inclusion debate is a crucial element of Citizenship: if certain groups of people have rights by law, but are still excluded from other aspects of society through various mechanisms they therefore cannot be seen as full citizens, according to this dimension of the Citizenship model.

Barbalet (1988) proposes that:

> The development of Citizenship has two analytically distinct aspects: there is the inclusion of new categories of persons into existing Citizenship rights, and there is the advent of new types of rights in Citizenship, the creation of new components or elements of Citizenship. (p. 98-9)

that is an expansion in the number of citizens and changes in new types of citizens: the latter bringing in previously excluded sections of population into a national community. Those 'previously excluded' have included women and disabled people. Recently, these groups have achieved legal rights and thus an element of protection and inclusion.

The next section will address some of the issues of exclusion/ inclusion and citizenship in relation to the distinct groups of women and disabled people.

> The universalist cloak of the abstract , disembodied individual has been cast aside to reveal a definitely male citizen and white, heterosexual, non-disabled one at that.
> (Lister, 1997, p.66)

It can be seen that Citizenship, in terms of exclusion/inclusion, is very relevant to the position of women. Generally, women can be seen to have legal equality but may not be considered equal citizens because they do not have, in Marshall's definition, access to full political and social rights. It can be argued that the exclusion of women from certain rights is manifest, among others, in the family, legal rights, employment, and political participation. Bryson and Lister (1994) suggest that:

> ...if men are the norm, then women's gender-specific needs must be denied and 'special classes' can only be second class citizens. (p.3).

In this way, Marshall's focus on 'class' in relation to citizenship rights is being challenged. Bryson and Lister further comment that Marshall's focus on rights implies a focus on independence and autonomy. This, they regard as in conflict with the general position of women because there are many cases where women are economically dependent on men and are denied independence and autonomy. They argue that a theory of Citizenship needs to consider complex human interdependence, which includes the crucial position of the family. In putting this view forward they are arguing for greater obligations of the state and the community to the family as a unit. They are therefore saying that often women are excluded from having full citizenship rights but that there are ways in which this could be rectified, given a commitment from the state and from the communities in which they live.

Specifically, the exclusion of women as citizens is often visible around the public/private divide, that is, the divide between public life (implying paid employment and politics) and private life (implying domestic). Traditionally women have been more visible in the private realm and men in the public realm. Mouffe argues that:

> ...the way we define Citizenship is intimately linked to the kind of society and political community we want. (1992a, p. 25)

that is, traditionally, a society based on male construction. The public/ private debate also implies issues of power and domination; and issues of supposed lack of physical strength are often used as justification for exclusion. It is frequently shown in public life that politics has been very male-dominated and that there is a higher percentage of managers of organisations or companies that are male (Lister, 1997). Power and public inclusion and influence, therefore are often associated with maleness. In this way, women are excluded from a 'public' world:

> The history of women's exclusion from Citizenship in Western societies is thus intimately linked with their relegation to the private side of the public-private dichotomy. (Lister, 1997, p.71)

Although there is much discussion within the literature concerning the citizenship status of women, there is very little literature suggesting a connection between citizenship, and disabled people. This could be due to:

> .... the result of a public perception of the disabled [*sic*] as largely the *objects* of public administration laws and agencies rather than a category of persons representing any significant challenges to the polity of the nation. (Buck, 1993, p. 180).

Disabled people, therefore, are perceived to have a lack of power and visibility. Often, when citizenship has been related to aspects of disability, it is more within a medical model of rights to provisions and services than within a social model of participation and inclusion. Buck's (1993) opinion has been that:

> What was lacking was any analysis of the processes by which disabled people were defined and socially constructed in such a way as to become disengaged from the mainstream community, and the myriad ways in which the obstacles to full participation in society would create disadvantage requiring remedial action. (Buck, p. 180.)

I would argue that there are three main areas which affect the inclusion, and thus the right to Citizenship, of disabled people. They are access, attitudes and employment. I shall address each of these aspects in turn.

In terms of the Social Model of disability, physical *access* is a significant barrier in society that interacts with a disabled person's impairment and can create exclusionary practices affecting their participation in society. The inability to use a voting booth, for example, can be seen as one way in which a person's Citizenship rights are reduced.

There has been some legislation around issues of access for disabled people. The Disabled Persons (Services, Consultation and Representation) Act, 1986, for example, states that the Local Authority has a duty to assess the needs of disabled people with a view to providing services. The 1970 Act, section 4 states that there is a requirement for public buildings to accommodate the needs of disabled people as far as possible and the Building Regulations (1985) ask for reasonable provision to be made for disabled people's access in single storey buildings. More recently, the Disability Discrimination

Act (1995) legislates that public goods and services have to be made accessible to disabled people, which may include making 'reasonable adjustments'.

Although some legislation is in place to improve access for disabled people it is often the case that their experiences still include difficulties with access, particularly within the area of transport and education (which are not as well addressed in the DDA, for example, as public goods and services.) However, very recent legislation, the Special Education Needs and Disability Act, 2001 (Disability Discrimination Act, 1995, Part IV) defines recommended practice in relation to a disabled person's access to education. This is currently undergoing its second period of consultation and is expected to be finally adopted in January 2002. This legislation, therefore, recognises the need to enforce managers of services to change their practice in order that access should be improved for disabled people.

Another barrier that disabled people face which has exclusionary consequences is the 'attitudes' of non-disabled people. Attitudes to disabled people can be associated with stereotypes of passivity, being 'looked after' and being weak and vulnerable (ie. based on the Medical Model of disability). In organisations of disabled people, it can be seen that there are differences between organisations run *by* disabled people themselves (which are usually based on a Social Model of disability) and organisations run by non-disabled people *for* disabled people (often based on a Medical Model of disability) and the differences are often shown in the attitudes of those running the groups:

> A major thrust of this criticism of organisations run by non-disabled people is that they operate within a framework which assumes that disabled people cannot take control of their own lives and therefore, require the 'charitable' assistance of well-meaning professionals, voluntary workers or politicians. (Oliver, 1990, p. 115).

This stereotyping is also often prevalent in mainstream society.

It can be seen that in order to fight against some of the stereotypes that they experience, disabled people have sometimes used collective empowerment around Direct Action as a political tool:

> It seems clear that the tactic of conspicuous, direct action campaigning is something that the disability movement will increasingly adopt in proportion to the increasing frustration felt with the potential of 'welfare enactments' and the traditional disabled persons' organisations' inability to deliver full Citizenship. (*op cit*, p. 190)

Although the Disability Discrimination Act has forced employers, and managers of goods and services, in particular to address issues of access for disabled people, stereotypes and attitudes may still prevail. In terms of attitudes, therefore, disabled people often experience an element of exclusion. The present research has been able to explore this issue to a large extent.

The final area of exclusion which has been seen to be prominent in relation to disabled people is that of employment. I shall first comment briefly on the situation of women in relation to employment to show diversity among citizens and then relate that to the situation of disabled people.

In certain areas, women are disadvantaged in employment because they are often in part-time employment, temporary work, lower paid work and work in jobs which continue the gender stereotypes of work in the home (Lister, 1997). Furthermore, there is often an economic dependence by women on men and on the state. This can be seen as counter to the ideal of full Citizenship:

> Independent Citizenship is often seen as incompatible with reliance on state benefits. (Bryson and Lister, 1994, p. 15).

Another issue in terms of employment is that of time. Bryson and Lister (1994) and Seymour (1992) argue that, in general, women have less leisure time than men due to their traditional roles in the home. They suggest that this is an area which needs further consideration in terms of citizenship:

> If women are to become equal citizens, the inequitable distribution of time and the way in which this is affected by public policies must both be recognised. This suggests that time may be seen as a form of property, a Citizenship entitlement which can be protected or regulated by the state rather than an infinite resource. (p. 17).

They are thus arguing that Marshall's model of Citizenship ignores the private gendered world of the family. If Citizenship is defined in terms of membership and participation then women's perceived family responsibilities often exclude them from full citizenship. This can also be said of the issue of employment:

> Active Citizenship requires not only time and economic independence, it also requires the kind of contacts and links with political processes and the public sphere that maybe found through employment. (Bryson and Lister, p.16).

It can therefore be seen that women's potential difficulties in accessing employment, and their prominence in the private sphere, rather than the public sphere, may cause them to experience elements of exclusion.

Further developing issues raised by the discussion around women and employment, it can be seen that disabled people have similar experiences. Disabled people are more visible in the private sphere than in the public sphere and are often financially dependent on the state. Often, their lack of visibility is related to the attitudes and stereotypes of employers. However, it can be argued that there are many advantages to disabled people accessing employment:

> ... when persons with a disability give up public subsidies for jobs they leave funds in the public coffers. When they become taxpayers, they contribute directly to public treasuries. When persons with disabilities become consumers in the marketplace they strengthen the economy. (West, 1992, p. 9).

In preparation for implementing the Americans with Disabilities Act (1990), one advantage of improving access to employment was the reduced dependency on welfare benefits. It was suggested that the new Act would:

> .... free millions of people with disabilities from the bondage of dependency, enabling them to become employees, tax payers and customers. It will save billions for government and directly profit every business and every citizen. (Dart, 1990, p. 1-2).

This is suggesting, therefore that disabled people should be encouraged to access employment and, in turn, there are strong financial benefits. However, this is not to suggest that benefits should be replaced totally by employment. It is important to note that many disabled people still need both financial and practical support to assist them in their lives. This is also the case even if they are in employment. As I will explore further in Chapter Four on a discussion around difference and equality, disabled people need to be treated equally in relation to accessing employment, but their differences also need to be addressed in order for them to participate equally.

The previous discussion has been around the experiences of disabled people in relation to exclusion. It has been suggested that the areas of access, attitudes and employment are prominent in terms of the experiences of disabled people and exclusion. Furthermore, the experience of exclusion is directly related to the ability to be a full participating citizen. Following on from this I shall now address the issue of participation as an element of citizenship, particularly in terms of how it relates to Marshall's definition and also its integration within structures of state obligation.

In defining participation as 'crucial to a contemporary discourse on citizens' rights', Turner (1988) contests Marshall's tripartite definition:

> Citizenship may be defined in various ways (by reference to civil, legal and social features) but Citizenship rights are essentially concerned with the nature

> of *social participation* [my italics] of persons within the community as fully recognised legal members. (Turner, 1986, p. 134).

In this way, Turner is arguing that Marshall's model of Citizenship is too simplistic in its definition because a person can have all the three elements of Citizenship (social, political and civil) but may still not be a full participant in the society in which they live due to other factors such as physical access to buildings and facilities, lack of power and influence, attitudes, low expectations and poverty. As an example, present Community Care policies define rights to receive services in terms of professional definition of need rather than a universal right (Barnes, M., 1997). This, therefore, constitutes an inability, on the part of disabled people, to participate in society as equal, integrated citizens.

Barbalet (1988) also talks about the importance of participation:

> Citizenship, as equal participation in a national community , is one means of achieving social and political integration, either through the general acceptance of common values, or through the negation of divisive inequalities. (p. 81).

This, therefore combines the need for participation with the need to challenge inequality, with the result being integration.

M. Barnes (1997) suggests that participative Citizenship includes collective organisation based on shared identities as well as participation within the constitutional processes of the state, so that, for example, individuals dependent on the welfare state have been encouraged to be 'active citizens':

> The challenge is to transform the existing relationship between the government and citizens from one in which little exists to give expression to citizens' collective voice beyond the blunt mechanism of the ballot box, to one in which citizens are active contributors to processes of collective decision making. (Prior, Stewart and Walsh, 1995, p. 20).

In other words, this viewpoint is about individuals succeeding, within a state structure, through their own initiative. This, therefore suggests the need for individuals to participate in society at all levels of structures and decision-making. Participation, therefore, is related to Citizenship and the obligations of the state.

I shall now turn to the concept of 'membership' as an element of citizenship. I shall also make reference to membership in relation to an economic market.

> ... the concept of Citizenship implies full membership of, and active participation in, society. (Bryson and Lister 1994, p. 1)

Citizenship and the concept of 'membership' can be seen to be inextricably linked, particularly in relation to participation and exclusion: In order to be included as a participant in a community, an individual needs to have some kind of membership *status*:

> Citizenship is a *status* bestowed on those who are full members of a national community. (Barbalet, 1988, p. 18).

Citizenship is often referred to in terms of having a geographical base for membership. However, some people are not classed as full citizens even though they have a national status of Citizenship, for example, children, people with certain mental illness, people with learning difficulties and prisoners. Lister (1997) suggests that a person with a level of Citizenship but without full membership could be defined as a 'partial' citizen. In terms of 'membership', therefore, it can be argued that disabled people are often seen as 'partial citizens', since, although geographically they may be defined as citizens, they are often denied membership because of difficulties such as access and attitudes. This could suggest that there is in fact a Citizenship 'continuum', depending on the level of membership of the citizens.

In terms of Citizenship, it is not only the case that members of a community are bestowed Citizenship, but also that non-members, by implication are denied Citizenship. There can be some very clear-cut boundaries of nationality, culture, participation and rights. This is very pertinent when considering the obligations of the state to its members. In order to clarify who is entitled to receive from the state, it is imperative to assess, also, who is *not* entitled. As an example, refugees, asylum seekers and immigrants all have differing legal status and therefore differing levels of membership. This, consequently, affects their entitlement to services from the state and thus their ability to be full members of the national community.

> Citizenship has a role in the integration of society because it has a special significance for participation in social life. (Barbalet, 1988, p. 87)

This implies that in order to *participate* as a citizen then there must be an element of *membership* of a community. Although the basis of Marshall's theory is around rights, he does recognise the importance of membership by saying that Citizenship requires:

> ... a direct sense of community membership based on loyalty to a civilisation which is a common possession. (Marshall, 1950, p. 93)

This implies that individuals are linked by national and societal values. Marshall also talks about citizenship as a status:

> Marshall (1950) argues that the development of Citizenship provides an equal status which in reducing the social significance of class inequality tends to reduce class conflict and tension and thereby enhances social integration. (Barbalet, 1988, p. 95).

In order to achieve integration, therefore, citizens need to participate in society as full members.

It can be seen that as a member of a state, an individual is also entitled to be a participant in 'the market' and become entwined within market forces. Plant (1990) argues that although the rhetoric of market forces is about choice, control and freedom, that in fact the market does not give freedom, but instead, a set of Citizenship rights to social and economic resources *outside* the market gives freedom. He is thus proposing that Citizenship is about having a common identity rather than being an individual consumer. In this way, Citizenship is a very fluid concept with ideological, political, academic, economic, geographic, collective and individual elements. Therefore the context in which it is applied will affect its meaning.

The literature on citizenship described in this chapter, therefore, explores some of the relationships between rights and obligations. Marshall's theory of citizenship shows the development of civil, political and social rights. This has been developed by other authors (eg, Lister, 1997, Barbalet, 1988, Oliver, 1990) to show the importance of the notion of inclusion in a citizenship model. Although the inclusion/ exclusion debate is well substantiated in the literature, its relationship to the position of disabled people is rather sketchy. However, there are many parallels with Lister's (1997) discussion on women and inclusion/ exclusion. The present study seeks to ratify the importance of locating disabled people in the inclusion/ exclusion debate and furthermore seeks to site this debate within the citizenship framework, particularly around the notion of 'partial' citizens.

Since the beginning of the present study (1995) the debates in citizenship have developed and diversified beyond Marshall's model of rights, obligation and inclusion. This is, in part, due to various political, social and global changes, such as the devolution of communism in Eastern Europe and the former Soviet Union, the global problem of refugees, and the institutional growth of the European community (Mullard, 2002). These issues of national and political identity are obviously not new phenomenon, but their recent recurrence and visibility have brought about a major revival of citizenship as a concept. Its revival has often occurred under the process defined as 'globalisation' (Turner, 1990, Roche, 1992, Mullard, 2002). The contemporary focus, therefore, is still around issues of membership and inclusion, but also added to the picture are issues of identity, entitlements, community and consumerism. Coupled with a focus on Human Rights (eg. Human Rights Act and human rights around various ethnic groups) and the commitment to,

> ...the recognition of difference of living with a plurality of paradigms (Mullard, 2002, p. 15)

citizenship's re-emergence has opened the debate wider than the earlier academic theorists.

Recent literature (Isin and Turner, 2002) suggests that the concept of citizenship is contested and broadened depending on political contexts and social struggles, among other things. They state that,

> The three fundamental axes, extent (rules and norms of inclusion and exclusion), content (rights and responsibilities) and depth (thickness or thinness) of citizenship are being redefined and reconfigured.' (Isin and Turner, 2002, p. 2)

These authors go on to say that modern citizenship calls on society to address difference and diversity in a positive way. Much of this has come about through the struggles of specific groups, such as aborigines, immigrants, refugees, homeless people among others, and through broader political contexts defined as 'postmodernisation' and 'globalisation'. Isin and Turner (2002) suggest that Marshall's viewpoints were very much based on a 1950s UK model. Since the development of globalisation, wider communication technology and political developments, it has become apparent that citizenship, as a concept, needs to be expanded. Isin and Turner show that the rights of citizenship vary between nation states (for example some states deny the civil rights of access to courts and counsel), as do the obligations of the state. They go on to say,

> While cast in the language of inclusion, belonging and universalism, modern citizenship has systematically made certain groups strangers and outsiders' (*op cit*, p. 3)

The composition of citizens, strangers and outsiders is then determined by a given nation-state trajectory and its consequent priorities for its citizens. The authors also go on to say that in the last two decades of the twentieth century, rather than focusing purely on legal rights as the main route to citizenship, there is now an agreement that citizenship involves a process of engagement with individuals and social groups around claiming, expanding, or losing rights (Isin and Turner, 2002).

The current status of citizenship in recent literature, points toward issues of cosmopolitan or global citizenship, that is, veering toward more global decision-making:

> Citizenship must be a central component to whatever answers and policies emerge towards global governance (*op cit*, p. 9)

Following on from the global perspective, and drawing together the strands around the rights of particular groups of people, it is important to emphasise the importance of race and ethnicity as an issue in the more recent debates. Since much of current thinking (Mullard, 2002, Roche, 1992, Turner, 1990) has evolved from a global standpoint in which membership and identity of ethnic groups, in particular, became a focus of debate, it follows that race would come under scrutiny as an element of citizenship. This is in contrast to Marshall's basic theoretical perspective which was grounded on class relations. It also complements the literature described in this chapter around feminist debates in citizenship.

It is important to recognise that both race and gender are raised equally in relation to citizenship literature. Some authors (Brubaker, 1989, Dwyer, 2000) show how citizenship in relation to black people has distinct similarities to citizenship in relation to women. Brubaker (1989) suggests that, similarly to women, in reality, many rights are denied black citizens. Added to this, and resonating with literature on women and on disability in relation to citizenship, black people have experienced racial violence, discrimination and prejudice impinging on basic civil, political and social rights (Gordon, 1989). Modood (1992) talks about the concept of 'difference' in relation to ethnic groups and states in the UK,

> The more distant an individual or group is from a white upper middle class British Christian/ agnostic norm, the greater the marginality or exclusion. (Madood, 1992, p. 54)

The concept of 'difference' was a substantial finding in this research in relation to disabled people and will be discussed further in Chapter Four.

Within the present study, the focus of enquiry lay with disabled people as an oppressed group who are affected by citizenship rights, membership and issues of exclusion. However, this is not to negate the importance of gender and race as factors in the citizenship discussions and they will obviously cross cut the experiences of disabled people (Vernon and Swain, 2002).

Within the analysis of the interview data in this study, neither gender, nor race were seen as being high priority in relation to citizenship of disabled people. It is interesting to note that at the beginning of the research (1995) the university city in which the research was undertaken had a very small population of people from ethnic minorities (under 2%, with a large proportion being of Chinese or South Asian origin) and therefore race issues were not highly visible within the city. However, toward the end of this research (December, 2002), the impact of the dispersal system has produced between 1,500 and 2,000 asylum seekers and refugees to the University City. The tensions inherent in such changes have highlighted the issue of race as more prominent. In this way, therefore, if this study was repeated, there may be more discussion, experience and viewpoints around race as an element of citizenship.

Although I have discussed the literature around gender, the findings of this study did not single out gender as a specific factor in relation to citizenship and disabled people. However, I was able to show how the findings in this study also resonated with much of the literature around feminist perspectives on citizenship since it focused on oppression, visibility, the difference between the public and private spheres, acceptance of diversity and recognition of differences and different needs.

Whilst acknowledging the more recent literature, the plethora of viewpoints, theories and paradigms around citizenship in all its contexts is too great to summarise or debate within the present limitations of this thesis. However, it is pertinent to note that at the beginning of the research (1995), the traditional Marshallian model was a key player in the arena, while, by the end of the research (2002), the explosion of citizenship as a concept created far reaching implications.

Although I recognise and value the more recent literature, I feel that the basic tenets of Marshall's theory provide a starting point for the discussion. This research was particularly sited in the academic and political arena of disability rights as a result of the introduction of the Disability Discrimination Act (1995) and my own personal and practice background, as described in the introduction to this thesis. Marshall, therefore, provided a platform, grounded in the rhetoric of rights, on which to build a coherent research paradigm around disabled people and their experiences around rights and the struggle for those rights.

In chapters 3, 4 and 5, I show how literature around attitudes, difference, consumer and risk help to reflect the findings of the research. I also refer to the literature and debates that explore other dimensions of citizenship identified in this study, such as differentiated universalism, the acknowledgement of social movements and struggles, disablism, the consumer citizen, risk and protection, moral rights, entitlements, 'otherness' and personal identity.

In Chapter Six, I go on to provide a more in depth critique of Marshall, drawing on aspects of this thesis and other literature to propose a development of citizenship theory that has particular relevance to the experience of disabled people.

I shall use the literature on citizenship, discussed in this chapter, as a basis for the present study both in terms of subject area and in terms of methodology. In the study, I shall be addressing issues of citizenship rights in relation to disabled people, specifically around the attitudes of professionals *to* disabled people. In terms of method, I shall show how I used the inclusionary focus of citizenship as a basis for developing an emancipatory methodology. The outcomes of the analysis and the conclusion of the study will address ways in which the citizenship model can be developed in the light of the findings.

CHAPTER 2: METHODOLOGY
AN EMANCIPATORY APPROACH

This Methodology chapter will describe the methodological process undertaken in the present research. Following on from the model of Citizenship outlined previously in the literature review, the methodology employed reflected the importance of 'inclusion' within the research process. To this end, an Advisory Group of disabled people played a crucial role in guiding and informing the process by providing a critical analysis of the data, and keeping me (the researcher) in touch with the priorities and experiences relating to being a disabled person.

This methodological approach can be defined as 'emancipatory' (Mies, 1991; Harding, 1991) since it challenges the power imbalances between researcher and researched and it recognises the oppression of disabled people.

The first section of this chapter will discuss the literature around emancipatory research, describing its ethical base and drawing on examples from disability (Oliver, 1992, 1996) and feminist researchers (Lister, 1997). Following on from this, I shall focus particularly on the role of the Advisory Group, describing a model by Tozer and Thornton (1995) , and showing how I adapted this model within the present study. I shall then reflect on the role of the Advisory Group within the present study, and the contribution of the group to the research process.

Following on from this, I shall describe the process of carrying out the research in collaboration with the Advisory Group, and I shall discuss the practicalities and problems I experienced in carrying out research in this way. Within this section, I shall discuss the tensions between emancipatory research and the process of achieving a PhD within the academic community. I shall then explain the process of producing the 'accessible' report and finally I shall discuss the analysis process undertaken, outlining the fact that within this thesis this part of the process is more transparent than is perhaps usual.

Defining Emancipatory Research

The present research was carried out using an emancipatory model of methodology. This section will consider the literature around such research methodology. It will reflect on issues in emancipatory research and will draw on some practical research examples. It will be suggested that an emancipatory approach was an appropriate tool for this study on Disability and Citizenship because it reinforced aspects of *inclusion* exemplified by a Citizenship model and, furthermore, it accommodated the Social Model of Disability.

Historically, research has taken on different roles and purposes. Oliver (1996) suggests that there have been various stages of development in the research learning curve. He suggests that this development started with a *positivist model*, where social research was seen as a development of research in the natural sciences and hence would be value-free and unbiased. This view claims that, like *natural* science, the value base of *social* research must result in *objective* knowledge. It also emphasises the following of a single method of enquiry (rather than the growing tendency in social sciences to utilise a variety of methods). Hammersley (1995) suggests that the positivist mode of research was based on a number of assumptions, including:

> - that what is taken to be the method of the natural sciences is the only rational source of knowledge;
> - that this method should be applied in social research irrespective of any supposedly distinctive features of social reality;
> - that quantitative measurements and experimental or statistical manipulation of variables are essential, or at least ideal, features of scientific research;
> - that research can and should be concerned with producing accounts which correspond to an independent reality;
> - that scientific knowledge consists of universal laws;
> - that research must be objective, with subjective biases being overcome through commitment to the principle of value neutrality.

(Hammersley, 1995, p. 2)

In this way, the focus is on elements of objectivity, logic and measurable empirical evidence.

Hammersley goes on to say that the thinking of social research methodology in this way,

> ....obscures both potential and actual diversity in orientation and it can lead us into making simplistic methodological decisions. (Hammersley, 1995, p. 3)

Hammersley, therefore, is recognising the importance of interpretation and diverse approaches, particularly around a qualitative dimension, that may be more relevant to social science.

More recently, in recognising the difficulties and constraints of a positivist approach, social research methodology has developed the idea of the *emancipatory* research paradigm which centres around the illumination of the experiences of the inequality of social groups and their struggle and is therefore based on the idea that research should promote change. It can be seen that the positivist angle is based on the *individual* unit of data as a focus for research, whereas the emancipatory paradigm which I describe below challenges this approach and considers the *political* problem as an appropriate starting point (Hammersley, 1995).

The tradition of emancipatory research, which will now be discussed, was the basis for the methodology of the present research around Disability and Citizenship.

> Ideas on the reduction of power in participatory [emancipatory] research extend from the symbolic interactionist perspective in which the respondent's account is, in part, a function of the interview, and meanings are negotiated between the researcher and those being researched. Feminist research has also attempted to develop ways in which to reduce hierarchy between the researcher and those being researched, to improve the dialogue between the two. (Kirby 1999, p. 19)

As part of a critical paradigm starting with Marxist research in the 1960s followed by feminist research from the 1970s onwards, the concept of emancipatory research has now begun to have prominent influence in the disability field. The idea of emancipatory research has been to illuminate the experiences of social groups and their struggles, to confront oppression and power, to change social relations of research production and to change the focus away from individuals and onto the oppressions of society (Oliver, 1997).The importance of emancipatory research can be seen in,

> ...establishing a dialogue between research workers and the grass-roots people with whom they work, in order to discover and realise the practical and cultural needs of those people. Research here becomes part of a developmental process including also education and political actions. (Reason, 1988, p. 2).

Reason also goes on to say that such a view of research:

> ....is part of a new world view which is emerging through systems thinking, ecological concerns and awareness, feminism, education, as well as the philosophy of human inquiry. (*op cit* p. 3, 1988).

This suggests that emancipatory research is part of a democratic ideal in which participation is related to Citizenship.

The emancipatory paradigm seeks to address issues of power, ie. between the powerful (researcher, with knowledge and skills) and the powerless (the oppressed group). It challenges the traditional view of research where researchers 'do' research to those seen as powerless. Taylor (1989) argues that the traditional view of research exists to protect the 'powerful':

> ...the powerful are so rarely studied because they have the resources to protect themselves from scrutiny. (Taylor, 1989)

Oliver (1992) points out that emancipatory research is important in terms of challenging the role, and power, of the researcher. He suggests that traditional, positivist research (particularly in relation to disabled people) has often been perceived as alienating and oppressing. This is, he argues, in part, due to the position of the researcher in such studies as an expert in the field, a role not usually allocated to research subjects who have experiential knowledge of the topic under investigation. In contrast, within the model of emancipatory research, the researcher is situated as (only) one member of a team. They are often conceptualised as providing methodological tools and skills to others involved in the research project but, in its purest form, the definition of topic, data collection, data analysis and dissemination is conceived as a joint enterprise. In terms of disability research, Oliver (1992) advocates a challenge to the traditional model when he asks:

> ....do researchers wish to join with disabled people and use their expertise and skills in their struggle against oppression or do they wish to continue to use their skills and expertise in ways in which disabled people find oppressive? (Oliver, 1992, p. 102).

The view is, therefore, that, ideally, disabled people should undertake their own research so that disabled people are in control of the agenda. However, Morris (1992) suggests that there is a role for non-disabled researchers within disability research, which could be compared with that of an ally.

An interesting discussion on the issue of non-disabled people doing disability research was raised within consecutive volumes of the journal, Disability and Society (Drake, 1997, Branfield, 1998, Duckett, 1998). The call for debate on the issue, raised by Drake (a non-disabled researcher), suggested that, although non-disabled people should not speak 'on behalf' of disabled people, that they could play a role in exposing disabling aspects of society, supplying resources and assets to disability groups, and responding to requests for information and other forms of help from disabled people's groups. Branfield's response (as a disabled researcher) to Drake, states that the historical and political nature of the relationship between disabled and non-disabled people makes it inappropriate for non-disabled people to do disability research. She claims,

> For them [non-disabled people], their experience, their history, their culture is our oppression. (Branfield, 1998, p. 143)

She goes on to suggest that the development of 'disability studies' in academia should be led by disabled people and should not be 'hijacked or reappropriated' by non-disabled people:

> And whilst I am not suggesting a completely separatist movement, we must, if we break from our past, be the initiators and designers of our own liberation. (p. 144)

The response to Branfield came from Duckett (1998), who did not define himself as either disabled or non-disabled, but focused on the need for non-disabled people to be allies in the disability movement:

> The voices of non-disabled allies should be heard, as voices that add to the vociferous activities surrounding the disability movement. (Duckett, 1998, p. 628)

He suggests that the segregation of non-disabled people from disabled people is not particularly helpful, and draws parallels with the political situation of apartheid in South Africa. That is, he suggests that it is entirely appropriate for the 'international community' (including non-black people) to speak up against the oppression of the black community in South Africa. In applying this to disability, therefore, if the aim of the disability movement is to change society, then, at some point, it is necessary to embrace those outside the disability movement who have been convinced of their argument and include them in the campaign for change. He puts forward the argument that, even though historically non-disabled people and their institutions and organisations have been oppressive,

> To class all non-disabled people alike is as ideologically violent as the tendency to treat all disabled people alike. (p. 626)

These viewpoints illustrate the debate around non-disabled people doing disability research.

Within the present study, these issues were prominent since my own position was as a non-disabled researcher undertaking disability research. The introductory chapter in this thesis explains my background and interest in disability issues. I considered myself an 'ally' in the context of this research, and the process as a 'joint enterprise'. The research involved incorporating an Advisory Group of disabled people. In this way I recognised my limitations in terms of my knowledge of the *experience* of being disabled and I subsequently acknowledged the need to involve disabled people in directing the priorities of the research. However, within the remit of working toward a PhD in an academic environment, the notion of 'ownership' of the research became an important issue. That was, if disabled people were guiding the research, this could affect the extent to which I could justify claiming *ownership* of the final product of the research (eg. ultimately, the PhD qualification). I shall discuss this issue later in the chapter and I shall show how I resolved some of the dilemmas that arose. By prioritising the use of an Advisory Group, I shall also show how the agenda of disabled people did in fact guide and influence both the methodology and the findings of the research.

The emancipatory model also addresses the importance of *education* and learning from each other. Hall (1992), who discusses the educational element of emancipatory research, identifies its different components as : the research involves recognition of the knowledge, skills and power of the oppressed group and develops these through research; research questions arise from the priority of the oppressed groups who become active subjects rather than passive objects; that all those involved have a collective commitment to the research, including the researcher himself, rather than adopting the detached researcher role of a scientist (as in the positivist tradition). Furthermore, he suggests, emancipatory research works towards *social action* and proposes to effect change.

Martin (1996), again in relation to education, states that the benefits of emancipatory research are that professionals are challenged to consider their position in relation to those who use their services:

> ...to become facilitators of participation, development professionals need to rethink dominant attitudes to oppressed groups instilled in them through years of formal education and professional training and to ask where they see themselves in relation to poverty and social injustice: as part of the problem or part of the solution? (p. 7).

Therefore, it can be seen that emancipatory methods have an educational dimension. Added to this, Kirby suggests that this kind of research can add to levels of democratic participation and social justice when she talks about research involving young people:

> emancipatory research is not just about improved research methods. It is also about achieving democratic participation and social justice for children and young people. By influencing what is researched and how their lives are represented, they participate in institutional decision-making processes. The more young people become actively engaged in research, the more they personally gain, and the more they may expect- and demand- that changes come out of the findings. (Kirby, 1999, p. 1)

Feminist researchers have also critiqued 'traditional' research because it typically replicates wider structural hierarchies between professionals and those in socially less powerful positions, rather than trying to challenge these imbalances (see Olesen, 1998). They have therefore attempted to define additional criteria of research adequacy and credibility- which addresses the power dynamics in the research context- rather than confine themselves to the simple measures of validity typically used in traditional research. Child-focused research similarly needs to consider the extent to which it challenges- or replicates- the professionals' position of power over children and young people. Hobbiss *et al* (1998), for example, expressed the need for 'added value' measures when assessing the quality of young peer research, such as egalitarianism, shared ownership and equal opportunities to participate.' (Kirby, p. 28)

In using emancipatory principles to underpin methodology, researchers can adopt differing practical ways of undertaking the task. There are various techniques, terms and schools of thought which can be included in a process defined as 'emancipatory' research. They include Participatory research (often used where people become participants in the process rather than mere subjects); Action research (where the main aim of the research is to effect change, the term often being used in research to do with education); Participatory Appraisal (a variety of simple techniques often used in rural communities and developing countries where literacy levels may be low); Community research (where the whole community has an opportunity to research itself in order to influence decision-making); Peer research (where people are trained in research skills to research their peers); and Systems research (usually used in management consultancy where all members of a system are seen as participants in the research, rather than just the management team) among others. Invariably, the differing terms have often been used synonymously to explain similar or same processes and it is difficult to be clear about the boundaries. I would argue that the main difference in terminology is in the area of original definition, that is, whether the originating discipline is education, sociology, social and community sector, or management.

Within this thesis I refer to the methodological process undertaken in the research as 'emancipatory'. This is, in part, because researchers in the field of disability (Barnes, 1991; Oliver, 1990; Reason, 1988) prefer to use this term, clarifying it in terms of 'establishing a dialogue...part of a developmental process' (Reason, 1988, p. 2). Other disability researchers (Zarb, 1992; Mercer, 2002) who have further explored the debate around terminology, argue that the term 'emancipatory research' is more appropriate for research that aims to change the social relations of research production. These authors suggest that, when researchers are committed to undertaking emancipatory research (rather than participatory research) research becomes part of a wider process of facilitating the emancipatory struggles of disabled people. Humphries (1997), for example, claims that the emancipatory mode is geared to praxis-oriented research that exposes social oppression and facilitates political action to transform society. 'emancipatory research' is also a term that has been used in feminist research (Ramazanolgu, 1992; Stanley and Wise 1993; Haraway, 1988) to show that research is part of a political process that challenges oppression. I am therefore siting the research within the context of a disability and feminist paradigm.

Some researchers (Kirby, 1999; Hart, 1992) have used the term 'participatory research' to describe the process of involving young people in research. Although I recognise that participation was an important element of the research process I undertook, I feel that the term 'emancipatory research' is more appropriate since it recognises my role as an 'ally' in the struggle against the oppression of disabled people. In essence, the present research had a political element and, in discussions with the Advisory Group of disabled people, sought to effect change. This, then, constitutes more that 'participation'. It reflects being part of a wider process of challenging oppression and power imbalances.

One of the key ideas of emancipatory research is for a process of empowerment to take place in which the oppressed group gains power in the research process and effects change in relation to their own lives. Oliver (1992), however, points out that the use of the term 'emancipatory' to describe the research process could be seen as inappropriate since no-one can empower people but themselves. He suggests that the real issue is how research can *facilitate* or *contribute to* the emancipatory process, rather than how it can empower individuals. I would argue that empowerment should come through self-empowerment rather than the researcher ' giving power' to someone else as this implies that the researcher is in an initial position of power and has not relinquished that position of power. Morris (1991) also suggests that research should turn the spotlight on the oppressors rather than the oppressed and should make the personal political, hence, in the case of disability research, focusing on the manner in which society produces disability. In addition, Zarb (1992) has drawn a distinction between emancipatory research which seeks to change both the social and material relations of research production and Participatory research which he considers deals only with the former and does not address the issues of the funding and resourcing of research. He goes on to say, however, that emancipatory research can only take place in a post-capitalist society. While acknowledging these arguments, I shall continue to use the phrase *emancipatory research* to describe the methodological base which this study seeks to follow not least because it is the terminology used within the area of disability research.

emancipatory research, therefore is different from traditional research in that it seeks to address the issue of *power* in the research process. It thus expresses a desire for the researcher to want to understand the culture and dynamics of the people they are researching rather than presuming that, because of their position, the 'researcher knows best' (Hammersley, 1995). Furthermore, it therefore can be seen to have a *political* bias in that it attempts to address issues as part of the 'struggle' of an oppressed group. However, some 'traditional' researchers argue that this affects the objectivity and creation of knowledge inherent in the research process.

The model of emancipatory research (deliberately) contradicts with the view of the expert researcher prevalent within higher education establishments and particularly with the individualised construction of research degrees (such as PhDs) which requires a thesis to be the exclusive product of one individual. It may be that university regulations discourage students from adopting this model of research whereas other settings such as non-academic communities or organisations may be more pro-active in encouraging an emancipatory approach. Much of the discussion in the second half of this chapter will address the tensions inherent in conducting an emancipatory research model within the PhD framework.

Reason (1988) talks about the different *levels* of participation which can be involved in emancipatory research, ranging from a 'token gesture' to full control by those being studied. This also indicates that participation can take place at various points of the research process. Participants could be involved in the whole, or parts, of the research process, such as, planning the research, gathering data, analysing data or report writing. The following examples show how different projects have employed participants in varying levels of participation:

i) A project working with people with learning difficulties (Townsley, 1995) had a high level of participation:

> Working in small groups, with the help of a service worker and a researcher, the users involved in one project decided which methods to employ, devised questions to ask in a postal questionnaire and fed back the results at two seminars. The group are paid for their work and decide how the money should be used. (Tozer and Thornton, 1995, p. 3)

ii) A recent Save the Children research project (1999) on youth transitions used a reference group of young advisors who discussed the work throughout the research project. The reference group helped to amend the research aims and methodology and piloted draft interviews. The adult researchers conducted the interviews and discussed the findings with the group. It is the intention that the group will have an input at the analysis stage and dissemination.

iii) Research was commissioned by Barnardos (Ash *et al,* 1996) around further education for disabled students. The research employed a research manager, a research officer, and 3 young research assistants who had left a special school. The research assistants were involved at all stages of the research process- they designed the interview schedule, were given training in interview techniques, and co-authored the final report.

Kirby (1999) reviews varying levels of participation when working with young people as co-researchers. She suggests that there are different ways of involving young people, such as: being informed; expressing a view; influencing decision-making; making joint decisions with adults; and making final decisions. Kirby suggests that the level of participation depends on numerous factors, such as who commissions the research, what role the researcher adopts (eg. youth worker, educator, helper, statutory power, researcher) and how much power the young people are expected to have. Research around involving young people with impairments or high support needs has been done by B. Beresford (1997). She showed that disabled young people could be involved in research if given enough support to help them participate. Support could be in terms of additional time to ensure understanding, being aware of access issues, providing extra worker support between sessions, providing information in accessible formats, and running disability equality training for workers and other young people. Within the methodological process of the present study, I needed to acknowledge such support, particularly in relation to the provision of information, access issues, and individuals' understanding of the process.

The Children's Rights Development Unit (Hart, 1992) have developed the idea of the 'level' of participation when involving young people as peer researchers into a chart which they refer to as a 'Ladder of Participation', which is summarised below :

Figure 5: Ladder of Participation

Children have ideas and use adults for advice and support. Adults do not direct but offer expertise for children to consider.	8. Child initiated shared decisions with adults	
Children have the initial idea and decide how the project will be carried out. Adults are available but don't take charge.	7. Child initiated and directed	DEGREES
Adults have the initial idea and children are involved in every step of the planning. Their views are considered and they are involved in the planning.	6. Adult initiated shared decisions with children.	OF
Project is designed and run by adults but children are consulted. They have full understanding of the process and their opinions	5. Consulted and informed.	PARTICIPATION

are taken seriously.		
Adults decide on the project and children volunteer for it. They understand the project and know why they are involved. Adults respect their views.	4. Assigned but informed.	
NON-	3. Tokenism	Children are asked to say what they think about an issue but have little or no choice about how much they can express and whether it will be acted upon.
PARTICIPATION	2. Decoration.	Children are asked to take part in an event but have no understanding of the issues.
	1. Manipulation.	Children do or say what adults suggest they do but have no real understanding of the issues or children are asked what they think, adults use some of their ideas but do not tell them what involvement they actually had in the final decision.

(Hart 1992)

It could be suggested that the levels of participation of peer researchers in the research process are often related to the dynamics of power. Kirby (*op cit* p. 42) makes this point by suggesting that a distinction needs to be made between a) making decisions about what has to be done and b) carrying out tasks. She argues that the decision-making element involves more power.

In this way, then, it can be seen that the main focus of emancipatory research is around participation. This, in turn, links with the Citizenship literature around inclusion. However, as the discussion has shown, there are varying levels of participation, ranging from 'token gesture' at one end of the scale, to full ownership by participants, at the other end. The degree of participation I achieved in the present study will be discussed in more detail later in this chapter. The discussion will show that, although the present research aimed to be truly emancipatory, the *level* of participation achieved was affected by the nature and process of completing, and owning, the final product of a PhD within an academic environment.

The role of the researcher in emancipatory research

emancipatory research involves the researcher drawing on the knowledge and experience of others as equal participants. Tozer and Thornton (1995) comment that this is not always easy:

> For the researcher, drawing on lay advice is novel. (p. 4).

In their study of older people and Community Care, in order to 'justify' using an Advisory Group, they also had a PAG (Project Advisory Group) and they claimed that:

> The PAG is constituted to achieve a balance of research, academic, policy and practice expertise. (p. 4) .

Tozer and Thornton talk about the need to give the research credibility and the role of the PAG to ensure that the research was carried out to a high standard. However they claim that both groups were 'truly advisory' and that neither had authority over the research:

> ...there was no overt transfer of power from the researchers to either group during its lifetime. (p. 5).

In terms of managing the practicalities of undertaking research in this way, they employed two main researchers (rather than one) in the process. One researcher was used to set up a focus group, sort out the practical arrangements, chair the meetings and provide administration and take the minutes of group. The second researcher made brief notes during the meetings and about the process and there was mutual support between the researchers and also a sharing of tasks. In this way, they could share the 'role' of the researcher.

Although Tozer and Thornton were keen for the members of the group to have some power, in their early meetings, when the researchers suggested that the group members could chair the meetings and take the minutes to 'spread' the power, the group declined because they did not feel confident enough at the time. Therefore,

> ...the responsibility for the running of the meetings rested firmly with the researchers. (p. 18).

In fact Tozer and Thornton state that they controlled the agenda of the meetings, which usually involved a project update and a task to be done.

I would argue that it is difficult to define a clear role for the researcher in an emancipatory process and it is also difficult to attain a fair and just balance between different roles. Kirby, when talking about research with young people suggests:

> Traditionally, a researcher is expected to interact in an (apparently) detached and impartial way, while a youth worker's role is more typically about education and development of young people. emancipatory research demands a combination of these roles- what Hart (1992, p. 19) describes as the 'de-

> professionalisation' of the researcher's role into a 'democratic participant'. Here the workers provide the necessary technical support for the young researchers to carry out the tasks themselves, and they educate the young people by sharing knowledge and facilitating critical awareness, rather than imposing views and ideology. (p. 57).

Hart goes on to say:

> A very important role for the researcher, is to use whatever knowledge or insights she may have of the larger causes influencing the problem, and to engage in a democratic dialogue with the participants over these larger causes. Through the process of carrying out this emancipatory research the participants not only transform some conditions related to a practical problem in their lives, but they also educate themselves about their general situation, thereby empowering themselves more generally for future action. (Hart, 1992, p. 19)

The experience in the present study created difficulties in terms of the role of the researcher. In writing up some notes after an early meeting I reflected:

> It's a difficult balance between facilitating the group and ending up guiding which way to go. If I don't guide it I can get a bit lost- however I'm not there as a teacher, but as a co-researcher.

Maguire also considers the balance to be difficult:

> I had difficulty juggling the emancipatory researcher's triple roles of organiser, educator and researcher. (p. 162).

I would suggest that in emancipatory research, the researcher may have to take on numerous roles rather than just that of the researcher. These could be: organiser, researcher, group facilitator, transcriber, administrator, motivator, activist, and trainer.

Zarb (1992) proposes that an emancipatory approach could be used to generate genuine *partnership* between researchers, the 'researched' and their organisations. He suggests that in disability research, disabled people should be involved in the *process* of research rather than merely as subjects. He proposes that ideally disabled people should undertake the research themselves, or the researcher could make themselves available to disabled people for them to use the researcher's skills and knowledge. Ultimately, he argues for disabled people controlling the research agenda. Finkelstein (1980, p. 63) also adopts this position and calls for research to address the behaviour, roles, perceptions and attitudes of 'helpers' (eg. carers, professionals), to involve disabled people in the actual process of research rather than being passive subjects, and that the purpose of the research should be to contribute to improving the quality of life for disabled people.

The traditional role of the researcher, therefore, is greatly challenged within an emancipatory research process. I also experienced tensions within the process due to the context of attempting to achieve a PhD in an academic environment. The significance of this dilemma became the essence for a joint conference paper (Garbutt and Seymour, 1998) and shall be discussed in greater depth later in this chapter.

It can be seen that there are benefits to using an emancipatory approach. By initiating research from a political base, it sets the research in its wider socio-historical context, which aids a greater understanding of the situation. Furthermore, while all research can be seen to be value-laden, emancipatory research makes its values explicit. Finally, this kind of research is important in that it directs its efforts toward countering oppression.

Criticisms of the emancipatory approach

Although an emancipatory methodology can be seen to have benefits, Hammersley (1995) suggests that its emphasis on a political base can cause problems around authenticity and bias. In response to the above justifications for emancipatory research, he suggests that with such diversification of political causes, there are numerous contexts in which to begin research. He goes on to say that no one context will give a true picture. The purpose of research, he suggests, should be the intrinsic task of producing knowledge rather than being political. He argues that undertaking value-based research provides no legitimate function and finally, he refutes the view that traditional research supports oppression and emancipatory research counters it (p.40-41).

Following on from this, Hammersley also criticises emancipatory research because it assumes that research has a role to play in the lives of those being studied (p. 108) whereas, he suggests, in most cases research is not a crucial factor in a person's life. He suggests that as no human activity is neutral, and therefore no research has value-neutrality, all research should seek to look at contrasting views. Haskell (1990) concurs with Hammersley's view that research should not have a political bias, in that he emphasises the need for:

> ...an ascetic self-discipline that enables a person to do such things as abandon wishful thinking, assimilate bad news, discard pleasing interpretations that cannot pass elementary tests of evidence and logic, and most important of all, suspend or bracket one's own perceptions long enough to enter sympathetically into the alien and possibly repugnant perspectives of rival thinkers. (Haskell, 1990, p. 132)

Hammersley argues that researchers can have many reasons for doing social research and that while no restrictions should be placed on the indirect goals that researchers should pursue (p.116),

> ...all that is required is that the goal to which their work as researchers is immediately directed, and which primarily controls how they do it, should be the production of valid and relevant knowledge. (P. 116)

He disagrees with researchers such as Gitlin *et al* (1989) who suggest that all research methods should embody 'the purpose of emancipation'. Hammersley states that this takes away from the true purpose of research to fulfil the task of *producing knowledge*. Feminist researchers, (such as Ramazanoglu, 1992; Stanley and Wise

1993; and Haraway, 1988) however, maintain that the production of knowledge can also be undertaken within a political context. These authors, like many disability researchers, propose that one's personal experiences are relevant to, and useful in research. This contrasts with traditional research with its emphasis on an objective, scientific method. Furthermore, these authors argue that women's experience of *oppression*, can provide a useful and positive dimension in researching the oppression of other women. In this way, they suggest that research about women should operate within a distinctive political and philosophical framework. Feminists writers, therefore, suggest that Hammersley's argument is too narrow, because it does not take into account the possibility of undertaking research and producing knowledge within a political and emancipatory context.

Ultimately, Hammersley suggests that research should not be political because, in undermining the pursuit of knowledge, you take away the authority of the research and knowledge produced (p. 118). He quotes Haskell to reinforce this viewpoint:

> When the members of the scholarly community become unwilling to put intellectual values ahead of political ones, they erase the only possible boundary between politically committed scholarship and propaganda, and thereby rob the community of its principal justification for existence. (1990, p. 151)

I would suggest that although a researcher needs to validate the use of a political base, the importance of emancipatory research is in challenging the traditional barriers between academia and society/ community. In this way, I would suggest that 'committed scholarship' does not need justification in order to exist in an academic community. However, it can be recognised that a great deal of research within a loosely based emancipatory paradigm has been done within development and community work (eg. see examples quoted earlier within the section on 'levels of Participation'). It may be that the political base in these situations (ie. not within an academic environment) could be seen to be more relevant and accepted.

Furthermore, much of the research with disadvantaged groups has arisen out of a particular standpoint in conjunction with service users rather than in an exclusively academic environment. I would suggest that any style of emancipatory research attempts to make research more accessible and to disseminate results beyond the confines of an academic environment. It could be suggested that there is a fear of the de-professionalising of the specialist knowledge and skill of academics. The challenge of the present study was to locate an emancipatory research project within an academic environment where the context was in terms of achieving a PhD.

Research based on emancipatory principles, therefore, can be seen to be particularly relevant to disabled people. emancipatory research involving disabled people can be seen to reflect a Social Model of Disability in that it can accommodate the political dimensions of recognising oppression and power. It can also be *part* of the process of the self-emancipation of disabled people.

Oliver (1992) argues that in the past research has not influenced policy or the lives of disabled people, but has merely increased academic knowledge. Although increasing academic knowledge is a viable purpose of research, Oliver suggests that, when doing research related to an oppressed group, the results of the research should seek to effect change. He recognises the oppression of disabled people and suggests that researchers should not be outsiders but should join in the struggle and challenge society and governments to change. Research, he concludes, is part of the problem of alienation of disabled people, not the solution.

An emancipatory approach can be seen to be particularly relevant for the research in this study in relation to disabled people because the paradigm aims to illuminate the experiences of social groups and their struggles. Stone and Priestley (1996) suggest that the following are the core principles of the emancipatory research paradigm in relation to disability research:

1. The adoption of a Social Model of Disability as the ontological and epistemological basis for research production.
2. The surrender of falsely-premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation.

3. The willingness only to undertake research where it will be of some political benefit to the self-empowerment of disabled people and/or the removal of disabling barriers.
4. The devolution of control over research production to ensure full accountability to disabled people and their organisations.
5. The ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers.
6. The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.
(Stone and Priestley, 1996).

I would suggest that in the present study, I particularly emphasised Stone and Priestley's notion of '...the ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers....' This was achieved through a complex analysis process, which will be described later.

The next section will consider the role and purpose of the Advisory Group in emancipatory research. The present study utilised an Advisory Group of disabled people to keep me (as the researcher) focused on the 'personal voice' of disabled people. This gave the study an added dimension since the experiences/ opinions of the group focused the research at an early stage and gave direction to the analytical process. The utilisation of an Advisory Group is particularly appropriate in relation to emancipatory research since it keeps the researcher (in the case of the present study, a non-disabled researcher) in touch with the experiences and 'struggles' of disabled people.

Using Advisory Groups: previous examples

In this section, I shall discuss the role of an Advisory Group in the research process. The present study used an Advisory Group of disabled people to guide and control the research process. This was due to the fact that I was not a disabled person and in order to prioritise the views and priorities of disabled people, I needed to consult and collaborate with them. I would like to discuss three areas in relation to Advisory Groups: the *Model* of an Advisory Group; the *Role* of an Advisory Group and the *Process* of incorporating an Advisory Group into the research.

Model

In terms of the *model* of an Advisory Group, I shall draw extensively on examples by Maguire (1993), Kirby (1999) and Tozer and Thornton (1995), to illustrate different methodological emphases in relation to emancipatory research and Advisory Groups.

Maguire (1993) undertook research with the Battered Family Services (BFS) as part of a doctoral research project in Connecticut, USA. At the time when the research was undertaken, there was no mechanism for users of the service to have a say in agency decisions and the battered women had little or no power or participation in their operation. Maguire states:

> I thought that the ideal emancipatory research project ...would hold empowerment, liberation, and social transformation as long-term goals...

The staff at the BFS supported this because they said that several women had expressed an interest in forming a client support group.

Maguire states that she immersed herself in literature about emancipatory research with its agenda for emancipation, social transformation and 'pretentious rhetoric' and found that it presented an idealistic model. She recognised the male-centred aspects of former emancipatory research, such as 'male' agendas and male subjects as the focus of enquiry, and found that using a feminist perspective helped to focus her project. She felt that other emancipatory research projects had largely ignored issues to do with women who were invisible, submerged, unheard, and hidden. She found that in most of the literature she reviewed many projects worked only with male community members:

> Feminist theory and issues were largely absent from emancipatory research theoretical debates. (p. 163).

She was interested in finding out which people and social systems emancipatory research was trying to empower. Her understanding was that:

> Although emancipatory research wanted to break the monopoly on knowledge creation, it seemed to be duplicating or colluding with the monopoly of male-centred traditional social science research. (p. 163).

Furthermore,

> emancipatory research has highlighted the centrality of power in the social construction of knowledge, yet it has largely ignored the centrality of male power in that construction. (P. 163)

In her study, Maguire formed a women support group. This played a similar role to a research 'Advisory Group' since it informed the researcher of the priorities and insights of the women.

Another author, who draws on numerous examples of emancipatory research in practice, this time with young people, is Kirby (1999). Kirby frequently calls the process she describes as *peer research*, rather than emancipatory research, but the process generally involves the same ethos of participation, involvement and addressing issues of power. It could be argued, however, that some 'peer research' with young people may not always be truly emancipatory since it does not usually involve the researcher in 'joining in the struggle' of challenging the oppression of young people. Peer research with young people has generally come from the areas of education and youth work, with the aim of 'empowering' young people. I would suggest that there is rarely any ultimate *reduction* of power of the *researcher* involved. However, that is not to invalidate the role of peer research. It could be argued that very rarely does any researcher achieve a truly emancipatory role due to various restrictions and agendas. In terms of young people, their legal status as 'minors' makes it difficult to grant them total responsibility and ownership of research since, ultimately, the adults need to assume responsibility for the young people (depending on their age).

The third example I shall reflect on is a model by Tozer and Thornton, (1995). The aim of their research was to:

> ...discover what opportunities were developing for older people to have a say in the planning and evaluation of Community Care services. (Tozer and Thornton, p.1)

The research was therefore looking at which methods of involvement suited older people in terms of participating in decision-making and having an influence. They describe their experience of setting up an Older Persons Advisory Group (OPAG). The purpose of the group was to keep researchers in touch with the priorities of older people, particularly those using Community Care services, to advise the researchers on different aspects of the research process, such as commenting on the research questions, fieldwork methods, research findings; and finally, for the researchers to learn from the process of setting up and working with the group with the aim of using similar methods in the planning and providing of services for elderly people. They also had a Project Advisory Group (PAG) which was made up of academics and practitioners and which had final control over the process. The idea of the OPAG was to challenge the assumption of the researcher as the expert and to look at the elderly person's own explanation of his/her experiences. They also wanted to provide a partnership and two-way communication with those whom they wished to find out about (ie. in this case, older people). Furthermore, they wished to be more accountable to those people they were researching and to promote active participation. They suggest that, by using an Advisory Group they were able to address issues of user involvement within the context of Community Care:

> The impetus for this involvement in research has often come from researchers who are, or have been, service users themselves and are active in the disability movement. (Tozer and Thornton, 1995, P. 2).

They comment that this approach was different from a more traditional approach where users were seen as subjects.

Tozer and Thornton argue that the benefits of doing research in this way were: the researchers saw the elderly people as partners rather than research material; the group helped the researchers gain an insight into the experience of being older; and the researchers were reminded of the range of situations for older people (which helped to reduce stereotyping in service provision). Similarly the Advisory Group became more visible in that local organisations learnt about them, it promoted user involvement in services and it provided an example of such a group being used for other research projects and service providers. In conclusion, therefore, Tozer and Thornton described the process as a learning experience for the members, the researchers and others and the discussion and process of the Advisory Group became research material in itself (*op cit*, p. 41). In a later section I shall discuss their experiences at some length and then show how I drew extensively from their experiences of using an Advisory Group within the present study.

Role

In the same way that the *model* of an Advisory Group differs (eg. in its make-up, numbers, focus, purpose), the *role* of Advisory Groups also differ. Some groups may lead and advise the research process on a continuous basis, while others may be called upon at various points of consultation. Likewise, the tasks of groups vary from project to project. In the study by Tozer and Thornton (1995), the researchers did not hold preconceived ideas about the way the group might develop, but,

> ...they anticipated that a group of older people might be more difficult to form than a group drawn from younger disabled adults or people with mental health problems. (p. 8)

They explained this by suggesting that older people perhaps have less stamina and would not generally be used to groupwork.

Tozer and Thornton's aim was to look at the ways in which older people could be involved in influencing service planning. However, they thought that explaining the role of the group might be difficult and,

> ...users would understandably be focused on local Community Care services and would probably prefer to express views about these rather than the *methods* that Community Care interest groups might use in gaining the views of older people nationwide. (p. 8)

Some of the early discussions within the Advisory Group centred on the practicalities of access, comfort, transport, and timing in order to make the group as accessible as possible to a large number of older people. They attempted to recruit a cross-section of older people, to represent a wide group and to be representative of typical views of their peers. They also wanted to recruit people with a degree of confidence and 'know-how'. Their strategy for recruitment involved producing a handout and sending it to local voluntary organisations asking for those who were interested to contact them. They also recruited through their local Social Services Department where potential participants were identified through members of staff.

Tozer and Thornton commented that people were surprised to be asked:

> One member, who was asked if she would take part by a member of staff, initially said, 'why me? I'm not clever enough to go to university' but was told, 'because you've got a bit of gumption and will speak up for yourself' (p. 9).

Another commented that,

> ...it was a pleasant surprise when I learnt that the home care manager had put my name forward!. (p. 10)

Tozer and Thornton's Older Person's Advisory Group had a mixed membership in terms of gender, age, background, and place of residence. Some people knew each other but others did not and some held positions in other groups , clubs and networks. Tozer and Thornton felt that whether people knew each other or not did not make a great deal of difference to members' experiences of the group as the research gave them a common interest.

In their group they had a married couple who commented:

> It had been supportive, at least initially, to come together because at the beginning I was very, very dubious. We thought we weren't as good as some of the other people. (p. 12)

The mixed membership also reminded the researchers of the diversity within any group of older people. The early meetings of Tozer and Thornton's Advisory Group tended to be tinged with curiosity and apprehension. One member commented:

> I had no idea what to expect. I didn't know really what you were looking for. I was a bit apprehensive. (p. 13)

Initially, members had '...some suspicion that it was the token older people's group' (p. 13). Apprehensions were also evident because the meetings were based in the university and some members had expectations of a classroom situation. This caused some concerns for certain members. In hindsight, the researchers state:

> The possible significance of the University connection had not been considered by the researchers. (p. 13)

Although there were negative aspects to the location, the group did acknowledge that they felt it was important to be independent from Social Services and eventually, some felt that being within an academic environment gave the project added status.

Kirby (1999) also comments on the role of Advisory Groups within her work with young people as co-researchers in an advisory role. She states that the young researchers can be seen as: a project user/ volunteer; a partner/ colleague; or a trainee / employee. She points out that the choice of role has implications for how workers relate to members of a group and to their responsibilities. She suggests that the role of Advisory Groups can be: forums for discussing ideas; a place where outsiders can offer their informed views; a place where professionals help to identify other resources and support; an opportunity to establish a dialogue between professionals and young people; and a way to encourage a wider ownership and commitment to the research findings (p. 44).

In contrast, Maguire (1993) describes the role of her women's group within the Battered Family Service research project, as a *support* group rather than an *Advisory Group*. In this project, the women controlled the agenda. She was also able to have some women participating in the process but choosing not to be a member of a group. She emphasised the importance of building up relationships with individuals before establishing the group in order to foster trust and explain the process in which they were to be involved. She refers to this process as a 'dialogue' whereby participants (including the researcher) established their own boundaries and priorities.

The different examples (Tozer and Thornton, Kirby, and Maguire) not only outline differing levels of participation but also varying views about what constitutes an Advisory Group in research.

Process

Using the aforementioned examples, I would like to outline some of the *processes* involved in using an Advisory Group. Tozer and Thornton's Advisory Group met on 12 occasions, on average, once a month. They used a ground floor meeting room on what they call 'home territory', that is, the university. I would point out that although this was home territory for the researchers, the other participants (the older people) may not have considered it in the same light. Evening meetings were deemed unsuitable because of perceived fatigue and the expected preference of members of the

OPAG not to go out after dark. The group met regularly in the same place (in the university) and other academics became aware of their existence and input:

> The group was also more visible to other researchers, which generated questions about their meetings. It was, perhaps, one step towards making academia more accessible to, and in touch with, the people to whom SPRU's [the research unit] work often relates. (p. 15)

As the meetings developed, the researchers initially led some task-centred work such as getting the group to structure a questionnaire; devising a skills list; commenting on an interview topic guide; raising questions about fieldwork; commenting on a draft leaflet about a service. Another aim of the group was to challenge the assumptions, stereotypes, and attitudes towards growing old and thus they instigated general discussion about older people's concerns and priorities. In addition to the set agenda, the group discussed other topics. The members could share their experiences/ expectations of attitudes towards growing old and, in this way, take some ownership of their own meetings. It is interesting to show how the experiences and 'stories' of the participants gave 'added value' to this kind of research. However, this can blur the distinction between participants acting as co-researchers, that is, being involved in the research process and participants acting as subjects, providing data for the study. This issue will be discussed later in relation to the present study.

Within the study by Tozer and Thornton, therefore, there were elements of a set agenda by the researchers and a shared agenda with the Advisory Group. However, as I go on to explore later in this chapter within a discussion of ownership of the research in the present study, a great deal of research, including research within an academic setting, has tensions created by conflicting and contrasting demands. Within academic institutions, for example, research agendas may be set by funders/ commissioners of the research, the priorities of the academic department, the focus of the individual researcher and the wishes of the individuals and organisations being studied.

Within the present study, there were particular tensions around the agenda of being a PhD student in an academic institution and undertaking the research in an emancipatory way by using an Advisory Group of disabled people as part of the process. The ideal of disabled people being equal participants in a research team contrasted with the academic requirements of a PhD being the original product of one person. These tensions illustrate that, in reality, there are often different agendas to negotiate in the research process within an academic setting.

Maguire (1993) describes the process she undertook in her study. The main aim of her study was to test a method. However, although she defined a general problem, she left it for the women to refine it. She proposed and followed up three phases (plus a writing-up phase) within her process:

Phase I- dialogue, organisation of group, problem formation
Phase II- formation of the women's group/ research process
Phase III- collective assessment of the research process
Final phase- writing and defending the dissertation

As in Tozer and Thornton's (1995) process, there seemed to be three sets of goals: one set by the group themselves, one by the researcher, and one by the Battered Families Society (BFS) Board (With Tozer and Thornton it was the Older People's Advisory Group (OPAG) and the Project Advisory Group (PAG)). According to Maguire, the BFS board's agenda was to find out information about the problems women faced when they left the shelter and to provide recommendations for a support group. The researcher's agenda was to help the women to gain power, confidence and skills and the women's agenda was to influence change in the organisation. Consequently, these obvious differences in agendas could easily affect the process of the research. Other goals that may impact on the research process are, the agenda of the funders/ commissioners, the agenda of an academic institution and wider political agendas.

In terms of process, Kirby (1999) also outlines a proposed schema to follow in carrying out peer research with young people, which can be adapted to other participatory methods and groups:

1. Introduce the research to the young people
2. Set aims and objectives- either by the worker, jointly or by the young people
3. Explore research issues- talk about own views on topics chosen
4. Choose research methods
5. Design research tools, eg. questionnaires, interview schedules, mapping/ ranking

Different stages in designing research tools:

- decide subject areas to include
- word draft questions
- design how to ask questions
- order of questions
- discuss draft questions, order and methods

6. Conduct face-to-face research methods

ie. young people given training/ practice in interview skills.

7. Recording data

eg. tape, written, by young people or workers, video etc.

8. Accessing respondents- who, why, where, involving different groups, equality issues, negotiating access, convincing agencies that young people should be OK/ respected.

The *process* of the Advisory Group, therefore, evolves from the aims, context and priorities of the research and the researcher(s). Although the process can be fluid, the examples cited give some guidance concerning the elements that need to be included.

The present study used an Advisory Group to advise on a *long-term* basis within the aims and objectives of the research. The research looked at the attitudes of professionals towards disabled people and was based on an established research enquiry arising from a literature review. Although the Advisory Group guided and changed the elements of the research, the original theoretical base was still used as a focus for the process. The purpose of the research was to explore a research question using an emancipatory approach. The research also set out to test the methodology. Although I had ultimate 'control' of the final product, the Advisory Group shared the ownership of the process. This will be discussed more extensively later. This, then, differs from Tozer and Thornton's study in which the *researchers* and the *PAG* had control of the research process although they also purposefully set out to test a specific methodology. It can be seen that Tozer and Thornton followed an approach based on issues relating to Community Care services. In the example by Maguire, it can be shown that she started with an 'ideal' and gave control to the women's group to set the agenda with the emphasis on empowering the participants. She seemed to provide fewer clear aims and objectives about the outcomes of the research and little training or explanation of research skills. Finally, Kirby outlined some clear principles for emancipatory methodologies with young people where there is a shared agenda.

Within the present research, therefore, I was able to draw on, but not necessarily duplicate the above examples in defining and developing an Advisory Group as part of an emancipatory based research process.

The Advisory Group- the present study

Within this section, I shall outline the way in which I drew on the examples of Tozer and Thornton (1995), Maguire (1993) and Kirby (1999) to develop the idea of using an Advisory Group. I shall also highlight this process in relation to the research with disabled people and the role of the researcher.

Kirby (1999) states that there are different reasons for doing emancipatory research. She suggests that when involving young people in research the researcher could be in any one of the following positions:

- wanting young people to participate in research
- working with young people and wanting to use research as a tool
- educating young people, including teaching about research.

In this way she is referring to the position of the researcher. However, she also indicates that there are other reasons related to empowerment, ethical values and influencing change, such as:

1. Creating better research both ethically and democratically: using young people to interview their peers creates better methods of collecting data.
2. Involving young people as citizens and increasing their knowledge of decision-making structures and enabling them to take action.
3. Young people gain in terms of personal development. They gain skills, knowledge and confidence. (p.7)

Following on from these ideas within the theoretical standpoint of Citizenship, and keeping in mind the aims and objectives of the study, I felt that my own research should follow an emancipatory methodology.

This could be done in a number of ways:

1. Have disabled people doing the research themselves, a preferred option by most disability activists and researchers. However, this would not be a practical solution in my case as I am not disabled.

2. Talk to disabled people and ask them what they would want from the research ie. involve them in the planning and process of the research, the emphasis being on partnership.
3. Have a consultative, advisory committee of disabled people to give continuous feedback and advice. Since I am not disabled myself, I cannot speak as a disabled person so I have to represent their views by having continuous consultation and being accountable to them. I would thus be able to offer my research skills to the group to use.
4. Refocus the research away from the disabled person and onto the environment/ society in which they live, in this way focusing on the social model of disability.
5. Formulate the research so that the conclusions can challenge oppressive systems of society (eg. in effect, challenging disablism) and effect change.

In planning the research, points three, four and five were prioritised. The level of participation of disabled people within this study was influenced by the academic context of the research. This will be discussed later in the chapter. I decided to utilise an Advisory Group (point three) of disabled people. In this way, I was recognising the contribution of the *experiences* of disabled people to this study and my own role as a non-disabled researcher. Furthermore, I decided to refocus the research away from disabled people as subjects and onto a disablist society (point four). To this end, I chose to interview professionals who worked with disabled people rather than disabled people themselves. This also challenged the usual power relations in research ie. those in a position of power would become the subjects of the research. Finally, my aim was that the research should become relevant and useful to those whom it concerned and could challenge oppressive systems (point five). I was therefore concerned to produce the findings of the research in a format that was accessible to those outside the academic community, encourage the Advisory Group to translate the findings into useful recommendations for policy and practice change, and actively promote these recommendations to other organisations.

The Advisory Group was recruited by sending out invitations to all local Voluntary agencies relating to disability. This included agencies relating to physical impairment, learning difficulty, mental health, mild learning difficulties such as dyslexia, and other disability-related support groups such as those to do with tinnitus and M.E. By doing this, the ethos of inclusion was adhered to and also the recognition that much disability research focuses on physical impairment or learning difficulty as discrete conditions rather than drawing people together as an oppressed group.

In terms of my professional practice as a Social Worker in Social Services, and later as a Development Worker in the Voluntary Sector, I recognised that I had useful contacts in relation to disabled people on which to build. Within my work I had developed good relations with many disabled people themselves and also with other practitioners who worked with disabled people. This kind of networking had given me a useful starting point from which to recruit an Advisory Group: I had developed good relationships with some of the disabled people in the Advisory Group before the group was formed which meant that from the beginning of the group, a good rapport was established which kept the momentum and commitment throughout the process. This saved time in terms of the formation stage of the group. As the process continued, the Advisory Group developed its own identity. Although this meant there was good group cohesion, there were still varied experiences and opinions expressed. I felt that any possible bias expected as a result of my personal contact with some individuals beforehand was largely diluted by the voices of those I had not known as well. The constitution of the group and the range of abilities and understanding within the group is an issue that will be discussed later in this chapter.

Although many of the disabled people within the Advisory Group had known me outside of the research environment, they were all aware of my research work and interests. My work as a practitioner had been useful in building up relationships with disabled people and gaining the respect and trust of disabled people, but within the context of the present study, the members of the Advisory Group accepted the different roles that were played within a research context. Although I had been a practitioner, my relationship had not been a purely formal professional-client relationship. I had shown a personal interest and taken part in their organisations to the extent that I was accepted and trusted within the disability community. This made my role as researcher more straightforward. I did not have to spend a great deal of time giving reassurance and stating my position.

I found that, as a researcher in the context of utilising an Advisory Group, there were various roles I undertook. As suggested earlier in the chapter in the review of the literature on emancipatory research processes, the roles of the researcher in emancipatory research can include organiser, researcher, group facilitator, transcriber, administrator, motivator, activist and trainer. Managing these roles can create tensions and some difficulties. I feel that emancipatory research is more easily achieved with more than one researcher to accommodate these different roles, and/ or a team of administrative support. There were difficulties, for example, in the present study, in undertaking the roles of researcher (which involved carrying out a systematic enquiry) and facilitator of the Advisory Group (which involved coordinating discussions and managing group dynamics). I was able to manage these two roles by being mainly the facilitator during the Advisory Group meetings and then playing the role of the researcher after the meeting whilst listening to the recording of the meeting on tape. In this way, I could reflect more on the discussion and the points raised with an element of detachment. I would then make a note of any points I needed clarification on or needed to cover again within the next meeting. In this way, I could facilitate the group, bring in my own questions and discussion points and reflect on the answers in more depth at a later point.

Maguire (1993), in her study on battered women, recruited her participants by going through the board of directors of BFS to get their permission to contact former clients. She comments:

> ....there were difficulties and contradictions trying to start a 'people's' organisation by going through a social service agency. (p. 165)

Initially, I experienced similar problems because I attempted to reach disabled people by asking permission to recruit through the Social Services Disability team in Hull. This request was turned down and I therefore approached Voluntary agencies related to disability instead. In this way, it could be seen that the statutory agencies (ie. social services) presumed a 'gate-keeping' role over its service-users. The voluntary agencies seemed to possess less 'ownership' of the users of their service and gave them more freedom to decide for themselves.

The Advisory Group in the present study was a group of disabled people who voluntarily gave of their time to be involved in the research. It was:

- a group to guide the research process;
- a group to decide who to interview and what questions to ask;
- a forum for debate;
- a way of getting to know the views of disabled people;
- an attempt to challenge the imbalance of power in research;
- a way of sharing in the research process;
- a way for disabled people to have control;
- a group to comment on and analyse data.

In these terms, the Advisory Group in the present study had a large amount of ownership of the methodological process. However, this created tensions in relation to the process of achieving a PhD, since the nature of a PhD was seen to be around a student 'owning' the original 'product'. A large part of the discussion in this chapter will relate the issues and dilemmas in this process. I accommodated the two dimensions (ie. An emancipatory approach with the gaining of a PhD) in various ways which will be discussed later, but the main compromise was around the point at which the research shifted from being led by the Advisory Group, to the further systematic analysis of the data within the theoretical base of Citizenship. The Advisory Group, therefore, played a vital role but I needed to acknowledge and defend my role in terms of ownership of the process in order to submit the research for the award of a PhD.

As the Advisory Group progressed, the clarity of its role increased for the members, and individual understandings and contributions became more productive. However, there were issues identified throughout the research process around the type of contribution required of the Advisory Group. Frequently, the topic of conversation focused on the *experiences* of the members of the group. This was particularly pertinent in the early stages of the group's formation but as data were collected the aim of the sessions needed to move more toward the analysis of the interview transcripts.

The emancipatory approach needed the input of the group as co-researchers who could analyse and make comments on the data rather than as sources of experiential data. Although I would not wish to devalue the experiences of the disabled people, it is pertinent to address the difficulties in keeping the group focused on analysing the interviews, rather than expressing their experiences.

Tozer and Thornton (1995) point out some of the same issues. They reflect that in their study, there was also some confusion over the role of group. They state that their group found it hard to grasp the focus of what was required of them and Tozer and Thornton felt that either they had not explained it well enough, or that the group had not clearly understood. They produced handouts for the early meetings but with hindsight felt that the role of the group was not clear. They had an independent evaluator at the end of the process who commented that lack of clarity about aims and objectives was a problem common to Advisory Groups.

Tozer and Thornton (1995) also commented that their Advisory Group worked best when it had a specific task/ focus (devised by researchers), but that the early meetings spent time looking at what the research aimed to do. The group felt that when they were doing tasks then they had actually achieved something. In Tozer and Thornton's study, to start with, members were not sure how much to talk about their own experiences. It was anticipated that members would contribute in this way which allowed people to talk about common ground.:

> ...when we got onto something that related to my experience, something I knew about, I could say what I felt then. (p. 23)

Tozer and Thornton point out that there was a need for shared experiences:

> Groupwork theory suggests that shared themes often develop to help establish a group's particular profile. (p. 24) (also see Whitaker, 1985 for Groupwork theory).

Furthermore they admit that their agenda was more difficult to get through if people went off on a tangent:

> There was a general feeling, looking back, that some sort of tacit compromise was reached between the researchers' current interests and topical issues for members. (p. 24)

It can be seen that, in contrast to the present study, within Tozer and Thornton's study, the experiences of the group were seen as important data since one of their aims was to find out some of the issues faced by older people concerning Community Care:

> The issues raised by the group members did inform the researchers first hand about the concerns of a group of older people which was seen as one of the purposes of the group. (p. 24)

Finally, they relate that sometimes discussion strayed from the point and suggest that a balance was needed between doing the tasks and having a relaxed enjoyable meeting.

Maguire also points out the value of hearing the 'stories' of the participants as well as including them in a process. She calls it a 'dialogue' process where experiential data was shared: she found out their stories and also let them define the criteria of the group.

Issues over the role of the group, therefore, arise out of lack of clarity, lack of experience of 'doing' research, and lack or direction from the researchers. However, it should be emphasised that in all the examples, the participants of the Advisory Groups were all keen to tell their 'stories' and therefore maybe this should be seen as a valid part of the process and one that the researchers should take on board if they are asking people to take part. I would suggest that within the present study, the experiences of the individuals in the group were a useful starting point for focusing the research and for cementing the formation of the group in the early stages. Although the 'stories' could be seen to 'go off the point', I was able to use this experiential data within the analysis process to confirm the relevance of the generated concepts to the lives of disabled people. I shall describe the way in which the Advisory Group's experiential data contributed to the development of previously underworked dimensions of citizenship in the analysis section of this chapter and in Chapters Three, Four and Five.

'Early days'

In the present study, as with Tozer and Thornton, the first few meetings were taken up with meeting each other, talking about the research, finding out about individual views, experiences and issues, and eventually planning the interview schedule. I facilitated the group and set the agenda based on their ideas.

In the 'early days' the group spent some time reflecting on what was going to be required of them, gaining clarification from me, asking questions about the outcomes of the research and talking in general about their experiences and viewpoints. These experiences and viewpoints became a valuable source of information which could be used within an 'experiential synthesis' in the analysis process. However, their main role was to be as co-researchers guiding the process rather than providing myself with data about themselves. As the research progressed, the Advisory Group also took on the role of providing a preliminary analysis of the interview data. Each meeting of the group was recorded on tape and later transcribed. I also kept a reflexive diary in which I described my thoughts and observations about how the process was developing and considered my role and experience of the research.

There was some apprehension about the research in the early days, as the following comments from the Advisory Group discussion show:
(N.B Throughout the thesis, different speakers in the Advisory Group will be denoted in the text by different letters)

> *B: It [research] can certainly give organisations an opportunity to do things and change things, but there's got to be a will to bring about change...*

> *B: Will the research go further, ie. Will it change anything? There is lots of research done on behalf of disabled people but it needs to lead onto something where changes will be made. It needs to bring about change.*
>
> *B: What are you hoping to do after your thesis?*
> *Researcher: I don't know maybe do more in the Voluntary Sector or maybe go more into research..*
> *B: I need to know where you are going so I know how much time to give you!*
>
> *E: Research needs to have the will to bring about change*

After the first couple of meetings, I reflected in a research 'diary' on how things were going and some of my comments included:

> .... Lots of enthusiasm/ humour.... Good numbers.... Maybe not focused enough- a lot of discussion on their experiences/ thoughts .... People seemed enthusiastic but wanted to know what they would get out of it- feeling that we can challenge things to change?....It was a good meeting- varying impairments and viewpoints.... Most of them didn't seem to identify with Direct Action but did identify with day-to-day prejudice against them....The group acknowledged disability rights have come a long way but move slowly.

The 'early days' of the present study, therefore, were a chance to build up the relationship with the Advisory Group and identify a focus for the research.

The influence of the Advisory Group: focus of enquiry and choice of interviewees.

Since the present study focused on using an emancipatory methodology, I found that the Advisory Group was particularly influential in guiding the process of the research in particular areas, that is, the topic of the interviews and the choice of interviewees.

One way in which the group specifically guided the research was the focus of enquiry. A literature review was completed *before* the group was assembled since otherwise, as the PhD was being carried out part-time, the Advisory Group would have been in existence for four years. The initial direction of enquiry centred on issues of rights and Citizenship and a development of Marshall's tripartite model of Citizenship as consisting of civil, political and social rights and exclusion. In introducing this focus to the Advisory Group, their initial reaction was one of challenge and disagreement; their reasoning being that, to them, it was the way ordinary people treated them that was important rather than establishing rights in legislation. They considered that a more appropriate focus should be the attitudes that affected their day-to-day lives.

The minutes of this particular meeting (where the group re-directed the enquiry of the research) said the following:

> I explained what was meant by emancipatory research. The rest of the meeting concentrated around discussing issues of disability rights and Citizenship. In general the group felt that rights were only a part of the wider picture and that attitudes were as important, if not more so than rights. It was felt that when interviewing professionals we should concentrate on finding out about their attitudes.

Within the meeting, the definition of citizenship was discussed. The Advisory Group included the following definitions in a 'brainstorming' exercise:

> *Citizenship means equality, 'normality', rights, membership of society, lack of prejudice, equal treatment, other people are ignorant- in order for disabled people to have rights we need to educate people to change their attitudes.*

Some of the comments in the meeting around establishing a focus for the research included:

> *S: We don't want any rights as such, we want to get rid of prejudice.*

> *B: I don't think Citizenship can cover everything...you've got to change attitudes as well.*
>
> *D: The word 'citizen' grates a bit. I'm a citizen because I was born here.*
>
> *Researcher: My background reading is to do with Citizenship but its interesting that that may not be the answer, that may not be what's important- it's attitudes and perceptions that are important.*
> *C: This of course, is the danger of doing emancipatory research. We don't all come up with the answers you want!*
> *B: If we sit round this table and help you scratch your head then that's good...!*

After the meeting, my reflexive diary included the following thoughts:

> This was a more difficult meeting, with fewer numbers and not so much participation. I had planned in detail to talk about Citizenship. However, as the discussion continued, it turned out they felt attitudes were more important - can't have rights without changing attitudes as well.
> I felt I was thrown a bit and did not want to push on them my ideas. The purpose of this research, after all, is to be led by the Advisory Group. However, it does not make it very easy.

As suggested in this extract, I felt that it was important not to lead the Advisory Group into areas that I wanted to research, but to be lead by them. This process would reflect an emancipatory methodology process. Although their main priority was to focus on attitudes in this study, there was, in fact, extensive discussion around the concept of citizenship and its usefulness to disabled people. I was able to clarify their understanding of citizenship and suggest to them that disability researchers (Oliver, 1990, Barnes, 1991) had used the terminology extensively and found the concept useful in relation to articulating issues around oppression and rights. The members of the Advisory Group were confident in their discussions and acknowledged the use of the terminology in academic contexts, but still maintained, that for them in their daily lives, attitudes were more important than citizenship. Within this discussion, and throughout the research as a whole, although I had my own viewpoints and understanding, I was careful not to lead the Advisory Group into responding in ways that I wanted them to. Any prompting by myself was more around gaining clarification on points of discussion, rather than influencing their responses.

Considering the work that had gone into the literature review on Citizenship, this created a few dilemmas about the direction of enquiry. Kirby (1999) also reflected on this dilemma. She discussed the need for the researcher adopting this methodology to have a tolerance of ambiguity and to reconcile their competing desires of promoting participation and having a clear idea of what they are doing in the research. She states that:

> ...where workers do enable young people to develop their own research topic, they must be prepared to find that it does not fit in with their organisation's priorities. (p. 78)

She goes on to say:

> Abstract conceptual research themes which might appear to be relevant to young people's lives such as children's rights- are often not as interesting to them as are concrete subjects that have direct and immediate relevance to them, such as the quality of their services. (p. 78)

In Chapter Three and four, I shall show how the expansion of focus by the Advisory Group, to incorporate attitudes within the citizenship debate, affected the conceptual outcomes generated by the interview data.

In this way, therefore, the Advisory Group influenced the direction of the research. This meant that there was a need to return to the citizenship literature with this in mind. It was therefore also necessary to reflect on literature on attitudes in relation to disability. However, I felt that, with the recent introduction of the Disability Discrimination Act (1995), in particular, issues around citizenship were still pertinent to the research. Disabled people had, for the first time in the UK been given anti-discrimination legislation. This legislation, like other anti-discrimination legislation, acknowledged the need for disabled people to have rights in law, and thus acknowledged, to an extent, their status as citizens. The question I wished to pose in the research was:

> To what extent are disabled people perceived as citizens?

I wished to use the Disability Discrimination Act as a basis for exploring this question and I felt that the Advisory Group's focus on attitudes was not in conflict with this, but opened up a further area of exploration that was relevant to issues around citizenship. By finding out the attitude of professionals (priority of the Advisory Group) I could explore some of the barriers that disabled people experience in relation to their full participation as citizens. I therefore felt that 'attitudes' was not a separate topic of investigation, but was part of a wider discussion on citizenship.

In Chapter Six (Conclusion) I shall show how both attitudes and citizenship are encompassed by the concept of 'disablism'. The findings of the study showed how disablist attitudes and practices affected the extent to which disabled people were perceived as citizens. In this way, therefore, the Advisory Group, by highlighting attitudes, was the initial catalyst to the development of a debate around disablism.

Another way in which the research was influenced by the Advisory Group was in the choice of interviewees. The original research proposal intended to focus on welfare professionals and their attitudes and responses since my experiences of working in social services and the voluntary sector raised some pertinent issues around workers' understanding and ideologies of disability issues. The Advisory Group recognised these professionals as a potential source of conflict as indicated by their remarks about practitioners:

> *S: Professionals have the power...very rarely does someone sit down and say 'what do you think?'*

> *S: Community Care was supposed to change things but it hasn't.*

E: Choice, user consultation and empowerment are just words.

S: Doctors and social workers infringe civil liberties by the way they treat people.

The Advisory Group also pointed out that other people affected their daily lives as much as welfare professionals. They therefore drew up a list of those they wished to be interviewed which included: social services professionals, health professionals, architects, town planners, solicitors, supermarket managers, restaurateurs, leisure centre managers and organisers of transport systems. These suggestions were followed up in the data collection process and as one member of the Advisory Group later reflected the range of people included had expanded the focus of the research from the (narrowly interpreted) welfare professional viewpoint to a managerial view point. Chapter 5 will show how this change in focus in terms of interviewees affected the conceptual outcomes generated by the interview data.

By using an Advisory Group in this research as part of an emancipatory paradigm, the research became re-focused from citizenship onto attitudes and from a welfare professional viewpoint onto a managerial viewpoint. The involvement of the Advisory Group, indeed strengthened the methodological process in that the voices of the disabled people were given priority and the individuals were valued members of a research team. It also strengthened the analytical process (which will be described later in this chapter) since the further systematic analysis of the data by myself could be viewed through the lens of the Advisory Group analysis. Furthermore, the experiences and opinions of the Advisory Group offered an experiential synthesis, which, in turn grounded the conceptual findings into the daily experiences of disabled people.

Chapters 3, 4 and 5 discuss the findings of the research and places the findings within a theoretical framework that develops the concept of citizenship. The influence of the Advisory Group in this study greatly shaped the project and, in turn, affected the findings of the data, as will be discussed further in chapters 3, 4 and 5.

Although the use of the Advisory Group strengthened the research, it also created tensions between the original focus and subsequent focus. I was able to accommodate the views of the Advisory Group by addressing some of the wider literature around attitudes (which is discussed further in Chapter Three) and also by interviewing managers of retail/ leisure services in addition to welfare professionals. In this way, therefore, the tensions created by using an Advisory Group could be reconciled within this study. These tensions illustrate some of the difficulties involved in undertaking emancipatory research. As described in the Abstract of this thesis, one of the aims of the study was to test an emancipatory methodology within an academic doctoral context. To this end, therefore, the process developed my learning and highlighted tensions that are inherent in the emancipatory research context. As described earlier in this chapter, other authors (Tozer and Thornton, 1995, Kirby, 1999, Maguire, 1983) who have also undertaken what can be described as emancipatory research, experienced similar tensions. I would suggest that by challenging the power of the researcher and redistributing power within an Advisory Group, these tensions will be made transparent. By acknowledging, and responding to, these tensions, disabled people were indeed given a voice in this study.

The Advisory Group therefore played a critical role in the focus of the research and the way in which the research was carried out. I shall now discuss the way in which the research was carried out, highlighting the Advisory Group's influence in terms of preparing the interview schedule and the process of data collection.

Process of carrying out research

The data collection consisted of 30 semi-structured interviews with professionals. Semi-structured interviews were felt to be an appropriate form of investigation within the context of this study because they provided a framework from which to collect the viewpoints of the interviewees. It was considered that, since all the interviewees were professionals/ managers of services then their time would probably be limited. By using semi-structured interviews, therefore, the interviewees had opportunities to talk about issues outside of the questions, but the interviews could also be fairly focused and time efficient. The questions for the interviews were negotiated between myself and the Advisory Group, by looking at issues around their experiences as disabled people and around the Disability Discrimination Act (1995) and basing the questions around these areas. In the 'early days' the group seemed to be more happy talking about their *experiences* rather than deciding on the questions. Due to this, it took some time to encourage their participation as co-researchers, rather than talking about their experiences. In my reflexive diary I wrote:

> The group didn't seem to have any ideas so far about what questions to ask professionals. Maybe it is too soon?

Eventually, we drew up a list of topics that were pertinent to them as disabled people. These were: social/medical model of disability, empowerment, what professionals mean by disability, what experience the interviewees have of disability (either themselves or someone close to them), power, perceptions, image and staff training.

The questions were then developed, based on this list. The *overall* aim of the questions (linked to the overall aim of the whole study) was to find out the extent to which the interviewees perceived disabled people as citizens. The questions, therefore, also included investigating their *own* understanding of citizenship and rights in relation to disabled people. Following this, there was a process of refinement of the questions. In general, the questions asked interviewees for their views on disability and their attitudes towards disabled people, both from a personal view and from the point of view of the policies and practices of the agency in which that person worked.

This was important since it was the attitudes of people *as professionals* that most interested the Advisory Group. In a way it was looking at the preconceptions and stereotypes held by the interviewees. A pilot interview schedule was drawn up, and with it, a list of potential interviewees. Within the Advisory Group discussions, the disabled people made the following comments around the development of the questions:

> *N: I think an important question to ask professionals is, does the system of which they are a part allow them to be creative and empowering? They are under constraints, I know through personal experience.*
>
> *Researcher: What then, do we want to find out in the interviews with professionals?*
> *C: It would be very useful to find out what their attitudes are.*

In discussing the pilot interview schedule, the group made several comments:

> *R: are the interviews going to be written or are you actually going to ask them?.....it's just that question 9 asks about the DDA and question 10 tells them the answer so it's like if it were written down, you'd have the answer...*
>
> *C: it seems to me that the questions were devised with typically a social worker or a nurse.... in mind....doesn't seem to me that a lot of these questions are strictly appropriate to ask of someone like the hotelier.*
>
> *C: you can ask about legislation because of course a businessman is presumed to know the law which applies to businesses...*
>
> *R: one question to ask of hotel people and others is if they think their building is accessible to all...*
> *C: question 2 seems a bit loaded, 'how do you define disability'. If they work with disabled people you could expect them to know the difference between a*

medical model and a social model…but if you ask a hotel manager, for example, I can't see you're going to get a useful answer.

After accommodating the aforementioned points and refining the questions, the following interview schedule was drawn up:

1. What is your job? What do you do in your job?
2. How do you define "disability"? (If I said "disabled" what does this mean to you?)
3. What is your image of a disabled person?
4. What experience do you have of disability (either you or someone close to you) ? (Do you have any experience of disability?)
5. Has your experience of disability/disabled people affected your attitudes to disabled people? In what way?
6. Do you have any policies in your organisation relating to disabled people?
7. Do you think disabled people have rights?
8. In which areas *do* they have rights?
9. In which areas *don't* they have rights?
10. Do you know anything about the Disability Discrimination Act (1995)? (If not, explain what it is: It is a law that tries to make sure that disabled people are treated fairly in employment, education, shops, leisure facilities)
11. Do you think anti-discrimination legislation like the Disability Discrimination Act (1995) is effective? (Do you think laws that try to make sure everyone is treated fairly work?)
12. Do you think it (laws like this) changes people's attitudes?
13. What else could you do to change people's attitudes?
14. Does Direct Action (give examples such as chaining yourself to a bus) work? Does Direct Action change people's attitudes?
15. What is your role *as a professional* in relation to disabled people (Both "customers" and staff)?
(For Welfare professionals: Are you aware of the Social Model of disability?)
16. Are the staff in your organisation given training in disability issues? If yes, what form does this take?

17. Is your building accessible? In what way?

Any other comments?

The Advisory Group also drew up a list of potential interviewees, including: medical professional, politician, occupational therapist, TV producer/ someone in the media, teacher/ someone in education, solicitor/ legal professional, supermarket staff, someone working in banking, someone in leisure services, someone from a disability charity, someone from DSS, someone from restaurants/ cafes, carer, hotel manager, restaurant manager, PACT (Placement, Assessment and Counselling Team), Employment Services, psychologist, counsellor and Travel Agencies.

The final list included most of these occupations. The following is the final list of interviewees:
Art gallery manager (2)
Solicitor (2)
Bank manager
Architect
Community worker
Supermarket manager (2)
Cinema manager (2)
Health Services manager (hospital based) (2)
Psychologist (learning disability)
Social worker (2)
Retired social worker (2)
M.P.
Town planner
Transport manager
Newspaper editor
Restaurant manager
Teacher ("special school")
Residential home manager (elderly people) (2)
Manager of Age Concern

Manager of Council for Voluntary Service
Manager of MIND (Voluntary Sector Mental Health organisation)
Methodist minister

It seemed that a great deal of the reasoning of the Advisory Group in deciding who to interview was based on who they felt was presently not seen as very aware in terms of disability issues. This was based on their individual and local experiences. It seemed that they were curious about why certain professionals/ managers held negative or uninformed views and that they wished to prove that the group's negative experiences of people's attitudes were correct. Some of the comments included:

> *C: I would suggest that places like hotels and restaurants should be interviewed because they are notorious for turning away blind people because they've got guide dogs, people in wheelchairs because they upset other people, and, you know, all this kind of thing...*
>
> *D: how about PACT [placement, assessment and counselling team]? ...because the feeling amongst a lot of disabled people is that they're not the most disability-aware bunch of people in the world.*
>
> *C: I would be interested if you interviewed educational psychologists and occupational psychologists...I'm thinking of one in particular....she deals with people with head injuries which result in malfunctions of the brain and her ideas on disability are bizarre to put it mildly.*
>
> *R: apparently, BA are not very good as far as disability is concerned. The person who runs our support group, she has got a letter saying ' we are not in the business of transporting disabled people... '!*

The thirty interviews were undertaken by myself. In discussion with the Advisory Group and my PhD supervisor, and by reflecting on the literature around qualitative research (Mason, 1996) I felt that 30 interviews would be an appropriate number for generating enough data for analysis. By interviewing 30 people, I was able to gain a variety of viewpoints and have widespread representativeness in terms of profession of interviewee. I was also able to follow up most of the suggestions of the Advisory Group in terms of choice of interviewee. By undertaking 30 interviews, we were able to compare and contrast different individuals and draw out thematic material. Since it was a qualitative study, the 30 interviews provided some rich qualitative narrative and discussion. I did not feel there was any particular advantage in doing more than 30 interviews. The richness of the discussions provided enough data in itself.

Added to this, I recognised that I was also utilising the experiences and opinions of the Advisory Group as a tool for reflecting on the data. In this way, the methodology process itself was a form of data, not just the narrative of the interviews. Hence, in this way, the volume of data in this study was extensive. Although there would have been more detail with undertaking additional interviews, I did not feel that this would alter the focus of the conceptual development of the analysis. The process and reflections that developed the conceptual material were as important as the interviews themselves.

The interviewees were selected by myself approaching different agencies, explaining the nature and purpose of the research and asking if they had individuals willing to be interviewed. The interviewees chosen were based on the priorities of the Advisory Group in relation to who they felt they would like to be interviewed (as discussed earlier). All the interviewees were recruited from outside the University City in order to retain confidentiality.

Two pilot interviews were undertaken initially and reported back to the Advisory Group. As a result, the Advisory Group was able to refine some of the questions and finalise the interview schedule for the remaining interviews. The interviews were taped and transcribed. The data from the interviews were summarised to an extent in order to enable the Advisory Group to be involved in the analysis process and to focus on many interviews in a short period of time and in order to compare and contrast the content of different interviews. This initial analysis process by the Advisory Group, I defined as the preliminary group analysis. It was an opportunity for the group to give their views on the interview data and to compare some of the attitudes coming out of the interviews to their own experiences. This process was followed by my own further systematic analysis of the interview data in which I was able to develop the conceptual material and relate it to a theoretical base. Finally, the discussions within the Advisory Group highlighted the experiences and opinions of the disabled people in the group. These experiences and opinions were seen as a useful way to explore the extent to which the outcomes of the analysis resonated with the daily lives of disabled people. This, I defined as the experiential synthesis. In this way, the analysis process was grounded in the experiential level of the disabled people in the Advisory Group. I shall describe the analysis process in more detail later in this chapter. Chapters three, four and five describe the findings of the research and explore the way in which the input from the Advisory Group influenced the analysis of the data.

In order to maintain confidentiality all the interviews were undertaken outside the area where the group were based. Many members of the Advisory Group were familiar with local professionals related to disability and, although interviewees were not named, their identity may have been revealed through details in their discussion.

There was a fairly equal (though random) spread of male and female interviewees (about 45% male and 55% female). I did not ask interviewees personal details (such as age, race, disability) but, as an estimate, I would suggest that most interviewees were between the age of 30 and 50. In the sample there were three people from ethnic minorities. I would argue that this was probably representative of the area where interviewees came from which has a low percentage of people from ethnic minority communities. The interviews took place between September 1997 and July 1998. Most interviews were between 30 and 40 minutes long. Most interviews were taped, although one or two people asked not to be taped, in which case I took comprehensive notes during and after the interviews. All interviews were transcribed in full, some by myself and some by an independent transcriber.

The interviews were transcribed verbatim, including the indication of hesitations in the discussion by the use of 'um' and '.....'. Since the Advisory Group were keen to ascertain information about professionals' attitudes to disabled people, the use of verbatim transcription helped to develop the picture of an interviewees' attitudes more than, say a 'notes and quotes' approach may have done. The gaps in speech, the hesitations and the indication of laughter, for example, all added to the information on the way in which the interviewees answered questions, and thus added to the meaning given to the analysis. I felt that this method gave a better 'feel' to the qualitative nature of the data and it was useful in developing interpretations about hidden agendas and sensitive issues. In this way, I felt that verbatim transcription added to the quality of the analysis process.

Some interviewees were liable to talk about areas outside the direct questions. I allowed this to continue as I felt their experiences and opinions of the issues were of importance and it also fitted with a semi-structured technique. However, I always tried to direct the conversation back to the question/ issues when appropriate. Since the interviews were semi-structured and asked viewpoints, it could be seen as inevitable that answers were not simple/ short and that the qualitative information produced was necessary and valuable.

In terms of conducting the interviews, most interviewees were willing to give their opinions, however there were occasions when gentle prompting/ encouraging increased their discussions of particular points.

The analysis process will be discussed later in this chapter but first I shall consider some of the issues related to working with an Advisory Group and attempting to carry out emancipatory research.

The Advisory Group: practicalities, problems and their resolution

I should now like to consider some of the practicalities and problems I experienced in undertaking an emancipatory research process and to describe how I resolved some of these dilemmas. The following problems will be considered: practical issues, variation within the group, sustaining interest and ownership of the research. A final evaluation of the 'success' of carrying out research in this way will be discussed in the conclusion of the thesis.

Practical issues

Within this research, the process of using an emancipatory methodology involved a number of practical issues, such as higher costs, paperwork, and issues around payment, transport, and child care.

I discovered that the process of undertaking emancipatory research had higher costs associated with it than some other forms of research. This included the costs of running the Advisory Group, such as room rental, administration, refreshments, and also the need to reimburse travel expenses for the disabled people in the Advisory Group. Although I was self-financing, eventually, I was able to secure some extra funding from Northern Foods (a local firm) and from the University to support this process. The issue of extra 'cost' should be taken into consideration when allocating funding to emancipatory research projects.

Within the process of this emancipatory methodology there was also a larger proportion of administration than there may have been in other styles of research. This consisted of summarising transcripts, producing handouts, producing minutes of meetings, typing letters to the Advisory Group and putting interviews into a more accessible format. These additional tasks also added to the amount of time and resources needed.

Tozer and Thornton (1995) comment on this issue in relation to an emancipatory approach. They talk about the paperwork associated with agendas, minutes, other information. They also talk of the need to make sure that any paperwork was jargon-free. In terms of the present study this was crucial because the group included individuals of varying abilities and impairments. I was also particularly aware of the necessity to produce information in a format that could be accessed by the people with learning difficulties in the group. Finally, it was also necessary to offer information in other formats if necessary eg. large print or on tape as I had informed the group that I could make this available. Although the information for the Advisory Group needed to be accessible, within my own analysis and writing, I also needed to expand on the theoretical concepts in a form that contributed to academic debate. This was exacerbated by the need to create a *final product* that met the academic requirements of a PhD. In this way, the process needed to accommodate differing styles and outcomes.

In terms of expenses, Tozer and Thornton (1995) argue that Advisory Group participants should be paid appropriately for the contribution of their time in the process. However, within the present doctoral study, which was self-funding, I lacked the monies to address this issue. Yet, the Advisory Group continued to support and be committed to the project, even though they were not gaining anything financially.

There are both advantages and disadvantages to the payment of participants in an emancipatory study, as outlined by Kirby (1999) in relation to young people's involvement in such methodologies. She suggests that the advantages to payment include: recognition of young people's contribution, making young people feel valued, young people being taken more seriously by professionals, increasing motivation/ interest in the project, helping to ensure tasks are completed and, finally, bringing young people into decision-making structures to have more influence. However, she also highlights some disadvantages, such as: it can be a form of control, it can change the relationship between adults and young people- the workers become managers and direct the young people, it makes workers more accountable to the young people, some young people may participate for the money rather than being interested in the research, the payment may set a precedent for future projects, it may inhibit inclusion of under 16 year olds due to employment restrictions, and finally, it can interfere with social security benefits (p. 54)

Although I was unable to give the members of the Advisory Group any payment for their contribution to the research, I was, however, able to secure a small amount of funding to provide travel expenses. I felt that, particularly in terms of disabled people's access to research, travel costs needed to be considered a priority. The participants arranged their own transport. Tozer and Thornton were able to organise transport for the members of their Advisory Group through a local volunteer driver scheme. Although this could be seen to be more straightforward way to address transport, I felt that , to take on the role of organising the transport for the group in the present study, perhaps would have been in conflict with the focus on the Social Model of disability and the need to address the access barriers. It may also have been perceived as taking power and control away from disabled people themselves. Since the focus of this methodology was about addressing power imbalances, I was cautious about taking power away from the disabled people involved in this study.

Within the study by Maguire (1993) of women experiencing domestic abuse, she noted that the issue of childcare also needed to be considered. She found that in her first meeting, several of the women asked for childcare cover in order to attend the subsequent meetings. Maguire admits that this was an issue she had not considered before the meeting. Rather than secure childcare from outside sources, the women organised themselves to share childcare and costs between themselves. Although this was possibly their first task of self-empowerment, I would argue that in order for the women to be successful co-researchers childcare costs should have been built into the research budget. In the present study, there were no issues arising in terms of childcare. However, the expenses budget provided by Northern Foods could have covered some of this type of cost if necessary.

Variation within the group- 'representativeness' and abilities.

Within the Advisory Group in the present study, there was much variation between individuals, both in terms of different impairments, and in terms of level of understanding and ability. However there seemed to be a greater prominence of proactive, intellectual, vocal people who had a deep understanding of the issues and a capacity for debate. Although there may be an inevitability in proactive intellectuals becoming involved in a research project, it is important to recognise the potential for bias in terms of vocal individuals having a more prominent voice than non-vocal individuals.

I also became aware of some of the difficulties in including people with learning difficulties in this style of research. The issues were around making sure information was accessible to them, and in finding ways to facilitate their involvement within a group of confident, articulate people. The difficulties were concerned with 'pitching' the discussion at a level to which all individuals could relate. Kirby comments:

> Working with a mixed-ability group can be difficult and time-consuming for workers. It is important to assess whether workers can meet very diverse needs within one group or whether there is a danger that those with higher support needs will be excluded, and set up to fail...(p. 73)

The membership of the group posed various issues around representativeness and level of abilities. Although not all members attended each meeting, there were about 10 'core' attendees. Out of these ten people, four were actively involved in a local political, disabled-led group, and two were involved in other (non-political) groups of disabled people. Two out of the ten used day services with Mencap, one had a higher degree, and two used a Social Services day service for physically disabled people. There were five unemployed people within the group and two people from ethnic minorities. The ages of the individuals in the group ranged from 30 to 55. Although the individuals in the group were not specifically picked in terms of their representativeness of a wider population, there was a diverse mix of individuals. This diversity was useful in terms of gaining a wide range of viewpoints in relation both to their individual experiences and to their analysis of the interview data.

Sustaining interest.

The Advisory Group met nine times over eighteen months and within that time, they made many definite contributions to the research process. It was unfortunate (but perhaps predictable) that after several months the numbers dropped considerably, from 15 in the first meeting to a regular group of four or five individuals at any one meeting. These numbers stayed fairly constant although it was often a different group of four or five. One, perhaps more articulate, member of the group pointed out that this may be due to the kind of people that make up the group and the range of their backgrounds and level of skill and understanding. He was suggesting that the process of 'doing' research was perhaps unfamiliar to many members and that the length of time taken to achieve 'outcomes' might deter people from maintaining a long-term commitment. Many members were also possibly disillusioned by the lack of effect or change they felt the research could achieve. As mentioned previously, one person pointed out:

> *Research needs to have the will to bring about change.*

It was noted that invariably in the disability movement there are a small number of proactive, independent and forthright individuals who try to promote change. There are also others who disagree with some of the ways in which change is promoted. In this way, conflicts can arise, for, as one member constantly reminded me:

> *There are as many conflicts within the disability movement as there are outside it.*

I feel that this individual stressed the need to see people with impairments as separate individuals, rather than seeing them as one mass of people all with similar viewpoints. He was also saying that disabled people, as a group, have some similar issues of group dynamics, as do groups of non-disabled people.

Kirby (1999) found that there are various ways to help sustain motivation and interest in emancipatory research. She listed the following as appropriate motivation points within research with young people:

- review the progress with the group
- provide tasks appropriate for ages/ abilities
- keep the timetable short.
- have regular meetings
- do not use jargon
- provide training relevant to group's interests/ experiences
- emphasise experiential learning
- keep sessions quick and moving
- encourage young people to help organise training sessions
- encourage young people to choose which parts of research process they wish to be involved in
- provide incentives eg. food/ payment
- provide residentials
- accommodate young people's other commitments eg. exams
- do research about issues that are important to them
- be realistic in terms of the potential to change services/ policies
- realise the potential of group to carry on working together after research is finished

Within the present study, I was able to accommodate several of Kirby's points. In particular I benefited from keeping the meetings to no longer than one and a half hours, once a month, and I was able to research the issues that were important to the individuals in the Advisory Group. I did not attempt to involve the individuals in the Advisory Group in planning or organising sessions, and , although I was keen for all the participants to be involved in the whole process, by the nature of the process of a group, some individuals were more involved at different points of the process. There was a core number of people whose interest was sustained throughout the process. I would anticipate that this was partly due to their curiosity around whether the results would bring about change.

Although the whole research process (including literature review, fieldwork, analysis and writing up) was undertaken over several years, the length of the involvement of the Advisory Group was kept to about 18 months of that time. This was due, in part, to the recognition that it is difficult to sustain the interest of a group of people for a long period of time, as explained in this section. As I have suggested earlier, for many members of the group, the process of 'doing' research was unfamiliar and there were not many short-term, tangible outcomes. In this way, therefore, I was required to achieve a balance between keeping people's interest and assisting them in having ownership of the process. I feel that it would have been useful to have involved the group at an earlier stage, that is, before the literature review was undertaken, in order to give an earlier focus to the research. However, if the group had been in existence at an earlier stage, their participation would have been for a longer period of time and I feel it would have been difficult to sustain interest. There may also have been longer periods of time between meetings in order for a review of the literature to be undertaken, which may have affected the continuity of the process. one of the concerns of the Advisory Group was that the research should effect change. To this end, in collaboration, we produced an accessible report outlining the findings of the research (this will be explained more later in this chapter) and this was sent to about 200 agencies (including the organisations of those interviewees who had taken part in the research, organisations relating to disability (both local and national), and other local and national agencies). I felt that this was an appropriate point at which to discontinue the group. They had played an important part as participants in the process and they had ownership of a product of the research (the accessible report).

As this chapter will describe, the members of the Advisory Group were participants in the research process, rather than subjects. That is, they participated in guiding the research, making decisions about who to interview and what questions to ask, and gave a preliminary analysis of the data. Within this study, the interviewees (the 'professionals') were the subjects of the research, since it was the attitudes and viewpoints of professionals that were the focus of enquiry.

As I explain later in this chapter, the analysis process was complex and there was a point at which I undertook a further systematic analysis of the data, as a separate process to the preliminary analysis by the Advisory Group. I then explain how the research findings developed theoretical concepts. In this way, therefore, the process that I undertook after the Advisory Group had finished meeting, constituted my ownership of the final product (the PhD thesis) of the research. The element of 'ownership' will be explored in the next section.

I recognise that any research process can be affected by the life span of an Advisory Group and the ways in which the members participate in the process. In the present study, the members of the group were participants in most of the process. The point at which the group ended was influenced by the PhD process and issues of ownership, to which I now turn.

Ownership of the research.

The issues around academic attitudes can be seen to be part of a wider debate on 'ownership' of any research. The initial question by a member of the Advisory Group,

> *C: Do we all get a PhD out of it or do we share it?*

was the starting point for a wide ranging discussion of the issues, both within the Advisory Group and within the academic department of the university. This also led to the production of a joint paper (Garbutt and Seymour, 1998) which was presented to the British Sociological Association Annual conference, with the title:

> 'Do we all get a PhD?' Attempting emancipatory research relating to disability in an academic environment.

Part of the discussion from the paper is reproduced, in a revised version, here. Large parts of the next section have been written jointly. The original paper was written jointly with my supervisor and the perceived need to rework it for this thesis again acknowledges and demonstrates the collaborative nature of the research and the issue of 'original' PhD production.

The question of the ownership of the disability and Citizenship study is complex. As I was largely self-funding (with a bursary from the University and a small contribution from Northern Foods, a local firm) the research, including the data, did not belong to any funding body. As the research was ultimately carried out with the aim of myself gaining a PhD this differs from the work carried out by Priestley (1997) who gained a doctorate while conducting *commissioned* research for a disability organisation. My early perceptions of the requirements of a PhD thesis led me to believe that ultimately I needed to be the *owner* of the research and also to be seen to be conducting the fieldwork. Hence, while the Advisory Group guided the process and responded to the interviews, I, as the researcher, went on to analyse the Advisory Group's responses and to undertake a further systematic analysis in order to relate the findings to academic theory. Investigations into the regulations of postgraduate theses led to a reconsideration of these initial perceptions.

In addition to a PhD thesis I produced a shorter accessible report of the findings with the help of the Advisory Group and made it available for local and national disability groups, educational establishments and workplaces. In this way, some ownership of the outcomes of the research was retained by the Advisory Group and the results of the research were made accessible to those who may be able to benefit from them. In this way, the emancipatory research process had become, with the group,

> ...a working partnership towards mutually beneficial outcomes. (Priestley, 1997, p. 105).

The production of an accessible report was an appropriate outcome in relation to the present study in terms of emancipatory research. However, a cautionary note about the extent to which such research can be successfully carried out in a *university environment* was introduced by Janet Lewis, Research Director of the Joseph Rowntree Foundation. She considered that the model of users being active participants throughout the research procedure was 'not a process for which the existing short-term research contract culture of the UK academic social science was well suited' largely because of the associated demands for time and expertise. (*Network*, March, 1998 p. 5).

Although there is considerable evidence that research based on an emancipatory methodology has been carried out in a range of university departments (for example: Criminology, Davidson *et al*, 1997; Development, Hall *et al*, 1982; Education, Hustler *et al*, 1986; Health, Kanani 1996; Management, Flood and Romm, 1996; Disability, Booth and Booth, 1997) and indeed incorporated into postgraduate courses (such as education cf. McNiff, 1988), I wish to explore in this section the extent to which it can be carried out during the writing and submission of a PhD thesis. One can argue that postgraduate researchers have the element of time on their side (particularly in relation to the short length of some research contracts) but when carrying out their doctoral study are usually only in the early stages of developing an expertise in research methodology; hence they may not have all the requirements (time *and* expertise) considered necessary by Lewis to conduct research in this way. More importantly, the way that PhDs are conceptualised within an academic institution may prevent the adoption of an emancipatory model of research. The following discussion outlines attempts which have been made to reconcile the tensions inherent in adopting such a model for PhD research including my own experiences of researching this doctoral thesis on Citizenship and disability.

To appear to state the obvious, degrees in institutions of higher education are awarded to individuals. Although increasingly at undergraduate level, students produce group projects and may be given a collective mark, their final degree certificate is seen as the property of, and reflecting the effort of, one person. This individualised model of recognition continues with research degrees. The regulations for the degree of Doctor of Philosophy by thesis for Hull University state that a candidate shall be examined by means of a thesis and 'such a thesis to be the result of *original* research' (my emphasis). For published work, the applicant is,

> ...required to give proof of a significant contribution of scholarship and if the candidate submits work published jointly with others, evidence shall be

> submitted as to the extent of the candidate's own contribution to these works. (The University of Hull, 2002).

The model of researching in a team but submitting an individual thesis is frequently used in the sciences where researchers work as part of a group project. Usually students are encouraged to concentrate on a specific area of the research topic which can be identified as 'belonging' to that individual. Hence, there is a scientific model of collaborative work but this involves input from other researchers ie. other 'acknowledged experts'. Significantly here, one researcher who was familiar with this mode of working mentioned the important role of the technician as a source of advice in such projects which drew attention to the relevance of experience over qualifications. (Of course, as this informant pointed out, in some ways all researchers do 'collective' research by drawing on other researchers' literature although again the model remains rooted in the community of scholars.)

When discussing the university regulations for Hull with the administrative officer responsible for the submission of PhD theses, an interesting distinction arose between original work and individual work. Interestingly, in the regulations the word *individual* is not used in relation to the contribution but the phrase employed is *original research*. It was considered that if a research project followed the emancipatory model and was produced by a group of individuals, this would be acceptable to the university for the award of a higher degree if only one person from the group submitted a thesis. The issue that the institution would find problematic would be if several people submitted a joint thesis and all wanted to be awarded a PhD. (This would be in addition to issues for the university of multiple funding and registration). It would also not be possible for a second individual to submit a thesis based on the findings of the groupwork at a later date for an individual award- on the principle that you cannot discover gravity more than once.

What emerges from these regulations then is that the real issue is not carrying out research work on your own but that one piece of research can be claimed only by *one* person for a higher degree and that the findings of the project are only submitted a *single* time. That is, that the 'originality' of the PhD research comes from one person being awarded the degree (and hence being publicly recognised as 'owning' the idea) not from one person alone producing the research findings . (These attitudes are also reflected in problems the RAE exercise has with joint authored papers; some researchers have argued that such papers would not have existed without people working collaboratively and hence all authors should be given 100% credit).

In contrast to the university regulations for Hull, CNAA guidelines in the early 1990s were much more explicit about the individualised nature of the work in its entirety. They stated that the student's contribution must be 'distinguishable for the purpose of assessment' and then go onto state that 'Where the candidate's research programme was part of a collaborative group the thesis should contain a clear statement of the candidate's *individual contribution* and of the extent of the collaboration' (emphasis of Garbutt and Seymour, 1998). And again, the researcher should present a thesis,

> ...resulting in an *independent and original* contribution to knowledge. (p. 94) (our emphasis).

These more specific guidelines suggest that the award of a higher degree is for originality throughout the whole research process not just for being the individual whose name is on the thesis.

Both sets of regulations have implications for carrying out emancipatory research with the aim of achieving a PhD qualification. The CNAA guidelines appear to militate against being able to adopt such a model. Although collaborative work is accepted as a common model, it would be interesting to see how far examiners were comfortable with the input of so-called 'non-experts' in the process. In contrast, the university model, in theory, does allow for an emancipatory methodology to be adopted. This, however, perversely, also allows for the most potentially exploitative form of research to take place. A group of people may carry out the research but only one person is allowed to enter into the academic community on the strength of it and reap the subsequent benefits. Such potential exploitation could be reduced if multiple outputs of the research are produced, for example, a thesis but also a report for the participants or organisation which is intended for wider dissemination. If we consider Lewin's (1946) model of the cycle of participative research (an iterative circle of plan, act, observe and reflect) there are several points in the cycle where the researcher can leave the project at a tangent in order to achieve additional outputs. Thesis writing could be a point in the reflection stage where the researcher writes their personal account of the process, the PhD. Indeed this model has been carried out by researchers in the disability field such as Priestley (1997) and Vernon (1997). Doing emancipatory research does not necessarily mean giving up the PhD (although as with feminist researchers such as Oakley (1974a, 1974b) it may mean doubling your output) for as Priestley says when discussing his own work there was, among the disabled groups he had worked with:

> ...much resistance to the idea that emancipatory research should involve a *reversal* of the social relations of research production. Rather, they felt it necessary to stress the importance of a working partnership towards mutually beneficial outcomes. For us the goal became one of *equalising* power rather than devolving it. (1997, p. 104-5, author's emphasis)

While the university regulations for Hull can thus accommodate a model of emancipatory research it is not yet in a position to expand this accommodation to the presentation of degrees to all participants of a project based on a single thesis. The individualised model of *reward* remains.

Following on from this, and addressing the issue of Intellectual Property Rights (IPR), one way in which the ownership debate can be accommodated is to construct with the participants, in this case, the Advisory Group, a kind of contract, setting out a series of IPR statements, clearly setting the different points of ownership within the research. This contract would state, for example, that the Advisory Group would not have ownership of the final PhD thesis , but that they would have ownership of the findings of the research in a different form (in this case, the accessible report). In this way, the point at which I claimed the final ownership of the PhD thesis would be made clearer.

This model of having 'parallel' projects and different products has also been used by Priestley (1997) in a study around user involvement. In his research, Priestley produced various accessible reports for Derbyshire Centre for Integrated Living

(DCIL) and Derbyshire Coalition of Disabled People (DCDP), along with a PhD thesis.

Maguire (1993) also undertook her emancipatory research as a doctoral student. She argues that, within this style of research, there is a need to build relationships and that the researcher cannot remain detached:

> I was never a detached social scientist. I became involved in the women's lives and they in mine, on a day-to-day basis, not simply during 'project time'. (p. 175).

As in the present study, Maguire found that she needed to make academic allies in the process in order to justify her methodology. She advises others wishing to carry out such research to:

> Seek out faculty promoting, or at least open to, alternative paradigm research approaches. The ideal is to find faculty as open to learning with you as they are to teaching you. (p. 175)

In terms of 'ownership' Maguire states that she was 'uneasy' with the research which,

> ...may have been complicated by the fact that I was doing this in part as my doctoral research. (p. 176)

In this, she recognised that she would gain from the process but that there was also a danger of trying to make the project a success in order to have a 'good' dissertation. She refers to this as possible 'contamination" of a true emancipatory research project. She points out that project control was the key issue. She wanted to let the women take over some of the organisation but none of them wished to adopt this role.

The question of ownership arose for Tozer and Thornton (1995) as well. Since they had two groups: the Older People's Advisory Group (OPAG) and the Project Advisory Group (PAG) there were concerns that some members of the OPAG felt that their group was in fact tokenistic. In relation to this, there was also perceived difference in power between the OPAG and the PAG , with the PAG being seen as having more authority and status. The OPAG felt they might be seen as 'amateur' by comparison because of their perception that the PAG were somehow in charge. In this way, the OPAG felt that the PAG somehow 'owned' the research. Furthermore, Tozer and Thornton state that initially the members of the OPAG lacked confidence, especially since the PAG was established earlier and its members seemed more experienced in certain tasks. Their reasoning for having two groups arose from the funding:

> Somewhat ironically, previous experience in the JRF (Joseph Rowntree Foundation) had suggested that there were difficulties in accommodating users into traditional Project Advisory Groups; this was one of the reasons for proposing a separate group. (p. 21).

I wish to emphasise their use of the word 'accommodate', which implies that there is an established way of doing this kind of research, and that researchers have to accommodate users into this way. It can be seen that, alternatively, the method needs to be totally rethought in order to put users first and to give them some power. If their experience is seen as useful and important then a users' group such as the Older Person's Advisory Group (OPAG) should reflect their importance and not be just a token gesture.

As part of Tozer and Thornton's research, the OPAG undertook a visit to a day centre (initiated by one member of the group). This was seen as positive in that the group were taking ownership of their actions. The researchers put on a seminar for service providers about the outcomes of the research and five people in the OPAG attended and participated. It was useful for service providers to meet the group. One group member commented:

> ...chatting to people at lunch, I got the impression from those that were on the provider side of things, that they were more involved in job security themselves, talking about budgets, really far away from the users and services they've got to provide. (*op cit*, p. 27).

However, the OPAG stated that they felt they had had some influence over the way in which decisions were made by the service providers and that their voices had been given some authority. In this way, they felt that they had played an important part in the research and had gained ownership in terms of influencing change.

In the present study, various conferences were attended by myself at which papers were presented. It was the intention that the Advisory Group could be involved in helping to present papers and benefit from the conferences but this was not possible. Part of this was due to the practicalities of conference costs, preparation and transport. Although there were 'ideals' in emancipatory research, these often were compromised due to various practicalities and circumstances. Being a part-time student with other personal commitments, unfortunately time and money could not always be prioritised for the research. John Stanfield (1998) points out that ,

> Whilst emancipatory research may go some way to empowering local people it is rarely the participants who gain the 'career rewards' such as co-authorship. (p. 35)

This co-authorship/ collaboration was attempted within the accessible report, to which I shall now turn.

Process of producing the report.

The 'accessible' report (see Appendix) was produced in consultation with the Advisory Group. The report summarised the process and outcomes of the research and offered policy and practice recommendations as a result of the research. It also included information on the Disability Discrimination Act (1995), Disability Equality training, local disability groups, and definitions of the Social and Medical models of disability.

The report was written in an accessible way in terms of language and was purposely kept short and succinct. The intention was also to use pictures/ symbols so that it would be easier to understand by people with learning difficulties but, after discussion, it appeared that the report seemed accessible enough without this. In consultation with the Advisory Group, it was felt that pictures/ symbols were not necessary for the report.

The purpose of the report was to address issues of ownership (ie. the Advisory Group owning a 'product' of the research), to make the results of the research accessible to a wider community (outside the academic community) and to make recommendations for change. This ties in with the Advisory Group's concerns that there should be short-term outcomes (ie. a report) that could bring about change. An early comment by one member reflected their concerns:

> *K: How do we know this research will make any difference to anything? A lot of academic research just stays in a dusty report on a shelf and makes no difference to anybody.*

After consultation, in general, the Advisory Group was positive with regard to the content and layout of the first draft of the report. Written comments on feedback sheets included:

> *Clear, concise, comprehensive*

Very clear and thorough.

Is it a bit lengthy for employers?

I like the colour of the paper- it is suitable for people with a visual impairment.

Action plan should be at the front of the report- maybe employers would look at this when they wouldn't wade through the whole report.

Useful names/ telephone numbers- could you include other national addresses

The importance of images of disabled people (page 12) should be enlarged as the power of the media in creating stereotypical images must not be understated.

Following their comments, I amended the report, reducing the length of the report, putting the action plan at the beginning, adding other names and addresses and stressing media images.

One of the questions addressed on the feedback sheets sent to the members of the Advisory Group was 'Do you want to put your individual names on the accessible report?' I felt that, since I regarded the members of the Advisory Group as co-researchers in the process, then their role as owners and co-authors of the product should be recognised. However, in response, one or two members stated that they only wanted their names on the report if other members of the group did. However, a few members stated categorically that they didn't want their names on the report. In consideration of their responses, when the report was produced, the front cover stated that the research was by 'Ruth Garbutt and the Advisory Group'. Although , in order to reflect the emancipatory nature of the research and the contribution of all individuals involved in the research, the ideal would be to acknowledge each individual equally as owning the report, I needed to take into account the wishes and feelings of all the members of the group and this was the compromise that was reached. When I sent the final draft out to the members of the Advisory Group for feedback they were all happy with this as the format.

The accessible report was distributed to about 200 organisations relating to disability and employment and to all participants in the study (the members of the Advisory Group and the interviewees). The following are representative of comments received as a result of the report:

> Thank-you for your report which I was interested to read and have shared with my colleagues in Personnel. It was good to see the finished product of all your hard work. (Northern Foods, Hull)

> I was very interested to read your report 'Disability and Attitudes' and hope that it raises awareness about issues relating to disabled people....I would like to invite you to the next meeting..... (North Bank Forum, Voluntary Sector, Health and Social Care agency, Hull)

> Thank-you for sending to the Council a copy of the report entitled 'Disability and Attitudes' I read this with interest. I recognise many of the comments made in the report from discussions I and others have had with various people. Hopefully things will change as awareness of the Disability Discrimination Act increases. (National Disability Council)

Although, these comments represent a positive response to the report, it is, in fact, more difficult to assess the real extent to which it had any impact in terms of influencing change.

Mercer (2002) states that,

> [emancipatory] research has an important part to play in challenging disabling social barriers, particularly where it is unashamedly rigorous and transparent in its methodology and partisan in its objectives (Mercer, 2002, p. 246).

Since an important element of emancipatory research is to challenge the social relations of research production (Zarb, 1992), by undertaking research in and emancipatory way, the possibility of change can be brought about by contributing to the challenging of social relations and disabling barriers *outside* the research process.

In terms of the present study, by endeavouring to make the methodology 'rigorous and transparent', and by focusing on the emancipatory nature of the study, I feel that I was able to work towards challenging the social relations of research production, and therefore contribute to the challenging of social relations and disabling barriers outside the research process. I shall address the extent to which the methodology was successful in terms of emancipatory research in Chapter Six (Conclusion chapter). In Chapter Six I show how the extent to which the research could claim to be 'emancipatory' was limited particularly by undertaking the research in the context of doing a PhD in an academic environment. I also show that, by using an emancipatory methodology, additional factors arose which could be considered 'added value'. These were in terms of gaining greater understanding of the priorities of the Advisory Group through the experiential synthesis, increasing the dialogue between the academic community and disabled people, adding to the process of the collective empowerment of disabled people, and distributing the accessible report to make the findings accessible to those outside the academic community. In this way, therefore, the research can be seen to have had a wider impact than just the gaining of a qualification (PhD). This impact had the potential to effect change.

An earlier comment from one member of the group was:

> *E: Research needs the will to bring about change.*

Within the final meeting of the Advisory Group, while reflecting on the process and outcomes of the research, the members of the Advisory Group felt that the accessible report, in particular, was a valuable product that could help to bring about change.

Prior to the production of the report, the data had to be analysed and it is to this process I now turn. The analysis was particularly influenced by the Advisory Group. The description of the process of analysis of the interview data will be more explicit in this thesis than may often be found in research accounts. This is in order to make the process fully transparent since it involved a complex development of different types of analysis. These levels were seen to be integral to the emancipatory nature of the research and therefore need to be fully defined and laid open for scrutiny.

Analysis process with the Advisory Group.

As mentioned previously, the Advisory Group met nine times over a period of eighteen months. Each meeting was audio taped and transcribed by myself soon after the meeting. Most of the 30 interviews were transcribed by an *independent* transcriber and returned to me, although I transcribed some myself. In initial Advisory Group analysis meetings, I shortened/ summarised the data from one or two of interviews and sent them out in advance of the group meetings. After a few meetings I realised that some group members were struggling with the amount of reading material; it was a reminder that many people (not just disabled people) do not partake in much reading activity on a regular basis. Subsequently, I put interviews into chart form so that they were conceptually simpler. This involved summarising further what had been said. I acknowledge that this would ultimately involve losing some of the detail/ nuances of the interviews but I considered this was a compromise I needed to make to achieve a balance between presenting the information and ensuring individuals could spend time engaging in the debates rather than struggling over the details of the interviews. My aim was to encourage group members to compare the content of the interviews and the charting process made this more manageable. In the group meetings, the participants said that they found that the chart was useful for discussion.

In all, the Advisory Group analysed 20 interviews (of 30) and developed some conclusions and recommendations (see user report in appendix). In terms of practicalities and time, it was not possible for the group to analyse any more interviews. I recognise that this detracted from some of the commitment to full participation. However the Advisory Group agreed that they had met sufficiently and now were keen to see some outcomes. It must be noted that very few members of the group had a background that involved concentration/ studying/ long-term intense thinking processes and they were keen to reach short-term goals/ results.

The Advisory Group discussed the interview summary transcripts and charted material. Sometimes they addressed emerging themes while at other times they considered the responses of the individuals and made comparisons with other interviews. Their preliminary levels of analysis were mainly those of astonishment at the lack of knowledge of many professionals and to relate what emerged from the interviews to their own experiences and views. I sought to provide some structure to the meeting by encouraging them to develop the themes, bringing them back to the discussion and prompting them to address the deeper meanings in the words used. This was not always successful as very few group members were used to vigorous academic debate. They also tended to be more focused on their own experiences/ opinions, rather than on the interpretation and analysis of the interviews.

The priority of the Advisory Group was to make sure that the research process resulted in some action. In writing the collaborative 'accessible report', I drew together their action points. Their points of action were mainly practice and policy issues, such as the need for professionals and managers to access training on disability issues in order to develop a greater awareness (see appendix for full report). The report, therefore, represents the preliminary analysis of the interview data. My further systematic analysis took the process a stage further and developed the conceptual themes. The further systematic analysis would have been different had I not had the benefit of the preliminary insights, experiences and discussions of the Advisory Group.

After transcribing the tapes of an analytic group meeting I summarised the comments and sent them out with details of the next meeting and additional interview transcripts so that the Advisory Group members could read through the material before the subsequent meeting.

There were a number of individuals who wished to be involved in the research process but could not commit themselves to regular meetings. I was able to send them the same reading material and I received regular comments and feedback from those individuals. At the end of the project they commented that they appreciated the opportunity to be involved. In the present study the role of the group from the beginning was to be part of the analysis process and this continued throughout the research.

I now wish to describe the way in which the complex analytical process of this research followed a number of stages. The analytical process for this study used, as its basis, an outline proposed by Mason (1996). She suggests that the process of qualitative analysis should follow some of the following steps:

1. Data saturation
2. Organisation of data
3. Categorisation of data
4. Generation of themes
5. Relating concepts
6. Testing concepts

She advocates that, as a result of this schema, the researcher would be able to generate 'the most plausible argument' from their data (p.135). In the present study, I have developed this structure and added other elements to the analytical process. The additional elements take into account a reflection on other work, such as the relevant literature, and also, they recognise the emancipatory nature of this study by reflecting on the lived experiences of the Advisory Group in relation to the concepts generated.

The following diagram, shows how the present study follows the core processes defined by Mason (1996):

Figure 6: Analytical Process

Analytical Process (Developed from Mason, 1996)	**Present study**
1. DATA SATURATION	Early organisation of work: Listening to interviews and Advisory Group meetings/ transcribing.
2. REFLECTION ON OTHER WORK	Early organisation of work: reflection on literature (see chapter 1)/ reflection on early Advisory Group meetings.

3. DATA ORGANISATION	Early organisation of interview data by myself and the Advisory Group. Summarising transcripts/ charting.
4. CATEGORISATION/ CODING	Advisory Group generates themes from the interviews in discussion with myself (Preliminary group analysis). This leads to the production of accessible report, with practical and policy recommendations.
	I code and categorise the interview transcripts independently.
	I code and categorise transcripts of Advisory Group meetings.
5. DESCRIPTION	I describe categories and outcomes of data.
6. GENERATE ANALYTIC CONCEPTS	I draw out a conceptual analysis, keeping in mind the Advisory Group analysis and comments and using their analysis as a lens through which to see the data (Further systematic analysis). I generate the concepts of moral rights, attitudes, difference/ equality, consumer and risk from the data categories.
7. EXPERIENTIAL SYNTHESIS (Relating concepts)	I reflect on the experiential knowledge and concerns of the Advisory Group in relation to the concepts generated.
8. THEORY CONSTRUCTION/ TESTING	I relate analysis of data to theories of disability and citizenship [This constitutes a section of the 'conclusion' chapter.]

By following an emancipatory model in this study, in which an Advisory Group of disabled people constituted part of the process of the research, two forms of information were generated, that is, the thirty interview transcripts and the twelve Advisory Group meeting transcripts. It is crucial to consider all this information since the Advisory Group's contribution was such an important part of the process.

The analytical process was also complex, encompassing the Advisory Group's preliminary analysis of the interviews, a further systematic analysis of the interviews by myself and the reflection of opinions and experiences of the Advisory Group in relation to the concepts generated (experiential synthesis). In this way, there was a recognition of different levels of analysis. The Advisory Group categorised the interviews in relation to their personal priorities and at a level that reflected practical considerations in their day-to-day lives. Although they were considered part of the research 'team', it is important to acknowledge that their analytical skills were not engaged at the academic level of developing theoretical concepts. This is reflected in the accessible report, (produced by themselves) which highlights the analysis of the interviews in relation to the subjective way disabled people experience interaction with professionals and proposes practical and policy recommendations to its readers.

My categorisation, on the other hand, attempted to follow, in some way, a more systematic approach of categorisation but I was also able to take into account the priorities of the Advisory Group. I also established and developed the theoretical concepts as a result of the analysis and reflected on the relationship of the concepts to the existing literature. In this way, there was a stage at which I veered away from the Advisory Group analysis and onto a tangent in which my aim became the production of a PhD thesis.

Although the Advisory Group's analysis was at the level of relating the data to personal experience and practice recommendations, this does not imply that there was a hierarchy of analysis. The restrictions of the Advisory Group were mainly around time and resource constraints. If the Advisory Group had met for longer, and perhaps been paid to make a commitment to the research, recognising the importance of their contribution, then it is likely that they would also have contributed to the theoretical analysis process. There was a variation of abilities in the group but, by spending time explaining and discussing conceptual material further, the individuals could indeed have articulated their views more on the theoretical issues. The terminology used in this thesis of 'preliminary group analysis' and 'further systematic analysis' was chosen to reflect this. That is, the analysis by myself as the researcher, was undertaken in perhaps a more systematic way than the Advisory Group's discussion of the themes. The Advisory Group could have developed a more systematic approach given time and resources. In the present study, the theoretical knowledge and background can be seen as one of the 'tools' the researcher can bring to the process, to complement the experience, knowledge and skills of the Advisory Group.

The opinions/ experiences of the Advisory Group provided an added dimension to the research and were useful for assessing the extent to which the generated concepts resonated with the lived experiences of disabled people. This experiential data provided an insight of the day-to-day life for a disabled person which would not have been available to the non-disabled interviewees (or the mainly non-disabled authors of the literature on citizenship). I have called this part of the analysis 'experiential synthesis' since it is an attempt to synthesise the theoretical concepts generated from the systematic analysis with the disabled people's lived experiences.

In this way, the initial analysis of the interviews by the Advisory Group provided a framework for the basic categorisation. My further analysis of the interviews developed the theoretical concepts and related these to the literature. The reflections of the Advisory Group's opinions and experiences as an experiential synthesis brought the analysis back to the level of the lived experience of disabled people and thus reflected on the concepts in relation to a practical and policy base to ascertain whether the theoretical concept still had meaning for disabled people. In this way their experiences/ opinions were re-visited through the conceptual lens generated. The concepts were then tested within the data. As part of the testing of the concepts I was also able to consider the frequency/ data/ emphasis spent on each concept generated by the data in order to assess its significance in the development of citizenship theories.

By treating the data in this way, it was noted that, out of the five *new* concepts generated (that is, moral rights, attitudes, difference vs. equality, consumer and risk), the Advisory Group spent more time prioritising attitudes and difference, while the interviewees spent more time prioritising consumer and risk. This can be seen to reflect the lived experiences of the two sets of people (ie. the disabled people in the Advisory Group and the non-disabled people in the interviews) and highlights the extent to which they considered each concept important. By following this process of analysis it was suggested that the interviewees used the rhetoric of business (ie. consumer and risk) to justify the exclusion of disabled people, while the disabled people in the Advisory Group used the rhetoric of their lived experiences (ie. attitudes and difference) to explain their exclusion.

In terms of the *validity* of the research, I would suggest that the research did achieve its aims. The aim of the research, through the guidance of the Advisory Group, was to find out the attitudes of professionals to disabled people. It was specifically looking at the extent to which disabled people were perceived as citizens. The analysis of the data found that the attitudes of the professionals were mainly around their perception of the disabled person as a consumer and around factors of risk. The Advisory Group also found that the attitudes of the professionals centred on perceptions of stereotypes and difference. Thus, the research has a strong level of validity in terms of finding out the attitudes of professionals to disabled people. The research has also developed the concept of attitudes and related it to a wider context of citizenship.

In terms of *reliability*, it can be suggested that, due to the focus on an emancipatory approach, if the research was carried out again, the detailed group discussions and the interview data may not be the same, and this initially suggests that the level of reliability may not be high. The focus for the enquiry was guided by the Advisory Group, a collective of individual people with impairments, with personal priorities related to their lived experience. It could be argued that, if a different set of disabled people made up the Advisory Group, then this may have altered the focus of enquiry. They may also have produced different interview questions and may have had alternative ways of categorising the data. Finally, with regard to synthesising the experiential data from the Advisory Group with the concepts generated, this, too, is dependent on the nature and individual make-up of the group and their lived experiences. It could, therefore, be suggested that an emancipatory approach can pose some dilemmas around the level of reliability, since the research agenda, and the analysis of the data, has a fluidity that is channelled by the lived experiences of the individuals of the Advisory Group. However, the analysis did follow a rigorous process and the findings of the research were able to develop the theoretical model of Citizenship in relation to disabled people. I would argue that a similar generation of the concepts and the development of theories of citizenship could be a likely outcome of a further, or repeated, study. In this way, the *reliability* of the analysis, as with most interpretative research can be seen at the theoretical level, rather than the empirical level.

Having described the stages of the analysis process I shall now describe in detail the systematic analysis. The research generated different forms of data. The main data were the 30 interviews with professionals. I familiarised myself with the interviews during the interviewing sessions, afterwards (listening to the tape), and during the Advisory Group meetings (where the group gave their comments on the interviews), I also read through the interviews after transcription (some transcribed by myself and some transcribed by an independent transcriber).

The Advisory Group meetings were also a form of data, since the group gave opinions, experiences and analysis of the interviews. However, it was necessary to avoid directly comparing the views of disabled people (ie. the Advisory Group) with the views of non-disabled people (ie. the interviewees) as the aim in this research was not to view the members of the Advisory Group as 'subjects'. Instead, the data from the Advisory Group was used as a heuristic 'lens' through which I could reflect on and categorise the interviews independently. The opinions and experiences of the group were used to reflect on the extent to which the concepts generated resonated with the lived experiences of disabled people.

The Advisory Group themselves organised some of the interview data and generated categories and policy/ practical recommendations. Their preliminary analysis process was not one of systematic categorisation and coding but was based on qualitative discussions and meanings. The Advisory Group's preliminary analysis was used as a base on which I could build a more systematic analysis process.

First, while reading every interview, I wrote summary notes alongside the transcription for each question, that is summarising what was said and the main points raised (that is, following Mason's process, not addressing in any detail particular words used or opinions expressed). These were then written out separately in a chart so that it could be seen clearly how much the interviewees responded similarly or differently. From these summaries it became apparent that some themes were common to most interviews (eg. use of language, definition of disability, opinions about rights). The themes at this stage reinforced many of the discussions about the interview data by the Advisory Group since they arose from the responses to the direct questions.

I then analysed the data further, seeking to explore interviewees' opinions and attitudes (since this was pertinent to the Advisory Group's priorities) and their specific examples and experiences. These often arose as a result of interviewees 'going off at a tangent' ie. when expanding on an answer within the semi-structured format. These points were also summarised in order to compare and to draw out common themes. The categories generated by the Advisory Group analysis, the summary of the question responses and the further analysis of the data outside the question responses, therefore, was grouped into a number of thematic headings. These were subsumed into five main concepts: moral rights, attitudes, consumer, difference and risk.

I then reviewed the Advisory Group meetings. The transcripts of each meeting were read and coded into two main headings: opinions/ experiences of the Advisory Group and Advisory Group analysis of interviews. The quotes and discussions under these headings were then read alongside the different concepts identified above in the systematic analysis of the interviews. Hence, there were opinions, experiences and interview analyses from the Advisory Group that related to each concept that emerged from this systematic analysis. This meant that the Advisory Group's (ie. disabled people) comments were not being directly compared with the interviewees' comments (ie. non-disabled people) but that the concepts produced by the systematic analysis of the interviews were being grounded within the priorities of the Advisory Group. In this way the Advisory Group was part of the process of the data collection and of the analysis rather than being the subject of the research. Their opinions and experiences represented 'added value' to the research, backed up some of their comments/ analysis of the interviews and were used to reflect on the extent to which the concepts resonated with the lived experiences of disabled people. In this way, the grounded reflection of the concepts led to the development of 'abductive reasoning' which is,

> ...the process of moving between everyday concepts and meanings, lay accounts, and social science explanations. (Mason, 1996)

The tripartite framework of analysis described was seen to be necessary in order to accommodate the different processes involved in this study. In analysing the data, the Advisory Group played a vital role beyond that of mere participants. Their contribution to the analytical process helped to define and consolidate the conceptual framework that was developed. As described earlier in this chapter, there was a point at which the process I undertook as a researcher undertaking a PhD in an academic environment, veered off at a tangent to the Advisory Group's process. In some ways this was necessary in order to acknowledge my ownership of the final product of a PhD qualification, that is, the written thesis that develops theoretical concepts and produces further knowledge and understanding. This is similar to Priestley (1997) who produced an accessible report with Derbyshire Centre for Integrated Living (DCIL) and Derbyshire Coalition of Disabled People (DCDP) in addition to a PhD thesis for his research on User Involvement in Derbyshire. In this way, DCIL and DCDP retained ownership of the findings in the form of the accessible report, while Priestley, who continued the conceptual development of the material further gained ownership of a different product of the research, that is, the PhD thesis. The issues around ownership were discussed earlier in this chapter and describe the tensions in doing emancipatory research within and academic setting for the purpose of doing a PhD. The strength of using a tripartite model of analysis, are around giving all the contributors to the research a voice and working in a collaborative way.

However, the weaknesses of the tripartite analytical process are around the lack of involvement of the Advisory Group in *all* the stages of the analysis. As discussed earlier, this was, in part, due to lack of time and resources in order to keep the Advisory Group committed for a longer period of time. There would certainly have been benefits to continuing the group for longer and the Advisory Group would have been able to contribute to the further analytical processes and the development of theoretical concepts. As individuals, their contribution to the analysis could have continued for longer and been at a more systematic level, given further input from myself to explain, discuss and give clarification to the systematic process. However, as discussed earlier, the lifespan of the group was finite and, during recruitment of Advisory Group members, this was made clear. Their priorities were around making sure research affected change and making the products of the research accessible. To this end, and within feedback sheets and final reflections, they expressed their satisfaction at what they had achieved, and the process they had been involved in.

The complex analysis process will be reflected in the discussion of the data in the next three chapters. The next three chapters describe the findings of the research. In each chapter, I shall first describe the preliminary analysis by the Advisory Group and then my own further systematic analysis of the interview data. I shall then move on to describe the experiential synthesis in order to show the extent to which the generated concepts resonated with the lived experiences of disabled people. Finally, the generated analytical concepts that were developed as a result of the analysis will also be put into the context of the existing literature. Five concepts emerged as a result of the analytical process. These were: moral rights, attitudes, difference, consumer and risk. These have been organised into three chapters which allow a discussion of the 'discourses' in which these concepts are variously given prominence.

The discussions of citizenship, which emerged from the data, were seen to reinforce and develop the academic discourse on rights outlined in the literature review. The present research, however, also expanded the concept of citizenship rights by introducing the element of 'moral' rights. This will be discussed in Chapter Three, entitled, Academic discourse: Developing rights and exclusion. This title indicates that the concept of citizenship embodied in the academic literature has, unsurprisingly, re-appeared as a result of the analysis of the interview data in the present study. Although the data indicates a development of the work on citizenship to include 'moral' rights, the context of the citizenship rhetoric is grounded in the academic debates referred to in Chapter One, the Literature Review.

In contrast to Chapter Three, Chapter Four is entitled the 'Advisory Group' discourse. The concept of attitudes and the concept of difference both emerged from the interview data, and were seen to be an important discourse of the Advisory Group in their preliminary analysis. Their discussions of the interview data considered the way in which the professionals' attitudes to 'different' people (in this case, disabled people) affected the extent to which disabled people were perceived as citizens. In Chapter Four, Advisory Group discourse: Adding attitudes to the citizenship literature/ Difference in relation to disabled people, these findings will be explored.

Finally, the concept of consumer and the concept of risk were also generated by the data. These arose mainly from my further systematic analysis , rather than from the Advisory Group's preliminary analysis and could be seen to reflect the discourse of the professionals interviewed. The discussion in Chapter Five, Professionals discourse: disabled people as consumers/ articulating or experiencing risk, shows how the professionals considered disabled people as potential customers in the market they served. However, the element of risk could be seen to affect the level of inclusion of disabled people as customers, and as potential employees. Although the Advisory Group did not articulate risk within their analysis process, they did recall several experiences where they, as disabled people, were perceived as potential risk factors.

The experiential synthesis outlined within chapters Three, Four and Five played an important role in grounding the five concepts generated. Although there were differences within the preliminary and systematic analysis processes in terms of the relative importance given to each of the concepts, the experiential synthesis was able to give further clarity to the relevance of all the concepts to the lived experiences of disabled people. This therefore prevented the thesis from being purely an abstract/ theoretical piece of work.

I now turn to the findings of the data, which are discussed in the next three chapters.

CHAPTER 3. ACADEMIC DISCOURSE DEVELOPING RIGHTS AND EXCLUSION.

Arising from the analysis of the data, additional elements relating to the concept of citizenship were developed. The basis of citizenship in the academic literature (see chapter 1) encompassed civil, political and legal rights. Since the present research used citizenship as its base and the interview schedule reflected this, it would seem a reasonable supposition to expect a reinforcement and development of these dimensions of rights. However, to add to the academic discourse, the analysis of the interviews produced another element of rights, that is, 'moral' rights. The Advisory Group defined 'moral rights' as rights to respect, privacy, dignity and being treated fairly and they discovered this element fairly early on in the interview data. It could be suggested that the element of 'moral' rights reflected their emphasis on attitudes, since through it the interviewees were implying that disabled people had a right to receive respectful attitudes. It is worth reiterating that within the research process, the Advisory Group had not found the academic concept of citizenship very helpful.

The findings of this part of the analytical process, therefore, address the dilemma of the academic vs. the lay perspective and develop the concept of citizenship so that it has more resonance with the lived experiences of disabled people. The discussion on 'moral rights versus legal rights', within this chapter, therefore describes the way in which the interview data and the Advisory Group expand on the concept of citizenship, already in the literature.

This chapter will also show how the concept of exclusion can be developed as a result of this study. The analysis of the interviews found that two elements that were of particular relevance to disabled people could be added to discussions on exclusion. They were ‘barriers’ and ‘visibility’.

Finally, I will briefly return to Marshall's focus on state obligations. Although 'state obligations' was seen as an important element of Marshall's theory of citizenship, within the present research, there was very little reference to state obligations.

This chapter will show how the findings of the research created a need to return to the concept of citizenship and suggest new dimensions to explore in relation to citizenship.

Preliminary Group analysis

Developing rights: moral rights vs. legal rights

Within the preliminary group analysis of the interviews the discussions of the Advisory Group expanded the concept of rights (as outlined in the citizenship literature, Chapter One). Within their analysis, the Advisory Group identified that many interviewees talked about disabled people as 'having the same rights as everyone else'. They recognised that, in fact, usually the interviewees were suggesting that disabled people *should* have the same rights as everyone else. These quotations from the Advisory Group discussions offer examples of comment on how the professionals defined rights.

> *C: another answer she [social worker] gives, she says 'of course disabled people have the same rights as everybody else...as long, of course, if you're mentally able of exercising them...'*

> *S: it's interesting that they both [two supermarket managers] believe that disabled people should have rights. I think that's really not their own opinion, it's more a company's policy because they don't want to lose custom from disabled people. I don't think, reading between the lines, that they really believe most of what they are saying which I find worrying, it's just PR.*

> *S: the clinical psychologist, question 8, in what areas don't disabled people have rights? He says 'none'- that's amazing- total over-compensation there, lack of awareness of the rights that we have......*
> *R: ....maybe the clinical psychologist felt that that's the way it should be- that there should be no areas where...it's a very one word answer so it could mean anything.*

The Advisory Group defined the rights that the interviewees were talking about as 'moral' rights, that is the right to be treated with respect, dignity, equality, and care, that is, that people's attitudes should be 'humanistic' towards disabled people. The Advisory Group noted that the issue of 'moral' rights was found in many interviews, and was not just associated with certain interviewees. The following are examples of the Advisory Group's discussions on the interview data around 'moral rights':

> *R: I think that when they talk about rights, they mean 'moral' rights, like respect, dignity and being treated fairly, rather than rights in law...*
>
> *Researcher: It's interesting that people just presumed, well, disabled people have rights.*
> *C: well, yes, I think partly when you talk about rights for people in general, you are talking about civil rights in the sense that officials can't enter their homes without a warrant and as you say, freedom of speech, freedom of assembly, freedom of association, no rules against them getting together in unions or social clubs or being pigeon fanciers, or whatever... and that's what they think of as being the area in which we all have rights and in that sense, most disabled people are not disadvantaged and then I suppose they think beyond that and think there's nothing to stop a disabled person getting on a train except physical barriers and you know, it's just one of those things- it's not a matter of rights, its just hard luck.*
>
> *R: well he's [contracts manager, health service] really talking about social mores and social attitudes and moral rights, rather than, as you say, legal rights. But when you're asking about people's rights, I would expect a professional of any sort to think in terms of categories of rights- distinguish legal rights from the sort of usage of rights in everyday language, like 'he didn't have no right to say that, did he?' [everyone laughs]*

> *K: ...I still think that a lot of these people, you see one's an Member of Parliament, another one's a newspaper editor, another one's a contracts manager and therefore a statutory service provider, and you would have thought all these people would be more aware of the difference between legal rights and sort of 'social rights' or 'moral rights' than the average person, simply by virtue of their training.*

With regard to legal rights, the Advisory Group were generally surprised that the interviewees lacked knowledge about disability rights and that, in general, the responses showed an ignorance of the introduction in 1995 of the Disability Discrimination Act. The Advisory Group recognised that in general the interviewees who tended to be potential employers knew very little about the DDA. They saw this lack of knowledge as significant and made sure it was an issue noted in the accessible report (including information about the DDA in the appendices). One member commented:

> *C: one of them [the two supermarket managers] suggests that the information [about the DDA] he's been given by the people who provide information for his service has simply been taught about the employment aspect and employment is a very major part of the DDA, but it's not the whole of the DDA and the provision of services is another important part, and er, very convenient of these professionals not to have heard that bit!*

In discussion, the Advisory Group talked about the DDA not going far enough and they were pleased when the interviewees recognised this:

> *S: there are one or two hopefuls though.*
> *Researcher: yes, I felt there were a few hopeful signs. Like what?*
> *S: like they did actually feel that there was discrimination and that there should be anti-discriminatory legislation. One of them [two cinema managers] was even aware that it's not effective as it should be, which is a beginning because at least*

> *he's not swallowed the whole thing and thinks that this is what disabled people wanted and that there will be no discrimination.*

In general, the element of 'rights' identified in the interview data echoes Marshall's (1950) model of citizenship ie. civil, political and social rights. Although Marshall's model was generated around class dimensions it can be seen that the interviewees in the present study suggested that 'rights' were also crucial in relation to disabled people. It is interesting to note that Marshall talked about people gaining rights in a chronological order ie. civil rights, then political rights, then social rights (see Chapter Two), whereas the Advisory Group point out that in the interview data professionals talk about rights as an ideal ie. disabled people 'should' have rights. There is also the added dimension of 'moral' rights, which seems to be referring to rights of respect, dignity, fairness, rather than rights in law. The interview data suggest that these 'moral' rights should be accepted as given, that is, they are *not* rights to be achieved in any particular order.

The 'moral' rights referred to by the Advisory Group were seen as different from the rights described by Marshall (eg. civil, political and social). Moral rights were seen in terms of the way a person is treated. This, they suggested, may be affected by social rights and entitlements to services, in that services can increase an individual's quality of life. However, the members of the Advisory Group, and the interviewees, were referring more to an underlying attitude of respect toward disabled people, than to an entitlement to a service.

Buck suggests that:

> It is undoubtedly the case that the disability movement has pursued the goals not only of autonomy and integration but also of the achievement of 'rights'. (Buck, p. 179)

but Hudson, (1988) argues that there should be a distinction between 'claim rights' and 'moral rights'. Claim rights, he argues, can be seen to be important within areas of routine discrimination, such as employment and access to leisure. Moral rights, on the other hand are important within areas where there is fundamental discrimination, such as the exclusion of people with learning difficulties from basic human rights such as rights to life, procreation and parenting. However, Plant argues that we have to arrive at a consensus about what is appropriate in terms of 'the right to life' at the time. Therefore, this becomes an *agreed* entitlement. He questions whether the right to life means the right to not be killed (moral right can be enforced with rules) or the right to be kept alive by resources (dependent on availability of resources and therefore based on discretionary judgement, therefore not a right/ no rules). There is therefore an implied choice and judgement on 'moral' rights, including the idea of enforceability of rights. In terms of 'moral' rights for disabled people, Barton makes the case that disabled people are a long way from full and equal citizenship on a par with non-disabled people. He concludes that:

> ..the struggle for citizenship is viewed as an affirmation of the value of choice, independence and control which disabled people conceive in terms of human rights. (Barton, 1993, p. 233).

Marshall, therefore, can be seen to neglect 'moral rights' due to his narrow emphasis on civil, political and social rights.

Other recent commentators have also defined areas of rights that have been neglected by Marshall. Turner (2001), for example, talks about environmental rights, aboriginal rights and cultural rights, none of which were considered by Marshall, but which are now seen as important in citizenship thinking. In relation to cultural rights, he emphasises the need for 'ontological security', in which,

> ...the right of security is a right to human existence...(Turner, 2001, p. 206).

He goes on to suggest that ontological security also includes the right of respect for cultural differences and the right to a regard for human dignity (Turner, 2001). The elements of the right to respect and dignity relate to the notion of 'moral rights' in the present study. Turner also suggests that these rights relate to,

> ...the Declaration of Human Rights and more recently in the legal recommendations arising from a variety of UN conferences on the environment, population, and human settlements...(Turner, 2001, p. 207)

Turner's work therefore, resonates with the findings of the present study in that he proposes that a framework of citizenship should include elements of 'moral rights'. However, he also recognises that,

> ...there is no set of governmental arrangements at the global level that enforce or match these rights... (Turner, 2001, p. 207)

In this way, therefore, although, both within the present study and within the proposals of Turner (2001), it has been suggested that the element of moral rights should be included within a framework of citizenship, it needs to be recognised that enforcement of this proposal would be difficult.

Other authors, such as Janoski and Gran (2002), identify further types of rights that have been neglected by T.H. Marshall. They talk about the area of participation rights, which refer to the right to take part in decision making, both in the public sphere and in the private sphere. They also refer to categorical rights that are specific to different groups and not to other groups. Such groups include immigration rights, women's rights, and regional, rural and urban rights.

There has also been more recent emphasis on the notion of Human rights, particularly with the introduction of the Human Rights Act, 1998, which embodies such concepts as a right to a fair trial, respect for private family life, freedom of thought, freedom of expression, prohibition against discrimination, among other points. Finally, several authors (Meade, 1996, Finch, 1996, Newby, 1996) have talked about rights in relation to employment, families and the environment, respectively.

In this way, therefore, the findings of this study complement the aforementioned authors by highlighting the narrow viewpoint of Marshall's focus on civil, political and social rights.

Developing exclusion

Within the citizenship literature (see Chapter One), the element of exclusion has been developed (Lister, 1997, Barbalet, 1988). The literature showed that some groups (for example, women and disabled people) experienced exclusion from full citizenship rights and struggled to gain inclusion. Within the preliminary group analysis, the Advisory Group did not talk much about the term 'exclusion' as a category, but the following comments highlight brief discussions in relation to this part of the interviews:

> *Researcher: one of these people [social worker (2) and community worker] said he preferred the word 'difficult' and saying that everyone has difficulties in some aspect or another.*
> *C: yes, well, this is all very well, I think it's a mistake from a good motive. The good motive is 'inclusiveness'.....but from a legalistic point of view, if you're going to have an act to help disadvantaged people, you absolutely have to be able to define the people who are disadvantaged.*
>
> *C: this solicitor says he doesn't see many disabled people in this practice, first of all because they live in a graded historical building which is totally inaccessible and secondly, because they charge ridiculously high prices and no disabled person's daft enough to pay them!*

One of the areas where exclusion was seen as pertinent by the Advisory Group was that of visibility, that is, if disabled people were visible in their community then this could indicate that they were *included* as citizens and members of a community. The Advisory Group commented on the issue of visibility arising from the interviews, particularly in terms of the interviewees' lack of awareness of hidden disabilities. These extracts are some of several comments on the issue of visibility, by the Advisory Group:

> *Researcher: I think they both [Member of Parliament and social worker],recognise that there were hidden disabilities*
> *C: yes, oh yes, they recognise it but I don't think they are consistent...*
>
> *S:...I thought the horrendous part was the way that the people in the hostel [social worker interview] regarded disabled people and how they wouldn't admit they had a disability. I think that stands out.*
>
> *S: no-one seemed to grasp the concept of hidden disabilities...*
>
> *Z: How does he/she [architect] know?! They may not have wheelchair users but might have people with mental health problems, or dyslexia , or asthma, or obvious scars etc. (covered by DDA as 'disabled people') and so on.*

Again, these comments are representative of their preliminary analysis of many of the interviews and were not specific to particular interviewees. The Advisory Group also commented that the interviewees were saying that it would be a good idea for disabled people to become *more* visible in society. This extract illustrates one of several examples on the point:

> *C: well, I think in context of the interviews generally, what it means is that one or two say at different points that they think that actually getting more disabled*

> *people out of the woodwork and into their area of society would be a good idea, that they or their colleagues would become more aware of what disability was if that happened.*

The Advisory Group also saw that within the interview data the issue of 'barriers' was significant to the category of exclusion. The Advisory Group's comments on the interview material centred mainly around the barrier of *access*, for example:

> *J: They [solicitors] trot out when buildings are listed and they can't be altered, it comes out really quickly does that, but yet some of the listed buildings have been altered.*

> *Z: Question 14, b) 'disabled access'- does this mean wheelchair access- or have they [solicitor] built in access features for people with sensory impairments, learning disabilities etc?*

It is interesting to note that these two examples show how solicitors were responding to the issue of access. The Advisory Group noted that, although, in general, the solicitors had more knowledge of the Disability Discrimination Act (1995) than many other interviewees, in terms of access (such as door widths, ramps, and fire regulations), they tended to be guided by legislation (eg. building regulations) rather than by any principles on developing access (or inclusion) for potential customers. Although the Advisory Group tended not to define the term 'exclusion' within a citizenship paradigm, they did, however recognise *areas* of exclusion (such as visibility and barriers) within the interviews.

In this way, the preliminary group analysis has highlighted the development of the rights theme and has shown how the interviewees reinforced the element of exclusion as an aspect of citizenship.

Further Systematic analysis

Developing rights

Following on from the preliminary group analysis, within the further systematic analysis I found that the issue of rights was developed further in the same way as the Advisory Group. I noted that the interviewees referred to disabled people as having equal rights, *in the same way* as everyone else. The discussion around equal rights and equal treatment will be explored in more depth in Chapter Four within the context of whether disabled people are different to non-disabled people, or equal, or both. It will be suggested from the analysis of the data that, in order for disabled people to participate 'equally' then their 'different' needs should be addressed. In this way they are both different from, and equal to, non-disabled people and therefore, the treatment of disabled people should reflect this. In other words, the aim is that disabled people should be equal to (and should be treated equally with) non-disabled people, but the route to achieving that equality may be different.

Within the further systematic analysis, I noted that the interviewees were saying that disabled people were no different to anyone else, eg.:

> Researcher: [laughs] Um, do you think that disabled people have rights?
> Customer Services Manager (Bank): [long pause] Yes. To me, there's no differential, as far as rights are concerned - between a disabled person and an able-bodied, or whatever you want to call the rest of the population.
>
> Researcher: Exactly. Do you think disabled people have rights?
> MIND Officer: Of course they do! Why shouldn't they have rights?!
> Researcher: What rights do they have and are they any kind of rights they don't have?

> MIND Officer: Well... because of the way I view people, I would say they have the same rights as I have.
> Researcher: Right. Right.

> Cinema Manager (1): Um... it's clear that as an employer...
> Researcher: Mmm.
> Cinema Manager (1): ...they have rights.
> Researcher: Mmm.
> Cinema Manager (1): Um, from my own point of view I can't understand why the issue has to be raised. Because everybody has equal rights. Um, but that's... furthermore, I would say, seeing life through rosy-tinted spectacles.
> Researcher: Yeah.
> Cinema Manager (1): We all... yes, they absolutely must have rights.

> Supermarket Manager (2): They have the same rights as everyone else. They have the same rights in our store.

These extracts are typical of the majority of the interviews. My analysis also indicated that disabled people were perceived as having *equal* rights and equality, as the following text, which is also representative of other interviews, shows:

> Researcher: Absolutely. Do you think that nowadays disabled people have rights? And if so, what kinds of rights do you think that they do have?
> Disability Officer (Methodist Church): [pause] I think in terms of having the same rights as all of us. I think that's the important thing. That any rights that I think I have, they should have equally.

In a similar way to the preliminary group analysis, my further systematic analysis also suggests that the professionals presumed that disabled people have the same rights as everyone else. This can be seen to be related to the concept of 'moral' rights, in that, if rights consist of respect, dignity and fairness then, ultimately, the interviewees are saying that all human beings should specifically have access to *these* rights.

In developing the conceptual material further, the further systematic analysis of the interviews also highlighted the issue of ideal rights versus reality, that is, interviewees recognised that disabled people should (and maybe *do*) have rights, but that in reality some of those rights are denied them. This develops the preliminary group analysis which also highlighted the professionals' perceptions that disabled people *should* have rights. The following quotations show some of the typical examples of interviewees' discussions around ideal rights versus reality:

> Researcher: Do you think disabled people have rights? In what areas do they have rights, what areas don't they have rights?
> Social Worker (for disabled people): I think they have very few, in reality. I mean, in theory - yes, they have the same rights as everybody else. But I mean, in practice... um, certainly around, I've found, employment. Must be the major issue. Um... housing, to a degree. But maybe not so much.
>
> Social Worker (for disabled people): Well, yeah. I mean, in theory they have lots of rights and lots of things people say they can do. But in practice...
> Researcher: yeah.
> Social Worker (for disabled people): ...exercising those rights are extremely difficult.
>
> Supermarket Manager (1): They clearly do have rights. It's a question of using common sense because some won't be able to do what others can do or go where others can go. Probably there are some rights denied disabled people because of their disability and because of other people's ignorance.
>
> Researcher: Do you think disabled people have rights?

> Social Worker (2): Yes, I think everybody has rights.
>
> Researcher: What kinds of rights do they have and what kind of rights don't they have?
>
> Social Worker (2): I think they should have the same rights as everybody else, whether they're abled or disabled, but in reality I don't think it is like that. I think they have a lot of rights taken away from them...I think they have a right of their own legal affairs, if they're mentally able to do that, they have a right to live where they want.

This data resonates with the preliminary group analysis which found that the interviewees were saying that disabled people *should* have rights. It also suggests that there are often difficulties in exercising these rights. It is interesting that these quotes show two different social workers who felt that disabled people should have rights. Within the discussions on this issue it was noted that, in general, the welfare professionals had more conviction that disabled people *should* have rights. The social worker (2) above, went on to say that although the ideal is for disabled people to have equal rights, as a professional, he was restricted in enabling disabled people to exercise rights due to lack of resources and inflexible working practices. This matched the views of other welfare professionals who recognised that, in reality, disabled people were hindered by the 'system' and by other barriers in society. It would seem that, in the interviews, the retail/ leisure managers were *less* aware of the way in which disabled people's access to rights was hindered. In the citizenship literature (see Chapter One), the achievement of rights was seen as a 'status to be gained' (Marshall, 1950, Lister, 1997). These authors also recognised that the achievement of rights for oppressed groups tended to be as a result of *struggle* and *negotiation*. The data , therefore, is confirming the existing literature: although the ideal would be for disabled people to have the same rights as non-disabled people, there is a recognition that disabled people have difficulties exercising those rights. The interviewees also reflected that the journey for disabled people in achieving citizenship status could be as a result of a 'struggle', which again, reflects the literature.

The Advisory Group's opinions/ experiences around the Disability Discrimination Act (1995) were that generally it did not go far enough. In a way, my further systematic analysis of the interviews indicated that the professionals also held this opinion. Many interviewees suggested that there needed to be other changes in order for the legislation to be effective, for example, education, and attitude change.

Within the preliminary group analysis the Advisory Group also noted a *lack of awareness* about the Disability Discrimination Act on the part of many interviewees. Within the further systematic analysis, I also noted this point, but, to develop the discussion further, I found that the interviewees tended to talk a great deal about 'accommodating' disabled people rather than about giving disabled people 'civil rights'. The professionals therefore reflected the UK legislation (Disability Discrimination Act, 1995) which talks about making 'reasonable adjustments' in order to *accommodate* disabled people. In contrast to the UK legislation, the Americans with Disabilities Act (1990) emphasises civil rights for disabled people, not just the 'accommodation' of disabled people ie. suggesting that UK professionals reflect the discourse in which they work.

This was most noticeable among non-welfare interviewees, since, having shown in the previous examples (p. 150) how the welfare professionals were fairly consistent in their views that disabled people *should* have rights, the following quotations illustrate that professionals in other fields (eg. mainly leisure/ retail managers), talked about the way in which disabled people were accommodated (ie. treated as a separate group of people). In this way they were perceiving disabled people to have *different* rights, and therefore possibly to be subject to different treatment than that received by non-disabled people.

> Art Gallery Manager: Well, we've got member of staff who's got a mental disability. He's on drugs for depression and everything else. And we certainly try to accommodate that wherever possible.

> Art Gallery Manager:...and you can accommodate it. There's certain parts of the collection we can allow people to handle, y'know, with gloves and etc. and so on. So, yeah...to a certain extent.
>
> Researcher: right, so...
>
> Art Gallery Manager: I don't think you can accommodate every time.

> Manager of Council for Voluntary Service: So... what I'm saying is we're not denying the right of people coming to this office, up a very twisty flight of stairs. We're not denying that. We're saying that we will do our best to accommodate you in situations that are unsuitable for you. Which may mean that actually we can't say "Come into this office" but what we will say is "Go into somewhere suitable".
>
> Researcher: Right.
>
> Manager of Council for Voluntary Service: And I think there's a subtle distinction between people in that therefore you as an individual also have, um... a right as it were, to appreciate... what is within your surroundings as well. That's right, um... equal responsibilities.

In contrast to the above discussion, other interviewees (again, more prominently, but not always, in the welfare professions) discussed the need for disabled people to have *full* civil rights. They also talked about the issue of discrimination. The following extracts highlight this view:

> Social Worker (for disabled people): Probably. I mean, again... I don't know anything, really about it [The ADA]. But I mean, I suppose from civil rights point of view, yeah. I mean, we're not very strong on civil rights in this country, are we?

> Age Concern Manager: And they could do. They could do. Y'know, we could be leading the world in a way, couldn't we? If they got their act together. I mean, I'm

> sure in other countries… um, the disabled aren't discriminated against like they are here.
>
> Researcher: Do you think there's any areas where they don't have rights?
> Solicitor (1): [pause] Yes, I mean… I think one's bound to get, um… in certain areas - one's bound to get discrimination in employment and that type of thing. Um, I don't deal very much with employment law but I'm sure one gets a number of cases where people are discriminated against purely and simply because of the disabilities. Perhaps they don't get the, er… um… promotions and things that they're perhaps entitled to. Perhaps life's made difficult for them because one has companies where they're not prepared to adapt or whatever and deal with that. It is a very difficult situation, I think, Um… and one's always going to come up against a situation where they're discriminated against by certain narrow-minded individuals.

The main dichotomy highlighted by this discussion is therefore around whether disabled people should have the *same* civil rights as non-disabled people (in line with the Americans with Disabilities Act, 1990), or whether they should be *accommodated* within a non-disabled framework of rights. It was suggested by citizenship commentators such as Buck (1993) that:

> It is time for more powerful legal measures to attempt to strike a sensible balance between a duty to 'accommodate' the needs of the disabled and the reasonable needs of employers and others in order to enable the disabled citizen to achieve the fullest possible participation and integration in society. (p. 195)

Furthermore, Lister (1997) has also suggested that, like disabled people, *women* have had to be 'accommodated' into a 'male' version of citizenship, rather than being granted full civil rights independently, eg.:

> The historical legacy has been to contribute to an image of women as incapable of true citizenship. (p. 66)

In this way, therefore, the focus on 'rights' generated by the data supports and develops the existing citizenship literature on rights. It also reinforces the view that Marshall's linear model of the achievement of citizenship status is overly simplistic because it is based solely around the recognition of class issues, which dominated the 1950s, rather than the diversity of different types of oppression acknowledged in the twentieth and twenty-first centuries.

The examples from the interviews highlight some of the developments in the implementation of the Disability Discrimination Act (1995). Originally the DDA sought to reduce the discrimination of disabled people by emphasising the need for employers/ goods and services to accommodate disabled people. More recently, however, the present government has shown a greater commitment to a civil rights model, by amending the Act to emphasise the need for services and buildings to be *fully* accessible for disabled people, whether they have disabled customers/ employees or not. The development of the Disability Rights Commission in the UK is also an indication of further commitment to the rights of disabled people. Within the interview data, it was seen that very few people had knowledge of the Disability Discrimination Act (1995). However, those who had knowledge talked about it more within an employment framework, rather than in terms of the development of civil rights. This could be due to the fact that the parts of the Act that were implemented first were focused on reducing discrimination within employment practices. This part of the Act would clearly have implications for professionals responsible for recruiting and managing employees, and it was particularly relevant at the time the fieldwork for this research was undertaken.

Exclusion

In contrast to the preliminary group analysis, within the further systematic analysis of the interviews, I found that there was a *larger* amount of data around the category of exclusion, as an element of citizenship. Many interviewees suggested that they were proud of the way in which people with disabilities were 'included' in their service (usually as customers). This Art Gallery Manager reflects other examples on the subject:

> Art Gallery Manager: At the moment [chuckles] we're going through a bit of a tough time with artists. And so, I mean that obviously with catalogues for exhibitions, and that sort of thing. An artist will send in a statement and literally I'm turning round to the Education Officer saying "Can you please translate this please?" So that it is accessible to everyone. Or as many people as possible. So that when they do come we're not, as it were, being too elitist...
> Researcher: No.

It was interesting to note that a teacher, who taught in a segregated college for disabled people advocated for disabled people to have *special* facilities in the college. However, she pointed out that the drinks bar at the college was not particularly accessible because that would not be reflecting the 'real world'. In this way, she is suggesting that although inclusion is the ideal, maybe in practice it may not be very realistic:

> Teacher (College for Disabled Young Adults): There are, um... the toileting facilities and the washing facilities and things like that, are, particularly considering the disabled. But things like the bar, and, um, other places won't be like that... because one wouldn't think that is the real world.
> Researcher: No
> Teacher (College for Disabled Young Adults): And our big thing is to teach people about the real world.

In this way, the teacher is suggesting that disabled people should learn to accept an element of exclusion as part of the 'real world'.

Following on from the preliminary group analysis in which the element of visibility was highlighted, the further systematic analysis also noted this element in relation to exclusion. However, the preliminary group analysis gave *greater* weight to visibility. The following extracts illustrate many examples of comments by interviewees on the issue of visibility:

> Teacher: Yes. And I think people are able to show disability more than they could. Um, when I was younger there would be nobody in town obviously disabled . Whereas, now there will always be, there will always be two or three people who are obviously disabled. Um...so at one time, presumably those people didn't go out. And were kept in the house. Or maybe didn't have the facility to get out.
> Researcher: Quite, yeah. Exactly.

> Restaurant Manager: [long pause] I think again, it's... I think it's going to have to happen over time. When people see more disabled people in restaurants, in pubs... it's like anything else, you get used to something new.

> Restaurant Manager: I think they need to get into more day-to-day situations. I mean, when I was at comprehensive we had a disabled school next to us.
> Researcher: Right.
> Restaurant Manager: And... the first two years I was there I never saw any of them. And yet they were like, fifty yards away. Then they built a tunnel between the two schools, then all of a sudden you had disabled people in the classes. Y'know... doing Art, doing English, doing Maths. And for the first few weeks it was weird. Didn't know what to say to them, or how to treat them.
> Researcher: No.
> Restaurant Manager: But after a while, they were just 'somebody elses' in the class. Their chairs and their crutches became invisible. In education, people have more

> experience of them. Otherwise they'd grow up not knowing. I think ignorance is a big thing.
>
> Supermarket Manager (2): There are more disabled people about now and in the schools the children are more aware. Disabled children are in the schools rather than being segregated.

It is interesting to note that there were several comments from service managers in the leisure and retail industries, as shown above, who noted the increase in the visibility of disabled people. In Chapter Five I will show how, through their responses, these service managers were giving prominence to disabled people as potential customers in the market they served. In this way, the managers of retail and leisure services were beginning to focus on the need to increase the visibility of disabled people within their service.

The further systematic analysis also showed that, although very few interviewees recognised *hidden disabilities* (ie. that some disabled people would not be visible by their impairment), a social worker (specialising in disability) did make the following comment:

> Social worker: Well, I think it's this thing that if you've only got one leg then you're obviously disabled, if you've got a disability you can't actually see, people don't perceive you to be disabled.

This recognition of hidden disabilities was the exception, rather than the rule, however, but when noted, was exclusive to welfare professionals.

The interviews generated much discussion around the category of visibility, that is, the view that, generally, disabled people are more visible in society than they used to be. Oliver and Barnes (1993) suggest that there are many reasons for this, mainly around the widespread practice in Britain earlier in the century of maintaining large institutions in which disabled people lived and conducted their daily lives. In this way, disabled people were segregated from mainstream society and therefore, to a large extent, became invisible. This was also linked to widespread stereotypical attitudes about the 'usefulness' of disabled people to production and to society.

Furthermore, exclusion can also be related to the literature around membership:

> ...the concept of citizenship implies full membership of, and active participation in, society. (Bryson and Lister, 1994, p. 1)

Such writers consider that in order to be full members and active participants, disabled people need to have a visibility in (and thus be a member of) the communities in which they live. It can be seen, therefore, that lack of visibility is a component of exclusion and therefore, the interview data reinforces the emphasis on exclusion in the literature.

Following on from the preliminary group analysis in which the Advisory Group identified in the interviews the issue of *barriers* as an element of exclusion, the further systematic analysis also emphasised this issue. For example, the following statement shows how the barrier of *access* was noted by an Art Gallery Manager:

> Researcher: And again, it sounds like you're willing to listen to what people are saying?
> Art Gallery Manager: Yeah, we'll listen to views of anyone and everyone. Em, as I say, at the end of the day, it still comes down to resources. Or whether it's practical, or whether it's right for the building. Y'know, the type of building- it's a listed building, em and that sort of thing. So you've got to be very careful...and let's say, sympathetic.

This comment was typical of many of the interviews in that although, in general, professionals worked to encourage disabled people as consumers of their services, they did recognise some of the inadequacies within their service that created barriers.

It was also suggested from the further systematic analysis that in order for disabled people to reduce some of the barriers they face, the *government* needed to provide assistance to make it happen. This example from a disability officer in the Methodist church is typically reminiscent of other interviews, particularly many leisure and retail managers who were trying to entice disabled people as potential customers.

> Disability Officer (Methodist Church): Um... so it's... not a static thing at all. But of course, there's got to be statutory provision, for instance. There's got to be some barriers that you've got to cross.

The data in this study generated the category of barriers in relation to disabled people. Again, the particular barriers identified reinforce the exclusion literature (Buck 1993, Oliver, 1990, Dart, 1990) concerning disabled people and citizenship, particularly in the areas of employment and access. Transport barriers may also fall into the heading of access. The category of barriers can be seen as a sub-set of *membership* since barriers can affect a person's ability to be a member of a group or community. In this way, the interview data add to the academic debate on membership and exclusion. Chapter One describes how the citizenship literature explores the notion of exclusion. The data in the present study relates the specific situation of disabled people to exclusion. This, therefore, can widen the concept of citizenship so that factors in relation to disabled people are included in the debate.

In addition to the themes generated by the preliminary group analysis, the further systematic analysis added to their analysis by identifying the area of *consultation* within the concept of exclusion. Many interviewees, particularly retail/ leisure managers, suggested that if disabled people were to be consumers of services, then they should be consulted around the services they use. The following extracts reflect this perspective:

> Supermarket Manager (1): we consulted with our local disability access group about our store. These stores are designed as a direct result of customer research. However disabled people have asked for parking nearer our store but this has not been practical. We try to do our best but we have to be reasonable.

> Researcher: And do you consult disabled people?
> Art Gallery Manager: Yes, we've been working with a day centre and one or two individuals and so on. We'll be doing the same when we look at the ramp.

> Researcher: Do you consult the students at all? In how they want things, or...
> Teacher (College for Disabled Young Adults): There's a student council here. And they meet regularly. And when we're making any major decisions the students are consulted. Probably... as much as any student body is consulted. But there obviously has to be a certain... They often complain that they're not consulted enough.

However, in contrast to the above, one architect felt that he did not need to consult with disabled people because he was led by the *legislation* on making buildings accessible.

> Researcher: Do you ever consult disabled people?
> Architect (2): No, in the sense that we are led by legislation, this is the D of E [Department of Environment], and they produce the legislation that talks about stairs and refuges and access and textured paving and things like that. It's a great source of information about disability actually.

Although the further systematic analysis identified consultation as an issue, the extent of discussions on this issue was not considerable. However, some retail and leisure managers who were beginning to focus on disabled people as potential customers had started to talk to their customers in order to provide services that the customers wanted. The issue of 'consultation' can be seen to relate to *exclusion,* in that it recognises that disabled people need to be included in having some kind of ownership of the services they receive and a say in the way they are run. In this way, therefore, the element of 'consultation' generated by the analysis of the interviews is connected to the element of exclusion in the citizenship literature. This, therefore, develops the academic discourse because it adds to the academic literature around citizenship.

State Obligations

'State obligations' was an area of citizenship highlighted by the literature (Marshall, 1950; Rees, 1996; Barbalet, 1988). It was suggested that the state had an obligation to provide services (eg. social rights) and implement rights. The citizenship literature (see chapter 1) discusses in full the balance between the obligations of the state, the community and the individual to ensure that individuals are included as members of a community.

In the present study, however, neither the preliminary group analysis nor the further systematic analysis raised significant issues about state obligations. This can be seen as surprising in view of Marshall's focus on state obligations/ entitlements in terms of rights. In general, in the interviews, rights were seen as the 'moral' rights of respect, privacy, and courtesy, rather than rights to entitlements and services by the state. However, a transport manager who was interviewed reflected on the implementation of accessible transport by the government (as part of the Disability Discrimination Act, 1995):

> Transport Manager: The older ones [buses]... Um... and I think it will come. But it will be a long time and it's gonna be expensive.
> Researcher: And at the moment it's not enforceable is it?
> Transport Manager: No, that's right. That's what it needs. It needs to be.
> Researcher: Good practice?
> Transport Manager: That's right. The government are doing something about it and, um... we're looking at the consultation document now. So they are

> proposing… I think it will be enforceable by law. They're looking to make it by the year 2020. For all public transport.

However, this example is not representative of the other interviews. It is interesting that the data in this study generated very little discussion around the obligations of the state, except for one or two examples (an architect, for example emphasised the need to follow the legislation around building regulations, rather than talking directly to disabled people, which implies an observation of state obligations). However, it could be suggested that the literature produced by academic writers on Citizenship has tended to be more theoretical and may not actually reflect the *experiences* of some people (ie. in this case, disabled people, and also the interviewees). In this way, the present study further highlights the tensions between the priorities of academic researchers and the agenda developed through an emancipatory paradigm. It has been shown that 'state obligations' was not a category generated by this study. However, it is useful to consider the element of obligations of the state within this section since there is a plethora of literature around the issue that argues that the obligations of the state are a mechanism by which discrimination can be reduced.

Citizenship: Experiential Synthesis

Both the preliminary group analysis and the further systematic analysis show how the interview data develop the literature on citizenship, particularly in terms of rights and exclusion. I would now like to explore the experiences/ opinions of the Advisory Group in order to locate the conceptual analysis within experiential material. This experiential synthesis is useful in terms of reflecting upon the extent to which the concepts generated by the data resonate with the lived experiences of disabled people.

Developing rights

The opinions and experiences of the Advisory Group concerning citizenship continued the theme of rights. They recounted examples of the denial of rights, reiterating a focus on 'moral' rights. They also gave resonance to the element of exclusion by recalling barriers of access and barriers of attitudes. The experiential synthesis shows how the concept of citizenship, as discussed in the academic literature, is also reflected in the priorities and the lived experiences of the Advisory Group and therefore confirms its importance. This is interesting, since, within the methodology chapter it was noted that the Advisory Group felt that the concept of citizenship was not very useful to them.

Within the experiential synthesis (ie. the experiences and opinions of the Advisory Group), the issue of rights highlighted by the Advisory Group mainly focused around rights of access and the effectiveness of the DDA. These two extracts exemplify some of the discussions:

> *J: I think they are doing something to aid getting in and out of buildings in one or two places.*
> *Researcher: Are they?*
> *J: Yeh*
> *Researcher: You've noticed some changes?*

J: I've heard of it, sort of thing, yes.
Researcher: Right, yeh.
J: So it's [the DDA] been of benefit generally really, just wants a bit of a push.
Researcher: Yeh.

M: Have you found direct action works?
J: No, it doesn't seem to work with me really. I've written a few letters, tried to do a little bit toward pushing it forward, sort of thing. The main question that you ask doesn't seem to get answered... they give you an explicit answer to something that's not really very relevant...
Researcher: So you think when people are political and chain themselves to buses and get themselves on TV, do you think that's a valid way of trying to change things?
J: Yeh, I think it does really, but not too often, just occasionally, sort of thing. But it's got to be cleverly thought through so it gets people on their side, 'cos a lot of people think it's ridiculous.

The last extract was part of a wider discussion around Direct Action. The Advisory Group had discussed what constituted Direct Action and had given examples and opinions. The example of 'chaining yourself to a bus' was used since it followed on from previous discussion. This is not to suggest that Direct Action is only equated with chaining yourself to a bus and the Advisory Group were aware of this. It merely clarified the discussion and offered a concrete example. The discussion by 'J' had been around his general views on Direct Action, not just around the example of 'chaining yourself to a bus'.

The Advisory Group discussions focused on the debate around disabled people being perceived as wanting *more* rights than non-disabled people. An overview of these issues is shown in several extracts below:

C: I'm sorry, but with the DDA, supposedly, I find all it's actually done is given people[ie. Non-disabled people] the right to say 'this isn't reasonable'... because in a way it's actually given them more rights, whereas before we could scream and shout and we might get our own way, whereas now, they can actually turn round and say 'Well no, it's not reasonable for us to do that'. They've got the right on their side now.

Researcher: J, I don't know whether you have any views on disabled people, whether they have rights or not?
J: Yes, they should have the same rights as everybody else, of course.
Researcher: They should have?
J: Yep
C: Do you ever think disabled people should have more rights than others?
J: No, I don't think so, no... ...they should all be the same, shouldn't they, yes, we should understand everyone as best we can really...

S: ....basic human rights, the right to participate fully and equally in society, I mean it's presently being denied to many people at the moment.

K: I think there's a genuine ambiguity in language because, in a sense disabled people do have the same rights as other people, that is, disabled people are not denied the right to vote, they're not denied the right to police protection if they're robbed, this kind of thing, so in many issues disabled people and able people are on the same footing. It is with particular relevance to discrimination against someone on the grounds of disability ...

The main focus of the Advisory Group therefore was practical issues as a result of their experiences in trying to exercise rights. Their experiences and opinions therefore reflect much of the preliminary group analysis and the further systematic analysis of the interview data. They also reinforce the academic literature on achievement of the *status* of citizenship by gaining *rights* by showing that, for many disabled people, the achievement of citizenship is achieved through a struggle. The above examples show how the issue of 'moral' rights generated by the interview data was reflected in disabled people's own experiences (eg...*we should understand everyone as best we can... basic human rights...).*

The final Advisory Group extract above (by K) relates to the issue of attitudes. In discussion, the group was more concerned about attitudes than rights (see discussion in Chapter Two) and their experiences were that negative attitudes were more discriminatory (or had more effect on their lives) than a lack of rights in most cases. Chapter Four will show how the concept of attitudes was also developed as a result of the research, reflecting some of the priorities of the Advisory Group.

In terms of civil rights the Advisory Group felt that, in general, disabled people were denied civil rights The following is one of several examples on the subject:

> *S: Eugenics is going on in this country, where an entire disability is wiped out by ensuring people with learning disabilities don't have children. It's an infringement of civil liberties. The medical model system- doctors, social workers infringe civil liberties by the way they treat their clients or patients. It's pretty disgusting really.*

This individual goes on to suggest that disabled people need to empower themselves to achieve rights for themselves:

> *S: I think we have to do what the women's movement did, what the black movement did. We have to free ourselves from the shackles that society has placed about us and we have to liberate ourselves which is a long, hard job*

In this way the issue of rights that was generated by the interview data also resonated with the lived experiences of the disabled people in the Advisory Group.

Developing Exclusion

The experiential synthesis also shows that the element of exclusion generated by the interview data was meaningful to the daily experiences of disabled people. In a similar way to the concerns of the interviewees, the Advisory Group's experiences of 'exclusion' were mainly in terms of access and attitudes. These two examples, from people with learning difficulties illustrate this point:

> *B: When I was 15 or 16 years old, I didn't get benefit allowances, care allowances or callipers. Either you were tough or you didn't survive.*
>
> *D: I mean, there's certain shops he [a disabled friend] can go in and there's certain shops he can't go in...I mean he's been banned from [a local supermarket].*
> *Researcher: He's been banned?*
> *D: Yeh*
> *Researcher: Why is that?*
> *D: Don't know, ask them. They just won't let him in.*
> *Researcher:... because he's in a wheelchair?*
> *D: I think that's what it is.*

In this way, the focus on barriers and visibility generated by the interviews, which was subsumed under the heading of 'exclusion', were also important to the experiences of the Advisory Group.

Although the Advisory Group noted the issue of *barriers*, they did not refer to it to a large extent, except for the barrier of attitudes (discussed in Chapter Four). They did, however note the barrier of access, as the following examples indicate:

> *D: Well, take, for instance, my neighbour. His mum is in a wheelchair. It's been a good 20 years in there and they've been asking for a wheelchair accessory to be put*

onto his front [of his house] - he's been turned down that many times and now he's fighting to go through the court but he doesn't want to spend too much money, but yet he used to work.

E: We went to one place and it was an open day and I said, well I said, we weren't consulted as disabled people... and I said, well I said, it's the same problem. They said 'what problem?', I said 'you've got a ramp and the loo is downstairs but all your amenities what we're going to have are upstairs and there's no toilets even for the staff upstairs, never mind disabled people, so I says that's hardly in line with working conditions....

J: [The local buses] have got about 9, I think of these low floor buses....they're accessible from the point of view that they're lower, wide door and I suppose nice, shallow step onto the road and you can get your wheelchair straight in more or less, but it hasn't got a ramp so for anyone wanting to go on independently, unless they've got really strong arms, you've got to have someone to tilt you up and push you on...

Although these extracts indicate *some* experiences around barriers within the category of exclusion this issue was more important to the interviewees than to the Advisory Group.

The Advisory Group did not spend much time discussing the issue of consultation. This suggests that the issues around consultation were more important to the interviewees than to the disabled people in the Advisory Group. However, the Advisory Group did decide to mention 'consultation' in the accessible report. Within the Action Plan for the accessible report, it states:

> - *it is very useful for professionals to **consult** with disabled people (usually through a group run by disabled people) over issues to do with their organisation e.g. access issues, customer service, staff training and attitudes.*

In this way, the disabled people in the Advisory Group were recommending consultation as a vehicle for challenging ignorant attitudes and stereotypes and raising awareness of disability issues. The element of consultation, therefore, arose out of the Advisory Group's focus on attitudes, not as an element of the dimension of exclusion.

In general, therefore, the concept of 'moral rights' generated by the interview analysis is also echoed by the experiential level of the disabled people in the Advisory Group. Moral rights is an area neglected by the academic literature on citizenship. The Advisory Group spent some proportion of time discussing issues relating to rights and exclusion. Although they didn't find the terminology of 'citizenship' very useful (see Chapter Two) it could be suggested that in fact their experiences and opinions reflected the importance of the concept of citizenship in their day-to-day lives. Therefore, even though citizenship was not deconstructed in the same way as in academic writing, it was clearly quite relevant to the disabled people in the Advisory Group. It is interesting to note that in neither the analysis of the interviews, nor in the experiences/ opinions of the Advisory Group was the category of 'state obligations' generated. This contrasts with Marshall (1950), who highlights state obligations as a crucial part of citizenship.

The experiential synthesis reinforces the early Advisory Group meetings when the main focus was around finding out about professional's *attitudes* to disabled people. They stated that what affected their daily lives were attitudes, rather than citizenship rights: although the literature highlights the obligations of the state to provide services in terms of social rights, it would seem that this is not the primary concern of the disabled people in the Advisory Group (nor was it the primary concern of the interviewees). The concern of the Advisory Group seemed to be more around interactions with others on a daily basis rather than a legislative infrastructure. It may be argued that disabled people in Britain can talk about attitudes as important simply because the infrastructure to provide for them is in place, in which case, their primary needs are being met and they can focus on the next level of need eg. being treated fairly in the daily environment in which they live. In this way, the Advisory Group's experiences reflect the data from the interviews (but not the focus of the existing literature) in that they do not highlight state obligations within the concept of citizenship.

Academic discourse: Developing Rights and Exclusion

Some conclusions

In this chapter, I have suggested that the concept of 'moral' rights develops and expands the academic discourse of citizenship. 'Moral' rights were defined as the right to be treated with respect, dignity and fairness, and represented moral values and attitudes, rather than legislation. This became a valuable distinction because it was also the area in which the Advisory Group led a change of focus in the methodology: they were more concerned about the attitudes they experienced on a daily basis, rather than rights and legislation.

Although the rights aspect of writings around citizenship has been reinforced in this study, it has been noted that the data generated very little discussion around obligations of the state. There was thus some point of difference between the present literature on citizenship and the data, specifically, around disabled people. However, although the interviewees did not specifically define the obligations of the state as contributing to citizenship status, their discussions did expand on the notions of rights and legislation, thus, acknowledging that the state played a role.

The analysis of the interview data created a need to return to the concept of citizenship (discussed in Chapter One). I have illustrated the level of interest in issues around citizenship by including a large number of quotations from the interviews. This reflects the vast amount of data produced which focused on elements of rights and exclusion, in particular. The majority of the interview *questions* were focused around attitudes, rights and the professional's role in relation to disabled people (see Chapter Two or appendix for interview schedule). The analysis of the data has therefore shown that there was a large amount of information generated around concepts relating to citizenship, despite the number of questions in the interview schedule around elements of citizenship being fairly small.

There were no interviewees who felt that questions about rights were not relevant to disabled people. All interviewees answered the questions about rights, and offered further information. This could be due to the fact that the legislative context of the fieldwork ie. the Disability Discrimination Act had begun its implementation in 1995 and the fieldwork took place between 1996-1999. In this way, the interviewees may have had more awareness around issues of rights for disabled people than they might have had prior to 1995. However, the Advisory Group identified some interviewees who had very little knowledge of the Disability Discrimination Act (1995) but still found the element of rights relevant to disabled people.

Although the review of the literature (see Chapter One) focused on citizenship, Chapter Two shows how the Advisory Group re-focused the research onto 'attitudes'. However, the fact that elements relating to 'citizenship' later emerged independently from the data indicates its importance and shows that the review of the citizenship literature was in fact relevant. There were also examples in the interviews where issues were generated that had not been identified in the literature, such as 'moral' rights. There was also very little discussion in the interviews around obligations of the state, which contrasts with the emphasis given to it in the literature.

The significance of the concept of citizenship is in the way in which the concepts of moral rights and exclusion, generated by the data, could be added to the debate. Moral rights and exclusion were seen as important elements affecting the citizenship status of disabled people and the experiential synthesis also confirms these elements. This therefore gives clarity to developing the model of citizenship. The further systematic analysis developed many of the issues arising from the preliminary group analysis. In this way, the emancipatory nature of the research resulted in an additional layer, which acted as a way of testing the importance of the concepts generated by the interview data. This chapter has therefore shown how the research data have developed the academic discourse of citizenship by adding new elements to the debate.

This chapter has shown how the findings of the research add to the concept of citizenship within the academic discourse. The concept of 'moral rights' was not defined in the citizenship literature discussed in Chapter One. The concept of exclusion had also not been applied to disabled people in the citizenship literature. This implies that Marshall's theory of citizenship failed to acknowledge the prevalence of exclusionary and disablist attitudes and therefore failed to recognise the importance of 'moral rights' to disabled people. I will return to the disablism, which arises from disablist attitudes, in Chapter Six (Conclusion), but now I will discuss the way in which the analysis of the interview data developed the concepts of attitudes and difference and how these concepts further expanded the understanding of citizenship theories.

CHAPTER 4: ADVISORY GROUP DISCOURSE

ADDING 'ATTITUDES' TO THE CITIZENSHIP LITERATURE. 'DIFFERENCE' IN RELATION TO DISABLED PEOPLE.

This chapter describes how the interview data expanded the concepts of *attitudes* and of *difference*. This develops the Advisory Group's emphasis on attitudes in the data-gathering process. It can be suggested that since the Advisory Group had sought to research attitudes, it is unsurprising that they would be highlighting the issue of attitudes in the analysis of the interview data. It was the general opinion of the Advisory Group that the concept of citizenship neglects the element of attitudes. The data described in this chapter reinforce this opinion. In this way, the discussions in this chapter explore the predominant discourse of the Advisory Group.

The chapter also explores the dimension of 'difference' as an element of the concept of attitudes. I shall show that many interviewees saw disabled people as 'different' and therefore treated them differently in terms of their attitudes toward them.

This chapter will also reflect on some of the literature concerning attitudes and difference. Since the focus of enquiry in the preparation of the research was on citizenship, Chapter Two looked specifically at the literature on citizenship. By undertaking an emancipatory methodology in which an Advisory Group was used, the direction of the analysis of the interview material can be seen to highlight new areas for discussion. The attitudes/ difference literature, therefore, becomes particularly relevant within this chapter.

This chapter will take attitudes and difference as two separate concepts and each will be discussed in turn. The outcomes of the analysis of the data argue for 'attitudes' to be incorporated into the citizenship literature.

Adding 'attitudes' to the citizenship literature.

Preliminary Group analysis

This chapter will show how 'attitudes' was a concept generated by the data. The preliminary group analysis, in relation to attitudes, particularly noticed issues of lack of awareness; language; experiences affecting attitudes; and changing attitudes, some of which are discussed below.

Lack of Awareness

Within the preliminary group analysis it was found that there was a general lack of awareness of disability issues among the interviewees. The Advisory Group were particularly critical of 'welfare' professionals since they felt that the training they had undertaken should have covered issues relating to disability. The following quotations, both by the same individual, act as eloquent examples of some of the discussions.:

> *C: It seems curious that the community worker, although obviously not very clued up on disability, at least is sort of groping towards the points on which he needs to be clear, whereas the social worker appears to have just landed from Mars...*

> *C: Well, I think it's pretty self-evident. I think they both [Community Worker and Social Worker(2)]show a relative lack of awareness, given that the training they've had. Perhaps it's a reflection on their training..*

In this way, the Advisory Group members showed their surprise at the lack of knowledge and understanding shown toward disability issues by welfare professionals.

Language

The Advisory Group noted that language was an important issue within the interviews. Their comments on the interviews were mainly around people's use of negative or inappropriate language, as considered by the disability lobby, for example:

> *R: I like the cinema manager's use of the word 'varieties'- Heinz 57!*

> *Researcher: Is there anything you have seen in the interviews? [supermarket manager]*
> *R: Well the sharp intake of breath was when I read 'wheelchair bound'.*

Other typical comments by the members of the Advisory Group, such as those below, concerned the difference between language and practice:

> *C: ....they [art gallery manager and transport manager] have the language and they know how to use it... but they don't follow through the implications and apply them to their own practice as far as we can see.*

> *Researcher: Do you think this Member of Parliament is typical then?*
> *C: er...*
> *M: She's giving all the right answers to a certain degree isn't she?*
> *Researcher: you think so?*
> *M: I think so, but then that's probably to be expected...*

They did note, however that the main interviewees who did *not* use appropriate language were those from the retail/ leisure industries, and not usually from the welfare professions. They felt that this was indicative of different working environments. The Advisory Group felt that it might reasonably be assumed that welfare professionals would indeed have a vocabulary that reflected a 'politically correct' stance. The mis-use of language was seen by the Advisory Group to be due to the ignorance of the interviewees around 'politically correct' language. They felt, however, that *both* welfare professionals and managers who have disabled people as customers should consider it important to use appropriate language.

Experience affecting attitudes

The preliminary group analysis also found that, based on the interview data, interviewees had more awareness of disability issues if they had had *experiences* of interaction with disabled people. The following extracts show this view:

> *D: Having spent an awful lot of time in the army where there are no disabled people, it's clearly affected his [architect's] attitude.*

> *S: a) [supermarket manager (1)] seems to have had a lot more interaction with disabled people because he had the friend who he took to the pub- he needed help to drink a pint and he was totally physically dependent, so in a way I suppose that's given him a slightly deeper insight into the problems.*

The role of experience was important in many interviews and the group noted that, even though there was an expectation that the welfare professionals should know more appropriate language, the overriding factor was a person's interaction with disabled people, rather than the extent of their professional training. The Advisory Group felt that if this was the case, then one way to change attitudes would be to have more integration of disabled people with non-disabled people.

Changing attitudes

Another way of changing attitudes, which the preliminary group analysis of the interviews highlighted, was the use of Direct Action. The following extract, in which the individual argues that the professionals interviewed would not be interested in Direct Action, is typical of some the discussions:

> *Researcher: They say that Direct Action can have a negative effect...*
> *C: Yes, well this is because of the class of person you're interviewing.*
> *Researcher: The class of person?*
> *C: Yes, the class of person is broadly defined 'professional class'- they benefit from the status quo and the last thing they're going to do is support civil unrest, civil disobedience, anything that threatens the status quo. They believe that all change should come through the ballot box....they've got status in the community, they've all got jobs otherwise you wouldn't be interviewing them and they're all reasonably well paid compared to the rest of us... they don't want people chaining themselves to buses because it will hold them up in the morning getting to the office. ....the people you are interviewing have a vested interest in keeping things the way they are.*

In general, the preliminary group analysis of the interviews found that the general view of the interviewees was that attitudes could be changed by integration, and by training rather than by Direct Action and these points were highlighted in the accessible report. Within the further systematic analysis, I also discovered these views, as will be discussed later in the chapter.

Medical Model of disability

The preliminary group analysis showed that most interviewees saw disabled people within a framework of a Medical Model of disability. In this way, disabled people were seen as 'different' from the norm and the extent of this difference affected a person's attitudes to a disabled person. The Advisory Group commented that the 'medical definition' of disability within the interviews centred around clinical diagnosis . This extract from an early Advisory Group meeting was one of several examples around the Medical Model:

> *C:...I think the Health Service is particularly affected by stereotyping of disability because they feel that the medical definition of disability has the force of scientific knowledge, in other words, it's the definition that is being used by doctors and clinicians generally and therefore it's sort of in the sphere of clinical diagnosis, rather than the sphere of political debate...*

The Advisory Group felt that many interviewees saw disability in terms of 'not being able to do things others can' [quoted from interview with transport manager]; that is, a functional definition of disability. In analysing the interviews, they offered the following comments, which reflect many discussions around this issue:

> *R: I'm very intrigued by the answer to question 2 'not being able to do what others can' [transport manager]- that would mean that everyone was disabled wouldn't it, really? Because obviously there's going to be things that I can do that you can't do and vice versa.*

> *R: I've been sat going through it and all the time it's how they [manager of MIND] can help, how much they can do for a person, it's not...*
> *S: Empowerment?- how we can alter the buildings, the surroundings, the society, so that disabled people can help themselves and not have to depend, victim-like on anyone else.*
> *Researcher: Sort of based on a person's limitations, needing help?*
> *R: Yep.*

> *C: When the psychologist trained in the health service was asked to define disability, the definition that he gave was a sort of concise summary of the test for DLA, and that in turn is reproduced in the DDA.*
>
> *Researcher: Right, but in terms of what?*
>
> *C: Well, in saying that a disabled person is one who cannot accomplish the daily tasks that most people take for granted.*

Again, the Advisory Group noted that this definition was prominent throughout the interviews, including those of the welfare professionals, which surprised them. The Advisory Group recognised that the attitudes of professionals are influenced by the way in which they see disability, ie. if disabled people are seen as people who 'cannot accomplish the daily tasks that most people take for granted', then it follows that the role of the professional is to 'help' the disabled person. This, therefore, develops the above quotation referring to the view that disabled people need 'help' in that it cites a reason for this way of thinking: its roots are in the epistemological underpinnings that people with impairments have some loss of function and are therefore physically *different* from non-disabled people.

'Sympathy'

Within the preliminary group analysis, the Advisory Group suggested that, in general, the interviewees also showed hints of seeing disabled people as needing sympathy, pity and help which they, as disabled people, found patronising. This develops the observations of disabled people being seen in terms of the Medical Model and therefore this 'difference' generated 'different' (sympathetic) attitudes. A need to make people aware of their 'patronising ' attitudes was acknowledged in these typical examples of comments made by Advisory Group members:

R: Well, it's just the same thing about helping people- that one where it, about Direct Action, sympathy- he [Town planner] makes you believe that that's what we want- help, assistance, pat them on the head, tell them it'll be OK.
S: We should have shouted to them 'Piss on pity!'

Researcher: They're all talking about helping people, where often people want to do it for themselves.
C: Yeh, your solicitor says, 'It makes you realise how many people need so much help' and, er, it doesn't say anything about making life a little bit easier for them.

S: They're usually patronising.

R: I don't think these people mean to be horrible, but they actually think they're helping. They actually think they're doing the right thing- that's the frightening thing really- they think they're doing the right thing.

The Advisory Group, therefore, recognised that in many of the interviews, the attitude shown in regard to disabled people emanated from an element of 'sympathy'. This reiterates the discussion around disabled people needing 'help'.

Further Systematic analysis

In the further systematic analysis, I noted some of the same issues concerning attitudes that were examined in the preliminary group analysis, such as: ignorance; language and changing attitudes. I found that some interviewees felt that attitudes were very important, and often of more significance than rights. This, therefore continues the Advisory Group's debate about attitudes cited in Chapter Two. The following two examples from the interview data are resonant of several discussions concerning rights and attitudes:

> Researcher: Are there any areas that you think they don't have rights? At the moment?
> Disability Officer (Methodist Church): [very long pause] I think what comes over to me most of all is the attitudes of people towards them. I think that's primary to me. Y'know, not the financial and so on. Although that's very important. But it's the attitudes of people towards those who have a disability.
>
> Contracts Manager, Health Services: Yes. I think it's the things though - it's the attitude. It's not so much the - the environmental issues. I think it's the attitudes. Um... y'know, as I say, I often travel with, um... with my friend Peter in his wheelchair. And it is really "Does he take sugar in his tea?"-syndrome. And this is a very articulate man in this chair. And I find that really difficult.

It could, however be suggested that these two interviewees, may have had more knowledge than other members of the sample of disability issues: the Disability Officer's role within the Methodist Church was to encourage disabled people into the church and the contracts manager played a part in consulting disabled people on the health service they used. In this way, their personal contact with disabled people may have given them an insight into some of the attitudes experienced by disabled people. Although many interviewees did comment on the attitudes that are shown toward disabled people, it was apparent that this issue was more prominent among those interviewees who had more direct contact with disabled people on a regular basis. This reiterates the findings of the Advisory Group, with regard to the role of interaction.

Following on from this, the following two extracts from discussions with the manager of an Age Concern organisation and with a Member of Parliament show a specific awareness of the *stigma* that disabled people can face (highlighting the way in which stereotypes can affect attitudes):

> Age Concern Manager: They're wonderful people. Um, but... there is, I think, a stigma attached to the word 'disabled' in any way. I mean... I mean people have said to me, they've been out in their wheelchair and, y'know... I'm not saying they've gone to the council offices, but it may be somewhere, right?
> Researcher: Yeah.
> Age Concern Manager: And it's for them that they've gone and they've not been spoken to. It's been the person behind them, y'know?

> Member of Parliament: Who's gonna employ a manic depressive?
> Researcher: Quite, yeah. And as you say, it's not understood is it?
> Member of Parliament: Noo!
> Researcher: People don't understand.
> Member of Parliament: Fear. There's a lot of fear.
> Researcher: Mmm, yeah.
> Member of Parliament: Well you only hear about it when somebody stabs someone!
> Researcher: Exactly. [laughs]
> Member of Parliament: Which of course, isn't acceptable.
> Researcher: No.
> Member of Parliament: But not all people who are mentally ill stab people.

This awareness of stigma and stereotypes, however, was not typical of many of the interviewees.

Language

As with the preliminary group analysis, the further systematic analysis showed many examples of the use of inappropriate language in the interviews. Words such as 'wheelchair-bound', 'spastic', 'mentally handicapped', and 'suffering' were all used frequently. The following extracts reflect the very many examples of inappropriate use of language which I noted:

> Customer Services Manager (Bank): Um... [long pause] I desperately try and steer away from the wheelchair-bound... helpless... type of... stereotype that you tend to see on the television.

> Supermarket Manager (1): I used to have a friend who was very severely disabled- he had polio. He didn't have the use of his arms or legs. He was totally wheelchair bound.

> Teacher (College for Disabled Young Adults):..... So I feel that, if you're open... and somebody calls you a spastic and you actually say "Yes I am" and "I've got this spasticity and it's caused by...". It's probably better than to... [voice drifts off]

> Cinema Manager (1): Um... loosely speaking, I have family...
> Researcher: Right.
> Cinema Manager (1): ...that suffer from a disability.

> Cinema Manager (1): Or perhaps, um... mentally-handicapped people. That's something I should perhaps target this year.
> Researcher: Right.

> Cinema Manager (1): To bring in for private screenings. We have a couple of privately-run organisations that do bring mentally-handicapped people to the cinema. I need to do more and more.

Those interviewees who tended to use 'appropriate' language tended to be welfare professionals. In contrast, the above extracts were drawn from interviews with an art gallery manager, customer services manager (bank), supermarket manager, teacher, and cinema manager, for example. It could therefore be suggested that those who did work in welfare professions generally had more understanding of a 'politically correct' vocabulary in relation to disabled people. This point also reinforces the findings of the preliminary group analysis in that they noticed that welfare professionals did, in general, use 'politically correct' language.

Changing attitudes

The further systematic analysis generated the element of 'changing attitudes'. In contrast to the preliminary group analysis, where the group noted *integration* as significant in the interviews in terms of changing attitudes, I found additional elements of importance. These included, seeing disabled people as valued customers, education and changes in legislation. These three extracts reflect the varied responses in terms of changing attitudes.

> Art Gallery Manager: 'We feel we are going considerably further within the resources that we have without actually, you know, having to spend money. Let's say it's an attitude change...

> Researcher: Yeah. [Do] you think there's any other way of changing people's attitudes?
> MIND Officer: [pause] Perhaps there has to be a lot more education. Like we're doing in mental health. And perhaps that's down to local organisations who are, um,

are into the disability field. Going out to schools - I mean, perhaps they might already do this, I might be wrong - but going to schools and colleges and church halls. Wherever anybody will listen. Because this is what we do with mental health.

Researcher: Yeah.

MIND Officer: It is a dripping tap. It really is. It's going to take years and - like in my field, I don't even believe in my lifetime - we'll get rid of the stigma.

Disability Officer (Methodist Church): Yeah. Yeah. Yeah. Yeah... I, um, think changing attitudes is a very slow process. But changes have been made. And I think changes for the good. Have been made during my lifetime in relation to the disabled. And it's very much on the terms of the government have done that. It gives a legislative, y'know, approval.

Attitudes: developing the debate

It is interesting to note that these three areas of 'changing attitudes' are around expecting non-disabled people to make changes, ie. the community, the state, and the social structures. Although the focus of Chapter One specifically highlighted the literature on citizenship, it is useful to reflect at this point on the way in which the analysis of the data dovetails with some disability literature concerning attitudes. The literature around attitudes is not vast, possibly because, as reiterated by one member of the Advisory Group:

> *C: Research around attitudes is inherently harder than research around rights. That's why people research rights.*

However, there are some useful observations on which to draw. In contrast to the above extracts, which discussed changes by non-disabled people, some authors have focused on the requirement for the individual ie. the 'different' person (in this case, the disabled person), to educate others and to be involved in collective action to bring about change. Hence, three disabled researchers variously comment:

> There are now barbershops where I am received with some of the calmness of old, of course, and hotels, restaurants, and public buildings which I can enter without engendering a feeling that something is going to happen.....the immediate circle of my family has long since ceased worrying about me, and so have most of my intimate friends. To that extent I have made a dent in the education of the world. (Chevigney, 1962, p. 75-6)

In this extract, Chevigney (1962), therefore, is suggesting that change has been brought about by his interaction with people and his own education of others toward disability. Similarly, Henrich and Kriegel (1961), in the following extract, suggest that it is the responsibility of the disabled individual to acknowledge that other people in society can be ignorant in relation to disability:

> I think it is not the responsibility of society to understand the cerebral palsied, but rather it is our duty to tolerate society and in the name of chivalry forgive and be amused by its folly....but this is something it takes a very long time to learn. (Henrich and Kriegel, 1961, p. 145)

Finally, Morris (1993) suggests that although, for disabled people joining together for collective action can strengthen individuals, ignorance and stereotypes by non-disabled people can be exacerbated when perceiving disabled people in a group.

> Many of us find that joining together with other disabled people brings a feeling of strength. However, when we take collective action together, or organise our own cultural events, we have to fight against the negative connotations of just being together in a group of disabled people. (Morris, 1993, p. 170)

In this way, therefore, these extracts illustrate the view that disabled people should tolerate ignorance to an extent, but should take responsibility to challenge ignorance and stereotypes themselves rather than expecting non-disabled people and organisations to change on their own.

In general, therefore, within this study, the data on 'attitudes' is in contrast to some of the existing literature concerning attitudes because some interviewees expressed the view that their own organisations/ society should be changing their practice to accommodate disabled people rather than it being the responsibility of the disabled person to make the changes. Thus, there has been an apparent move toward a Social Model. This may not have been revealed without the Advisory Group's focus on attitudes.

The literature around attitudes also suggests that the attitudes experienced by certain groups (usually oppressed groups) often have their roots in stereotypes or assumptions about that group. For example, Goffman's discussion around 'Stigma' talks about the assumption of certain life activity by others:

> We normals [*sic*] develop conceptions, whether objectively grounded or not, as to the sphere of life-activity for which an individual's particular stigma disqualifies him. (Goffman, 1963, p. 66)

He also suggests that some people will have feelings about a person perceived as ugly, for example, and may discriminate against him simply by responding to the way that he looks (p. 67).

When considering disabled people, as a group, it can be seen that their experience of attitudes is based on the stereotype of what it means to be disabled and, furthermore, disabled people, are seen as different, or 'other'. Butler and Bowlby (1997) suggest this is due to specific social discourses which are also perpetuated by the media and education:

> At a general level, the experience of having what our society classes as a 'disabled' body is clearly influenced by a number of social discourses......a discourse of 'otherness'.....the pervasive equation of beauty with goodness and strength and disability with evil or inadequacy...These discourses are constituted in and help to constitute the institutions of the media and of education and influence the social interactions of disabled people... (Butler and Bowlby, 1997, p. 418).

In relation to citizenship, therefore, a person's membership of a community, and thus their ability to be a citizen, is affected by the stereotypes and assumptions of that community and, therefore, its attitudes. In this way, the data relating to 'attitudes' can be seen to develop some of the citizenship literature: In opening the debate on attitudes (as a result of the interview data in this study), I am suggesting that attitudes should be an element that is taken into account in discussions of citizenship. One author summarizes very well the issues around attitudes and difference, highlighted in this study:

> It is unfortunate that people tend to think in terms of stereotypes and to have prejudicial attitudes towards those who are different. (Siller, 1969, p. 50).

In terms of citizenship, the area of prejudice can be seen to reduce a person's participation in society. This is particularly so in the present study and with disabled people in particular. Finkelstein (1980) stresses this and suggests that prejudice is a central issue in relation to participation:

> To most disabled people the problem of prejudice is one of the central issues in any move towards mainstream social participation. (Finkelstein, 1980, p. 29).

He goes onto critique the work by Goffman (1963) around 'Stigma' because Goffman focuses on the individual's experience, rather than society's responsibility to that person, when he says:

> Goffman (1963)'s concept of stigma mystifies the real nature of prejudice and enables bigots to escape responsibility for their own behaviour. It makes disabled people responsible for their own suffering. (Finkelstein, 1980, p. 32)

In relation to prejudice and attitudes, Morris (a disabled researcher) describes some of the experiences and opinions of disabled people around these issues. She suggests, as do the Advisory Group in the present study, that the prejudices that disabled people experience have a very large impact on their lives:

> The manifestations of prejudice which can also have an important impact on our lives are often not out in the open; they are the hidden assumptions about us which form the bedrock to most of our interactions with the non-disabled world. It is often difficult for us to identify why someone's behaviour makes us so angry, or feel undermined. (Morris, 1993, p. 18)

She goes on to say that the assumption about disabled people is that they do not have a good quality of life:

> One of the most undermining things about non-disabled people's assumptions about us is that they often assume that our lives are inevitably of a poor quality because of our disability. (*op cit*, p. 38)
>
> The common devaluation of our lives undermines our rights as citizens and as human beings to all the things which are an essential part of a reasonable quality of life. (*ibid*, p. 117).

Finally, she suggests that there is a struggle involved in combating assumptions and attitudes and that disabled people often feel that they lack power in the struggle:

> We have to struggle as individuals on a daily basis against other people's assumptions about us which are such an important factor in determining the quality of our lives. (*ibid*, p. 170)

In terms of attitudes, therefore, it can be seen that the analysis of the data in the present study develops some of the existing literature on citizenship because it suggests that attitudes should be added to the citizenship debate. The experiences of the Advisory Group and the discussion in the interviews, show that general assumptions can be made which create stereotypes and prejudice. Finally, Stubbins (1983) argues that prejudice is not just about the attitudes toward those seen as different, but is also caused by many external factors including power, economics and ideologies:

> The origins and maintenance of prejudice is not easily explained. But for me, essential explanatory dimensions must include a theory of society including politics in the literal sense of the sources of power, economics or the exchange of goods and services, and the role of ideologies in concealing the real mechanisms that keep a society functioning in a coherent way. (Stubbins, 1983, p. 84).

Medical Model

In a similar way to the preliminary group analysis, the further systematic analysis noted numerous examples of interviewees defining disabled people in a medical/ functional way. The large number of examples shown below reflect the numerous discussions within the interviews around the perception that disability is a medical issue:

> Researcher: How would you define disability? If I said 'disabled', what would that mean to you?
> Solicitor (1): Well, I think it's basically a degree of, um, a permanent medical condition which, um, the individual isn't able to, um, to get over. It's not one where they basically - I mean, one can, um, certainly cater for disabilities, but I think it's the

permanent... a permanent situation rather than a situation whereby the, er, the individual makes a full recovery. For example, in an accident where you recover from your injuries. So I would say that it is that, but it can be a physical disability or it can be a mental...

Researcher: How would you define disability yourself? If I said 'disabled' to you, what would that mean to you?
Manager of Council for Voluntary Service: Any impairment of... normal functions that would mean that you are unable to fully, er... function. Er... and access and deal with what 'normal' people do.

Researcher: Okay. And how do you define disability?
Member of Parliament: It is where someone is... um... and this is not - I'm not being judgmental about it, but... is not able-bodied or able-minded.
Researcher: Right.
Member of Parliament: In... the full sense that you'd expect. Um... and that may be a born-with disability. Or an acquired disability.

Supermarket Manager (1): Somebody who doesn't have use of one or more bodily functions, not the full use. There are degrees of disability. They could look perfectly normal or they may not.

Again, the definitions of disability in terms of the 'medical' model were seen to be generated mainly from those outside the welfare professions. There were also several interviewees within the welfare professions who referred to disabled people in terms of 'loss of function' (ie .not being able to do the things others can') rather than in terms of a medical condition or illness. The following examples, which include quotes from a clinical psychologist and a social worker, illustrate this:

Researcher: And how would you define disability?

> Restaurant Manager: [pause] That's a very good question. I would suppose how would I define it personally was anything which would detract from people's ability to do a job or any kind of function really. And anybody who isn't disabled would be able to do it, um... without thinking.

> Researcher: How would you define disability?
> Clinical Psychologist: I've worked with people with learning difficulties for 30 years and I see people first, not their disability. Disability can be seen in terms of difficulty in coping with day to day things.

> Social Worker (2): How do I define disability? I suppose its not being able to do things others can do, yeh, that's how I would define disability.

This reiterates the preliminary group analysis where the Advisory Group highlighted the extent to which disability was generally defined in terms of a medical condition and loss of function (functional model). It can be supposed that the attitudes of professionals were perhaps influenced by the model of disability they choose to work with, ie. medical/ functional. This could be particularly pertinent in relation to welfare professionals, who, traditionally, may have worked in the roles of 'helper' in relation to disabled people 'needing help'.

Although the concept of Difference was defined as a separate concept in the analysis of the interviews and will be discussed in greater depth in a later section of this chapter, it can be suggested that difference *in relation to* attitudes requires discussion on its own. Within the literature, some authors consider the issue of 'difference' to be particularly significant in assessing *judgements* of individuals. Rolph suggests that:

> ...personal identity is proved in courts of law, not by reference to names, not even mainly by direct testimony, but 'presumptively' by evidence of similarities or differences in personal characteristics. (Rolph, 1955, p. 18).

However, according to Goffman, the judgement is generally made by the 'non-different' individual, rather than the 'different' individual:

> It has been suggested that the stigmatised individual defines himself as no different from any other human being, while at the same time he and those around him define him as someone set apart. (Goffman 1963, p 132-3).

Goffman goes on to suggest that the process of being defined as 'different' constitutes four phases: firstly, a person learns that there is a normal [*sic*] way of being; secondly, they learn that they, as an individual, are disqualified from that way of being; thirdly, they learn to cope with the way others treat the kind of person they are; and, fourthly, they learn to pass for normal [*sic*] [Goffman's (1963) words]. This typology is reflected in the stereotypes of the interviewees in that disabled people were seen as not being able to do things others can., ie. the medical/ functional model of disability.

<u>'Sympathy'</u>

Following on from the discussion concerning the medical/ functional model and in developing the preliminary group analysis, the further systematic analysis also drew out points around disabled people *needing sympathy.* In the following example, a transport manager expresses this view.

> Art Gallery Manager: Y'know, the type of building- it's a listed building, em and that sort of thing. So you've got to be very careful...and let's say, sympathetic.

> Researcher: No. Do you think these kind of laws changes people's attitudes?
> Transport Manager: I'm sure they do. Yeah, I'm sure they do. Because if you're thinking about it and you've got it specifically in mind, you're actually then... becoming more sympathetic to it. And more aware.

> Researcher: Yeah.
>
> Transport Manager: I'm sure it does.

Disability, a 'problem'

In contrast to the preliminary group analysis, the further systematic analysis highlighted another area of attitudes. This was around the issue of disability being seen as 'a problem'. The following examples echo this:

> Teacher (College for Disabled Young Adults): Um, I didn't always teach people that had disabilities, really. But I've always had an interest in helping... people... um... who are having problems. And so, in my first teaching career it was people who were finding learning difficult.

> Manager of Council for Voluntary Service: Within our own family circle we've been lucky that people have not had that many disabilities. Some hearing loss. Using hearing aids. Some of them having cataracts and partial blindness. In the work situation I've worked alongside people in wheelchairs. Um... and, er... also done a certain amount of work with those with er, with mental problems as well. But not a lot. So done a spectrum of it, but by no means the full spectrum.

In this way, the interviewees are suggesting that if they put themselves in the position of a disabled person then they would have problems and would have difficulty in coping. Thus, they are seeing the life of a disabled person as 'different' from that of a non-disabled person and this, therefore, can affect their attitudes to, and treatment of, disabled people. The interviewees are suggesting that, by seeing disabled people as people 'with problems' then their role is to provide help in alleviating their 'problems'.

This develops some of the literature on the stereotypes of 'helper' and 'helped'. Morris (1993), for example, describes her experience as a disabled person, having to interact with non-disabled people, under the stereotype of disabled people being 'helped':

> When we interact with the non-disabled world it isn't just staring and people's feelings about our physical differences that we have to deal with. We also have to deal with the issue of help- the help which non-disabled people often offer us, and the help which some of us need in going about our daily lives. (Morris (1993), p. 31)

Finkelstein also states this by saying:

> It is inevitable that helpers, having their sights on human beings as their objects of concern, should develop particular attitudes...the product of their experience of the 'problem'. (Finkelstein, 1980, p. 15)

Stubbins comments that Finkelstein's definition of 'helper' and 'helped' is not as clear cut as suggested. Finkelstein (1980) is particularly focusing on the helper as 'professional' in a role of helping a disabled person. Stubbins suggests that, in fact, the issue is around wider definitions in the whole of society of exploited and exploiter:

> ...the consciousness of helper and helpee and their distinctive roles are not as clear as he assumes. That is because in a competitive hierarchically arranged society, almost everyone carries out roles of the exploited and the exploiter. (Stubbins, p. 83)

This widening of the views of who constitutes a helper was reflected in the Advisory Group's influence on the research process and their decisions concerning potential interviewees. Rather than merely focusing on the attitudes of welfare professionals, they emphasised that many other people, not just welfare professionals, affect their day to day lives (such as architects, transport managers, bank managers, supermarket managers, restaurant managers and leisure managers) and thus the sample was altered accordingly to accommodate the view of the Advisory Group. Stubbins, therefore, is highlighting the same point as the Advisory Group by challenging Finkelstein (1980)'s viewpoint of the 'helper' and the 'helped'. The present study also confirms Stubbin's viewpoint in that it highlights the issue of interdependence between professionals/ managers and customers. This will be explored in the next chapter in discussions about the disabled person as consumer.

It can be argued that the concept of difference, in relation to attitudes, is based on the need or desire to make a judgement about a person. These judgements can be based on stereotypes around an individual's lifestyle and behaviour as a result of their difference. Furthermore, stereotypes quite often produce a negative judgement in which the 'different' person is somehow seen as 'not as good' as the non-different person. Morris (1993) suggests that judgements can frequently shape an individual's (and society's) attitudes and are usually based on how 'normality' is defined:

> In our society prejudice is associated with the recognition of difference and an integral part of this is the concept of normality. (Morris, 1993, p. 15)

In terms of disabled people, the judgement of difference is often based around stereotypes of 'suffering':

> The attitude that a disabled person has 'suffered' a personal loss is a value judgement based upon unspoken acceptance of the standard being able-bodied normalcy..... (Finkelstein, 1980, p. 17)

and also physical difference:

> The prejudice that we experience is often a reaction to physical difference rather than a reaction to physical limitations. (Morris, 1993, p. 23).

Morris (1993) also proposes that reactions to difference are generally based around 'fear':

> The way that the general culture either ignores or misrepresents our experience is part of our oppression....fear and denial prompt the isolation of those who are disabled, ill or old as 'other', as 'not like us'. (Morris, 1993, p. 85)

This viewpoint can also be generalised to encompass other individuals and groups who are seen as 'different'. Butler and Bowlby (1997) recognise this fear:

> Hostility toward the presence of people from racial minorities or overtly gay and lesbian people in public space may reflect a simple fear of difference... (Butler and Bowlby, 1997, p. 420).

In this way, therefore, the further systematic analysis of the interviews develops some of the debates around dependence and independence. It also reflects the notion indicated in the interviews that disability can be seen as 'a problem'. The formulation by the interviewees of disability as a 'problem', therefore, reflects the attitude that disabled people are seen as different (as dependent) and therefore need to be treated differently.

In terms of the analysis of the interviews in the present study, therefore, both preliminary group analysis and the further systematic analysis showed that *attitudes* is a crucial concept . Both levels of analysis highlighted issues of ignorance, language and changing attitudes. The Advisory Group also highlighted the issue of interviewee experience affecting attitudes, which was not an element of the further systematic analysis. Some of the literature on attitudes (Goffman, 1963) reflects the importance of the concept of 'attitudes', but refers to the concept as 'stigma' and 'prejudice'. The data also suggest that attitudes by professionals can be affected by the stereotype of 'difference'. The issues discussed concerning attitudes and difference showed their location in a Medical Model of disability and the resulting area of 'sympathy'. In the further systematic analysis, and by referring to the relevant disability literature, the issue of disability being seen as a 'problem', was highlighted, an issue on which the Advisory Group did not focus.

Attitudes: Experiential synthesis

The experiences and opinions of the Advisory Group show how the concept of attitudes generated in the research resonated with disabled people themselves. Chapter Two describes the way in which the Advisory Group influenced the direction of the research away from citizenship and onto attitudes, and therefore, highlights the importance of attitudes to disabled people. The experiential synthesis shows that many members of the Advisory Group had experienced negative attitudes in their daily life. One area of attitudes was their experience of *bullying*. This was particularly the case for people with a learning difficulty, as shown in the following examples:

> *Researcher: G and D, do you think people treat you differently to others? Do you get some people that aren't very nice to you?*
> *D: Quite a few of them*
> *G: I didn't go to club on Monday - I got beat up once.*
> *D: We've got two club leaders and they won't do anything about it.*
> *Researcher: Why do you think people do that?*
> *D: They think they're better than us.*

> *G: I used to work all day for [a newspaper group]. I got robbed by a couple of kids, smashed up the barrows and nicked all the money. I had to fork all the money out, all £30 of it and they gave me the elbow and I said 'can I come back?' and they said 'no'.*
> *S: Do you think they attacked you because of your disability?*
> *G: Yes*
> *S: Do you get a lot of that?*
> *G: Yes.*

> *Researcher: What did you think of the other children [at your school]?*

> *D: They used to bully me. I used to run away from school and go home- I never attended school much.*

It is pertinent, therefore, that, due to their negative experiences, as a result of prejudice and stigma, disabled people should highlight the issue of attitudes as a focus for research.

One area, within the category of attitudes, over which there was much discussion, was ignorance and stereotypes. One individual suggested that within their *experiences* the stereotypes and stigma they have experienced were often due to ignorance:

> *K: When a label gets put on your head you know about it for life, it's there.....the attitudes of people once they see that label... it's down to ignorance. Its not so much the disability but their attitudes.*

The focus on negative language, which was generated from the interview data, can also be found in the experiences of the daily lives of the members of the Advisory Group. These two extracts show how the language some individuals had experienced was negative:

> *S: It's part of the language structure as well. The language of disability is very negative.*

> *Z: 'Wheelchair bound'- I don't think this is acceptable terminology.*

As a result of their experiences, the members of the group had several comments and opinions about the way disabled people are treated. There was some discussion on the subject of professional attitudes, such as:

> *B: People are labelled in terms of their condition but in fact we are all individuals. People in social services come in educated at university but they don't really know*

what the problems are- ask the people who have the problems....each person, each disability has different problems to everyone else. We are ordinary human beings.

B: People who have the power in organisations like social services, their values, attitudes, education, affect their perception of disability and we're never going to get anywhere until their attitudes are changed. ... the 1993 Community Care Act is a joke- supposedly choice, user and user consultation- it was supposed to change things.

K: professionals have no experience of disability- they don't know how your disability affects you- they're lost and when you try and tell them they think they know it all.

The experiences/ opinions of the Advisory Group concerning the attitudes of professionals, in general, resonates with the dual level of analysis of the interviews and the synthesis of the disability literature in that disabled people have experienced the notion of 'being helped' by professionals. It can be suggested, therefore, that the data in this research and the experiential synthesis show that attitudes of professionals are often based around the stereotypes of the role of the 'helper' and the 'helped'. The Advisory Group suggested that professionals, particularly welfare professionals, should be given specific training on issues around disability in order to see disabled people as individuals, rather than 'clients'. This, they included in the accessible report as a recommendation [quoted in full]:

> ***Training***
> *- "professionals" should have specific training in disability issues ("equality training"). It is felt generally by the disabled community that this training should be delivered by disabled people themselves (see appendices for useful contacts in relation to training). The research team felt that this kind of training should be available, in particular, to welfare professionals.*

- professionals (particularly employers) should develop their knowledge of the Disability Discrimination Act (1995). See appendices for main points of Disability Discrimination Act (1995) and where to go for further information.

- professionals should be aware of the importance of language and should keep up-to-date on language which is considered "politically correct". See appendices for guidelines on this.

- welfare professionals should have more training in disability issues, so that they are aware of issues to do with disability rights, rather than simply seeing disabled people as people to be "looked after".

- it is useful for all staff to have training on disability issues, rather than just one member of staff having the expertise: disability is relevant to everyone.

-it is important that staff training builds on putting examples into practice and is not just about "saying the right thing".

In terms of *changing attitudes,* the Advisory Group's experiences/ opinions also resonated with some of the analysis of the interview data. They felt that attitudes could be changed by legislation, education, training and publicity. There were many discussions on this issue, of which the following are typical examples.

Legislation:

> *C: Society's attitudes can be changed and legal changes , changes in legislation is one way of bringing it about...*

Z: Question twelve, I agree with this, but the government has always , in the past, promoted the ideas of education instead of legislation. I think that legislation ,even weak legislation like DDA, has actually made some organisations sit up and take notice, and start educating their staff. I have seen a number of positive examples of this.

Education and Training:

B: I don't think legislation as such is going to work. It will help in the short term but it's education and attitudes that make the difference.

S:...I think everyone should have a bit of equality training- certainly all the people involved in management, or goods and services, direct contact with disabled people.

Publicity:

Researcher: Do you think publicity changes people's attitudes?
C: It depends on the publicity, doesn't it? If it's successful publicity by definition it does, but advertising has a history of hit and miss. Some adverts are particularly counter-productive and what advertisers have to avoid is evolving resistance to the idea they're putting forward simply because they're over-selling it or in some way irritating the person they're supposed to be persuading.

Finally, the members of the Advisory Group recognised that it wasn't just professionals' attitudes that were influential. Two individuals recognised that the attitudes of *children, parents and other disabled people* could also be negative:

S: I think that when you get down to the individual children, they're still full of the same prejudices, the same discrimination- it's all about peer pressure, it's about not

> *being an outsider...I still see young children shouting at disabled people in the street, especially people with learning difficulties, calling them names....*
>
> *C: Parents are the greatest conditioning force in society. That's why they play such a large part.*
>
> *S: I think disabled people are often among the biggest oppressors of disabled people by the way they categorise disabilities and look down on some and up on others. It's not good.*

The Advisory Group focused mainly on the Social Model of disability within their discussion. However, there were a few examples of discussions around the way in which people are *conditioned* to think in terms of the Medical Model, as shown below:

> *N: People are conditioned, parents are conditioned to feel that their sons and daughters aren't capable so they feel they need to be looked after and in my experience, I've worked in a social work team, they live with parents that get old and they become worried that they might pop off in the next two or three years and who's going to look after their son or daughter? ...because that's the way they have been conditioned.*
>
> *Researcher: Do you think the medical service are particularly bad?*
> *C: Well, I suppose you could say they are particularly bad in as much as you would expect people who provide a service for people who are either ill or disabled and therefore see more of disabled people than most professionals, you would expect them to be more aware of the changes taking place in the thinking about disability and in fact they either are unaware of it or not willing to become aware of it...*

In this way, the members of the Advisory Group were suggesting that, in general, disabled people experience stereotypical attitudes towards their impairment and that other people (particularly family, friends, professionals) tend to see disabled people as people who have some kind of loss of function and, therefore need help. In this way, disabled people are seen as 'different' from non-disabled people and therefore need to be treated in a different way. This confirms the discussion within the two analytical processes and also reflects the literature around stigma and difference. However, in the above examples, the Advisory Group seem to be showing some sympathy toward the non-disabled person because they recognise the social construction of prejudice. In this way, they are saying that although they are not happy with experiencing negative attitudes, they feel that it is not helpful to blame individuals themselves as they act as a result of their social conditioning.

The Advisory Group's experiences and opinions also resonated with the further systematic analysis of the interviews in terms of disability being seen as a 'problem'. For example, one member felt that the employment services did not see him as a person, but as someone with a problem:

> *K: You know one thing, the employment people, I think you should start training them and getting through to them as much as anybody- when you go to them they don't look at you, they look at your disability...*

Another suggested that other people see disability as a problem because they don't like to think of their own frailty:

> *M: The thing is, a lot of people in that position* [in the army] *they don't want to think about it at all really, they don't think about it, you don't really want to consider it, it's like a failure to a certain degree isn't it, you don't think it would happen to you, you tend not to consider any of the issues involved.*

Another member reframed the discussion in the Social Model of disability and suggested that it was not disabled people who had the problem:

E: We don't have a problem, others do. [applause by others]

The Advisory Group's opinions and experiences therefore resonate with the emphasis of attitudes generated by the analysis of the interviews. However, the amount of discussion generated within the experiential synthesis around attitudes show that it was possibly a more important concept for the Advisory Group because of their lived experiences than for the interviewees.

In general, the concept of 'attitudes' generated by the preliminary group analysis and the further systematic analysis has also been reflected by the experiential level of the disabled people in the Advisory Group. The Advisory Group spent a large proportion of time discussing issues relating to attitudes, as shown in the amount of discussion in this chapter of their experiences and opinions. The concept was so important to them that it changed the focus of the present study. Their discussion about attitudes encompasses some of the issues raised in the interview analysis, such as ignorance, language, changing attitudes, Medical Model, sympathy and disability as a 'problem'. However, in their experiences / opinions, they put more emphasis than the interviewees on ways that attitudes could be changed. This can be seen to be significant because of the importance of the impact of attitudes in their day-to-day lives.

'Difference' in relation to disabled people

Preliminary Group analysis

Difference

The concept of 'difference' generated by the data can be seen to be related to the concept of attitudes discussed in the previous section. The analysis of the data identified a dichotomy within the interview data between disabled people being seen as *equal* and disabled people being seen as *different*. That is, some interviewees saw disabled people as 'special customers' who required segregated/ specialist services, while others felt that disabled people should be treated equally with non-disabled people and should not have specialist facilities. Within the preliminary group analysis, the Advisory Group mainly focused on the issue of difference, while, within the further systematic analysis, I explored the element of equality as well as difference. Later in this section I will expand on the equality/ difference debate by reflecting on the literature around women and citizenship. A similar debate arises in this literature (Lister, 1997) in terms of whether women have different needs and should be treated differently to men, or whether they should be treated equally and therefore have no segregated services. Lister argues for,

> The articulation of difference in which diverse voices...have an equal right to be heard (Lister, 1997, p. 81-82)

The view is also expressed by Lister, and will be developed later in this chapter, that some people have different needs (for example disabled people and women) and that in order for those people to *participate* equally in society, those different needs should be catered for. In this way, therefore, as I will show in the following section, the debate around equality and difference in relation to women can be applied to the findings of the present study in relation to disabled people. In general, the Advisory Group found that the attitudes portrayed by individuals in the interviews could be affected by the perception of a disabled person as 'different'.

The following examples show how the preliminary group analysis highlighted some perceived contradictions within the interviews:

> *R: question 15, about the deaf and dumb cleaner... they'd [community worker] forgotten about the cleaner being deaf and dumb and think that's good... I don't know, I'm not sure... I suppose it's good if you're treating that person like everyone else but there are occasions....*
>
> *S: What is interesting is that he [supermarket manager] says, em, 'you may not be able to see the disability, it could be hidden' and yet doesn't really make any mention of that whatsoever. In question 2 he gives a list, he's been on a course: 'hearing disability... 'and he doesn't really cover hidden disability, and yet he says a 'normal' person which, I don't know, it seems a bit of a contradiction.*

These contradictions also reiterate the comments in the previous section on attitudes concerning the lack of awareness of some of the interviewees. The Advisory Group was surprised that the community worker in the above example showed contradictions in her response. This was also evident in other interviews with welfare professionals where there was a general lack of awareness and knowledge. The Advisory Group felt that those who worked in the welfare professions should have been more aware of disability issues and were surprised that the training welfare professionals received did not seem to address such awareness.

The preliminary group analysis noted several comments by the interviewees around disabled people being 'different' to non-disabled people and therefore needing to be treated in a 'different' way. I shall show later in this section that the further systematic analysis noted this to a larger extent than the Advisory Group. In discussing the interview with the

Member of Parliament, for example, the Advisory Group recognised that, particularly within education, disabled children are seen as *different* and therefore treated differently. This extract is typically reminiscent of a few other discussions:

> *M: I disagree with the Member of Parliament.*
> *Researcher: You disagree with the Member of Parliament?*
> *M: Yeh, it's really shocking that the kids, when there is someone disabled in the class they're usually more sympathetic to the disabled person. I can't think of any case that I've seen in my experiences where there... There was no one picked on and they were sort of treated very well and they weren't discriminated against anywhere.*
> *Researcher: Really?*
> *S: I think kids to some degree, maybe it's for selfish reasons... become friends with a disabled person. Whether that's seen as a cool thing I don't know. Certainly my school was OK. It was kind of looked on as a 'different' friend.*

Within the preliminary group analysis, it was recognised that many disabled people were seen as different because they had a different 'image'. The Advisory Group noted that most interviewees saw disabled people as wheelchair users and also as people with physical mobility problems. Several examples follow on this subject which highlight the significant time given to this debate:

> *S: You know, it was interesting that they all thought that the disabled person was a wheelchair user- that's a really hard one to overcome.*
> *Researcher: The image?*
> *S: Yeh.*

> *Researcher: ...I think this is very much focused on physical disabilities..*
> *C: Well, I think to be fair, they're just picking on the most obvious cases of disability and it's the most obvious when you think of disability.*
> *Researcher: Right*

> *R: I mean, it's the image that's used all the time, isn't it, like the wheelchair symbol and things like that..*

> *C: The MP says, you know, 'I don't think the traditional view of people in a wheelchair is the right image of disability, it's wider than that, but it's usually around mobility, I think of people with walking difficulties...'*
> *Researcher: Yeh*
> *C: So, in other words, she's advanced from the point of view of thinking that every disabled person's in a wheelchair, about 10% of disabled people have wheelchairs, and progressed to the point where they say, 'Oh it needn't be a wheelchair, it may be walking with sticks', but always they think in terms of that sort of mobility...*

In this way, the Advisory Group have noted that in the interviews disabled people are seen as 'different' because of the image that is usually portrayed of them.

The Social Model of disability

The Advisory Group recognised that most professionals saw disabled people as different to non-disabled people and that they based their judgment on the perception of the Medical Model of disability (as discussed in the 'attitudes' section). They particularly noted the ignorance and lack of awareness concerning the Social Model of disability within the interviews, and were surprised when this also was shown by welfare professionals. One member of the group felt that professionals, and particularly health/ welfare professionals should have more awareness of the Social Model of disability:

> *S: I think in all the interviews, there wasn't one mention of the Social Model of disability- it all bases around the Medical Model- helping, curing, caring, all the negative connotations....*

> *Researcher: ... but as C said, should they know the difference, I mean, as he said, the image that they're getting and the feedback they're getting from the media and...*
> *R: You could say that about the cinema manager and the solicitor, but the clinical psychologist and the nurses, they're areas where they should actually go out and seek the information for themselves. They shouldn't be people that just absorb what's going on around them, they should actually be asking questions, and saying 'are we doing this right or not?'*

However, another member of the group suggested that, in general they would not expect many people to know about the Social Model as it is more prominent among political disability organisations than among professionals and managers of services, for example:

> *Researcher: Um, and what about their definition of disability? It's very, sort of, medically based isn't it?*
> *C: It is, yes um, but I think that the idea of the Social Model is something which only people in the disability movement and outsiders who are interested enough to follow what's going on actually understand and I think in the public at large there is hardly any awareness of two conflicting recognitions of disability..*

This group member went on to point out that there was evidence that professionals were beginning to understand the concepts around the Social Model, but were not actually using the term 'Social Model' in their discussions:

> *Researcher: In general, do you think they were knowledgeable about disability?*
> *C: About average, I would say*
> *Researcher: [laugh]*
> *C: They get ideas popping up from time to time which have obviously filtered down to them. They say things like 'well I suppose we've all got disabilities to some extent'. They're sort of beginning to think of what 'disabled' means and the variety and range*

> *and are you talking about the impairment and are you talking about the way the environment and society stops you doing things.*

The group, did note that although most interviewees had not heard of the phrase, the Social Model, there was one instance (out of 30) where it was referred to by the contracts manager in the health service:

> *C: Well, I think the first thing I noticed about it is the contracts manager in the health service said 'I think about my job in terms of the Social Model and, er, its unusual for people that are not sort of part of the disabled movement who've even heard of the Social Model, let alone think in terms of it.*
> *Researcher: Exactly*
> *C: At the very best, he knows what noises to make.*

However, another member of the group went on to query the contract manager's sincerity around being a 'champion of the cause':

> *M: Question fourteen, on the contracts manager again... 'What is your role as a professional?'.....'is to champion the cause' [loud] [all laugh].*
> *Researcher: A real flag-waver!*
> *M: Yes!*
> *Researcher: Yes, 'trying to influence GPs,...' I mean I suppose her reasoning behind it , for saying it is, comes from the heart if you know what I mean?*
> *M: Oh, yes, I believe it was sincere...It's just the way she says it.....I wasn't saying that she wasn't sincere.*

Within the Social Model of disability, it is recognised that people are disabled, not because of their physical 'difference', but because of the way in which society is not constructed to accommodate them and because of prominent attitudes and stereotypes which are discriminatory. Borsay's (1986) view that disability is,

> ... imposed by a society which expects all its members to conform to the yardstick of able-bodied normality and builds physical and social environments which penalise any 'misfits'. (Borsay, 1986, p. 183)

illustrates this model. In this way, the focus on the Social Model which was generated by the data, encompasses some of the debates in this section. That is, it suggests that disabled people are different, and have different needs and consequently changes need to take place in the environment to cater for those needs. It is also saying that disabled people should be treated as equal citizens. The debate around the Social Model can be seen as a debate about the participation/ inclusion of disabled people, that is, in order to include disabled people in an equal way, their differences need to be catered for.

The Social Model of disability can be seen as a way of consolidating some of the difference/ equality debate within the interview data. That is, even though disabled people have an impairment (ie. they are physically *different*), the Social Model of disability suggests that the way people experience their impairment is affected, to a large extent, by structural factors, rather than by the impairment itself. In this way, there is recognition of the importance and value of diversity among individuals.

The preliminary group analysis, therefore, identified some dilemmas in the interviews with respect to the difference/ equality debate. They felt that some of the stereotypes of difference were due to ignorance and they felt that welfare professionals were included in the general lack of understanding of 'difference'. The Advisory Group found that the notion of disabled people being seen as different could affect a person's attitudes to disabled people, generally in a negative way (eg. needing sympathy, being helped). Although the Social Model can be seen as a way of promoting equality within an environment that caters for differing needs, the preliminary group analysis noted a general lack of awareness among *all* interviewees around the Social Model.

Further Systematic analysis

Difference

Within the further systematic analysis, and developing the theme of the Advisory Group, I found that there were various comments made by the interviewees relating to 'difference' and about how disabled people are treated differently and have different needs. These two examples are typical of many comments by service managers:

> Customer Services Manager (Bank): But we don't have any, sort've, formal training on how to handle, or how to, um.... [long pause] address any special needs.

> Cinema Manager (1): And to do that I must maximise on all customer profiles. So... if you mean... what does disability mean to me? It means a member of the public...
> Researcher: Right.
> Cinema Manager (1): ...that, er... if I want them to come to the cinema, then I must cater for their needs. Just like I would cater for less disposable income or family tickets or student market or senior citizens...

These comments are about catering for the 'special' needs of the 'different' person. It was noted that many retail and leisure managers, in particular, saw disabled people as 'special' customers. The following extracts continue this theme by suggesting that disabled people are also seen as 'different' in the way they *look* and the way they *behave*:

> Researcher: What about, um - y'know when you see on the TV disabled people chaining themselves to a bus - Direct Action; do you think that's effective?
> Restaurant Manager: I think they're doing themselves down. On a personal level...
> Researcher: Yes.

> Restaurant Manager: I understand where they're coming from. But that's making them out to be... different... because a normal person who's demonstrating against something wouldn't do it. So in a way, they're using their disability.
> Researcher: Right.
> Restaurant Manager: Which makes them different.
>
> Researcher:...and what is your image of a disabled person?
> Art Gallery Manager (2): Well, obviously physically is something that shows.
> Researcher: Right
> Art Gallery Manager (2): Um...otherwise, mentally it might not be anything that would necessarily show.
> Researcher: No.
> Art Gallery Manager (2):...although you tend to think they're actually going to look different....
> Researcher: Right.
> Art Gallery Manager (2): ...matter of fact, they might not.

Within the further systematic analysis, it was also noted that some of the interviewees recognised the issue of difference relating to segregation/ integration, particularly in schools. This issue was discussed within the preliminary group analysis, and I shall also show how it was important in the experiential synthesis around difference, later in this chapter. A teacher in a segregated college for disabled people for example, felt that segregation could be good, whereas a disability officer for the Methodist church felt that it was not beneficial to disabled people. These views are illustrated in the following contributions:

> Teacher (College for Disabled Young Adults): ... I had two girls come on a work experience course, helping, nursery-nurse type-thing. And they both had spina bifida.
> Researcher: Right.

> Teacher (College for Disabled Young Adults): And one girl had been in a college, in a school for... everybody, from a comprehensive school. And one girl was from the special school. And the person who did the most to help, was the person from the special school. The girl who was in the integrated situation would say "But I can't do that. I have spina bifida." So if I asked somebody to wipe the tables clean, the girl that was from the school where everybody was disabled would race as fast as she could to clean the table. The other girl would hope that somebody would help her get there.

> Disability Officer (Methodist Church): I'm not too keen on segregation. No.
> Researcher: No?
> Disability Officer (Methodist Church): Even in education I'm not too keen on segregation.
> Researcher: Right.
> Disability Officer (Methodist Church): Because I saw the effect that it had on blind children that I knew. Um... when in my early days, we had to take... well, almost babies. And the deprivation... emotional deprivation was quite profound. Um....

It is perhaps an obvious observation that the teacher who worked in a segregated school was in favour of segregation, while the Disability Officer who worked in an integrative environment was in favour of integration because the views of the interviewees were probably affected by their personal experiences of segregation/ integration in relation to disabled people and their choice of work would reflect their standpoints. The other area in the interviews in which segregation/ special needs was an issue concerned events being put on for disabled people only, for example, special art exhibitions, special screenings in cinemas and also segregated ways of getting into a building. This was particularly pertinent for interviewees who were retail/ leisure managers, as these two examples show.

> Art Gallery Manager: Well, we do have special events, with, um, specialist groups and so on. And we try to make it as varied as possible. It's a case of...certainly, the

> education officer's been contacted in most groups- groups from social services who we work with very closely.

> Cinema Manager (1): So… I have to say, as part of my target and my appraisal this year, I need to take the training one step further.
> Researcher: Yeah.
> Cinema Manager (1): In that if I'm to invite more disability groups, say, in a group to come to the cinema.
> Researcher: Mmm.
> Cinema Manager (1): Or a group of partially-sighted [phone starts ringing] or fully-blind people.
> Researcher: Yeah.
> Cinema Manager (1): Then I need to do more training to do that.

In this way, by having segregated services/ events, the assumption was that disabled people were seen as 'different' from other users. These extracts were representative of many extracts (particularly among retail/ leisure managers) that talked about making segregated provision for disabled customers.

Following on from the preliminary group analysis in terms of 'difference', the further systematic analysis also generated the issue of *image* as a point of 'difference'. The preliminary group analysis noted that the main 'image' the interviewees had of a disabled person was of someone in a wheelchair. I also noted this in a large number of interviews. Here are a few examples from very many comments.

> Researcher: If I said 'disabled' to you, what would that mean to you?
> Age Concern Manager: Well… I think, perhaps… disabled, one pictures someone disabled. In a wheelchair.
> Researcher: Right, yeah.

Age Concern Manager: But, I say that because a lot of the people I deal with are disabled and perhaps in wheelchairs. But then you have to think to yourself, y'know... "Yes, but wait a minute. There are other disabilities."
Researcher: Yeah.
Age Concern Manager: And it does not necessarily mean a wheelchair.

Researcher: [pauses] Right. [pauses] Okay, fine. And do you have an image of a disabled person?
Member of Parliament: [pauses] Um, I think... it's not so much my image. I think I would say the traditional image is somebody in a wheelchair.

Newspaper Editor: But, um, of course whenever you use the word 'disabled', people think 'wheelchairs'. That's just a fact.

Social Worker (2): My image of a disabled person is a wheelchair, I'm afraid to say. I know it shouldn't be but it is.

The image of disabled people as wheelchair users was fairly consistent across all the interviews. The interviewees were suggesting that this image could contribute to an assumption that disabled people were 'different' because, they argued, if an individual looked different, they were likely to be treated differently.

Equality

An additional area which emerged from the further systematic analysis of the interviews, and which contrasted with that of Difference, identified issues for disabled people on the subject of equality. I noted that many interviewees commented on the notion of disabled people being treated as 'equal', and in this way they implied that everyone should be treated the same. The following extracts reflect the large amount of discussion generated in the interviews on this issue.

> MIND Officer: And okay, if someone is in a wheelchair and they're trying to manoeuvre through the door, I am going to open the door for them as I would anybody who is going to follow me into a shop.
>
> MIND Officer: Because if you try to treat them differently - they don't want to be treated differently - if you try to do that, you're pointing a finger at them and saying "Oh, look at this person, they're different". They're not different from us! Unfortunately, something's happened in their life so that perhaps they cannot walk on their own two legs. But they still think the same. They still cry and they still laugh the same as we do. It could be our turn tomorrow.
>
> Teacher (College for Disabled Young Adults): But I think I've always had an upbringing anyway that everybody's equal. And I feel that everybody is equal and it's not... [pause] You take people as they are. You don't have any expectations. And you feel... pleased, that what they can do is what they can do.
>
> Age Concern Manager: No, I really feel that whatever, y'know... everybody should be treated equally. And there should be the same rights to disabled as non-disabled.
>
> Supermarket Manager (1): The personnel manager is given training in how we deal with all customers, not just disabled people.

It is interesting to note that these first three extracts reflect many of the comments by welfare professionals, or those working specifically with disabled people. The last comment by a supermarket manager, however, was not particularly typical of managers in the leisure and retail industry. There was, instead, a tendency by these professionals to see disabled people as 'special' customers, rather than 'equal' customers.

The literature suggests that in terms of citizenship rights, equality is often something to be achieved through a struggle. The concept of equality and inequality, can also be seen to be based on rights and needs:

> ...citizenship is also pivotal to the definition and interpretation of needs and to the struggle for their realisation and conversion into rights. (Lister, 1997, p. 7)

Marshall advocates a journey toward equalisation:

> What matters is that there is a general enrichment of the concrete substance of civilised life, a general reduction of risk and insecurity, an equalisation between the more and the less fortunate at all levels- between the healthy and the sick, the employed and the unemployed, the old and the active, the bachelor and the father of a large family. Equalization is not so much between classes as between individuals in a population that is now treated for this purpose as if it were one class. Equality of status is more important than equality of income. (Marshall, 1963, p. 107)

It is interesting to note Marshall's mention of 'risk' as a factor in the element of inequalities. This was also a concept generated by the data and will be considered more in Chapter Five. He is also calling for people to be treated as equal individuals, rather than members of collective groups.

'Inequality' can be seen as a negative term that has elements of power, and therefore has led to a redefining of the 'difference' continuum to include division and diversity. This, therefore, recognises the need to have both difference and equality in the equation: within a framework of diversity, 'otherness' is celebrated but not subordinated:

> Diversity is used to refer to a shared collective experience, which does not necessarily imply relations of subordination, for example based on age, nationality, sexual identity. Division occurs where diversity is translated into relations of subordination.

> Difference signifies a situation where diversity becomes the basis for resistance against subordination. (Williams, 1996)

It can be suggested, from the data highlighted in this section, that the interviews reiterate this view. The analysis of the interviews generated the element of 'equality', that is, discussion around disabled people being treated as equal. This element, which is focused on disabled people, can be seen to develop and reinforce the literature on citizenship and diversity. In this way, although Marshall was seen to neglect issues of the struggle of oppressed groups in gaining citizenship rights, the present study does show how disabled people can be incorporated into the model of citizenship.

Difference versus equality: developing the debate

Although the present study focused on disabled people, the citizenship literature focuses mainly on the difference/ equal debate as it applies to *women,* that is, where the debate is around whether women are equal to men and therefore participate in the same sphere as men or whether women are different from men and therefore need different services and are acknowledged for having different responsibilities. Lister (1997), for example asks the question:

> ... is the goal a gender-neutral conception of citizenship which enables women to participate as equals with men in the public sphere ('equality') or a gender-differentiated conception which recognises and values women's responsibilities in the private sphere ('difference')? (Lister, 1997, p. 9).

She goes on to question whether, within the shifting and different identities that women may be part of, citizenship should be inclusive of women rather than additional to a male-gendered definition.

Lister (1997) argues that women's formal admission into citizenship is on different terms from that of men, that is, it is seen as an 'allowance' for women in terms of their status which is seen as 'other' (ie. different). She refers to this as a 'partial' inclusion into citizenship. It is also the case that the citizenship rights of men are seen as visible, whereas the citizenship rights of women are not seen as visible: men have rights automatically but, because women are seen to have different needs, they have had to fight for their rights as an oppressed group. She also talks about a commitment to the *value* of difference. She suggests that a commitment to dialogue is necessary to create a framework for '..the articulation of difference in which diverse voices, particularly those normally excluded from public discourse have an equal right to be heard.' (p. 81-82).

Gooding (1994) continues this discussion by suggesting that:

> ...for women, as for black and disabled people, assertions by the dominant groups that they are different have invariably meant less valued, carrying a tremendous stigma.... (p. 33).

This has meant that individuals have often attempted to deny the presence of significant differences.

The 'partial' inclusion into citizenship referred to by Lister can also be seen in the present study, firstly in that disabled people were not seen as 'visible' and therefore the awareness of their particular needs was limited, and, secondly, because there have been very few rights in legislation, (until recently with the Disability Discrimination Act , 1995) which recognised the rights of disabled people as a 'different' group. Other groups which are defined as 'other' (therefore having an element of difference and invisibility) include black people, disabled people, older people, gay and lesbian people; each individual within these groups is then regarded as,

> …unable to attain the impersonal, rational and disembodied practices of the modal citizen. (Yeatman, 1994, p. 84)

I would argue that the present study shows how disabled people, as a group, are seen as 'other' in terms of having 'partial' inclusion into citizenship, and of not being visible. Rather than prejudice being related to physical *limitations*, it could be suggested, therefore, that prejudice is related to physical *difference*. This could develop, for example, a model of disability into a *model of difference*. That is, by recognising *attitudes* as part of the citizenship continuum, the level of attitudes to a person's 'difference' may affect their ability to participate as full and active citizens. This viewpoint can relate to other groups of people who are seen as 'different', such as people from ethnic minorities, women, and gay/ lesbian people. In this way, the research develops the citizenship literature. Gooding (1996) suggested that,

> …for disadvantaged groups, these differences from the white, male, able-bodied 'norm' are often clearly the historical legacy of discriminatory treatment. (p. 33)

The concept of difference also serves to bring together issues that may be experienced by other oppressed groups. A politics of difference, argued by Yeatman (1993) requires both 'an inclusive politics of voice and representation.' She also says it involves:

> … a readiness on the part of any one emancipatory movement to show how its particular interests of other movements in contesting different kinds of oppression. (Yeatman, 1993 p. 231)

I have shown within this study how the Citizenship literature has been inadequate in terms of explaining the position of disabled people. For example, the traditional tripartite model of rights expounded by Marshall (1950) was shown to neglect issues in relation to specific groups of people. The present study has developed Marshall's theories by exploring citizenship in relation to disabled people. In doing this the concept of difference has been generated by the data. The usefulness of this can be seen in the way in which a *model of difference* can be applied to other groups.

The further systematic analysis of the interviews, therefore, develops some of the citizenship literature around difference in that it expands the application of 'difference' from women to disabled people, and further, to other 'different' groups of people.

The Social Model of disability

The further systematic analysis also developed the observations in the preliminary group analysis on the lack of awareness of the Social Model of disability. In a similar way to the Advisory Group, I found that there was only one person who talked about (and understood) the Social Model of disability (the contracts manager in the Health Service), as this extract shows:

> Researcher: Um, right... that's excellent. Um... how would you define disability yourself? If I said 'disability'...
> Contracts Manager, Health Services: Yes. Well I think of it in terms of the Social Model.
> Researcher: Right.
> Contracts Manager, Health Services: I think, really... um, in that sense. Er... and I think that's how we're promoting it. In the Trust - is the Social Model of disability. I think that's the difficult bit. People assume in hospitals that we... that we see disability as the Social Model and I don't think that we do.
> Researcher: Right.

This interviewee had seemed particularly aware of disability issues and terminology (as discussed earlier in the chapter) and she had explained in the interview how her contact with a consultative group of disabled people had changed her perceptions. Following on from this experience, she explained how she had put considerable emphasis on learning more about disability issues, including the Social Model of disability. This interviewee, however, was the exception. It does, however reinforce the view expressed earlier that the attitudes and knowledge a person has about disability can often be affected by the extent to which they have had contact with disabled people.

The further systematic analysis also showed that there were other comments by interviewees about the effects of the environment/ families/ attitudes on disabled people which perhaps implied an understanding of disability beyond that of the medical definition of *impairment*. A cinema manager, for example, suggested that a definition of disability would be around a person's experience of being dealt with in an unfair way:

> Cinema Manager (1): So my definition of a disabled person is someone that is - and I think I've made it clear - has a bad rap. Is someone that is treated with ignorance...
> Researcher: Right, okay.
> Cinema Manager (1): ...and is... er... is unfairly dealt with.

This was also taken up by a disability officer in the Methodist church who noted that some people are disabled by the *attitudes* they experience:

> Researcher: In terms of this particular role, how would you define disability? What do you mean by 'disability'?
> Disability Officer (Methodist Church): ..... a person can be handicapped sometimes by the attitude of others.
> Researcher: Right.
> Disability Officer (Methodist Church): Towards him. So that's the impairment, disability and handicap....

Finally, a social worker who worked with disabled people recognised the dynamics of the *family* in managing and affecting the life of a disabled person.

> Researcher: Um, how would you define disability? Or if I said 'disabled' to you, what would that mean to you?
> Social Worker (for disabled people): Um... to me it's a multitude of things. Because I tend not to think of disabled people, but more as disabled families, if y'like. To me it's more than just the physical disability.
> Researcher: Yeah. Yeah.
> Social Worker (for disabled people): Which, alright, has got practical problems. Um... but it's the other issues that go with it. It's the family dynamics that change. How it affects the family. Relationships that change. I suppose one of the biggest things I've found is frustration in people. And the difficulties in accepting limitations and things.

These examples, therefore, show that, although there were few incidences of interviewees using the term 'Social Model', there was at least some awareness among a few interviewees of factors, other than their impairment, impacting on the lives of disabled people.

In developing the difference/ equality debate further, I wish to refer to some discussions within the citizenship literature. Lister (1997) has used the term Universalism to describe a possible reconciliation of the dilemmas within the difference/ equality debate. It can be seen that women's exclusion, for example, is also mediated by other social divisions such as class, race, disability, sexuality, and age (Lister, 1997). Citizenship, therefore, has divisions which demonstrates the need for,

> ...a conception of citizenship which would accommodate all social cleavages simultaneously. (Leca, 1992, p. 30)

This could be achieved through an acceptance of diversity.

In this chapter I have shown how the theme of difference in relation to disabled people has developed. The Advisory Group were arguing for understanding and for the need to be treated within a construct of equality. This could be seen as the need for inclusion within an ethos of 'universalism'. The concept of 'universalism' is useful for describing an ideal where diversity and difference can be accommodated within a citizenship framework, as Lister (1997) suggests:

> I shall argue that this is the direction citizenship theory has to take, in relation to citizenship both as a status and a practice, if it is to match up to its inclusionary and universalist claims. Thus, rejecting the "false universalism" of a traditional citizenship theory does not mean abandoning citizenship as a universalist goal. Instead, we can aspire to universalism that stands in creative tension to diversity and difference and the challenge the divisions and exclusionary inequalities which can stem from diversity. (Lister, 1997, p. 66)

Lister (1997) suggests that the tension between universalism and diversity is not an irreconcilable tension but can be a creative tension under the umbrella of a 'differentiated universalism.' (Lister, 1997, p. 89) Universalism, therefore, can be seen to be the aspiration for oppressed groups (such as women and disabled people). The idea of a 'differentiated universalism', therefore is one way of accommodating debates around difference and equality into the citizenship spectrum.

In both the preliminary group analysis and the further systematic analysis, it was shown that 'difference' was a crucial concept. Both levels of analysis highlighted the dilemmas around equality and difference and also noted issues around the Social Model of disability. Within the discussion of 'equality' both levels of analysis discussed issues of being treated as equal and of the language of 'normality'. The discussion has shown that the analysis of the interviews has reinforced and developed some of the citizenship literature by relating the concept of difference to *disabled people*. The terminology of a 'differentiated universalism' used by Lister (1997) is useful to bring together the agendas of the equal/

different debate because it describes how there is a need for the inclusion and acceptance of diversity. The interview data showed that the element of 'difference' conferred onto disabled people was seen as a negative construct. Although Lister is promoting a positive construct of difference through the use of the term 'differentiated universalism', this study highlights how the discourse of the academics (eg. Chapter Three) contrasts with the actual experiences and voices of disabled people. This also brings into question differences between the ideal of citizenship and the reality, particularly in relation to disabled people.

Difference: Experiential synthesis

The experiences and opinions of the Advisory Group gave resonance to some of the issues within the difference/ equality debate. This section will show how they expressed their experiences around segregated services, particularly in terms of their experiences of education, in general suggesting that segregated schools had not been a successful experience for them. This contrasts with the analysis of the interviews in that many professionals showed a keenness to provide segregated services for disabled people as 'special' customers. Some of the members of the Advisory Group who had a learning difficulty expressed their surprise at being labelled 'different' since they considered themselves no different from other people. Finally, the discussion within the group around the Social Model of disability confirms the preliminary group analysis of the interviews, in that the Advisory Group felt that, in general, very few non-disabled people had much knowledge about the Social Model of disability. The experiential synthesis, therefore, confirmed the importance of the concept of difference in relation to disabled people, which was identified in the data in that the debates described were also of relevance to the everyday lives of the disabled people in the group.

The members of the Advisory Group's discussed their experiences of being treated as equal, which centred mainly around education. Some talked about being integrated into a mainstream school where, in reiterating the discussions within the interviews, the ideology was that everyone is the same, as this contribution shows:

> *Researcher: Would you have liked it in a school where there were people who didn't have a disability?*
> *D: No, I don't see any difference. I mean, you know, we've got a learning disability, we've got a learning disability. If you haven't got one, you haven't got one. If you can read, you can read. If you can't read, you can't read. You've got to try and learn somewhere....*

Discussion centred around segregated education versus integrated education as an example of whether disabled people should be treated as equal or different. In general, the Advisory Group felt that there were more advantages in being *integrated* into a mainstream school. However, they did comment that, in their experiences, although they may have been seen as equal in a mainstream school, they did experience assumptions and stereotypes by fellow pupils who considered them as different, for example:

> *S: ... because I spent quite a lot of time in hospital I did actually fall behind and had to have extra tuition, and being always very sickly, I kind of...yeh, it was difficult, it was not a good time, I must admit. But you survive and get by. At least I wasn't segregated which was a good thing.......*
> *Researcher: ... and did the children pick on you?*
> *S: I'm afraid so, yeh...I mean being sickly, having problems, not being able to run very well, so on and so forth, yep, the outsider type syndrome, definitely. Not a particular good time I would think, not a good time.*

> *E: I mean, I went to a mainstream school but then, I was well aware myself that I was the only one with a particular hidden problem but other people might have had other hidden problems... but I didn't see myself as different to anyone else. The only difference is I couldn't rush around and play games and keep up with them in that way, but then I could keep up with them in the classroom so I had to make do with what I could do and they found it a problem because they thought I was different.*

The general experience of segregated education by the group was also very negative, as this typical comment shows:

> *N: I attended special school- thank god I got out of it and eventually into mainstream education.*

However, the Group did recognise that in some cases there was an argument for segregated education, particularly for the Deaf community and for some people with learning difficulties. They also recognised that it was often easier for teachers to teach in segregated schools, as the following extracts highlight:

> *C: Integration is still a problem in the deaf community, there is still a lot of empirical evidence that people who are profoundly deaf get on better educationally if they are in an environment of deaf people.....but on the other hand, this seems to me to lead to a lot of social maladjustment, shall we say, because deaf people only relate to other deaf people...*

> *N: Another factor in the education of disabled people does to some extent depend upon the nature of the disability, the most obvious example is people with learning difficulties struggling to keep up in a mixed class....*

> *M: ...you know, it's difficult, you know, whether people should be segregated into their own school or whether they should be integrated and for a purely...from the kids point of view, I think they'd prefer it integrated with the rest of the kids, the rest of the kids who aren't 'special needs'. .....I think from the teacher's point of view they kind of work the other way round. They quite like it better to be segregated.*

One member of the group proposed a 'hybrid' system within schools where segregation could be combined with integration:

> *M: School isn't just for education, is it, though? You've got to bear in mind that a child learns most of its social skills mixing in schools, so if you segregate them, the only social skills they'll get are mixing with each other, so what happens later on when you adjust to the wide world?..............The only solution I can think of is to have two schools, one for special needs, with a shared playground so at least then,*

> *you get some social interaction with, non-disabled people and then they're also getting their own lessons so it's geared towards their needs.*

In general, the disabled people in the Advisory Group did not feel that segregated services had been very helpful to them. This seems to contradict to an extent the data from the interviews as, often, the comments in the interviews suggested that disabled people should be provided with segregated facilities and programmes appropriate to their needs. This experiential knowledge is useful as a counter-weight to the views put forward in the interviews and is an indication of the extent to which the conceptual data resonates, or not, with disabled people's daily experiences.

The experiences/opinions of the Advisory Group around being treated as equal or being treated as different were sometimes mixed. In general they felt that they should be treated as equal citizens but that society sees them as 'different' with different needs, as these two examples show:

> *B: I'm a bit wary of this...we're being discriminated against in the opposite way- we have to have Acts of Parliament so society treats us as 'normal'. That to me is the opposite- gratuitous prejudice....we don't want rights as such, we want to get rid of prejudice. It seems a shame that we have to go through Acts of Parliament to give us what is our right as a citizen.*

> *R: I think a lot of disabled people probably know in their own minds the difference [between the Medical Model and the social model] but they don't know the actual wording- they know that they want to be tret as an equal person, not as somebody who needs to have done this to or that to.*

Within the discussions by the Advisory Group, the concept of difference generally arose over definitions of disability, that is, what was it about a disabled person that defined them as 'different'? One member of the Advisory Group who had a learning difficulty focused on his lack of understanding of why he was defined as ‘different’, and as disabled:

> *Researcher: You can't always tell if someone's disabled, can you?*
> *D: No you can't. We're classed as disabled, but you see, I've gone to the doctor several times when I've had a bit of a problem with myself, and I say, 'what's my disability?' and he never tells you….he should tell you.*
> *Researcher: Do you class yourself as disabled?*
> *D: Yeh, I think I do, you know, otherwise I wouldn't be able to have a pass... otherwise they wouldn't be able to tell people what are registered disabled...As far as I know, I've always been classed as disabled...*

The discussion continued when another member of the group asked the same person about their impairment:

> *S: Do you have a learning difficulty? [to D]*
> *D: What do you mean?*
> *S: Well to me, you seem intelligent, in inverted commas 'normal' and yet you're saying you've got learning difficulties, you can't do certain things?*
> *D: Well, I can read up to a certain amount, without glasses on and I can put a pair of glasses on and read like a normal person.*

In this way, the person with a learning difficulty suggested that he had been defined as ‘different’ but that he considered himself to be able to do all the things others can do. In terms of the *functional* model of disability, therefore, he does not define himself as ‘different’. The opinions of the Advisory Group were usually that *visible* 'difference' was seen as a negative construct to which other people react badly, such as:

> *E: There's always going to be conflicts of interest, even within your own culture, whatever your background because everybody's different- some people might experience more hostility than others.*
>
> *N: I mean, some people cope by disability, or anything what's seen to be less favourable in any society and being seen as different, that you're inferior and that is something to be afraid of, or they're a threat to your existence and some people cope by ignoring it, walk away, walk away from the child, walk away from responsibility, walk away from...*

This contrasts with the literature discussed in the further systematic analysis of difference which suggested that within a framework of diversity 'otherness' should be celebrated, not subordinated.

The Advisory Group talked of some experiences and opinions where the Social Model was a factor. This was mainly in terms of ignorance and in terms of access/ attitudes, for example:

<u>Ignorance</u>

> *C: ... a couple of years ago I spoke to [a clinical psychologist] at a conference and I said, 'What is the model of disability used in the health service/' and she said, 'You know, the same model that everybody uses'. I said, 'Well, have you ever heard of the Social Model?'... 'What?' [everyone laughs]..so I told her what the Social Model was and she was just completely non-plussed, er and um sort of sat there sucking her thumbs...*

This is suggesting that often professionals are largely unaware of the definition and implications of the Social Model of disability.

Access/ Attitudes:

In terms of access and attitudes, the Advisory Group talked about the difficulties that they experience in the built environment in which they live. This, therefore, echoes the focus of the Social Model of disability and emphasises the difficulties of being 'different' in a society constructed by non-disabled people, for example:

> *T: Like once, we went down to Torquay on holiday and got there, the hotel weren't suited to disabled people but they ought to have explained that to us before we actually travelled.*
> *J: We put on the booking form, you know, uses wheelchair to get about and the bedrooms were on ground floor but it was on a hillside, sort of thing, so the dining room was down a very sheer staircase. I think a lot of elderly people go so it was difficult for them as well, really. It really wasn't fit to be a hotel really, I don't think. When we go abroad, the hotels are smashing for access and that, even old ones.*

The Advisory Group felt that, in general, it was important to move away from the Medical Model onto the Social Model, as the following comments, which I would suggest are representative, show:

> *N: We need to move away definitely from the Medical Model.*

> *B: It's only recently that they have started to make disabled access to the Art Gallery, the City Hall, only in the last three or four years because of the Disability Discrimination Act and now local authorities are having to look at what they do in relation to disabled people. Why? Is it only because of the DDA? Could they have done it if it had not come out?*

However, they also suggested that individual disabled people play a part in changing society and that some disabled people are in fact limited , in a medical way, by their impairment:

> *B: the problem is society. It's not society that's got to change the laws, its us that's got to change society.*

> *S: I think the only problem with the disability movement is that by the nature of the Social Model we are said to not have problems or difficulties and we've focused on society as being the real oppressive element and yet we haven't looked at how individual disabilities can limit us. We're not willing to accept that we may have some limitations.*

The Advisory Group spent a great deal of time discussing the Social Model of disability as they felt that an understanding of the difficulties in the built environment and the attitudes of others, rather than specific impairments and difficulties, would contribute to a greater awareness by others of the lived experience of disabled people. Their opinions/ experiences, therefore, concerning the Social Model acknowledge and reinforce the themes arising from the analysis of the interviews. However, the Advisory Group focused on the Social Model more than did the interviewees. Their epistemological and experiential base would perhaps influence their reading of the interviews.

In general, therefore, the concept of 'difference' generated by the interview analysis is also reflected by the experiential level of the disabled people in the Advisory Group. The Advisory Group spent a large proportion of time discussing issues related to being seen as different. They described experiences/ opinions around segregation, although they did not identify it as an important category within the analysis of the interviews. They reflected that they experience being treated differently because of the attitudes and ignorance of non-disabled people, which is also highlighted in the disability literature. They felt that there was a need to move away from the Medical Model and onto the Social Model within a recognition of diversity. This reiterates the analysis of the interviews and some of the citizenship literature on universalism.

Advisory Group discourse: Adding 'attitudes' to the citizenship literature/ 'Difference in relation to disabled people.

Some conclusions

In this chapter I have suggested that, as a result of this research, the concept of *attitudes* should be added to the citizenship literature. This also reflects the Advisory Group discourse concerning attitudes. It has been suggested that attitudes arise from notions of 'difference' and the way in which disabled people are perceived as 'different' has been highlighted. This, therefore, develops a theory of citizenship and adds to the exploration of 'moral' rights in the previous chapter.

Since the Advisory Group prioritised attitudes within the methodological process, and altered the focus of the research from citizenship rights onto attitudes, it was likely that within the preliminary analysis of the interviews, they would focus specifically on the perceived attitudes of the interviewees. In highlighting the lack of understanding and ignorance of some of the interviewees, the members of the Advisory Group were reinforcing their personal experiences. They, therefore, saw the concept of attitudes as particularly important. However, it could be suggested that the Advisory Group could be influenced by their experiences, in their reading of the interview data. Although it was important to use their experiences as a basis for the research, it will always be the case that this could introduce an element of bias in the analysis process. However, within the further systematic analysis, I *also* found the concept of attitudes to be important.

The 'bias' of the Advisory Group could also be related to the representativeness of the individuals in the group. That is, whether, the make-up of the group reflected the experiences and views of other disabled people. Individual differences could also be suggested in relation to gender, race, sexuality, age and other factors within the group. However, this would be the case given any group of people. The representativeness of the individuals in the group was discussed in more detail in Chapter Two. It is also important to note that the analysis of the interview data in this study was being filtered through the lens of the Advisory Group (preliminary group analysis) rather than being used as a comparison with my own analysis (further systematic analysis).

In non-positivist research methodology, such as this study, it is important to acknowledge the focus on generating social explanations and meanings, rather than on creating standardised factual knowledge. That is, the interactions within the group, the accounts of experiences, and the qualitative data of the interviews all contribute to the development of conceptual material. There is, therefore, a uniqueness to this kind of research in that the experiences and opinions of the individuals in the study are illuminated. These experiences and opinions may have been different, given a different group of people (both the Advisory Group and the interviewees. In positivist methodology, these issues may be seen to constitute 'bias'. However, as with any interpretivist work, these processes have been made transparent and, as Mason (1996) suggests, within this style of methodology,

> It is better to understand the complexities of the interaction, rather than to pretend that key dimensions can be controlled. (Mason, 1996, p. 40-41)

In this way the further systematic analysis gave strength to the preliminary group analysis and provided an element of triangulation within the analysis. In this section, the further systematic analysis, like that of the Advisory Group, also highlighted issues of ignorance, language and changing attitudes.

Since the concept of attitudes was found to be important in this study, I would propose that it is a useful concept to add to the theory of citizenship. The attitude literature (developed within disability studies) described in this chapter, therefore can be added to the literature on citizenship. This, then, creates an initial starting point to develop the links between the two disparate literatures of citizenship and of attitudes.

Both the preliminary group analysis and the further systematic analysis showed how the interviewees perceived disabled people as 'different' and how this in turn affected their attitudes. I particularly noted the large extent of data concerning the use of the Medical Model of disability to define disabled people.

Within the concept of Difference, both the preliminary group analysis and the further systematic analysis highlighted the elements of equality, difference and universalism. However, the further systematic analysis highlighted a greater emphasis on Difference than did the preliminary group analysis. It can be seen that the written sections on these topics in the preliminary group analysis are comparatively small. However, within the experiential synthesis, the Advisory Group highlighted the issue of the Social Model of disability as important to their experience.

The Advisory Group did not choose to accommodate the concept of Difference in the accessible report. 'Difference', therefore, is not a concept that has been as fully developed as the concept of attitudes in this research. It may also be the case that 'difference', as a concept, would be less understandable outside an *academic* arena. I would suggest that this concept could constitute a future area of research to explore the extent to which 'difference' is, in fact, of importance in relation to citizenship, as compared with other factors. The Advisory Group did not specifically articulate the concept of 'difference' but it was present in their opinions and experiences. Further research could relate the concept of difference to the theory of citizenship in relation to disabled people. Therefore, the literature around disabled people as 'different' could be added to the existing citizenship literature.

Although there is a need for further research on these issues, I would suggest that the concept of difference gave strength to the concept of attitudes. The concept of difference suggested that attitudes and stereotypes are based on an understanding of disabled people as 'different'. I would suggest that the importance of the concept of attitudes and of difference is in terms of adding to the understanding of citizenship theories: the data are suggesting that the citizenship rights of disabled people are affected by the attitudes and stereotypes towards them. This elaboration of the concept of citizenship to include attitudes and difference may not have been developed without this specific data. In this way, the empirical data demonstrates important connections and explanations that perhaps have not been considered before.

By adding attitudes to the citizenship debate, this chapter has helped to develop the concept of citizenship. It has also shown that attitudes can exclude disabled people from being full citizens. To deny people full citizenship because their physical or mental difference results in their being seen in a subordinate position can be referred to as disablism. The experiential synthesis shows that disablism has played a large part in the daily lives of disabled people. Disablism, as a concept will be further discussed in Chapter Six (Conclusion).

CHAPTER 5: PROFESSIONALS' DISCOURSE
DISABLED PEOPLE AS CONSUMERS.
ARTICULATING OR EXPERIENCING RISK?

This chapter describes the way in which the 'new' concept of 'consumer' emerged from the data. It develops to show how, although disabled people were considered by many professionals (particularly retail/ leisure managers) as consumer citizens, their participation beyond that of a consumer (for example, as employees) could be seen to be hindered by the notion of 'risk'.

'Consumer' was a new concept generated by the data. The majority of the interviewees saw disabled people as potential customers in the market they served. This was particularly important for managers in retail and leisure (eg. supermarket managers, restaurant managers, art gallery managers and cinema managers) and it was also reiterated in *some* discussions with welfare professionals. The interviewees also talked about the cost versus the benefit of having disabled people as customers and they talked about equal opportunities policies and practices. Finally, issues were generated around the area of providing services for the majority, that is, non-disabled customers.

The concepts of consumer and risk can be described as the professionals' discourse, since they were neither emphasised in the citizenship literature, nor by the Advisory Group. In fact, the Advisory Group did not focus on the concept of consumer or of risk to any large extent. It is interesting to note that they did describe individual *experiences* around being considered, as disabled people, a potential risk factor (eg. in terms of health and safety and protection) but they did not identify 'risk' as an important topic emerging from the data.

This chapter will also reflect on some of the literature concerning consumerism and risk. This literature was not discussed in Chapter Two since the focus for the research originated from a review of citizenship theory. The Advisory Group played an important role in the direction of the research. In particular, they advocated for interviewing non-welfare professionals as well as welfare professionals. By doing this, the concepts of consumer and risk emerged from their participation and direction of the research. These concepts may not have arisen without the influence of the Advisory Group. The consumer/ risk literature, therefore, is of particular importance and is thus included in this chapter.

This chapter will consider the elements of consumer and of risk within two separate sections.

Disabled people as consumers

Preliminary Group analysis

Consumer versus employee

In this chapter, I shall show that the concept of 'Consumer' that emerged from the data was of particular importance within the further systematic analysis. The preliminary group analysis, however, did not focus on consumer to the same extent. The following discussion highlights their comments. The Advisory Group found that there was a general lack of awareness of disability issues among the interviewees. In this way, they noted, although the professionals were encouraging disabled people as customers, they may not have developed their own knowledge/ understanding of disability issues. The Advisory Group referred to this as a contradiction between words and actions and suggested that what was said in the interviews was more of a PR exercise than a real commitment to empowering practices toward disabled people. They recognised that, although the interviewees saw disabled people as customers, they generally failed to see disabled people as potential employees. The following quotations exemplify many discussions within this area:

> *S: I think what came over was that both of them [2 architects] were paying lip service to the DDA and to the customers- it was a PR exercise more than anything. I mean, the one that says 'oh, our store is completely accessible' and then goes on to mention that if you work for us the canteen is upstairs and you can't get upstairs so we can't employ disabled people because they can't get to the canteen...but our building's accessible, completely.*

> *S: Ok, lets have a look, yes, he's [supermarket manager 2] at it again, [paraphrasing interview]' they have rights in our store, unless, of course, they work for us in which case they can't go to the canteen, they can't get up the stairs. We won't employ them because if they've got a false leg, they probably can't do the*

> *demanding work. Shop work is very demanding and tiring when you're on your feet all day...' so he's at it again and again. He's paying lip service to it.*
>
> *S: I've picked up a few bits. ' The personnel manager is the expert on that'- so really they [bank manager] kind of haven't been able to distinguish between disability rights for the customer and for their employees.*

This point was echoed in several discussions, particularly relating to data from managers in the retail and leisure industries. However, the group also noticed that within the interview data the same rhetoric was produced by welfare professionals who also considered service-users as customers. The following text from the Advisory Group shows this:

> *Researcher: ...and I said, 'what about disabled employees' and they didn't have any answers...*
> *C: Yes, I think though, that is partly because there's been a tendency for people , for instance in Social Services managers, to side, or to be told that they have to think of people as consumers of their services...rather than just to think of them as users or speak of them in any other way.....the idea that people are consumers strikes a chord with most professionals because directly or indirectly, they are catering for people as consumers, consumers of health, consumers of buildings, consumers of consumables!*

It is interesting to note that among the interviewees, there were no respondents who had an impairment themselves. In this way, the view of disabled people as consumers rather than employees was reinforced: it is likely to be the case that if a professional/ manager of a service needed alterations to a building/ employment practice in order to carry out their management duties, then the issue of providing facilities for disabled employees would have been more prominent.

The Advisory Group commented on their surprise that, given the introduction of the Disability Discrimination Act in 1995, employers' awareness of their obligations under the

Act was very limited. There seemed to be an apparent time lag between the Act coming into place and the appropriate knowledge being taken on board.

The Advisory Group mentioned in their discussion that in terms of being employed as disabled people, and in terms of participation in the market, often there was an element of 'cost', as one member commented:

> *K: I think another thing, of course, they say [supermarket manager, transport manager] sometimes about the cost. That's another thing.*
> *Researcher: Do you think that affects people's rights?*
> *K: The costing comes into nearly everything really when you work it out.*

The Advisory Group felt that it was mainly retail/ leisure managers, that is, ‘for-profit' business employees who talked about cost. The group did not notice any mention of cost by any of the welfare professionals.

Further Systematic Analysis

Consumer versus employee

The further systematic analysis developed the preliminary group analysis in that it found that professionals saw disabled people as potential customers, like other customers. These issues were particularly prominent in the further systematic analysis and were also seen to be dominated mainly by retail/ leisure managers, of which the following are only a few of very many examples:

> Art Gallery Manager: Unfortunately, we have to brand everyone as customers, but...yeh, they're all customers out there. And you know, we're always looking for new audiences as well. And, um, we'll try and do something for everyone.

> Restaurant Manager: We get the odd child [that] may have Downs Syndrome, something like that.
> Researcher: Right.
> Restaurant Manager: Um... so, y'know, we do have quite a variety. Well, we don't have that many to be honest with you. But they are valued customers at the end of the day.

> Restaurant Manager:... the whole... um, concept of good customer service is to treat the customer as Number 1.
> Researcher: Yeah.
> Restaurant Manager: And sorta like, cater for their needs. And within that, y'know, disabled people count as much as anybody else. So there's nothing specific.

> Supermarket Manager (1): Disabled people have needs in the market we serve. The store is designed with disabled people in mind because it is all on one level for customers.

There was also an awareness that disabled people were part of the market and that by valuing them as potential customers, there were also positive financial implications:

> Cinema Manager (1): ...the Disability Matters Ltd group suggested that they was a... significant.... monetary award... Sorry - significant revenue lost for businesses that do not cater for disabled people.
>
> Cinema Manager (2): So... yes, there is a commercial issue. And yes, there is money to be made but... in my opinion it's not being differentiated from anything else we do.
>
> Supermarket Manager (1): I see them first and foremost as a customer. Because I'm money-driven. I have to return capital expenditure on original investment.

Within this section I have shown that many of the interviewees considered disabled people to be consumers of services rather than potential employees. The quotes that I have included in this discussion provide evidence of this. However, it is important to note that these quotes were merely a few typical examples of the debate. The interview discussions, particularly among leisure/ retail managers, frequently referred to disabled people as customers in the market they served. There were too many examples to include in this discussion. The quotes chosen merely reflect the main points that were made. Within these discussions I was able to challenge the interviewees by asking the additional question, '...do you see disabled people as potential employees?' At this point most interviewees hesitated in their answer (again, reiterating the usefulness of verbatim transcription) and indicated that they did not, in general, see disabled people as potential employees. The evidence among the interviewees that disabled people were seen as consumers rather than employees was overwhelmingly consistent among most interviews with retail/ leisure managers and also among a large number of interviews with welfare professionals.

In this way, the interviewees are defining disabled people as a distinct sub-set of citizens, that is the consumer citizen. This explanation of the disabled citizen may not have been developed without this specific data (as suggested by the Advisory Group) and, therefore, the importance of this discussion cannot be underestimated.

It appears that the construction of citizens as consumers, as seen in the interview data, can be seen as a continuum of the inclusion/exclusion debates; that is, in this study, disabled people were seen to be included as consumers, but excluded as employees. Although the interviewees gave many examples of their commitment to customers, they tended to weigh up other factors (eg. risk, equal opportunities, cost versus benefit) when talking about disabled people as potential employees. They did not consider that disabled people had a right to work. However, in contrast, Laski argues that the state exists,

> ...in order that [its] citizens may realise in their lives the best of which they are capable. (Laski, 1938)

Blackburn continues this by saying that:

> Laski's work is an important acknowledgement of the reality that political citizenship does not operate in a economic vacuum. (Blackburn, 1993, p. 100)

In this way, he is suggesting that citizenship is not a construct purely around civil, political and social rights, but also includes economic rights for citizens as consumers and as employees.

The preliminary group analysis and the further systematic analysis, therefore, found that disabled people were seen as potential customers rather than potential employees. This analysis can be seen to develop some of the literature by suggesting that disabled people might be referred to as 'partial' citizens (see Lister, 1997, in reference to women), due to their relative exclusion from employment

Cost versus benefit

Within the further systematic analysis, the comments in the interviews followed the general view that disabled people should be 'accommodated' within the job market but that within this people should be realistic and that the cost should be weighed up against any benefits. This develops the analysis on costs by the Advisory Group. There were many comments on this issue which could be because many interviewees were very finance focused and therefore had to consider their profits. Furthermore, the view was also put forward by some interviewees that disabled people should not expect to have any *more* money spent on them than on other people. There were many discussions on this issue, of which the following are only a few examples:

> Art Gallery Manager: We've all done site access surveys and that sort of thing and, er, identified areas for improvement as and when funds become available. I mean, it all comes down to funding in the end and you have to make decisions. Y'know, are we talking about spending umpteen thousands on less than 1% of your visitors or actually would you have more visitors if you had it anyway?
>
> Art Gallery Manager: Takes time and money!
> Researcher: It does take time, doesn't it?
> Art Gallery Manager: To be honest, I mean if you look at the cost of the toilet that went in - that's talking about three or four years ago - er, total cost: 20 grand.
>
> Customer Services Manager (Bank): Um... but there's quite a cost involved [in adapting buildings]. And that's gotta be weighed up against the benefits.
>
> Age Concern Manager: But, er... I think automatic doors would be wonderful.
> Researcher: Right.
> Age Concern Manager: But I should think they'd be very expensive. I think that's the problem, really. Um, I mean... we want to do things here, we want to improve things. But we're not funded.
> Researcher: No.
> Age Concern Manager: We, y'know, at the end of the day have to balance the books.
>
> Contracts Manager, Health Services: We would obviously like to have slidin' doors wherever we can. Um... we've got them in the main areas but we've not got them, for example, in the maternity unit.
> Researcher: Right.
> Contracts Manager, Health Services: Er, really it's just money.

> Researcher: Yeah.
>
> Contracts Manager, Health Services: We're talkin' £40,000 to change some doorways.

In these examples, therefore, the interviewees are developing the concept of the disabled person as a consumer, but are also suggesting that other factors, such as cost, need to be considered. Although these extracts include interviewees who were *not* in retail/ leisure management, the majority of the discussion on this issue, and on the issue of disabled people as potential customers could be seen mainly among those interviewees who were managers of retail/ leisure services. It is interesting to note that these managers did not recognise that, not only would improvements in access assist people with impairments, but alterations could also greatly improve access for other groups of people such as parents with children and older people. In this way, by improving access, the potential increase of customers would be more than a fairly small percentage of disabled people.

The issue of 'cost versus benefit' has opened up an area that seems not to have been covered in the literature in relation to citizenship. In talking about citizenship, the focus has been around rights, the obligations of the state, and exclusion. The data in this study are suggesting that other factors are taken into account (such as cost) when bestowing citizenship status onto an individual, particularly the individual as consumer. This issue is pertinent for disabled people since the provision of access and of services involves a cost. This may not have been an issue considered in the 1950's definition of citizenship, since the focus was on 'class': the development of citizenship rights in terms of class was unlikely to constitute an element of 'cost'.

Within the literature on consumerism, it can be seen that, in general, consumers are required to 'earn' their right to consume through their inclusion in, and commitment to, the labour market. In Marxist terms, this can be seen as the necessity for a person to become a unit of production and also a commodity within the market, ie. they play a part in both creating the market and 'using' the market. However, Twine (1994) argues that:

> Market treatment of people as commodities threatens their standing as citizens. (p. 104)

This suggests that, in order to produce successful citizens, therefore, the state needs to play a part in enabling its citizens to be effective consumers, and this needs to be shown by its commitments to entitlements within a framework of social rights. This, therefore, relates the concept of consumer to the concept of citizenship in terms of defining the obligations of the state in enabling an individual to have citizenship rights and also consumer rights.

The element of 'social rights' plays a large part in the consumer debate because it represents provision and obligations of the state within a consumer market. Twine (1994) suggests that the state has a vital role to play in providing social rights:

> In the twentieth century, Marshall's three elements of citizenship must stand together: civil and political rights must be supported by social rights, otherwise the 'three-legged stool of citizenship' will be unbalanced. (Twine, 1994, p. 104)

By emphasising the interdependence of the three elements of citizenship- social, political, civil we can see the importance of market forces and state provision in the achievement of rights, particularly social rights:

> The element of social rights is essential to the emancipatory thrust of citizenship as it unchains people from their dependence on the vagaries of the labour market. (Twine, 1994, p. 104)

However, this requires a cost/ benefit analysis, ie. the cost of providing entitlements weighed against the benefit of individuals being included as citizens. This is reflected in the interview data with its focus on cost versus benefit. However, because of the nature of the sample the focus was more around cost versus benefit of including disabled people as potential customers, not the cost versus benefit of providing entitlements. The literature discusses disabled people as consumers of statutory services (social services, health services, benefits etc.) rather than consumers of leisure and retail services, ie. a welfare, rather than business approach. In this way, therefore, this study can develop some of the debates in the literature.

Following on from this, it can be seen that social rights requires a budgetary basis, administration and structure, which is generally administered under the obligations of the state. However, by focusing on social rights this has implications and creates an element of vulnerability for those receiving services. The development of the present study is proposing that disabled people were seen as *consumers* but not as potential *actors* in the society in which they were a part, that is, none of the interviewees considered disabled people as potential employees, for example. Barbalet (1988) suggests that:

> ... the nature of social rights, as those of consumers rather than actors, means that they are necessarily vulnerable. (Barbalet, 1988, p. 20)

and he concludes that:

> The logical relationship between different types of rights is connected with and in part reflects the social relations found in society at large. (p. 27)

In this way he is recognising that social rights also play a part in the treatment of disabled people in the consumer market.

Equal opportunities

In contrast to the preliminary group analysis, the further systematic analysis also noted the large amount of discussion on *equal opportunities* as an issue within the context of a professional discourse. There was discussion within the interviews concerning equal opportunities in relation to *employing* disabled people which seemed to generate some stereotypes about what disabled people *cannot* do, the emphasis being on a *functional* model of disability. This was particularly pertinent in terms of managers of retail/ leisure services, for example:

> Supermarket Manager (1): Customer service is a big part of our work but it probably would not be suitable for disabled people. Disabled people could do the IT and clerical work instead.

> Supermarket Manager (1): If I employed someone with a disability it would be difficult for them to get upstairs, but they would be able to work downstairs as the store is all on one level. It would, however be a problem because the restaurant is upstairs. I'm not sure how we would get round that.

In this way, assumptions were made that, firstly disability was seen in terms of physical impairment, and often mobility, implying lack of strength and fitness, and, secondly, employers were using assumptions about 'disability' as a justification for not employing somebody. This assumption constitutes 'disablist' practices and attitudes, including an implicit assumption that customers would not wish to have interaction with a disabled person.

Another reason some interviewees cited for having few disabled employees, was that disabled people do not actually apply for jobs. The following quotation by a supermarket manager and a restaurant manager exemplify this:

> Supermarket Manager (2): We do not have any staff with a disability at the moment. The jobs are very physically demanding, but there is no reason why they shouldn't apply. That may be the fault of their disability rather than our store because they think they will never get a job here. There are probably jobs they can do.

> Restaurant Manager: Um… I would have no problem in working with people that are disabled. Um, I think it's something that this industry as a whole needs to look at. The reason why there's not many people who are obviously disabled [who are] employed is because they don't apply.

However, one respondent suggested that the reason that disabled people are often not seen as potential employees is due to prejudice, such as:

> Newspaper Editor: If you have access… with the skills that we've got, if I've got 60 applicants for a job and I'm gonna look at all 60 without worrying about race or colour or disabilities…

> Researcher: Yeah.
>
> Newspaper Editor: ...I've got the potential of getting someone brilliant. If I'm gonna cut out 20 of those...
>
> Researcher: Yeah.
>
> Newspaper Editor: ...because of my prejudice, all I'm doing is robbing my own company...
>
> Researcher: Exactly.
>
> Newspaper Editor: ...of all possibility of an ideal worker.

This newspaper editor was particularly aware that a disabled person could represent to him potentially a very good employee. However, the insight of the newspaper editor was not representative of other interviewees. In general, the interview analysis implied that disabled people were discouraged from the job market due to assumptions, stereotypes and lack of positive action which were reflected in the data collected.

In terms of equal opportunities *policies*, in general, interviewees talked about policies in their organisation, but then some went on to say that they did not have anyone employed there who actually had an impairment. An Age Concern Manager stated that their 'door was open to anybody':

> Age Concern Manager: Um, well we do operate, as I've said, an equal opportunity policy.
>
> Researcher: Right,
>
> Age Concern Manager: There isn't anyone, I don't think, employed that I know about in this building anywhere, that would be classed as disabled. But certainly... certainly some of the volunteers.
>
> Researcher: Right.
>
> Age Concern Manager: Certainly the volunteers. Um, as for people coming in disabled... no, the door's open to anybody.

A teacher in a college for disabled young adults referred to their policies as a 'caring policy' in which anyone who had a particular impairment or illness would get special 'caring' assistance as this text shows:

> Teacher (College for Disabled Young Adults): Well, we've got staff that have disabilities here.
>
> Researcher: Right.
>
> Teacher (College for Disabled Young Adults): Um, and... er... I suppose that's a policy that we have- equal opportunities policies. ...And certainly when I developed - I developed a disability, I've got cataracts. And the college were particularly... caring about that. They employed an assistant for me..... So I suppose they do. They have a special caring policy.

Finally, in another interview, a cinema manager stated that equal opportunities was an issue that he was trying to address presently, but that he may need help to work through this issue, for example:

> Cinema Manager (1): Um... we are an equal opportunities employer.
>
> Researcher: Mmm.
>
> Cinema Manager (1): But... I as manager need to address the issue "How can we, at present - with our existing facilities - offer employment to... to anyone that has a disability of any kind?"
>
> Researcher: Yeah. Yeah.
>
> Cinema Manager (1): So... this is where I would need help. At some point.

Although it was seen that there were many examples of equal opportunities policies (particularly among the organisations of welfare professionals) , in practice, there were not many examples of the active *promotion* of disabled people as employees. In this way, the issue of equal opportunities was an important element in terms of addressing issues of citizenship in relation to disabled people as employment is seen to be an area where disabled people are not very visible.

This is particularly pertinent in relation to the introduction and progress of the Disability Discrimination Act (1995), where the rights of disabled people to be treated fairly in employment is a significant part of the Act. The Act implies that reducing discrimination in employment is a crucial element of gaining citizenship rights for disabled people. This is in contrast to the focus of many of the interviews where the disabled person is seen as *consumer*, not employee.

Providing for the majority

Another issue which emerged within the further systematic analysis was that of employers and managers providing services for the *majority*. This was an issue which was not noted by the Advisory Group. Within the further systematic analysis it was observed that, in general, many retail/ leisure managers felt that it was important to strike a balance between providing for disabled people and catering for everyone else eg.:

> Cinema Manager (1): So there's always going to be two sides of the coin and I think you have to strike the balance. And the problem is you're not going to please all the people all the time.
>
> Restaurant Manager: I think they have a right for someone to try to give them access. I think it would be impractical in lots of ways to... change buildings totally.
>
> Architect (1): I mean, it can be an expensive exercise...there are certain points where you might have to draw the line...if you cater for the minority, where exactly do you stop?

In this way, although disabled people were seen as consumers, managers were also considering the needs of other consumers within the market they served. These comments are typically resonant of other discussions on this issue, particularly with retail/ leisure managers.

Disabled people and consumers: developing the debate

Within the analysis of the interview data (particularly in the further systematic analysis), the concept of the disabled person as consumer has arisen. I would like to consider this concept further in the context of some of the literature around the consumer citizen.

During the 1990s the citizenship debate, in terms of market forces and economy was re-discovered and became popular. For example, the then prime minister, John Major produced a number of Charters which promoted the idea of the consumer with choices in the market:

> The theoretical citizen cherished by the Conservative government is not a member of any pressure group but rather a heroic lone consumer with time, money and information to back up his or her individual choices. (Pollitt, 1994, p. 11)

This approach views citizens as people not able to have collective power in conjunction with other citizens, but as individuals within the market. This reiterates the discussion expressed in the interviews that disabled people are individual consumers *in the same way* as other individual consumers. This view of the consumer also continues the individual focus of the Medical Model of disability. John Major's Citizens' Charter seems to add the dimension of 'consumer' to Marshall's tripartite theory of rights. In this way, the concept of 'consumer' can be added to the continuum of citizenship. The data in this study supports the literature around citizenship in terms of developing the concept of the consumer citizen.

The idea of the lone consumer can also be extended to encompass the need for personal empowerment within the market. Plant (1990) develops this and suggests that the ethos of consumerism has a base in the market economy in terms of market mechanisms being related to individual empowerment. He suggests that

> There is a case for considering a more complex model of empowerment, based upon the idea of citizenship rights as a complementary form of individual empowerment to that of the market. (Plant 1990, p. 3)

Plant is recognising Marshall 's emphasis on civil, political and social rights but also suggests that the market plays a part in terms of achieving those rights. By emphasising the role of the market, and the need to extend that role, he is suggesting that the individual consumer can be empowered. He implies that, as consumers, people are linked together by their need for empowerment, choice and advancement:

> There are a set of interests which we share in common, those to do with individual empowerment, choice and individual advancement. (Plant, 1990, p. 4)

In this way, the concept of consumer generated by the data can be seen to reinforce the more recent literature (Plant, 1990) in that it expands Marshall's dimensions of civil, political and social rights.

The emphasis on civil, political and social rights within the market, is also reinforced by M. Barnes (1997) who argues that the state has obligations and plays a role in *policing* the market to provide a safety net (eg. Welfare Benefits). She goes on to say that market forces can represent the freedom of the individual to choose but that choice is also affected by education, housing, economic development, health and other areas of policy, that is, individuals have a choice in the market but each person has a different starting point. The interview analysis, although promoting the disabled person as a consumer in the market, with relevant choices, does not emphasise the 'different starting points' that may affect different individuals. For example, it is only *recently* that disabled people have started to be considered as consumers in the Market and therefore they could be seen to have a different temporal starting point.

In terms of state provision, current UK Labour Party policy proposes that public services should be managed in the same way as private enterprises to maximise efficiency and attractiveness to consumers. This can be shown in the consumers/market force ethos that was introduced into the NHS, for example. In terms of Community Care, market forces also represent a clear purchaser/provider split, for example in health services, social services and other public services. The disadvantage of state provision, however is that it can create excessive dependence on the state and it can create an environment in which all individuals believe in their entitlements eg.:

> The belief in collective provision has tended to become a belief in uniform provision. Defining needs has become confused with meeting them. Provision has too often become paternalism. (Deakin and Wright, 1990, p. 2).

M. Barnes (1997) suggests that the user of a welfare service is therefore a quasi-consumer operating within a quasi-market (which doesn't include profit). Furthermore, this development into market forces for public services also links into the contract culture where contracts are negotiated with public, private and voluntary sector to create choice and control for the customer. It is interesting to note that the focus of the disabled person as consumer citizen within the interviews came mainly from profit-making organisations eg. leisure services, supermarkets, restaurants and banks rather than not-for-profit organisations. In this study, disabled people were seen as part of a wider society, not just as people receiving entitlements to state provided services. In this way, the data is expanding the focus in the Community Care literature, that sees disabled people as recipients of state provision, onto seeing disabled people as actors in a market of business and profit and confirming the importance of the revised sample suggested by the Advisory Group.

Market forces and economy, therefore, play a crucial part in the construct of the consumer citizen. Within a consumer market there is a strong emphasis on individual empowerment and choice as a 'right'. This can be equated with the concept of 'moral' rights (eg. freedom of choice, respect, dignity) as discussed by the Advisory Group. This is an area of rights neglected by Marshall (1950).

Although the preliminary group analysis did not highlight market forces as a crucial element within the analysis of the interviews, it has been shown that, within the further systematic analysis of the interviews and within the citizenship literature, the idea of the 'consumer' within the market has come to be very important. However, the data showed that, although disabled people are seen as potential customers, they are not usually seen as potential employees and in this way they experience exclusion. This adds to the previous chapter which put forward the view that disabled people are excluded due to attitudes and the perception of difference. This may reflect the differences in experiences and agendas of the two sets of people (ie. Advisory Group of disabled people and non-disabled managers of services), and shows how the focus on consumer dominated the professionals' discourse.

Some of the recent literature around Community Care and citizenship (M. Barnes, 1997) relates the concept of consumer to a context of the community and of community care policies. It can be seen that Community Care is an area which takes on board an element of defining individuals as consumers within a market. The Community Care Act (1990) itself is very 'customer-focused', with its shift from institutions to community bases and by its definition of service-users as customers. The philosophy of Community Care policies within a consumer/ customer framework emphasises the importance of individual responsibilities and the privatised consumption of services. This reiterates, Neo-liberal philosophy, for example, which sees consumers as individuals, implying that welfare is the responsibility of individuals rather than the state. It also implies that the 'community' is expected to provide for its own and that 'customers' can purchase their services within a framework of individual choice and control. Furthermore, this reiterates Marshall's distinction between the individual, state and community: Community Care Policies emphasise the obligations of the individual to themselves, rather than the obligations of the state to the individual. The root of this standpoint came from the idea that taxing people for welfare services they did not use was seen as an unacceptable restriction of freedom on citizens in how to spend their money. Community Care therefore developed the idea of the 'consumer' rather than the client/patient. Thus, the idea of citizenship as membership is re-defined since the focus of citizenship becomes the individual in the market rather than the individual as part of a group:

> The exercise of consumer choice is posited as the means through which individuals construct their own identities in a world in which such identities are no longer given through membership of a particular social class, nor are able to be derived from an

> occupation entered in early adulthood and left on retirement. (M. Barnes, 1997, p. 35).

The idea of having a choice also implies the ability to exit from the choices offered and to take custom elsewhere. However, it can be seen that frequently the services available are limited because of the lack of a plethora of alternatives. The recent legislation on Direct Payments (giving people money rather than services which was designed to give disabled people more choice and control over their care and mobility needs) for example, presents the idea of making choices in the market for disabled people, but again, the limitations still exist due to lack of availability of services. Added to this, the difficulty with seeing clients/ users as consumers arises when the ability to 'purchase' involves having the financial means to do so. Prior (1993, p.178) argues that people with mental health problems, for example, are disadvantaged within a consumerist society because, generally, they don't have the financial means to be consumers. This can also be seen with other groups of service-users, including disabled people.

By focusing on Community Care and choice in relation to the 'client' as consumer, the existing literature is focusing on only one area of the data: the data is also focused on the disabled person as a consumer in the wider market, rather than within the 'social rights' market of community care. However, it can be seen that in this way, the data develops the literature by highlighting the role of disabled people in the wider market.

Plant (1990) argues that the consumer needs choice and control but also needs to have a right to welfare provision:

> I believe that a politics of citizenship and rights is a vital ingredient of modern welfare provision and could provide a very important counterpart to the market-based consumerist approach adopted almost in its entirety by the present administration. (Plant, 1990, p. 32)

Developing the idea of choice further, some commentators (Ranson and Stewart, 1994, M. Barnes, 1997) argue that service users,

> Should be able to participate in determining priorities and should receive information not only about the availability of services, but also about their performance (M. Barnes, 1997, p. 164)

That is, in order for organisations and services to be accountable to their service users, there should be a shift in power around decision-making between service users and providers. M. Barnes suggests that this is particularly pertinent in the public domain. This shift in power is also part of the citizen jury model described by Stewart (1996) in relation to enhancing accountability to citizens as a whole, not just to users of community care. In this way, therefore, service users (ie. consumers of services) are given more choice and control as consumer citizens.

I would argue that a consumer approach does not need to be a 'counterpart' to a citizenship approach but can be part of a wider 'citizenship continuum' since this study has defined both as important.

In terms of the analysis of the interviews in the present study, therefore, both the preliminary group analysis and the further systematic analysis found that 'consumer' was an important concept. Both levels of analysis highlighted the issue of consumer versus employee, and this was also reiterated in some of the literature in relation to citizenship and economic rights (Blackburn, 1993).

I have therefore suggested that the concept of consumer was mainly prominent in the professionals' discourse. I would also argue for 'consumer' to have greater prominence within citizenship theories in a wider context. Although this chapter relates the concept of the consumer to the professionals' discourse, it was perhaps significant that the Advisory Group were keen to include retail/ leisure managers within the interviewees. By doing this, they were perhaps recognising that interviewing these people was particularly relevant to their experiences. In this way, they were showing the importance of their experience of being a consumer in their daily lives.

Consumer: Experiential synthesis

Although the concept of 'consumer' was a 'new' area that emerged particularly from the further systematic analysis of the interviews, the Advisory Group did not focus on the issue of consumer in terms of their *experiences* or *opinions*.

In a discussion about supermarkets, however, the following comments were made (all by people with learning difficulties):

> *D: They* [disabled people in a local supermarket] *were getting around all right in their wheelchairs and special adapted trolleys ....*
> *Researcher: ...do you think staff are helpful ?...with people with disabilities?*
> *D: Yeh, because, you see, there is a gate, plus a turnstile sort of thing...they had to get a special key to unlock it and lift it open...that was no problem.*
> *S: ...if you've got to ask someone and they've got to lift it, it really is not accessible is it?*
>
> *D: ...I saw a young lady, with her husband wheeling her, then they got their thing clamped onto the wheelchair, they asked the assistant by speaking over the mike, they got the key, pulled the barrier up, did what he wanted to do with shopping, with his wife, got through all right...*
> *Researcher: Do you think that's fair, that they have to get a key when everyone else can just go through?*
> *D: Well, not really, no. I mean that key's there...well it's supposed to try and stop the kids, but it doesn't- you know what little youngsters are like with crawling underneath...*
>
> *S: If you're in a wheelchair, can you reach all the shelves?*
> *D: Not all of them- But there is staff about. They've got them special things that are on wheels, plus the ladders. They can help you, you know.*

> *S: surely, accessibility is not about being helped? It's about being able to get things yourself, about being able to get in and out yourself. It's not about barriers that are out there which you then have to get someone to remove...get a key...*

These discussions show that some of the disabled people in the Advisory Group had experiences of being seen as 'different' customers. They confirmed that supermarkets, for example, were catering specifically for the needs of disabled people.

These quotes may give the indication that the researcher was prompting the respondent in relation to the accessibility of shops, ie. that I was leading the member of the group for certain answers. However, the extracts are merely an illustration of the wider discussion of the group around accessibility. Much of the prompting was intended to clarify points raised by people with learning difficulties in the discussion. The points had been suggested in previous discussion, but had been rather vague. In order to gain clarification and to make sure the people with learning difficulties understood the discussion, it was necessary at times to prompt for more clarification.

The issue of cost versus benefit, highlighted by the further systematic analysis resonated with some of the experiences of the members of the Advisory Group. Their experiences of cost versus benefit centred mainly on access, shown by these contributions, which exemplify other discussions:

> *S: I mean, it's not just wheelchairs, it's people with prams- it's all kinds of things. It would make sense but they can't seem to see the sense there because of the worry of how much it's going to cost.*
>
> *J: When the problem's* [eg. practical issues like getting on a bus] *brought to someone's notice though, they're very quick to defend the situation as it is and not want to look at doing anything about it as far as I see. It's going to cost these people. I suppose they realise that and that's only why they prefer things to stay as they are.*

> *M: I think it's the cost* [of the DDA] *they were worried about wasn't it?....new buildings...I think that's where it applies, doesn't it, new buildings have to be built in a certain way.*

They also talked about cost in relation to rights to services, as the following examples show:

> *N: I don't like it- resources and problems. The budget is reduced so we can't provide, its a fact of life. Its not about people's needs, its about what money you've got available at the end of the day- the whole breadth of services are affected and therefore we need to raise the criteria so those most in need get services.*

> *S: We shouldn't be asking if it's cost effective. Disabled people are human beings, not units of production.*

> *C: I think it's manifestly true that we do have rights but the argument that disabled people put forward is that we don't have as many rights and that we don't have the same degree of rights in some areas that we would have if we were not disabled people...mainly because of cost.*

These representative examples, therefore, are highlighting their experiences, which also confirm the conceptual development of cost versus benefit in the interviews.

In contrast to the large volume of comments on equal opportunities noted in the further systematic analysis, the members of the Advisory Group gave few experiences or opinions on this subject. They did, however, suggest that disabled people should be treated fairly and justly in relation to other people and should not be given any special favours, which are shown in the following texts:

> *B: My personal opinion is* [re. welfare benefits] *I would scrap them all and start from scratch. Those people needing them should be looked after to a proper standard and get an average wage, but I would make damn sure that those who wanted work could.*

> *N: The 3 % quota* [now discontinued since the DDA]...*employers don't take any notice. You also have to prove yourself twice as much to get a job in the first place, because there are a large number of able-bodied people possibly with the same qualifications and they will take those before they take you.*

In this way, the experiences and opinions of the Advisory Group confirmed some of the assumptions made by the interviewees. That is, employers often assume that disabled people could not do the same work as non-disabled people.

In general, therefore, the concept of 'consumer' generated by the interview analysis is resonant, to an extent, with the experiential level of the disabled people in the Advisory Group. The concept of consumer also develops some of the literature on citizenship, specifically in relation to disabled people. However, the further systematic analysis found the concept of the consumer to be particularly important, which contrasted with the focus by the Advisory Group. This could suggest that within the experiences and opinions of the disabled people in the Advisory Group, the concept of consumer was not particularly relevant in their day-to-day lives. It could also reflect the different priorities of disabled people and of professionals. That is, the identity of the disabled person as *consumer* was mainly the discourse of the professionals.

Articulating or experiencing risk?

Risk was a new concept generated by the analysis of the data. The interviewees often considered that the concept of 'risk' could be used as a reason for excluding disabled people from certain rights and from full participation in society. Risk, therefore, will be explored in the ensuing discussion as a potential factor in relation to citizenship.

Preliminary Group analysis

The Advisory Group did not identify Risk within their preliminary group analysis of the interviews although they confirmed the concept within the experiential synthesis. The term 'Risk' therefore, was generated mainly by the further systematic analysis of the interviews but the concept is also linked to other comments and discussion by the Advisory Group. Again, this difference may reflect the differing priorities and agendas of the two sets of people (Advisory Group and managers of services) and confirms the need for systematic analysis in research.

Further Systematic analysis

Within the further systematic analysis of the interviews 'risk' was identified as a 'new' factor in relation to citizenship ie. the rights of (in this case) disabled people were seen to be affected by the assessment of risk identified.

Risk tended to be discussed within the general areas of Health and Safety, Safety of others, and Protection.

Health and Safety

In general, the interviewees commented on their awareness and commitment to health and safety issues within their service/ organisation and often in relation to employees. They talked about keeping staff aware of health and safety issues such as protruding objects and being aware of problems with heavy lifting. In a similar way to the discussions concerning the disabled consumer, this was particularly shown in several interviews by managers of retail/ leisure services, as highlighted in the extracts below:

> Art Gallery Manager: It's having that awareness. And also keeping the staff fully aware. Going around and saying "Y'know, that's a bit sharp there. And that's a high level... and so on." It's getting people - everyone - aware of the situation. Health and safety as well. Y'know, being aware of problems.

> Cinema Manager (1): We have a fundamental problem in that we don't have a facility for anyone to go from ground floor level to staff level, projection suites...
> Researcher: Right, yeah.
> Cinema Manager (1): Er, with a lift. Because whilst we have a lift...
> Researcher: Yeah.
> Cinema Manager (1): ...that's designed to, um... transport films... I mean, that's a health and safety in itself - lifting a film with five reels in it.
> Researcher: Yes.

> Cinema Manager (1): Because generally, it's five to six cans or reels that will make up a film.
> Researcher: Right.
> Cinema Manager (1): And it's very, very heavy. So there is a safety-lifting issue on its own.
> Researcher: Right.

Another cinema manager continued this theme by commenting that health and safety is high on their agenda and that risk assessments took place within the cinema environment:

> Cinema Manager (2): I'm a manager of a cinema. Every year I have to assess any risk assessment issues.
> Researcher: Mmm.
> Cinema Manager (2): Any areas that we feel, um, could potentially be dangerous to a member of staff or a member of the public.
> Researcher: Right.
> Cinema Manager (2): And if it is a risk, we have to grade that risk.
> Researcher: Yeah.

Some also commented that within their health and safety procedures/ policies, they recognised the health and safety risks of having disabled customers. The following is one example of many around the issue of disabled people being seen as a potential fire hazard:

> Cinema Manager (1): ... as far as I'm aware they trained their staff in how to lift someone from a wheelchair into a seat.
> Researcher: Right.
> Cinema Manager (1): But there is an issue, you see, on a fire regulation issue.
> Researcher: Yes.
> Cinema Manager (1): I think if I could give any advice it'd be to approach a local fire authority on these. Because they see it as a risk to that person.

Safety of others

A second issue around the concept of risk was the 'safety of others'. Many interviewees showed their enthusiasm for having disabled people as customers but they also weighed up the 'cost versus benefit' of encouraging non-disabled customers. In this way, they were considering the safety of both disabled customers and non-disabled customers. An example of this comes from a cinema manager who talked about how guide dogs could be a hazard to non-disabled customers:

> Cinema Manager (1): Um, and certainly in the previous cinemas I've worked in we regularly had [blind] people coming in. But there's the issue of a dog sitting in an aisle.
> Researcher: Yes.
> Cinema Manager (1): And the safety of other patrons...

The safety of others was also seen to be significant in terms of potential disabled employees. The following contribution from an Art Gallery manager provides an interesting narrative on the subject:

> Art Gallery Manager [re. jobs] There are problems certainly if the job became available, say on the administrative side, in that we are in the building- as you've experienced coming in, there are steps down, steps up , um, unless we purpose build, I think it would be difficult to fulfil that wholeheartedly. Um, 'cos even in the main office there's a step in there. I think it would be very difficult to put something in without, y'know, causing a risk to everyone else who isn't chair-bound and so on, if that is the case.

Continuing this theme, in one interview, a transport manager talked about the way in which facilities for people with impairments (in this case, accessible toilets) had the effect of encouraging 'undesirables' [*sic*]:

> Transport Manager: Um, so it [the accessible toilet] was thought out well and purpose built. But really it was practicalities of it and the location that it's in. Um, unfortunately I think it would've caused problems. I think it would've. It would've been a haven for the undesirables [*sic*], if you like.

He stated this opinion, since the accessible toilets within the bus station had been used by drug users in his vicinity. He went on to explain that, as a result of these incidents, the toilets were closed at various times of the day to prevent such a situation happening again. In this way, however, by focusing on the issue of risk and safety of others, disabled people were denied certain accessible facilities at various times of the day. A recent newspaper article (Guardian, 2002) showed that this situation has also caused difficulties in other areas, (Derby and York are particularly identified). Within these areas accessible toilets were being closed for large periods of the day to reduce their use by drug users, homeless people and prostitutes. These examples reiterate the view that the rights of disabled people were affected by the assessment of risk identified.

The majority of the examples above concerning health and safety as a risk issue came from retail/ leisure managers (eg. cinema mangers, restaurant managers, art gallery managers, and transport managers). It is possible that in a customer/ business focused industry there would possibly be more need to minimise loss of custom and profits, and the possibility of lawsuits. In this way, these managers were more focused on how risk factors could influence their customers, than perhaps the welfare managers would be (who, in general, would not be profit based).

Protection

Finally, in the further systematic analysis of the interviews, the element of 'protection' in terms of risk was identified. Discussion also centred around the protection of service users in terms of their perceived level of understanding and competence. Again, the views highlighted in the following extracts are typical of several retail/ leisure managers:

Customer Services Manager (Bank): … actually opening an account isn't that much of a problem. But we do have to be satisfied that the person who's opening the account does understand the implications of having a card and a PIN.
Researcher: Right, right. Okay, that's fair enough really, isn't it?
Customer Services Manager (Bank): We're trying to protect them.
Researcher: And their money.
Customer Services Manager (Bank): And their money, yes.

Age Concern Manager: And I took a frame out to a lady this morning, only because I know her very well and I know she'll use it sensibly. She's had one before.
Researcher: Right, yeah.
Age Concern Manager: But you have to be very careful. Very careful.
Researcher: Mm, mm.
Age Concern Manager: We get requests to take people out in wheelchairs, but… we're not really.. we can do it. We can do it, ourselves. But we can't expect a volunteer to do it. We would have to offer them training to take somebody out in a wheelchair.
Researcher: Right. Right.
Age Concern Manager: I know some Age Concerns actually offer wheelchair training. And that's the other thing, though. Taking a wheelchair out - you've got to know how to do it, haven't you?
Researcher: Yeah. Yeah, sure. Is it affected by the kind of insurance, I mean - is that why you'd be cautious?
Age Concern Manager: Yes. I think so, yes. Definitely. Both for the volunteer and the person in the wheelchair.

Disabled people and risk: developing the debate

Continuing the focus on disabled people from the present study, the risks identified in the existing literature are around upsetting others and infringing on the rights of other members of the community due to meeting their 'protection' needs. This correlates particularly with the categories of safety of others and protection in the analysis of the interviews. Buck (1993) suggests that:

> The identification of the disabled citizen upsets the potential of other groups to achieve full citizenship. (Buck, 1993 p. 181)

This is suggesting that the protection of disabled people can be perceived as affecting the rights of other groups of people. In terms of this study, it can be seen that protection is concerned with reducing risks for both disabled people and also reducing risks for non-disabled people.

The literature on risk shows that the issues around the protection of disabled people can be broadened to exemplify the relationship between the 'powerful' and the 'powerless'. Furthermore, it suggests that the privileged (powerful) seek security and safety through their own protection:

> Security is no longer about the social, about the satisfaction of an "infinite" range of hope and fears, but is about the protection of privilege. (Culpitt,1992, p. 87-8)

This was also suggested by the experiences/ opinions of the Advisory Group in that they talked about professionals being over protective and 'knowing best'. The example was of a member of the group buying an electric reclining chair:

> *J: I've got en electric chair- one of these reclining chairs. I went to a shop to get it from, and when I tried it, when the lady saw me and how I have to use it to get out of it, she said, 'Oh, it's not good for you, you don't want that, you'll wreck it', or words to that effect, 'in a few weeks', so I says , 'well you know, it's the only way I can do it...and I would like one, sort of thing...'*

Another element of risk, related in the literature, is that of surveillance, which, again, is based on the perception of 'other' and can also be seen to be a protection of power:

> Risk in all its forms has shaped this transformation of 'surveillance'- i.e. the 'other' as excluded and dangerous. (Culpitt, 1992)

The element of surveillance can be seen to pose a professional 'gaze' such as in medical and social assessment in relation to the provision of welfare. Furthermore,

> What informed the medical 'gaze' was the necessity to create an arena for the exercise of professional power. (Culpitt, 1992, p. 87)

In terms of risk, it appears that now there is a need to protect the power of professionals, which, therefore shifts the medical gaze from 'surveillance' to risk. Although the analysis of the interviews drew out the issue of protection the aspect of surveillance in particular was not picked up as an issue. In this way, the literature is identifying an element of risk that was not significant in the data.

The literature also recognises the element of control as an aspect of issues of risk:

> ...while a possible sociology of risk involves the contemplation of overwhelming future threat it must also consider that risk involves aspects of control. (Culpitt, 1992, p. 12).

Control can be seen to emerge from an element of 'fear', that is, fear of losing control, authority and power. Not only this, but there is also a fear of the risk of 'contamination' and the need for individuals to protect themselves:

> The hurts and losses of others (the citizen-strangers) awaken compassion or revulsion and even fear. They are no longer used to generate a collective response to the risky nature of life but rather prove the new mandate that it is the solitary individual, and not the state, who must guard against risk. (Culpitt, 1992, p. 13-14)

This can often be seen in terms of responses to disabled people built on fear and revulsion; the fear of the unknown, and the fear that individuals are flawed and could pass on their flaws to others.

The literature around risk also suggests that protection is related to the protection of the *powerless* as well as the *powerful*. This can be seen in terms of social rights:

> The crisis now is how to protect the possibility of the social and not specifically how to protect professional 'space'... (Culpitt, 1992, p. 87)

In terms of the welfare state, there can be seen to be a dichotomy between providing protection for the 'vulnerable' and defending people's rights to being active citizens in terms of employment, for example and the right to take risks. This is reiterated in the interview data through discussions around health and safety and around competence. Hence, both the data in the present study and the literature around risk are talking about the protection of both the powerful and the powerless.

An aspect of the literature around risk that differed from the data in the present study, is that of risk in relation to community. The 'community' (which is made up of individuals) can also be seen to be an important element of citizenship. Culpitt, (1992, p. 8) identifies the issue of risk as important by saying that if the state is not identifying elements of risk then the community has a degree of vulnerability to do with the difference and diversity inherent in it. He talks about:

> ...the complex way in which risk is used to justify...exclusionary tactics, which morally stigmatise whole groups of people who have fallen outside the contractual arena... (Culpitt, 1992, p. 80)

Since, in asking professionals about their attitudes, the analysis of the interviews discovered that people identify risk as a factor in assessing to what extent they would exclude disabled people, it can also be seen that citizenship rights, exclusion and risk overlap to a large extent.

In terms of community, the exclusion of individuals, as citizens, by a community is shown to be affected by the risk they pose. Following on from this standpoint, risk is seen as being affected by the extent of 'difference' that is defined. Exclusion from a community can be affected by the extent to which someone is defined as 'different' and thus the perceived risks associated with that 'difference'. Foucault proposes that acting responsibly to otherness means,

> ...inevitably.....treating people as alike for the purposes of making consistent and defensible decisions about alternative courses of action. (Foucault, 1988b, p. 192)

This is implying that people make judgements about others based on the extent to which they are 'alike' or 'different'. Neo-liberalism talks about "the recognition of, and indeed tolerance of, difference" (Cooke, 1997, p. 280). Therefore, if judgements are based on levels and tolerance of difference, then there should also be an acceptance of diversity. However, to an extent the judgement of 'difference' may incorporate a judgement on degree of risk. This relates to the data in the previous section on difference/ equality; that is the definition of difference or equality affected a person's ability to become a member of a community, and thus a citizen. However, it is interesting that within the data concerning risk, the notion of risk being used as an exclusionary tactic within a membership of a community was not defined in these terms.

Another way in which the literature defines risk in relation to community is in the arena of the marketplace. Culpitt (1992) states:

> The depiction of risk as a market-place 'reality' is, quintessentially, a masculine view of the world. (Culpitt, 1992, p. 78)

This relates to Lister's (1997) division of public/ private, that is, traditionally, the market-place has been seen as the 'public' space of men being based mainly on employment. The 'welfare client' was seen as a new role and initially women were its "original and paradigmatic subjects" (Thompson, 1987, p. 104-6). This, therefore continues from the discussion about 'otherness': men were seen as 'the norm' while women were seen as 'other'; men were seen as public while women were seen as 'private'; men were seen as providers while women were seen as subjects of welfare. This can also be related to disabled people and non-disabled people in the present study in that disabled people are positioned as 'other'. This is therefore related to the element of 'risk' posed by being 'other' because judgement is made on a person's 'difference'.

The concept of difference and the concept of risk are therefore linked within the context of community in that the decision to include an individual in a community can be based on the extent to which they are different, and thus, the extent to which they pose a risk to the rest of the community. In this way, therefore, difference and risk can be seen as essential elements of a citizenship continuum since they relate to inclusion/ exclusion as discussed in the citizenship literature (see Chapter One) around citizenship.

In terms of the analysis of the interviews in the present study, it is mainly within the further systematic analysis that risk was seen as a concept. Although the Advisory Group talked about their experiences and opinions around risk, they did not highlight it in the interviews. The further systematic analysis highlights issues of health and safety, safety of others, and protection within a framework of risk. This develops some of the literature on risk and community by applying it to disability and citizenship. It was also prominent as the discourse of the professionals within this study.

Risk: Experiential synthesis

Although the Advisory Group did not consider risk as a concept in their analysis of the interviews the *experiential level* of the Advisory Group, echoes some of the issues raised by the systematic analysis of the data. This was seen particularly in the Advisory Group members' experiences around health and safety (an issue of importance in the interviews), upsetting others, and insurance (related to the issues of safety of others and of protection in the interviews).

Health risks:

In terms of health risks, one member of the group described the experience of a friend who was a wheelchair user when attempting to access a taxi service.

> *D: ...taxis won't let him [his friend] in, that carry wheelchairs, because they think he's got AIDS and he hasn't.*
> *Researcher: so they won't let him in a taxi?*
> *D: No they won't...only certain taxis, I won't mention it by name...*
> *S: and this is because they think he's got AIDS?*
> *D: yes*
> *S: and yet, if he's got AIDS what would being in a taxi...how would it endanger them? I don't quite understand that.*
> *D: I don't know. He's wrote a letter, he's phoned up [the local Daily Mail] as well and he's wrote to them but I don't know if he's got anywhere. I don't know.*

This exemplifies the fear of *contamination* as a risk factor. The opinions/ experiences of the Advisory Group, therefore, reiterates the suggestions in the literature that risk can be eliminated by reducing other people's fear. Another risk factor, in terms of health was the fear that a person's impairment would cause them to not be able to control their bodily functions and create embarrassment and awkwardness for someone else as the previous text continues (in relation to the taxi driver):

> *D: I know it should be stopped* [refusing to let someone in a taxi] *but I think it's their attitude...they're saying we can't carry this person, we can't carry that person because they pee or they wet themselves or they're sick in the back of the seat.*

These examples show that the potential risk factor of health issues focuses mainly on a person's ignorance and lack of awareness of disability issues. They are suggesting that often attitudes concerning risk involve an individual making presumptions about perceiving disability within a medical/ functional model.

Safety:

In terms of safety, the experiences of the Advisory Group centred around aspects of transport, leisure and employment. They suggested that often decisions were made by others (eg. managers of services) about risks, or potential risks to their safety. One member described his experience of public transport, and the assumptions from the bus driver in terms of having a disabled person as a passenger:

> *J: ...on public transport I've had quite an embarrassing time....we were in London waiting to cross from the centre out to, um Hampstead Heath, I think it was and this bus came along which was going in that direction...There were 3 little steps...and I got onto the 2nd step and the driver saw me and he said 'I can't allow you on, I'm sorry, you'd be a danger, sort of thing...'............anyway, I wrote a letter to the company and got a nice letter back, but they stuck up for the driver.*

The Advisory Group commented on experiences that they (and other disabled people they knew) had encountered within leisure services, such as cinemas and fairgrounds. Yet again, the decisions of the managers of the service showed that they assessed risk on the basis of safety issues, as the following recollection indicates:

> *M: I was thinking that, there was a documentary on about Blackpool Pleasure Beach. They stopped all the rides going didn't they. They* [people with learning difficulties] *weren't allowed on it till after dark or something.*
> *Researcher: Is that right? I didn't see it but I heard people talk about it.*

> *M: They could come back when the park was closed and use the rides then, but they couldn't actually use it.*
> *Researcher: Really?*
> *M: ...but they couldn't let them use it.*
> *Researcher: What was the outcome of that, then?*
> *M: They eventually moved away I think to avoid antagonising people too much because people were waiting to get on the ride...so I think they decided it was a wise decision to move on.*
> *J: They disrupted the ride for quite a while though, didn't they? I think the management could have said, 'look get them on quick, sort of thing, and we can keep going', but there could have been accidents. I've seen very bad disabled people on the big rides in Hull, you know, Hull fair, you know...people with no control over their body movements and it must have been painful for them, you know what I mean? To some degree, you can't go everywhere, sort of thing.*

> *R: They refused, his son has learning difficulties, and they refused to let him in* [to the cinema] *saying he was a fire hazard!*
> *J: Yeh, that's what they said to me, yeh.*
> *R: I mean, we're all going to burst into flames aren't we?*
> *S: ...spontaneously combust!*
> *R: Yeh!*

Finally, another member of the group cited *safety* as an issue in terms of being unable to obtain employment. He felt that employers reasoned that a disabled person would pose a risk in terms of safety and would, therefore use this as an excuse to exclude disabled people from employment:

> *J: I think it's very difficult for the disabled to get employment. It was when I was young. I got one or two interviews, sort of thing, but then they sent you away hopeful, sort of thing, but then you get the letter for whatever reason.*
> *Researcher: Yeh, yeh, why do you think that is?*
> *J: A lot of the things for so many interviews is safety grounds.*
> *Researcher: really?*

> *J: Yeh, safety comes into it quite a lot.*

Upsetting others:

Not only did the Advisory Group comment on their experiences concerning risk and protection, but they also suggested that protection was seen in terms of not upsetting others, that is, the protection of others from being *offended* by a disabled person. This comment exemplifies many other comments on this issue:

> *K: ...and there's also that other problem, sometimes these travel companies turn round and, 'oh no, you're not going to come on our bus because the only thing is, you will upset other people.'*

This correlates with the comments on health risks- it was inferred that, by being in contact with a disabled person, there could be an element of 'contamination', which would threaten and upset others.

Insurance:

The Advisory Group also discussed their experiences of accessing insurance policies, stating that they often had to pay more for the same policy as a non-disabled person, as this typical comment indicates:

> *K: ....disabled people are classed as an insurance risk*
> *S:...and a fire hazard!*

Again, in this way, disabled people are seen as a potential risk in terms of insurance and insurance claims. This person continued his comments by suggesting that professionals were wary of including disabled people in case any mistakes were made:

> *J: Yeh, they [employers] take a chance, sort of thing. I don't know if it's very sensible but you should give the disabled person, or whatever, a chance, but if there*

> *seems a loaded die against them could they do a disclaimer, sort of thing, so that, if anything drastic goes wrong...?*
>
> *Researcher: We're not responsible?*
>
> *J: Yeh, They like to go down the path that is well trodden sort of thing. They don't want to make a mistake.*

These examples highlight the way in which the exclusion of disabled people is justified by notions of risk. Furthermore, this shows how professionals legitimate their disablist attitudes and practices.

Professionals' discourse: Disabled people as consumers/ Articulating or experiencing risk?

Some conclusions

In this chapter I have suggested that the emerging concept of consumer is of particular importance to the notion of the disabled person as citizen. It has been suggested that disabled people are prevented from participating beyond the level of a consumer due, in some way, to the potential risk they pose. The debate highlights a need to investigate further the intricacies of the consumer citizen, in particular in terms of its relevance to disabled people.

Within the concept of consumer, both the preliminary group analysis and the further systematic analysis highlighted the elements of consumer versus employee, cost versus benefit, equal opportunities and providing for the majority. However, the further systematic analysis uncovered a larger number of discussions and examples than the preliminary group analysis.

In terms of the concept of risk, this was almost solely generated by the further systematic analysis of the interviews, rather than the preliminary group analysis. The further systematic analysis showed that the most significant element of risk was that of protection; that is a professional's need to protect disabled people (and other consumers) from risk. This was exemplified by a large number of discussions on risk in relation to protection. Within the experiential synthesis, the Advisory Group highlighted their own experiences of risk, particularly around health risks, safety, upsetting others and insurance. In this way, the concept of risk had meaning for the lived experiences of disabled people.

'Risk' seems to be a concept that has not been as fully developed as the concept of Consumer in this study. This concept, therefore, could constitute a future area of research to explore the extent to which 'risk' is, in fact, a significant factor in relation to the consumer, as compared with other factors. Further research could relate the concept of risk to a theory around the consumer in relation to disabled people.

The importance of the concept of consumer and of its related concept, risk, is in the way it adds to the understanding of citizenship theories: the data are suggesting that the interviewees saw disabled people as potential consumer citizens in the market they serve. However, they did not see disabled people as potential employees, in part due to the perceived risk they posed. In this way, the data are defining disabled people as a distinct sub-set of citizens, that is, as consumer citizens. This explanation of the disabled citizen may not have been developed without this specific data. In this way, the data demonstrates significant connections and explanations that perhaps have not been considered before.

This chapter, therefore, shows how the findings of the research have helped to progress the debates around the concept of citizenship. It has further shown how attitudes have an *impact* on a disabled person's participation in the employment market and also that risk is used to justify disabled people's exclusion. The use of the concept of risk, therefore can be seen as a justification by professionals for exclusionary practices based on disability; that is, disablism. It is to this disablism that I turn in the concluding chapter which is to follow.

CHAPTER 6: CONCLUSION

Different voices

This thesis attempted to address issues of disability and citizenship. It was suggested by the literature (Chapter One) that citizenship very much focused around civil, political and social rights and the obligations of the state (Marshall, 1950). Some later literature also suggested that citizenship addressed issues of exclusion (Lister, 1997). By focusing on the attitudes of professionals to disabled people, the research in this study was addressing the questions: to what extent were disabled people perceived as citizens and to what extent did this resonate with the citizenship literature? The analytical process, which was complex, incorporated an experiential synthesis, which considered the concepts generated in the data in relation to the daily lives of disabled people. In this way, therefore, the concepts generated, which developed citizenship theories, were explored by using the existing literature, the two levels of analysis of the data and the experience/ opinions of the Advisory Group.

The concepts generated through the analytical process, and described in Chapters Three, Four and Five highlighted the importance of the different voices in this study. The discussion of the academic discourse (Chapter Three) showed how the concept of 'citizenship' in academic literature (Marshall 1950, Lister 1997) had reappeared in this study. However, within a citizenship framework, the focus on rights was developed to include the issue of 'moral' rights and the focus on exclusion expanded issues of visibility, barriers and consultation, which were particularly relevant to disabled people. The discourse of the academic, therefore, developed existing theory. The importance of this is the way in which the citizenship model was specifically applied to the position of disabled people.

In contrast, Chapter Four, which highlighted the Advisory Group discourse, showed how attitudes played an important role in the perceived citizenship of disabled people. This applied the theme of attitudes added by the Advisory Group in the methodological process. It is likely that this concept would not have been as prominent, had it not been for the emancipatory nature of the methodology. By redirecting the nature of enquiry from citizenship to attitudes, the Advisory Group added to the direction of the research. By utilising the Advisory Group within the analytical process, their priorities were, again, heard and reinforced. The voices of the disabled people in the Advisory Group, therefore were particularly important in the development of this concept. The experiential synthesis showed that the concept of attitudes also resonated with the lived experiences of disabled people.

Within the discussion around 'difference versus equality' in Chapter Four it was seen that attitudes toward disabled people could be affected by the notion of disabled people being seen as 'different'. Discussion arose over whether disabled people were 'equal' and therefore should be treated in the same way as everyone else, or whether they were 'different' and should thus have different facilities and help. This debate was important in that it applied the element of difference to disabled people. It expanded on the debate by Lister (1997) that highlights the same dichotomy around citizenship and women. The Advisory Group's voices were, again, prominent in the experiential synthesis in this section. They talked of their experiences of integrated and segregated education facilities and showed how the difference/ equality debate was relevant to their daily lives. Again the concept of difference was made more prominent by the voices of the Advisory Group, thus highlighting the importance of the emancipatory nature of this study.

Within Chapter Five, the concept of the disabled person as consumer was developed. Again, the significance of this concept was affected by the emancipatory nature of the methodology. As described in Chapter Three, the Advisory Group specifically requested that the interviews should include people who worked outside welfare services, such as restaurant managers, supermarket managers and transport managers. In the discussion, these people were generally referred to as retail/ leisure managers. The discussion in

Chapter Five showed how the development of the disabled person as consumer was particularly prominent among these retail/ leisure managers. In this way, this concept may not have been developed if the process of the research had not included the utilisation of an Advisory Group to guide the research.

The concept of consumer was mainly prominent in the discourse of the professionals and it arose specifically from the further systematic analysis of the interview data, rather than the preliminary analysis by the Advisory Group. In this way, the voices of the professionals played a prominent role. The concept of the consumer also expanded on some of the citizenship literature. The literature discussed in Chapter Five was centred mainly on disabled people as consumers in relation to welfare services. The way in which the concept was developed in this study showed how it was also relevant in a wider arena, that is the 'for profit' industries, in this case, leisure and retail. Although this study focused on disabled people, the concept of the 'different' individual as consumer in the wider market has potential for further study. The discussion also suggested that disabled people were being seen as 'partial' citizens; that is, they were seen as consumers, but not as potential actors in their society. This study particularly highlighted employment as an area in which disabled people were not visible.

The professionals' discourse also expanded on the notion of 'risk' as an important factor in relation to a disabled person's access to employment. The professionals were articulating risk as a potential reason for the exclusion of disabled people. The notion of 'risk' was not identified by the Advisory Group within their analytical process, but they did confirm within the experiential synthesis, that they had often been perceived as a potential risk factor. This suggests that, although this arose from the voice of the professionals, the concept of risk, did in fact resonate with the daily experiences of disabled people.

This thesis, therefore, has highlighted the importance of different voices: the academic voice, the Advisory Group's voice and the professionals' voice. It has also highlighted the voice of myself as the researcher. My main role was to provide the systematic analysis of the data and to develop the theoretical concepts. The importance of the systematic analysis was particularly shown in Chapter Five, for example, where the process identified the concept of 'risk'. The Advisory Group had not discovered this concept in their preliminary analysis. In this way this concept would not have been noted without the voice of the researcher. My voice, as a researcher, added to the voices of the academics, the Advisory Group and the professionals. Each voice had an influence over the development of specific concepts and played an important role. The study may not have developed in the directions it took if all four voices were not considered. The Advisory Group in this study played a particularly crucial role in that it guided the process of the research, influencing the choice of interviewees and the focus of enquiry, which, consequently, affected the development of the concepts.

This thesis has specifically developed the theory of citizenship by confirming the traditional model of citizenship and also by adding the new concepts of 'attitudes' and 'consumer' to the debate. It has also shown how a citizenship model can be specifically applied to disabled people. In this way, the study has expanded on the existing literature and suggests areas for future research.

The conclusion chapter, therefore, will draw together these strands. First, I shall address the theory of citizenship in relation to disability, drawing on the outcomes of the analytical process. In this section I shall be asking: within this research, to what extent were disabled people perceived as citizens and how does this develop our understanding of the theories of citizenship? I shall also show how this study has highlighted and explored issues concerning the prevalence of disablism. Secondly, I shall refer to the process of the methodology and discuss the extent to which it was successful, the extent to which it was emancipatory, and some of the issues that arose from undertaking research in this way. Finally, I shall discuss how this research could have implications for policy and practice, drawing on recent legislation and policy developments since the fieldwork was undertaken.

To what extent are disabled people perceived as citizens?

This research used theories of citizenship in order to research the attitudes of professionals in relation to disabled people. I would like to briefly discuss whether, as a result of this study, theories of citizenship are useful in research relating to disabled people, how this study has developed some of the theories of citizenship, and to propose an answer to the question, to what extent are disabled people perceived as citizens? I shall also show how these perceptions are related to disablism.

It can be seen that the analysis of the data in the present study generated the concepts of moral rights, attitudes, difference, consumer, and risk. The following diagram (Fig. 7) summarises these concepts and shows how these concepts can add to the theories of citizenship.

Figure 7: Developing Citizenship

Academic discourse

Citizenship
[Development of
traditional model]
- Rights – adding 'moral
rights
- Exclusion- adding:
    - visibility
    - barriers
    - consultation
- Obligations of state
[literature]

Advisory Group discourse

Attitudes
['New' concept]
Including:
- Lack of awareness
- Language
- Experience affecting attitudes
- Changing attitudes
- Medical Model of disability
- Sympathy
- Disability a 'problem'

Difference
['New' concept]
Including:
- Difference
- Equality
- Social Model of disability

Professionals' discourse

Consumer
['New' concept]
Including:
- Consumer versus Employee
- Cost versus benefit
- Equal opportunities
- Providing for the majority

Risk
['New' concept]
Including:
- Health and safety
- Safety of others
- Protection

This diagram summarises the discussions in chapters 3, 4 and 5. I have suggested that the concepts generated as a result of the analytical process should be added to theory on citizenship because they identified other areas that exclude disabled people from being active citizens which had previously been unexplored within the citizenship literature. The analysis of the data in this study showed that disabled people were perceived as citizens to some extent, but that the definition of a citizen included aspects beyond the realm of rights, obligations and inclusion. In this way, by undertaking research around disability, the concept of citizenship can be explored and developed.

From the analysis of the data and the process of reflecting on the Advisory Group's experiences, it can be shown that the Advisory Group spoke more about concepts of attitudes and difference and the interviewees talked more about the concepts of consumer and risk. In this study it was shown that attitudes arise due to a notion of difference and that seeing someone as a consumer (and not as an employee) is related to issues of risk. It has also been shown that the priorities and experiences of the Advisory Group suggested that attitudes were used as a basis for exclusion and for the interviewees, the notion of risk was used as a basis for exclusion (ie. from employment).

It can be seen that the focus on rights and exclusion seen in the interview data *reinforced* the established theory of citizenship as exemplified by Marshall (1950). The four other concepts (attitudes, consumer, difference, risk) which were generated by the analysis of the interviews can be seen to have *developed* the literature on citizenship. The experiential synthesis, with the Advisory Group's opinions and experiences, confirmed that these concepts are also of importance to disabled people.

I have suggested in Figure 7 that the concepts of difference and of risk can be seen as sub-categories of the concept of attitudes and of consumer. This is due to the difference in the amount of data produced for each concept: the concepts of attitudes and consumer were clearly generated by both myself and the Advisory Group and were shown to have substantial relevance to disabled people and citizenship. The data on difference and on risk, on the other hand, were shown to be less substantially discussed and the connections in relation to disabled people and citizenship was not as strong. However, I would suggest that this was mainly due to the constraints around time and resources. That is, given more time, the issues of difference and of risk would have been discussed more fully.

The Advisory Group were clearly prioritising the concepts of attitudes and of consumer and discussion around these areas was far reaching and in depth. They suggested that the issue of difference was clearly related to attitudes and that risk had particular relevance to consumer. I would therefore suggest that the concepts of difference and risk have potential for future research, but for now, I would acknowledge their importance as elements of the more dominant concepts of attitudes and of consumer in this study.

Within this research, I developed an interpretivist analysis (Mason, 1996) in that I made an attempt to,

> ...understand everyday or lay interpretations as well as supplying social science interpretations and to move from these towards an explanation. (Mason, 1996, p. 140).

Furthermore, I developed a theory of citizenship as a result of data generation and a rigorous analysis process. I have also shown how the analytical process in this study was able to develop a set of issues which were central to a developing body of theory. The generalisations made, therefore, are theoretical generalisations, rather than empirical generalisations as appropriate for more qualitative research.

As mentioned, the research in the present study can be seen to *reinforce* the theories of citizenship as exemplified by Marshall (1950), in terms of generating the categories of rights, and of exclusion. It has also *developed* citizenship theories by generating the four concepts of attitudes, consumer, difference and risk. This suggests that Marshall's theory of citizenship may not be adequate to explain the experiences and the perception of disabled people in present day society.

The concepts generated, very much consolidate the ethos of the Social Model of disability in that, the Social Model argues that disabled people experience difficulties to a large extent due to outside factors such as lack of access to the built environment and negative attitudes of others, rather than their difficulties being mainly due to their impairment. The negative attitudes disabled people experience could also be referred to as disablism. By highlighting *attitudes* in this study, it has been shown that the existence of disablism may often affect an individual's perception of a disabled person as a citizen.

This study has highlighted *attitudes* as an exclusionary force. However, it has shown that, as *consumers*, disabled people may often have more of their needs met. The interviewees were keen to point out the ways in which they valued disabled people as potential customers and that they had altered their premises in order to encourage the disabled consumer. They also showed that, since they valued disabled people as potential customers, they had developed positive attitudes to disabled people. In this way, the interviewees had unwittingly become aware of some of the elements of the Social Model of disability although they may not explicitly recognise and articulate it as such. It was also interesting that the perception of disabled people as consumers was particularly emphasised amongst the retail/ leisure managers. The welfare professionals, on the other hand, did not define disabled people in these terms as much. The professionals interviewed, generally did not see disabled people as potential employees, and this suggests that they did not see disabled people as equal citizens. It can, therefore, be said that, although the concept of the 'consumer citizen' is useful in terms of its status and practice, it may, however, act as an exclusionary concept by defining categories of people as consumers rather than as equal citizens: the consumer status may not be considered full citizenship status. Hence, in Chapter Five I referred to the status of the disabled person as consumer as 'partial citizen' (Lister, 1997).

Added to this, the concept of difference can be used to propose an expansion of the Social Model of disability into a *Social Model of difference*. The analysis of the data in this study has suggested that disabled people were treated differently because the attitudes towards them were based on them being seen as 'different'. The interviewees highlighted the debate around whether disabled people were different and therefore should be given 'special' services or whether they were equal and thus should adapt to the services that 'non-different' people use. There was no general consensus in the study as to which viewpoint was more useful. The Social Model of disability perhaps consolidates both views: it does not deny that disabled people are 'different' due to their impairment, but it does suggest that the environment in which they live could be adapted to accommodate their needs so that they can live 'equal' lives.

The findings around 'difference' have opened up the debate on difference. They showed that the attitudes of professionals were influenced by the way in which disabled people were perceived as 'different', rather than being influenced by disabled people being seen as 'impaired'. The aspect of difference was particularly prominent in this study and evidenced well. The discussion in Chapter Four illustrated some of the discussions on difference. However, it is important to note that there were many other examples on this debate within the interview data that could not be included in this thesis due to the limitation on words. The evidence for 'difference' as a significant area of this research was high. The proposal of a social model of difference can be seen as a construct on which to place these findings. I have shown that the oppression of disabled people is due, in part, to attitudes toward them as people who are 'different' and I have also shown that the literature around women and citizenship (Lister, 1997) reiterates this view. The construct of a social model of difference, therefore, has developed directly as a result of the findings of this study and by reflecting on other literature. I have argued, therefore, that if the issue is around 'difference' rather than 'disability', then a Social Model of 'difference' could be useful in explaining the experiences of other 'different' groups of people, such as women, black people, and gay and lesbian people. That is, these groups of people (who are seen as 'different') are hindered by outside factors, such as the built environment, and most importantly, by attitudes.

Sarvasy and Siim (1994) talk about a 'feminist pluralistic notion of citizenship', that is, accepting differences between women and the multiple identities of women. Such a notion therefore recognises differences in the level of participation of women as citizens. This also relates to disabled people. In posing the question: to what extent are disabled people viewed as citizens, the present study has indicated that the perception of disabled people by professionals is as consumers rather than employees. This suggests one level of participation as citizens. However, quite clearly, many disabled people are involved in other levels of participation. Furthermore, there is a high level of diversity within the group known as 'disabled people'.

Some authors of disability texts (Oliver 1996, Finkelstein and Stuart, 1996, Morris, 1993) suggest that it is the responsibility of the Disability Movement to promote the value of difference for disabled people. Finkelstein and Stuart (1996) argue for this:

> It requires the transformation of a disabling culture, which is captured and entrenched in a health and welfare approach to disability, into an egalitarian culture which celebrates the validity of differing lifestyles. It is precisely this need to counter the prevailing culture that has motivated the UK disability movement to create its own celebration of difference in the form of a 'disability culture'. (p. 176).

Oliver (1996) suggests that disability equality training is an important mechanism for educating people in terms of the acceptance of difference. The 'old' view of integration, he states, is that people who are different should be accepted and tolerated because it is not their fault they are different, that is, it is a personal tragedy. He goes onto say that the 'new' view of integration is underpinned by the 'politics of personal identity' (Oliver, 1996, p. 89) and the demand that difference should be valued and celebrated. A person with a physical impairment or a learning difficulty, according to Mullard (2002), 'has to be treated differently only in the context that difference is a commitment to the rights of the individual.' (p. 15) In this way, difference is seen as a positive aspect of an individual. Morris (1993) also sees difference in a positive light and suggests that individuals who are different can influence other individuals into developing differing perspectives:

> Physical disability and illness are an important part of human experience. The non-disabled world may wish to try to ignore this and to react to physical difference by treating us as if we are not quite human, but we must recognise that our difference is both an essential part of human experience, and, given the chance, can create important and different ways of looking at things. (p. 106).

In this way, therefore, this research has highlighted the concept of difference. The findings of the analysis process showed that disabled people were seen as different and therefore were treated differently (Chapter Four). By opening up the debate, the focus on difference can be applied to other groups of people identified as 'different'. As a result of this research, therefore, it is useful to acknowledge Oliver (1996), Morris (1993) and Lister (1997) who all argue that difference should be celebrated and valued. A commitment to the *value* of difference, therefore, would positively influence attitudes and practices relating to 'different' individuals. A model focusing on a positive notion of diversity, therefore, highlights the way in which 'different' individuals are perceived and also suggests that difference should be accommodated and valued.

This study found that the attitudes of professionals were influenced by the way in which they perceived disabled people as 'different'. I would suggest that one of the important features of this study has been the focus on attitudes as a priority for research in relation to disability. As mentioned earlier, within the preparation of the Advisory Group, one member commented:

> *C: Research on attitudes is inherently harder than research on rights. That's why people just look at rights.*

Although the attitudes of the professionals were open to interpretation since there was no record of non-verbal communication, inferences or psychological testing, it was a useful starting point to open up the debate around attitudes and the concept of difference in relation to disabled people. Since a large amount of literature in relation to disabled people was focused on rights (particularly on the need to obtain civil rights through the Disability Discrimination Act (1995)) the continuous reflection on attitudes prompted by the Advisory Group perhaps demonstrates the importance of including the experiential synthesis of disabled people as part of the research process.

This study was also useful in that it was able to consolidate the focus of attitudes within a framework of citizenship theories: that is, it was suggested that the attitudes of others towards disabled people could affect their ability to achieve citizenship status. Although studying attitudes is possibly harder than studying rights, I have shown that the two concepts are not, in fact mutually exclusive, and that issues of rights within the concept of citizenship are often influenced and developed by issues related to attitudes. Since the Disability Discrimination Act (1995) was used as a heuristic device for exploring professionals' attitudes to disabled people, I would argue that the rights granted in legislation are slowly beginning to influence the perceptions of others to disabled people. This thesis showed that views of disabled people have moved on from them being perceived as passive recipients of services, to becoming viewed as consumers in a wider market. It will be interesting to track the development of attitudes and citizenship in future years, when the Disability Discrimination Act has become more widely used, understood and enforced.

Within the analysis, I included both academic synthesis (relevant literature) and experiential synthesis (Advisory Group experiences/ opinions). These syntheses show both how the study develops the academic debate around citizenship and also how it reflects meaning for disabled people. I also showed how the concepts generated were linked to, and compared with, each other and how the different levels of analysis generated differing emphases in the development of theory.

The analysis in this study was particularly focused on the experiences of disabled people and the attitudes of professionals to disabled people. The significance of this research, therefore, has been in the elaboration of the concept of citizenship in relation to disabled people. The empirical data demonstrate significant connections and explorations that can be seen to have been neglected in the literature so far. In this way, the data has contributed to an important development of citizenship theories.

Revisiting citizenship: acknowledging disablism

Marshall (1950) can be seen as a vital starting point for theorising issues of citizenship and particularly citizenship rights. In fact, Marshall's concept of citizenship provides,

> ...a framework for understanding ourselves and our relationships to the institutions of society in terms of civil, political and social rights. (Twine, p. 172).

Bulmer and Reece (1996) considers Marshall to be important because he traced the historical development of the incorporation/ inclusion of working classes into mainstream society through citizenship rights. Furthermore,

> The interest of Marshall's contribution to the theory of citizenship is that it places the conventional question of participation in political community in the important context of social institutions and processes (Barbalet , 1988, p. 108).

Therefore, Marshall was important because he talked about the links between political arrangements and social structure. I would like to discuss some of the ways in which Marshall's tripartite model of citizenship neglects certain areas and debates, and also offer a critique based on assessing the context, era and society in which he was writing. I shall look at the following areas: citizenship rights and the ideal of citizenship. I shall then move on to discuss the way in which the exclusion of disabled people from full citizenship constitutes disablism.

Giddens (1982) talks about Marshall's failure to recognise the role of 'struggle' of gaining rights within a citizenship framework:

> ...the insertion of the concept of 'struggle' in an account of the historic expansion of social participation may lead away from the idea that the trend of development is evolutionary and irreversible... p. 108.

Added to this, Barbalet comments:

> What he fails to treat, though, is the means through which the distinct sets of rights function together as components of a unified citizenship p. 109.

That is, his theory is seen as detached in that the different sets of rights can be seen to be discrete. Furthermore, it can be seen that Marshall takes the role of the state for granted and doesn't talk about its significance in the development of achieving rights. Mann (1987) also highlights the importance of the state in the process of social participation and formation of citizenship rights. The 'struggle', therefore, is related to the need to become 'participants' in society. Giddens argues that civil and political rights developed together (Giddens, 1982, p. 173) and that citizenship rights have only been achieved through 'struggle'. Marshall, on the other hand, has implied that citizenship emerged from the collapse of feudalism.

Buck (1993) comments:

> T.H. Marshalls' work...outlines the development of civil, political and social rights...but this analysis...has not provided a suitable account of the disabled citizen p. 180.

Furthermore, Blackburn (1993) states that:

> Marshall's identification of the twentieth century as the origin of 'social' rights does not fit easily with the experience of the disabled. (Blackburn, 1993, p. 180).

The present study also comes to a similar conclusion: the debate over the concepts of citizenship and attitudes by the Advisory Group exemplifies the view that disabled people did not relate to a research focus on citizenship.

Although citizenship is a useful concept, it is important to see it in the context of it being an 'ideal'. In reality, it is a concept that is difficult to live up to since it embraces elements of inclusion and universalism. Lister (1997) emphasises this by suggesting that citizenship is relative to the era and context, and can be seen as being a contributory factor to a wider struggle. She also states that the language of citizenship has changed to incorporate trends, ideals and contexts. Although there may be a tension between the ideal and the reality, the concept is useful, however, in that,

> Citizenship as a topic links the social sciences to wider public debate. (Bulmer and Reece, (1996) p. 282)

I feel that citizenship is an important starting point but this study has developed other concepts neglected within the original definition of citizenship that are particularly relevant to disabled people. In developing the discussion on citizenship, Turner (1986) argues that the contemporary discourse on citizens' rights is

> ...essentially concerned with the nature of social participation of persons within the community as fully recognised legal members. (Turner, 1986, p. 134)

Although Marshall's starting point shows potential for a development of citizenship theory, the debates have presently evolved so that Marshall seems somehow outdated, as suggested by one of the members of the Advisory Group in the present study:

> *C: It seems to me that having come across Marshall for the first time when you introduced him to us, that the most striking and interesting thing about him was how quaintly old-fashioned he seemed...*

The usefulness of this research has been in the connections made between disabled people and citizenship, which have tended to have been neglected in the literature thus far. It has shown how Marshall's model of citizenship with the focus on civil, political and social rights, was useful as a starting point for the study of attitudes toward disabled people. However, the analysis of the data in this study suggested some important ways to develop and extend the notion of citizenship to include elements of attitudes, difference, consumerism and risk. In this way, although Marshall can be criticised for the limitations of his model, it is important to accept the model within its historical context. The present study showed that within the context of the late twentieth century, other factors have become more prominent, and therefore must be included in a model of citizenship. Citizenship can therefore be seen as an ideal to strive for. I would agree with Lister in arguing for a 'differentiated universalism': that is, an acceptance of difference and a celebration of diversity within an infrastructure of accepted rights and responsibilities. If this does not occur then the exclusion of disabled people from full citizenship reflects disablism in action.

By disablism, I mean, discrimination in relation to a person's impairment: assuming a person's abilities and social functions are predetermined by his or her impairment. Although the word 'disablism' is used in general contexts to describe disabled people's experiences of discrimination and stereotyping, the word is not actually in existence in any English dictionary. It is interesting that disabled people did not have anti-discriminatory legislation until 1995. It is also apparent that they did not have a word to describe some of their experiences. Barnes (1991) suggests that this fact, in itself, has significance for disabled people:

> the word 'disablist', while answering the obvious need for an equivalent to 'sexist' and 'racist' has not yet become common parlance like the other two words. This fact in itself has some bearing on our discussion [around discrimination]. (p. 185).

He goes on to explain how disablist attitudes are developed:

> Just as racist or sexist attitudes, whether explicit or implicit, are acquired through the 'normal' learning process, so there is evidence that 'disablism' is learned in this way too (p. 197).

Disablism has been identified in this study both in the personal attitudes of interviewees (Chapter Four) and in their professional practice (Chapter Five). Disablism is therefore a useful term to define the practices which arise from the generated concepts in this study, that is, moral rights, attitude/ difference and consumer/ risk:

- in relation to the moral rights concept, disablism occurs when disabled people are not given the right to respect in their daily lives. This was particularly highlighted within the academic discourse.
- with regard to the attitude/ difference concept, disablism explains the development of negative attitudes in daily life. This was particularly clear within the Advisory Group discourse.
- in relation to the consumer/ risk concept, disablism is particularly obvious in employment practices and attitudes and emerged from the professionals' discourse. In this way, therefore, disablism can lead to exclusion for disabled people.

It is interesting that, although the term disablism does not formally exist, disablist practices have been identified within the UK. The progress of the introduction of the Disability Discrimination Act (1995) was largely influenced by disabled people campaigning against disablism. Before the introduction of the Disability Discrimination Act, Barnes (1991) stated that:

> ...this continual denial of equal rights to disabled people by successive British Governments is all the more astonishing when other disadvantaged groups have some protection under the law, and when legislation to combat institutionalised disablism is becoming increasingly common throughout the western world (p. 232).

The legislation (ie. The Disability Discrimination Act, 1995), was, therefore, an attempt to address many aspects of disablism. However, Gooding (1996) points out that:

> The UK laws against sex and race discrimination seek to address not only direct discrimination (hostile attitudes or stereotypes), but also institutional discrimination (p. 4-5)

The latter is referred to as *indirect discrimination*. The Disability Discrimination Act does not include the concept of *indirect discrimination* that is included in the other UK anti-discrimination laws. This is also different to the Americans with Disabilities Act (1990) which defines both direct and indirect discrimination. It is interesting that although the Disability Discrimination Act addresses some aspects of disablism, it does not incorporate the wider issue of institutional disablism, which affects disabled people's inclusion to some aspects of life, for example, employment attitudes and practices.

There were many suggestions by the interviewees and by the Advisory Group as to how disablist attitudes might be changed, including providing training and spending more time with disabled people. Therefore,

> ...the true challenge for rehabilitation in the 1980s is not the development of new technology and miracle drugs [ie. Medical Model] but to overcome attitudinal barriers in interaction and relationships through understanding and acceptance [ie. Social Model] (Rousch, 1986, p. 155).

There is therefore a need to promote the challenging of ignorance and stereotypes that create disablsim. This is particularly pertinent in professional practice, and personal attitudes, as shown in this study. Perhaps the valuing of difference (as suggested in Chapter Four) could lead to a reduction in disablism.

In referring to the issue of racism, Stuart (1993) states,

> Racism used to be seen in terms of discrimination based on skin colour. More recently it is seen as discrimination in terms of not fitting into the dominant culture eg. 'Englishness'....The question ceases to be 'what colour are you?' Instead it becomes 'can a black person of a different culture really be part of this society? This 'new' racism has the effect to exclude (p. 93-94).

Exclusion, therefore, can be seen as the characteristic experience of both black people and disabled people within this society. In this way, I would argue that Stuart's exposition can also be applied to disablism. The question posed of disabled people used to be 'What impairment do you have?' The present society is now asking the question 'Can a disabled person really be part of this society?' In this way, although the question has progressed from essentially a medical (individual) model, the underlying assumptions of the question are about whether people who are different can really 'fit in'. This is also therefore addressing the question, 'To what extent can disabled people be perceived as citizens?'

Some recent literature around disability and citizenship has explored disablism in relation to 'the body' (Hughes, 2002) and in relation to 'simultaneous oppression' (Vernon and Swain, 2002). Hughes (2002), for example, suggests that disablism occurs in practices that attempt to normalise the physical body:

> ...the contemporary world is a reactionary, disablist discourse which threatens to upset disabled people's bumpy ride towards inclusion and emancipation. One

> might call this the discourse of bodily perfection. (Hughes, 2002, p. 73)

He goes on to suggest that this process of bodily perfection exists due to a growth of interest in genetics and by attitudes toward the body that see the 'less-than-perfect' body of a disabled person as not compatible with the focus on beauty in popular culture. These two factors, then,

> Produce new forms of discrimination that are focused on embodiment and appearance. (Hughes, 2002, p. 73)

This, in turn, resonates with the findings of the present study that accounted for disablism in terms of the perception of difference, that is, in Hughes' terms, difference in 'embodiment and appearance'. Hughes points out that there is a rather institutionalised, dominant viewpoint that there should be a pursuit of beauty in today's culture, that is, bodies can be reconstructed and reformed by regimes of maintenance and enhancement. In this way, therefore, disabled people, whose bodies are seen as less than 'ideal', experience discrimination in terms of their relative lack of 'beauty'. He calls this 'body fascism'. This focus on the imperfect body as a factor of oppression has helped to add an individualised element to the discussion of the social model of disability, that is, disabled people experience oppression because the environment is designed with a certain type of body in mind and also discrimination is experienced due to judgements and stereotypes about the less-than-perfect body. The individualised element is different to a medicalised element, where impairment was seen as part of a medical paradigm and illness, sickness and the need to be 'looked after' due to physical limitations. Some authors (Hughes, 2002, Giddens, 1991) who focus on the concept of the body, suggest that disabled people's experiences are exacerbated by judgements around beauty and perfection, rather than illness and lack of function.

In contrast to Hughes, other authors such as Vernon and Swain (2002) place disablism in the context of simultaneous oppression, that is, experiences of oppression in relation to race, gender, disability, age and sexuality, among others. They suggest that these elements,

> Combine in important and varying ways to exacerbate and modify the experience of disablism, sexism or racism. (Vernon and Swain, 2002, p. 79)

Vernon (1998), suggests that often, it is not the specific 'ism' that is the crucial factor in relation to oppression. one of the participants in her research around simultaneous oppression, for example, stated,

> I feel oppression is the denial of opportunity. There are lots of things you will have to battle against and if they don't get you on one they will get you on another (Vernon, 1998, p. 81)

In this way, therefore, people experience simultaneous oppression.

In relation to black disabled people, for example, Stuart (1993) argues that their experience is of a unique form of discrimination, which is different to racism and disablism combined. This has also been identified in other social divisions. In research by Gillespie-Sells et al (1998), for example they found that disabled lesbians and bisexual women felt marginalized by lesbian and gay groups. Morris (1991) also shows how the experience of disablism is affected by a person's socio-economic status and access to resources and aids. In this way, therefore, other factors can interact and impinge on a situation and exacerbate an individual's experience of disablism.

Developing the discussion further, some disability authors (Oliver, 1996, Bradley, 1996) consider disablism and other experiences of discrimination to be related to economic forces and the social structures of capitalism:

> The oppression that disabled people face is rooted in the economic and social

> structures of capitalism which themselves produce racism, sexism, homophobia, ageism and disablism. (Oliver, 1996, p. 33)

Vernon and Swain (2002), in a similar vein to the present study around disablism, suggest that simultaneous oppression can be reduced by a recognition and acceptance of diversity and difference.

The recent literature explored in this discussion therefore, has identified disablism as a concept in relation to the body and in relation to simultaneous oppression. Recent literature, therefore, shows that the concept of disablism is being recognised and explored. The present study adds to these discussions by showing particularly how attitudes and practices combine to exacerbate disabled people's experience of discrimination. The importance of the present study is in the way in which the experiences, by disabled people, of disablism, affect the perception of them as citizens by others.

Practices and attitudes around disablism are also influenced by legislation in relation to disabled people. It is to legislation and policy that I now turn.

This thesis has shown that both the disabled people in the Advisory Group and the interviewees felt that the introduction of the Disability Discrimination Act (1995) could challenge some disablist attitudes and practices. In 1995 when this study was first initiated, the Disability Discrimination Act had only been in existence a few months, and its implementation was to be a gradual process with the sections on employment being brought in within a number of months and other sections (eg. goods and services; education; transport) taking longer and having amendments added as it was used and developed. It was unknown how this piece of legislation would impact on the lives of disabled people. The initial reaction to the Disability Discrimination Act by the Disability Movement was one of cynicism, in that disabled people claimed it 'didn't go far enough' (Oliver, 1996). The legislation focused on 'accommodating' disabled people, rather than granting them full civil rights and this contrasted with the American legislation (ADA) which focused on full and equal civil rights. The analysis of the data in this study shows that, in the early days of the Disability Discrimination Act (1995) many employers/ managers knew very little about the implications of this piece of legislation for themselves, and usually, there was only one person in an organisation who was given the job of having the relevant knowledge (ie. the personnel manager).

However, by the year 2002, there seems to have been much more awareness of the implications of the Act: information has been made widely available through free packs from the DfEE; media campaigns through advertising posters have been prominent in city centres; television and radio advertising slots (in 1996/1997 in particular) reminded employers of the importance of knowing about the Disability Discrimination Act; disability organisations (such as the British Council of Disabled People Organisations) in general have experienced greater consultation and more requests for training on disability issues; larger organisations and institutions have appointed specified Disability/ Access Officers to implement and monitor their response to the Disability Discrimination Act; and the Labour Government has amended and developed certain sections of the Act to make it necessary for organisations and employers to alter their practices and premises as a matter of course, rather than only altering them when challenged by a disabled person. Part III of the Disability Discrimination Act now places a statutory duty on 'providers of services' (with a few exceptions) to take reasonable steps to ensure that all buildings visited by the public have no physical barriers for people with impairments. From 2004, service providers will have to make reasonable adjustments to the physical features of their premises to overcome physical barriers to access. In this way, therefore, the position of disabled people, in terms of their citizenship status can be seen to have improved. Within this study, it has also been suggested that the implementation of legislation can also bring about a change in attitudes. Since the position and inclusion of disabled people has become more visible since the implementation of the Disability Discrimination Act, I would suggest that, this has, in fact assisted in challenging and changing the attitudes of others to disabled people.

In addition, the Disability Discrimination Act was also important in instigating the establishment of the Disability Rights Commission, which was modelled primarily on the Equal Opportunities Commission, the Commission for Racial Equality and the Fair Employment Commission in Northern Ireland. The role of the Commission has been to give advice to disabled people, business, the public, and the Voluntary Sector; arrange for conciliation services; assist individuals to secure their rights; bring representative actions; undertake formal investigations; and encourage good practice in any field of activity. The Disability Rights Commission, therefore, has been able to add additional weight to the Disability Discrimination Act and ensure that its regulations have been promoted and carried out. There is a yearly review of the Disability Rights Commission to establish its effectiveness, the first of which was published in 2002.

In more recent years, there has also been other new legislation that has supported the greater inclusion of disabled people in their society. In particular, the Human Rights Act (1998) which came into force in October 2000, brought some of the conventions on human rights into UK law, and thus has implications for disabled people. This Act can be seen to accommodate some of the issues concerning the concepts of 'moral' rights, as highlighted in the present study. This includes, the right to a fair trial (article 6); the right to respect for private and family life, the home and correspondence (article 8); freedom of thought, conscience and religion (article 9); freedom of expression (article 10); freedom of assembly and association (article 110 and prohibition against discrimination (article 14). Added to this, the European Court stated that the European Convention on Human Rights (as it was called in the European Courts) is a 'living instrument' to be interpreted in the light of 'present day conditions'. This suggests that its interpretation could be flexible and thus affected by contemporary attitudes and culture. In some ways, then, this Act has contributed to the proposed 'Social Model of difference' in that it particularly recognises that those who are 'different', and/ or those who experience the struggle of discriminatory practices and attitudes, need protection of their human rights under the law. This legislation, like the Disability Discrimination Act has yet to be used extensively, but its

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To what extent was the methodology successful in terms of emancipatory research?

The methodological process took an emancipatory model as its starting point. This was achieved by using an Advisory Group of disabled people to guide the process of the research. The Advisory Group specifically guided the research in relation to the development of the interview schedule and the sample of the interviewees. They also provided a preliminary analysis of the interview data. Finally, members of the group were able to offer their own opinions and experiences in relation to the interview data (experiential synthesis). As a non-disabled researcher, undertaking research in the field of disability, I was therefore able to call upon the experiences and guidance of disabled people in order to ensure that the research was focused on *their* agenda. This approach follows the ethos of emancipatory research, in which the focus is on '...establishing a dialogue...' (Reason, 1988)

Chapter Two shows how this research developed a model by Tozer and Thornton (1995) in terms of utilising an Advisory Group. This research has been defined as 'emancipatory' in nature. Chapter Two also showed how emancipatory research could involve varying levels of participation. In terms of the success of the method within this study, therefore, I would like to consider the extent to which it achieved the *status* of emancipatory research, as defined by the literature. I shall thus use Reason's (1988) exposition (above) to reflect on the extent to which it *established a dialogue.*

I shall firstly consider the elements of the process undertaken in order to establish how I defined it as 'research'. Although the model of Tozer and Thornton (1995) was followed, it can be seen that the process and the context in which I undertook research was different to that of Tozer and Thornton. Throughout the present study, and particularly in Chapter Two, I have highlighted the tensions between a model of the emancipatory research process and the requirements of studying and 'owning' a PhD in the academic community. My research process encompassed reviewing the literature, developing a method, and applying analytical rigour to the data. In this way, it could be traditionally defined as 'research'. It also, however, had an added dimension of utilising an Advisory Group of disabled people who acted as 'co-researchers' in the process. Although one of the reasons for utilising an Advisory Group was to address the power imbalance between disabled people and researchers, the tensions experienced in this process, were due to the extent to which I 'allowed' the Advisory Group to have power. The ideal was to 'share' power. However, both the Advisory Group and myself recognised that the rewards I gained would be different to those they achieved.

As a practitioner, working particularly with issues around advocacy, I would consider that there are differences between consultation, advocacy and emancipatory research. Tozer and Thornton's (1995) study, for example, could be seen as a process which was more allied with the notion of consultation since their Advisory Group was a discussion group that kept the researchers in touch with the views of older people. Their Advisory Group had very little control over the process of the research. Maguire's (1993) study, on the other hand, could be seen as a process of self-advocacy since there was no element of *design* of a research project: The group themselves decided the activities they wished to be involved in, in terms of self-empowerment. These activities may or may not also be defined as research.

In many ways, the 'added value' for the three studies described in Chapter Two can be seen to be similar, including, the confidence gained by the members of the group, the researcher gaining an insight into the experiences and viewpoints of the members of the group and greater understanding/ collaboration between the academic community and the non-academic community. However, the process seems to be affected by the context in which it takes place and the role of the lead agency/ person. Maguire's work, for example, was focused on a voluntary agency which aimed to give service-users more of a voice. Tozer and Thornton's (1995) study, on the other hand, had as its purpose the piloting of a specific methodology, which was instigated and controlled by the academic community. The process may also depend on the commissioning body for the research. For example, funders, service-users, organisations, political groups, universities, or independent researchers may all have differing requirements/ agendas. The Joseph Rowntree Foundation, a major funder of Social Science Research, for example, encourages the use of Advisory Groups in the research process and *politically motivated* groups may request research to be designed and run by members of their *own* group. Some research which defines itself as 'peer' research (Kirby (1999) describes this), or 'community research' argues for individuals, groups, or communities undertaking the process for themselves. It recognises the value of using people's own *experiences* and it suggests that the individuals themselves are *experts* within their own community. By definition, it also aims to help the community assess its activities and make changes to benefit the whole community as a result of the research. A conflict can arise here with the academic community as, by definition, it is assumed that academic researchers are the 'experts' in 'doing' research. I would argue that the main issue concerns the nature of the process and of the outcome and analysis and of the willingness of the trained researcher to work in collaboration with others (and thus let them take credit for some of the 'expert' work). emancipatory research, therefore can be seen as one tool in the process of change.

Maguire comments about her study that:

> In the traditional sense you could conclude that the group did not do 'research'. (P. 173)

It can be seen, therefore, that Maguire hesitates to call her process research. The outcomes she achieved covered more than the pure production of knowledge. The knowledge the group produced can be seen to be more focused on developing self-knowledge. The process she used may not have traditionally been understood as 'research' but more as a process of self-advocacy. The other outcomes she describes were support, giving and gaining information, learning about each other's experiences, providing an influential/ advisory role to affect change, and an element of education. These are valid outcomes, but without a clear theoretical and systematic methodological process or relating results to theory, it is difficult to define the process as research. I would argue that these outcomes of the research process could be seen as a by-product of research rather than an end product.

Maguire defends these arguments by stating,

> Our actions were not revolutionary, nor did they contribute to major social transformation. But we did begin to challenge the oppression of silence and isolation. (p. 174).

She argues that through the comments and evaluation of the group the project met the goals of collective knowledge generation and collective empowerment. (eg. support/ confidence):

> We began shifting the traditional power relationships between an agency for battered women and its clients. (p. 174)

She accepts that her group became very much a 'consciousness raising' support group, rather than a 'research' group. She argues that she lacked clarity about 'ideal participatory research' and ultimately proposed that in order to influence change you may need some conventional structure rather than being 'idealist', as she states:

> Now I understand the ideal nature of the organising and researching aspects of participatory research to mean that the purpose is to organise people specifically to do participatory research , not merely to organise people and hope that somewhere along the line a research need will emerge. (p. 168)

I would suggest that the present study had elements of both collective advocacy (comparable to Maguire's (1993) study) and of consultation (comparable to Tozer and Thornton's (1995) research) and I would argue that emancipatory research must necessarily include both elements. However, I would also suggest that the process undertaken in the present study could clearly be defined as 'research' in that it followed a methodological process of reviewing the literature, developing a method appropriate to the research agenda, collecting data, and applying an analytical rigour to the data. I would argue that the involvement of the Advisory Group *added* to the research process, rather than changing the process into something that would not be defined as 'research'. However, I have recognised, that in order to encompass an emancipatory research project within an academic community, tensions were apparent and compromises were made.

In terms of the focus on an *emancipatory* approach, I would argue that the methodological process within this study was successful to a large extent because it was able to achieve its aims and objectives within the emancipatory paradigm. Chapter Two shows how the Advisory Group influenced the process of the research by changing the focus from rights and on to attitudes and by widening the interviews to include non-welfare professionals. It also discusses the issues involved in terms of the *ownership* of the final product. These issues show how the emancipatory process involved tensions between the researcher and the 'co-researchers'. Although this created difficulties, it can be seen that it was a vital part of carrying out research in this way: I needed to work with (in this case) disabled people in order to 'establish a dialogue'.

Although this research attempted to adopt an emancipatory model as its methodological framework, I recognise, however, that the extent to which this was achieved was limited. The study could be criticised for the point at which the Advisory Group became involved that is, not at the original formulation of the research question. However, the key inputs of the group were the reconsideration of the focus of enquiry and the widening of the interview sample; in effect they necessitated that I restart the project taking their concerns into account. This also required me to widen my review of the literature to include literature around attitudes. The extent to which the members of the Advisory Group were able to be equal partners in the research process was hindered by the constitution of the group, the declining numbers of the group over time, the regulations governing research for a PhD and the practicalities involved. Compromises were made due to my overriding aim of securing a PhD. This could lead to the consideration that this model of research might be more fully realised in a non-academic, (community) setting.

The idea that 'pure' emancipatory research can be successfully undertaken in an academic setting has therefore been challenged. Yet Maguire (1993) considers the assumption that emancipatory research must be 'pure' as too idealistic and suggests that emancipatory research techniques should perhaps be seen as part of a continuum:

> ...perhaps we can free ourselves of some unspoken proposal that all research be pure or ideal Participatory Research. Instead we might look for ways to move deliberately along the participatory continuum. (Maguire, 1993, p. 33).

I would suggest that, within the present study, the process of the research had an impact on the Advisory Group itself, the researchers and the research.

In terms of the impact of the process on the Advisory Group, it appears that the way in which the members of the group gained was around building up their confidence, developing a sense of solidarity, socialising, increasing self-expression, becoming more 'political' and learning more about the subject matter and the process of research. One member commented:

> *J: I've got more confidence. I answer back now whereas I kept quiet before.*

Although the group found the process enjoyable, it was not always easy and was also a learning process for all those involved. Members of the group certainly did not come away feeling that participation was easy to achieve. During the last Advisory Group meeting, I received feedback from them, such as:

> *I enjoyed the experience very much.*

> *I have gained more understanding of the research process.*

> *I feel I was able to make my views known.*

This also resonated with Tozer and Thornton who felt that their research had a significant impact on its members:

> The role of the group meant that individual members anticipated their work influencing the research and researchers. They did not expect to change the way services were provided locally, which is the usual aim of user involvement. The impact on individuals through the group process rather than the objective outcome thus had particular significance in this group, though both are important in all attempts to advise and influence (*op cit*, p. 36)

The process of emancipatory research can also have an effect on the role of the researcher:

> ...research becomes a form of development and it involves the researcher in a number of roles which would not be regarded as traditional roles for the researcher to play. (Barnes and Wistow, 1993, p. 75)

Tozer and Thornton (1995) stated that their research had a significant impact on the *researchers* themselves. They also suggested that the researchers had different expectations of the process than did the Advisory Group. Maguire (1993) points out:

> ...the entire emancipatory research process takes time.....Although the dissertation shouldn't become a lifetime project, it cannot be disconnected from your values and philosophy. (p. 176)

I would agree that, in fact, the motivation for doing any such a project invariably develops from an individual's own values.

In terms of the present study, the research was a development of my own personal experiences, professional practice and political landscape as described in the introduction to this thesis. In this way it reflected my 'values and philosophy'. Since the PhD process provided initial training in research skills, my previous experience of *traditional* research was limited. In this way, therefore, I did not need to 're-learn' established ways of undertaking research. However, it also served to question some of the underpinnings of PhD work in an academic environment. I would suggest that the greatest impact on myself was the challenge of working successfully with an Advisory Group of disabled people and learning, by experience, the difficulties involved in emancipatory research. I feel the learning also influenced my professional practice in terms of creating more rigour to my work and in challenging the stereotypes and assumptions around disabled people.

In terms of the impact of the emancipatory process on the *research* itself, I would argue that the Advisory Group informed and influenced the research in a number of very concrete ways. The Advisory Group gave advice about the research process, they changed the focus of inquiry and they addressed the widening of the sample of interviewees (as discussed in Chapter Two). The Advisory Group therefore, created the need for the research to take new directions. In this way, the group guided and influenced the process of the study. This also reflects Tozer and Thornton's (1995) study, which emphasised that their group acted as a lens through which the fieldwork could be analysed:

> Analysis of fieldwork material inevitably requires sifting and prioritising of views expressed. Without the experience of working with the OPAG, the researchers' assumptions and selection would have operated differently. (p 38-9)

It can be argued that the input of an Advisory Group is particularly useful in qualitative research where *interpretations* are made about data.

In the present study, I would argue that the emancipatory research process gave a political bias to the research, was a learning process and that the accessible report may have had some influence. I would therefore argue that it did have an important impact on the overall study. Hence, I would suggest that the emancipatory approach taken in the present study was successful to a large extent. I would also argue that, by using this methodological paradigm, additional factors arose which could be considered 'added value', such as the following:

1. Apart from the Advisory Group having an input into the process, they provided a narrative about their experiences, viewpoints and ideas. Although this could create difficulties in keeping the group focused, it was seen as a 'bonus' to the process. The experiences of the group were not to be devalued or used simply as data, but their 'stories' added richness to the data and provided an experiential synthesis. Their preliminary analysis of the data provided a lens through which I could carry out a further systematic analysis and their experiences were also used as a tool to reflect on the extent to which the generated concepts resonated with the lived experiences of disabled people.
2. I was able to create a *dialogue* between the academic community and disabled people, not least in a spatial sense, by holding Advisory Group meetings on the university campus. I feel that this was a factor in the process of breaking down barriers and for the research process to be part of a wider political process of challenging power/ attitudes.
3. Although the process was not intended as a self-advocacy group, some of the outcomes in terms of individuals gaining confidence/ power/ belief they could influence change/ knowledge of the research process achieved this. The research itself added to the body of knowledge but the process also added to the development of collective empowerment.
4. The production of an accessible report made available to a wide variety of people was *added value* in comparison with other academic research since the report was a way of returning some of the work to the participants (and others) rather than keeping the knowledge and analysis within the academic community.

5. As an indirect result of the research I was able to continue my involvement with disability issues after the fieldwork was finished. For example, I became an 'advisor' on a local disabled people-led group; I presented research papers to various conferences, seminars and teaching groups about the process; I created a link with Northern Foods in Hull who contributed financially to the process, and received progress reports and a copy of the final accessible report; and I gained some positive feedback from the report with invitations to present it to other groups.

The research therefore can be seen to have a further reaching influence than just one person receiving a qualification in an academic department in a university and therefore has had (and will possibly continue to have) 'added value'.

It was suggested by one member of my Advisory Group that the methodological approach adopted in the present study could be defined as 'collaborative' rather than emancipatory, implying that within this research, due to the nature of gaining a PhD, the researcher still gained the ultimate ownership and the credit: that is, the researcher gained more than the Advisory Group. I would argue that there were in fact degrees of participation, as outlined in the review of the literature in Chapter Two (ie. the 'ladder of participation' in Kirby, 1999) and that this research was successful within one level of participation. This could indeed be called 'collaborative'. The process itself was experimental in nature and had to be justified in terms of the academic community. As an 'experiment' the process was successful and lessons were learnt for future methodological developments.

I would argue that my methodological process was successful in that it achieved its aims of testing a methodology. That is, it used an Advisory Group of disabled people to challenge the imbalance of power in the process of research. Its experimental nature and emancipatory focus reflected a learning process and an attempt at an ideal. The way I have also measured success is through the feedback sheets from Group members, discussions in the last Advisory Group meeting, in reviewing its aims, and in comparison with other studies.

Both the Advisory Group and myself stood to gain from the emancipatory nature of the research process in this study. This is clearly related to the issue of ownership. The Advisory Group gained experience of the process of research and a belief that they may be part of the process of affecting change. My outcomes were more around a learning process in terms of undertaking emancipatory research in an academic environment and gaining a research degree. This learning was centred around the theoretical base, testing a method, debates, issues, difficulties, practicalities and process. I feel that I was able to gain more understanding of the priorities and debates within the disabled community. Within this study it was also important that the experiences of disabled people were heard and hence the synthesis of their experiences with the interview data created a further learning process. I suggest that this thesis was an exploration into emancipatory research and was a learning process. During the process I was also able to discuss and deconstruct the issues of originality/ ownership implicit in the awarding of a PhD to an individual.

As a consequence of this study, therefore, I have shown that it may only be possible to adopt a *limited* version of the emancipatory model of research while studying for a higher degree since there are tensions between an emancipatory approach and the academic requirements of a higher degree. It may be that attempting to adopt this methodology at doctoral level is not the most appropriate way to introduce such models into university research since the nature of emancipatory research generally necessitates an element of final joint ownership. This can conflict with the need for original work by one person in terms of achieving a PhD qualification. Perhaps the issue is what the researcher does with these skills after the PhD has been awarded and how far they spread the 'reward' in terms of how the subsequent use of their research skills for others.

I now wish to cite this research in a wider arena by focusing on the way in which the findings have implications for practice and policy.

Implications for practice and policy.

This research has been useful in widening the knowledge and understanding of both the theories of citizenship in relation to disabled people and the emancipatory methodological process. I would also suggest that the outcomes of the research have implications in relation to both policy and practice.

The Advisory Group highlighted several areas of practice in which they felt recommendations could be made as a result of this study and they suggested that the importance of the research was in its ability to influence change. Recommendations, therefore, were an important part of the accessible report. The Advisory Group developed the following Action Plan:

Action Plan (Quoted from user report)

1. Training

- "professionals" should have specific training in disability issues ("equality training"). It was felt generally by the disabled community that this training should be delivered by disabled people themselves. The research team felt that this kind of training should be available, in particular, to welfare professionals.

- professionals (particularly employers) should develop their knowledge of the Disability Discrimination Act (1995).

- professionals should be aware of the importance of language and should keep up-to-date on language which is considered "politically correct".

- welfare professionals should have more training in disability issues, so that

they are aware of rights issues, rather than simply seeing disabled people as people to be "looked after".

- it is useful for all staff to have training on disability issues, rather than just one member of staff having the expertise; disability is relevant to everyone.

-it is important that staff training builds on putting examples into practice and is not just about "saying the right thing".

2. Disabled people as employees

- employers should be encouraged to see disabled people as potential employees, not just consumers of a service.

- this may require making "reasonable adjustments" (see Disability Discrimination Act, 1995) in order for disabled people to have fair treatment in applying for and doing a job.

3. Consultation

- it is very useful for professionals to consult with disabled people (usually through a group run by disabled people) over issues to do with their organisation e.g. access issues, customer service, staff training and attitudes.

- it is useful for organisations to have an access audit of their premises. This could be done by a local disability group or a disabled individual.

4. Challenging attitudes

- professionals need to be aware that it is often the environment and other

people's attitudes that cause more problems for disabled people than a person's own impairment. (This is the difference in views between the Medical Model and the Social Model of disability.)

- professionals should be aware that there are many hidden disabilities and just because someone is not "obviously" disabled that does not mean they don't have particular needs or that these needs may change from day to day.

- if non-disabled professionals were encouraged to spend more time with disabled people then they might gain more understanding of the issues involved.

As illustrated by the recommendations above, the Advisory Group has focused on practical recommendations in relation to the analytical concepts generated in the data. That is, the members of the group suggest that professionals need to think about challenging their attitudes in relation to the perception of disabled people as 'different', and of their perception that disabled people are only potential customers and that employing disabled people could be seen as a risk. The Advisory Group's recommendations (which came out of their preliminary group analysis of the interviews) were focused on training, consultation and awareness raising. In this way, they suggested that a reassessment of professionals' attitudes could help to benefit the promotion of equal citizenship for disabled people.

Embracing a Social Model of Difference

The importance of this research, I would argue, has been in the connections made between disabled people and citizenship; between the academic community and emancipatory research; and between the concepts of citizenship and attitudes. In addition the process and outcomes of the research will have further significance in a wider context of a 'model of difference'.

The terminology of disablism can be used to show the commonalities between the experience of disabled people and other oppressed groups:

> By reconceptualising disability as social restriction or oppression, it has opened up the possibilities of collaborating or cooperating with other socially restricted or oppressed groups (Oliver, 1990, p. 129).

Oliver argues that both the Disability Movement and non-disablist sociology have a part to play in eradicating the social restrictions and oppressions of disability. I would suggest that the present research argues for the same thing in terms of promoting the eradication of social exclusion and the oppressions of difference, both for disabled people and, by extension, for other citizens perceived as 'different'.

The Human Rights Act (1998) indicates that there is now a need to recognise and accept difference. Furthermore, this has implications for practitioners. Within a Medical Model of disability, for example, the way in which disabled people were seen as 'different' was in terms of having a 'problem' and needing help. This issue was also explored in the present research. Greater development and awareness of a 'model of difference' (discussed in Chapter Four) within academic research, therefore mirrors developments in legislation (eg. The Human Rights Act, 1998) and highlights the need to encourage practitioners to reflect on their own *responses* to difference. Hence, further research could draw on the Human Rights Act (1998), rather than the Disability Discrimination Act (1995) as a heuristic device for further extending and exploring issues of *difference* and citizenship for disabled people and other groups formerly considered 'partial' citizens.

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Having discussed the way in which this research has contributed to the development of citizenship theories and highlighted the practice of disablism, I now return to a discussion of the *process* of the research. The next section will examine the methodological process and evaluate its success in terms of emancipatory research.

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Research Report

DISABILITY AND ATTITUDES.

Ruth Garbutt (Researcher) and
Advisory Group
Hull University
1999

INDEX

Appendices.

Summary of the Report

This report describes the method and results of a research project about disability and attitudes.

The project involved setting up an Advisory Group of disabled people to direct the research and to analyse data.

30 interviews were conducted with "professionals". The interviews were asking professionals about their views on disability issues. The Advisory Group analysed the interviews and talked about their own experiences.

The following action points have been suggested as a result of the research:

1. Professionals should have **specific training** in disability issues (particularly "welfare" professionals). This training should be available to **all staff**, not just managers.

2. Professionals should develop their awareness of the **Disability Discrimination Act (1995).**

3. Professionals should be aware of **the importance of language** when talking to, and about, disabled people.

4. Employers should be encouraged to see disabled people as **potential employees**, not just consumers of a service. This may involve making **"reasonable adjustments"** within their organisations.

5. Professionals should **consult** with disabled people more.

6. Professionals need to be aware of, and to **challenge, their own attitudes** to disabled people.

7. Professionals need to recognise that some people have **hidden disabilities.**

8. Non-disabled professionals need to **spend more time** with disabled people in order to gain more understanding of some of the issues.

1.1 Acknowledgements

I would like to acknowledge the following in their help in carrying out this research:

All the members of the Advisory Group: for their time, commitment and comments during the research project and also with the production of this report.

All 30 interviewees: for their willingness to take part in the research.

Northern Foods plc, Hull and the Faculty of Social Science Research Support Fund: for sponsoring the process of the research, which enabled the research to be done in a collaborative way.

Dr. Julie Seymour (lecturer/researcher in The School of Comparative and Applied Social Sciences, Hull University): for her advice, support and direction.

1.2 Introduction

This report describes a research project about disability and attitudes.

It was a collaborative project between Ruth Garbutt (researcher) and disabled people (Advisory Group).

It took place between January 1997-June 1998.

The research project was part-funded by Northern Foods plc., Hull and the Faculty of Social Science Research Support Fund.

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1.3 Who am I?

My name is Ruth Garbutt.

I am a part-time researcher at Hull University.

I have also worked in various jobs in Social Services Departments and the Voluntary Sector.

I am particularly interested in issues relating to disability and disability rights (although I do not have a disability myself.)

I think it is important for disabled people to have choice and control in the way they live their lives.

Choice and control is also important in relation to research.

1.4 Background.

The “Disability and Attitudes” project was part of my PhD at Hull University.

As both practitioner and researcher I was aware of the conflicts between the perceptions of disabled people and the perceptions of “professionals” and felt research around issues of attitudes and rights in relation to disabled people would be useful.

1.5 What was the research about?

An Advisory Group of disabled people was set up in Hull to discuss issues and direct the research.

The group wanted to look at the attitudes and perceptions of professionals in relation to disability and disability rights.

They suggested the following professionals could be interviewed:

Architects and town planners
Social Services practitioners
Health Services practitioners
Voluntary Sector practitioners
Solicitors
Supermarket managers
Restaurant managers
Bank managers
Leisure Services managers
Transport managers.
Media managers
Teachers

The Advisory Group were also interested in the issues of rights and disabled people's experiences of discrimination, labelling, the imbalance of power in society, the "image" people have of disability, how well informed professionals are in relation to disability issues, the language people use, and what causes people to change their attitudes.

For a full list of people interviewed and the list of questions asked in the interviews please refer to the appendices.

The aims of the research therefore were to find out the perceptions and views of professionals in relation to disabled people and disability rights, and to recommend points of action as a result.

1.6 What was the Advisory Group?

The Advisory Group was a group of disabled people who voluntarily gave of their time to be involved in the research.

The Advisory Group was:

A group to guide the research process.

A group to decide who to interview and what questions to ask;

A forum for debate;

A way of getting to know the views of disabled people;

An attempt to challenge the imbalance of power in research;

A way of sharing in the research process;

A way for disabled people to have control;

A group to comment on and analyse data;

1.7 How was it done?

The Advisory group met 9 times over 18 months.

The group decided who to interview and what to ask.

The researcher conducted 30 interviews.

The group talked about what was said in the interviews.

The people in the group also talked about their own experiences.

They discussed what the "professionals" seemed to be saying in the interviews and drew some conclusions.

This report was written, in consultation with the Advisory Group, to inform people of some of the conclusions.

1.8 What came out of it?

The following points were made by the research team (Advisory Group and researcher):

language.
In many of the interviews, people used language and labelling inappropriately. As an example, one interviewee talked about someone being "wheelchair bound" rather than a "wheelchair user".

It was felt that sometimes professionals used the "right" words in their language but were not really doing the right things in their practice.

Definition of disability
Most interviewee's definition of disability followed a "Medical Model" approach rather than a "Social Model" (see appendices for more explanation of these approaches) e.g. "Not being able to do things others can".

"Disability" was generally defined in terms of physical disability. Very few professionals considered people with learning difficulties, mental illness or other "hidden" disabilities as obviously disabled.

Lack of awareness
There seemed to be a relative lack of awareness of disability issues amongst professionals. Surprisingly, this was particularly noted among "welfare" professionals. The research team felt that this was due, in part, to the ethos of "caring". They felt that welfare professionals should see themselves as "facilitators" rather than "carers".

Most professionals had very limited knowledge of the Disability Discrimination Act (1995) or its implications.

Most professionals seemed to be saying that there was one person in their organisation who was a specialist in disability issues (usually the personnel manager) and that other workers did not need to know anything about these issues.

Most professionals did not know what the "Social Model of disability" was. (This was a question asked to welfare professionals: see appendices for questions asked and for definitions of the Social and Medical Models of disability).

Many professionals stated that their building was accessible because they had a ramp. The research team felt that they had not considered issues to do with other forms of accessibility, such as, an induction loop for people with hearing impairments, or signs in black on a yellow background for people with a visual impairment.

Most professionals stated that disabled people have the same rights as everyone else. This in fact is not the case: disabled people have only had some rights in law since 1995 with the Disability Discrimination Act (1995). Their ability, for example, to access transport, to choose where to live, and to have a social life can sometimes be curtailed because the structures of help in place for disabled people can be inflexible and can deny a person's right to choice and control.

Influence on attitude

People's individual experiences of disability or disabled people seemed to affect their attitudes. For example, one interviewee had spent a great deal of time in the army before his present job and admitted that he had never really come across disabled people until 1986 and was therefore ignorant of some of the issues.

Financial cost

Most professionals talked about cost and resources as a factor when considering the rights and entitlements of disabled people. They rarely considered the benefits of increased access for all, better public image or increase in customers.

Disabled people as employees?

In most interviews, disabled people were seen as consumers, and never as employees. Hence one supermarket manager was very proud of the customer service provided to disabled people, emphasising that disabled customers were consulted about access and so on. However, he didn't feel a disabled person could be an employee in the shop because the canteen, offices and staff toilets were not on the ground floor.

Images of disabled people

Most interviewees (though certainly not all) felt Direct Action (such as, people chaining themselves to a bus) was not effective and that it created a negative image of disability. The research team recognised that, similarly, opinion is split amongst disabled people themselves on the effectiveness of Direct Action.

Most professionals talked about disabled people needing help, assistance and sympathy. The research team felt this was a bit patronising and that what disabled people really need is to be treated in the same way as everyone else. They felt the term "enabled" rather than "helped" is more positive.

The research team commented on the influence the media and "traditional" statutory services have in creating stereotypical images. They pointed out that the "stereotypical image" of a disabled person is usually based on the Medical Model of disability (see Appendices) which can emphasise dependency and "being looked after".

1.9 Action Plan

As a result of the research, the following points of action are recommended:

1. Training

- "professionals" should have **specific training** in disability issues ("equality training"). It is felt generally by the disabled community that this training should be delivered by disabled people themselves (see appendices for useful contacts in relation to training). The research team felt that this kind of training should be available, in particular, to welfare professionals.

- professionals (particularly employers) should develop their knowledge of the **Disability Discrimination Act (1995)**. See appendices for main points of Disability Discrimination Act (1995) and where to go for further information.

- professionals should be aware of the importance of **language** and should keep up-to-date on language which is considered "politically correct". See appendices for guidelines on this.

- **welfare professionals** should have more **training** in disability issues, so that they are aware of issues to do with disability rights, rather than simply seeing disabled people as people to be "looked after".

- it is useful for **all staff** to have **training** on disability issues, rather than just one member of staff having the expertise: disability is relevant to everyone.

-it is important that staff training builds on putting **examples into practice** and is not just about "saying the right thing".

2. Disabled people as employees

- employers should be encouraged to see disabled people as potential **employees**, not just consumers of a service.

- this may require making **"reasonable adjustments"** (see Disability Discrimination Act, 1995) in order for disabled people to have fair treatment in applying for and doing a job.

3. Consultation

- it is very useful for professionals to **consult** with disabled people (usually through a group run by disabled people) over issues to do with their organisation e.g. access issues, customer service, staff training and attitudes.

- it is useful for organisations to have an **access audit** of their premises. This could be done by a local disability group or a disabled individual.

4. Challenging attitudes

- professionals need to be aware that it is often the **environment** and other people's **attitudes** that cause more problems for disabled people than a person's own impairment. (This is the difference in views between the Medical Model and the Social Model of disability- see appendices for more explanation.)

- professional should be aware that there are many **hidden disabilities** and just because someone is not "obviously" disabled that does not mean they don't have particular needs or that these needs may change from day to day.

- if non-disabled professionals were encouraged to spend more **time with disabled people** then they might gain more understanding of the issues involved.

APPENDICES

2.1. The interview questions.

2.2. Who was interviewed?

2.3. Books to read.

2.4. Recommended language/vocabulary.

2.5. Main points of the Disability Discrimination Act (1995).

2.6. The Social Model of disability and the Medical Model of disability.

2.7. Useful names/addresses.

2.1 The **interview questions**

Below are the interview questions which were agreed between the researcher and the Advisory Group:
(These questions were asked to 30 different people.)

1. What is your job? What do you do in your job?
2. How do you define "disability"? (If I said "disabled" what does this mean to you?
3. What is your image of a disabled person?
4. What experience do you have of disability (either you or someone close to you) ? (Do you have any experience of disability?)
5. Has your experience of disability/disabled people affected your attitudes to disabled people? In what way?
6. Do you have any policies in your organisation relating to disabled people?
7. Do you think disabled people have rights?
8. In which areas **do** they have rights?
9. In which areas **don't** they have rights?
10. Do you know anything about the Disability Discrimination Act (1995)? (If not, explain what it is: It is a law that tries to make sure that disabled people are treated fairly in employment, education, shops, leisure facilities etc.)
11. Do you think anti-discrimination legislation like the Disability Discrimination Act (1995) is effective? (Do you think laws that try to make sure everyone is treated fairly work?)
12. Do you think it (laws like this) changes people's attitudes?
13. What else could you do to change people's attitudes?
14. Does Direct Action (such as chaining yourself to a bus) work? Does Direct Action change people's attitudes?
15. What is your role **as a professional** in relation to disabled people (Both "customers" and staff)?
(For Welfare professionals: Are you aware of the Social Model of disability?)
16. Are the staff in your organisation given training in disability issues? If yes, what form does this take?
17. Is your building accessible? In what way?

Any other comments?

2.2 Who was interviewed?

The following "professionals" (managerial level) took part in the interviews:

(N.B. None of the interviews was conducted in Hull. This ensured confidentiality when the interviews were analysed by the Advisory Group)

Art gallery manager (2)
Solicitor (2)
Bank manager
Architect
Community worker
Supermarket manager (2)
Cinema manager (2)
Health Services manager (hospital based) (2)
Psychologist (learning disability)
Social worker (2)
Retired social worker (2)
M.P.
Town planner
Transport manager
Newspaper editor
Restaurant manager
Teacher ("special school")
Residential home manager (elderly people) (2)
Manager of Age Concern
Manager of Council for Voluntary Service
Manager of MIND
Methodist minister

2.3 Books to read

The following are a list of "academic" books about doing research on disability and the subject area of citizenship:

1. Doing research about disability

Barnes, C. And Mercer, G. (1997) **Doing Disability Research**. Leeds: The Disability Press.

Oliver, M. (1992) "Changing the Social Relations of Research Production?" **Disability, Handicap and Society**, Vol. 7, No. 2. Pp. 101-114.

Tozer, R. and Thornton, P. (1995) **A Meeting of Minds: Older People as Research Advisers**. York: Social Policy Research Unit.

2. Disability

Barnes, C. (1991) **Disabled People in Britain and Discrimination.** London: C. Hurst and Co. Ltd.

Finkelstein, V. (1980) **Attitudes and Disabled People**. New York: World Rehabilitation Fund.

Gooding, C. (1996) **Blackstone's guide to the Disability Discrimination Act 1995).** London: Blackstone Press Limited.

Hales, G. (1996) **Beyond Disability: Towards an Enabling Society**. London: Sage.

Oliver, M. (1990) **The Politics of Disablement**. London: The Macmillan Press Ltd.

Oliver, M. (1996) **Understanding Disability: From Theory to Practice.** London: The Macmillan Press Ltd.

Swain, J., Finkelstein, V. And Oliver, M. (1993) **Disabling Barriers-Enabling Environments**. London: Sage.

3. Citizenship

Barbalet, J.M. (1988) **Citizenship**. Milton Keynes: Open University Press.

Bulmer, M. And Rees, A.M. (1996) **Citizenship Today**. London: UCL Press Ltd.

Lister, R. (1997) **Citizenship: Feminist Perspectives**. London: The Macmillan Press Ltd.

Marshall, T.H. (1950) **Citizenship and Social Class**. Connecticut: Greenwood Press.

2.4 Recommended language/vocabulary

Since the project has highlighted professionals' **use of language** as a problem, I would like to suggest possible alternatives to some terms that are commonly used/mis-used. These alternatives have come directly from disabled people themselves (kindly supplied by Choices and Rights Disability Coalition in Hull).

Don't say:	**Instead say:**
"The disabled" or "handicapped people" -the former suggests that we are all the same but people with disabilities are like everyone else, individuals. "Handicapped" is an unfavourable term because its original meaning is from "cap-in-hand"- begging.	**Disabled people/people with disabilities** -A disability can be "hidden" or "visible" and a person should not be judged because they do/do not look disabled. Comments like "well you're not really disabled are you" or "there are people worse off than you" can be very disabling, unhelpful and upsetting.
"able-bodied"	**"non-disabled"**
"Suffering from...crippled by...victim of...afflicted by" - these all judge a person's experience or approach imposing pity where understanding would be more help.	**"A person who has...or a person with..."**
"An epileptic"	**"A person with epilepsy"**
"Deaf and dumb"	**"A person who is deaf without speech"**
"Wheelchair-bound" or "confined to a wheelchair"	**"Wheelchair user"** -to its user, the wheelchair provides the freedom to get around.

“Mentally handicapped”	**“person with a learning difficulty”** -this term is the one which people with a learning difficulty themselves have chosen to use.

Other terms like “spastic”, “cripple”, “mongol”, “retarded”, “defective”, or “invalid” and phrases such as “mentally deficient”, “blind as a bat”, and “deaf as a post” are often used in conversation, but they all reinforce negative, and therefore, damaging and inaccurate images of disabled people and should not be used.

2.5 Main points of the Disability Discrimination Act (1995)

This research project discovered that many employers/employees had very limited knowledge about the Disability Discrimination Act (1995).

To obtain free booklets published by the government about the Disability Discrimination Act (1995) please phone 0345 622 633 (calls will be charged at local rate.) Booklets are also available in Braille and audio cassette.

As a brief outline, these are the main points of the act:

Disabled people should be treated fairly in employment, provision of goods and services, letting or selling land or property, education and public transport (the sections on education and public transport are not as well developed as the other sections.)

If disabled people are not treated fairly, they can complain.

The Act makes it unlawful for employers with 15 or more staff to discriminate against current or prospective employees because of a reason relating to their disability.

Employers may have to make "reasonable adjustments" if their employment arrangements or premises substantially disadvantage a disabled employee or disabled applicant.

If a disabled person feels they have been treated unfairly in relation to employment, they can take their case to an employment tribunal.

The Quota Designated Employment Scheme (where employers had a duty to employ 3% of disabled people) is no longer in existence.

People providing goods and services are required to make "reasonable adjustments" in order to make their services more accessible to disabled people.

2.6 The Social Model of disability and the Medical model of disability.

This research project was conducted within the ethos of the "Social Model of disability" and I have referred to the "Social Model" within this report. The following table outlines the difference between the "Social Model" and the "Medical Model":

The Medical model says:

You are the problem.

Your disability needs curing.

You can't make decisions about your life.

You need professionals to look after you.

You can never be as equal as a non-disabled person.

The Social model says:

"Disability" is not an individual problem.

Disabled people can't compete on equal terms because there are too many barriers.

We need to recognise that "society" (through government and its agencies) has a duty to remove these barriers.

Disabled people have the same right to full equality as do all other citizens.

2.7 Useful names/addresses for further help/information.

Local

Choices and Rights Disability Coalition
The Arthur Richardson Centre
Savoy Road
Hull
HU8 0TX
Tel.: Information Service: 01482-788600
Tel.: Office/ fax: 01482-788668
Minicom: 01482-789320
(They are a voluntary organisation run ***by*** and ***for*** disabled people and can provide training and an extensive database of information on disability issues.)

Humberside Law Centre
95 Alfred Gelder Street
Hull
HU1 1EP
Tel.: 01482-211180
(They can provide training and legal advice on a range of issues, including the implication of the Disability Discrimination Act (1995).)

National

British Council of Disabled People
Litchurch Plaza
Litchurch Lane
Derby
DE24 8DA
(They are a national organisation run by and for disabled people and are proactive in campaigning for disabled people's rights.)

Disability on the Agenda
Freepost
London
SE99 7EQ
Tel.: 0345-622 633
Textphone: 0345-622 644
(Calls are charged at local British Telecom rates)
(They provide free booklets on all aspects of the Disability Discrimination Act (1995))

Disability Research Unit,
Leeds University,
Leeds.
Tel.: 0113-2431751
(They specialise in academic research in relation to disability issues and sell many of the books from the "Books to Read" page.)