The ‘Struggle’ for Citizenship: Citizenship, Social Movement Theory and Disability

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Chapter 1

Introduction

Overview

In recent years, the concepts of *citizenship* and *social movements*, especially the so-called *new* social movements have become major issues for academics from a wide variety of perspectives. The reason why citizenship has returned to centre stage probably rests, as Kymlicka and Norman (1994) have written, upon the notion that "*the health and stability of a modern democracy depends, not only on the justice of its basic structure but also on the qualities and attitudes of its citizens.*" (p.352) Connected with this upsurge of interest in 'citizenship' is a growing support for the idea that: "*the institutions of constitutional freedom are only worth as much as the population makes of them.*" (Habermas, 1992: 7) Such thinking may explain the increased interest in social movements since in many respects they can be seen to be the major sites of struggle and negotiation between the individual members of society, albeit working en masse, and the chief 'institution of constitutional freedom' in the form of the *state*.

Despite the recent upsurge of interest in citizenship and social movements, the position of disabled people as 'citizens' and the structure and functions of the disability movement has been largely over-looked. The absence of disability from these important areas of theorising is all the more interesting in the light of the increasing interest in the notion of embodiment and the impact that this has, for example, upon theories of human rights. The empirical aspect of this research, therefore, seeks to provide a platform for disabled people to voice their opinions on issues relating to citizenship and the disability movement. Within the thesis, 'disability' is then used as a *case study*, contextualised by an interest in the manner in which an understanding of embodiment may impact on citizenship and social movement theorising. The central focus of this research is, therefore, to *reconsider citizenship and social movement theorising in the light of disability.*

There are three major research questions that have arisen from the central concerns of the research:

Question 1

How might it be possible to reconsider citizenship in the light of the experiences of disabled people? Answering this question will involve a consideration of the possible effects that changes to society, such as the move towards late/r modernity and the development of discourses of human rights, may be having upon the notion of citizenship.

Question 2

What do disability organisations believe to be the basis of their 'struggle'? Oliver (1997) claims that the disability movement is a 'new' social movement. This research considers the accuracy of this claim by analysing evidence from the field regarding the aims of a number of organisations that can be considered to be part of the disability movement. The research seeks to establish whether the disability movement is currently acting within a broadly defined socio-cultural sphere, as Oliver suggests, or whether it remains largely concerned with persistent issues of social inequality.

Question 3

Thirdly, drawing upon a consideration of the first and second questions, how might we reconsider current theories of social movements in the light of understandings of citizenship and the 'disability movement' gained through this research?

Whilst these three research questions provide the central focus of this research, there are also clear empirical aims underlying this thesis. The first is to ensure that the theoretical analysis is grounded in empirical evidence. It is also an aim of this research that this evidence should be as *internally valid* (Williams and May, 1996) as possible. It is for this reason that a qualitative approach has been utilised since it is though that such approaches, if done well, improve the likelihood that research respondents will be able to construct meanings that are valid to them within their specific social context. In other words, this quest for internal validity is not about seeking out an objective 'truth', but rather about asking respondents what *they* consider to be the truth. As Williams and May (1996) have commented:

> *In one sense, truth is put to one side and validity is considered to be that which is important to the respondent. (...) it is the reasons that people offer for what they do and the ways in which the meanings they use make sense of their lives that are of interest, not whether the basis of their beliefs are true as such.* (p.141-2)

The second empirical aim of this research is to introduce the voices of disabled people into two areas of sociology, citizenship and social movement theorising, in which the views of disabled people have, historically, been largely absent. For this reason a data collection method was chosen that was thought to encourage and enable disabled respondents to talk in depth about their experiences and their views are reproduced at some length within the thesis. In addition, in order that the views of respondents be accurately represented within this thesis a process of data analysis has been used that seeks to minimise the fracturing of texts and instead to maintain the narrative dimension of the data. Such a process also seeks to avoid overly interpreting respondents' views.

The final empirical aim of this research is to contribute to the development of the emancipatory research paradigm. To this end, this research has aimed both to empower individual respondents and through adding to knowledge in this area, to contribute to the empowerment of disabled people more generally. This is not to say, however, that this research has adhered to the model of emancipatory research espoused by authors such as Barnes (1996) or Oliver (1992). For Barnes (1996):

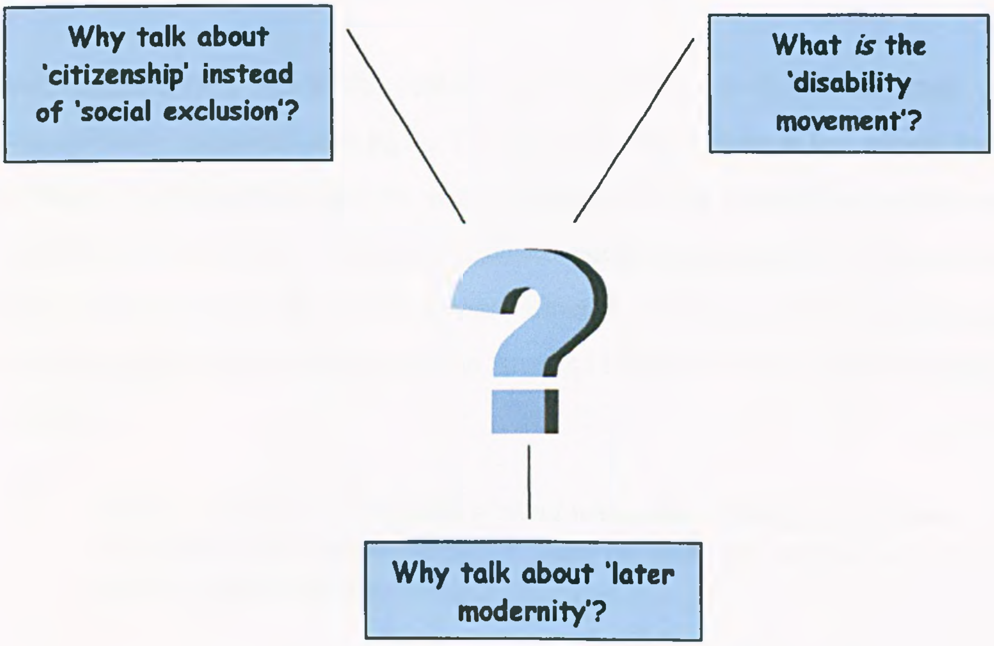
> *There is no haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed.* (p.110)

There are some major problems with this 'partisan' type of emancipatory research for there are risks that research carried out in this way may become value laden. This problem is likely to be heightened under circumstances in which researchers have personal experience of the issues they are studying and may feel justifiably angry about some of those issues. It is the argument here that this problem is impacting on the efficacy of a significant amount of research being produced within Disability Studies and thereby the soundness of some theorising in this field. It is a central argument of this thesis, therefore, that whilst the emancipatory research paradigm is of great importance epistemologically, it must be redefined if it is to become a major methodological approach. These empirical issues will be considered in more depth within chapter 2.

Before providing an over-view of the various chapters of this thesis it is important, however, to acknowledge a number of central ideas that underlie this research and about which this author maintains a particular standpoint.

Setting the Scene – an introduction to the key issues underlying this thesis

Underlying this thesis are three issues that need to be addressed within this opening chapter. These issues are as follows:



Why talk about citizenship not social exclusion?

In recent years, the term social exclusion has become somewhat of a 'buzz word' both in academic and non-academic circles in the UK. The importance currently being given to the idea is demonstrated by the Government's commitment to its 'Social Exclusion Unit', for example. Whilst the term may have become a 'buzz word' that is not, however, to deny its value, for it is a powerful way of expressing the fact that practices can exist in a society that have major consequences in terms of disadvantage for some of the people in that society. For some authors such as Jordan (1996) to talk about 'social exclusion', is arguably preferable to discussing citizenship since the past twenty years have witnessed the development of a dominant definition of citizenship that is highly individualist. He dismisses citizenship as a way of analysing social exclusion because the term has become all too associated with individual rights and duties, "*at the expense of interdependency and collective action.*" (Jordan, 1996: 85) For Byrne (1999) this problem with the term 'citizenship' has arisen because it: "*(...) has been formulated as a concept almost entirely in terms of abstract philosophical discussion rather than by reference to the real historical social politics* (...)" (p.24) He goes on to argue, convincingly, that this overly philosophical approach to theorising on citizenship has allowed for the appropriation of the concept by the New Right and other proponents of 'possessive individualism'.

It is certainly true that during the 1980's the term citizenship became linked in the minds of many with the writings of people such as Charles Murray (1990, 1994) and his notion of the 'underclass'. In this way, 'citizenship' as a concept became a political tool with which to categorise certain individuals and groups as 'failed citizens'. The term thus became far 'narrower' in definition than had historically been the case, and its transformative and collectivist properties appeared to have been largely forgotten.

As the end of the 20th Century approached, however, 'citizenship' again became fashionable and continues to be so. The reason for this resurgence in interest in citizenship is not entirely clear. One possible reason may be that sufficient time has now elapsed since the hey-day of the New Right, for citizenship to now have lost some of its individualist connotations. Many authors are now returning to the concept of citizenship as a way of explaining and mediating the changing relationships between the state and its population. Concern with governance, with the nature of the rights that form part of citizenship and with the extent to which the role of citizen is an 'active' one, have become 'hot-topics' again both inside and outside of academia.

Despite the resurgence of interest in the idea of citizenship, however, the risk that new work in this area may continue to be predominantly abstract and philosophical, remains. Indeed, some of the most recent work on citizenship theory by authors such as Delanty (2000) has been intensely philosophical. Whilst this philosophical work is of considerable value, there is now research currently taking place that is more empirically grounded in real social politics. This complementary theorising, grounded in evidence, is an important new step in the history of citizenship theorising. Dwyer (2000) for example, has moved discussions about social citizenship away from the purely theoretical level by making the practical concerns of citizens an integral part of current debates. Dwyer's work is just one example of a growing trend towards injecting the voices of presently marginalized groups into citizenship theorising.

The new approach to citizenship theorising, of which it is hoped this research will be a part, is not therefore, an alternative to theorising on 'social exclusion' but is instead about placing citizenship at the heart of discussions surrounding social inclusion and exclusion. It is the argument here that the 'ideal form of citizenship' is one in which each citizen is socially, politically and legally *included*. Evidence of disadvantage amongst those who are, officially, *'legally' included* suggests however, that many people are not being *'socially' or 'politically' included*. In other words when we talk about people being socially excluded, we are talking about people being excluded from important parts of citizenship. This having been said, the question facing theorists within this field must then be: what is the *basis* of the *social inclusion* dimension of citizenship? It is hoped that a consideration of the first question of this research will contribute to some degree to answering this question.

Why talk about 'later modernity'?

When this author uses the term 'later modernity' it is not without an awareness that it is a contested concept. The debate surrounding the term, however, appears to lie less with the idea that there has been a 'crisis in modernity' and more surrounding what epoch has come in its place. In other words the debate surrounds the relative appropriateness of the terms 'later modernity' and 'post-modernity'. Whilst it is not the intention here to engage with this debate in any great depth, since it warrants a fuller consideration than is possible within the confines of this thesis, it is important to explain why the term 'later modernity' is used throughout this research in preference to 'post-modernity'.

As previously stated, it is now widely, if not unanimously, accepted by sociologists that the past fifty years has witnessed such significant social, political, economic and cultural change as to cumulatively render the concept of *modernity* increasingly problematic. Opinions tend to differ, however, surrounding the extent to which there has truly been a movement *beyond* modernity. Many theorists favour the idea that what has occurred is a transition from modernity to late modernity, two factors being referred to most frequently as having brought about the greatest change. Firstly, there is what Ellison (1997) has referred to as changing patterns of social and political 'belonging' characterised by the disruption of 'traditional' social divisions (Ellison, 2000). Secondly, there is the impact of globalisation and the so-called demise of the nation state, factors considered in some depth by Roche (1995). The threat that such changes pose to the coherency of societies has become the chief concern of those who favour the notion of 'later modernity'. The concept of 'later modernity' does not, however, imply that at the current time the nation state has declined beyond importance, nor does it imply that there has been a total decline in the importance of older social divisions such as class.

In other words, to talk about 'later modernity' is to remain cautious about claiming an 'end to history', and to be sceptical about claims such as those made by one group of post-modern authors that:

> *Our world is being remade. Mass production, the mass consumer, the big city, big-brother state, the sprawling housing estate, and the nation-state are in decline: flexibility, diversity, differentiation, and mobility, communication, decentralisation and internationalisation are in the ascendant. In the process our own identities, our sense of self, our own subjectivities are being transformed. We are in transition to a new era.* (Hall et al, 1988)

It is the argument here that the world post-September 11th 2001 is not being *remade* in this way. The threat of global terrorism has, arguably, brought about the reinforcing of the power of certain nation-states, as demonstrated by the decision of the USA and the UK to go against the wishes of the UN in the recent war in Iraq. Such a climate of fear has also led to the further control of migration, as demonstrated by the current UK refugee 'crisis'. At the same time as this 'crack down' on global mobility is occurring, within the UK continuing problems of social exclusion suggests that despite rises in absolute social mobility, relative social mobility remains a problem. These issues, amongst others, convince this author that it may be premature to suggest that a post-modern era has arrived and that it may be better to utilise instead the idea of 'later modernity'.

What is the disability movement?

In his well-known introduction to sociology, Giddens (1993) has provided a useful 'broad-brush' definition of social movements as:

> *A large grouping of people who have become involved in seeking to accomplish, or to block, a process of social change.* (p.746)

In addition to his definition, drawing upon the work of Blumer ([1951] 1995) it is the argument here that the activities of social movements may not always be about social change, but may also be 'expressive' in nature. The combination then of these two broad definitions has provided the basis, within this thesis, of categorising the various *episodes* of collective action by disabled people as the 'disability movement'. As will become apparent within the subsequent chapters of this thesis, however, a certain degree of diversity in terms of aim and action between the various constituent groups and individual members of the disability movement is something that characterises this movement. On the basis of such diversity some might question the idea that a social movement of disabled people truly exists. It is the argument here, however, that many widely recognised social movements are equally diverse, the women's movement being a prime example. Total homogeneity in terms of all aims and forms of action is not, therefore, something that needs to be considered as a defining feature of a social movement[1]. There does, however, need to be some common ground between the various individuals and groups that comprise a movement. Just as the various strands of the women's movement can be seen to be united on the basis of such things as a shared understanding of the need to challenge pre-conceived ideas about women, so the various strands of the disability movement are united in their view that we live in a 'disabling society' in which many people with impairments are socially excluded in a number of ways.

Having established this fairly loose framework with which to define the 'disability movement', determining a *coherent* body of disability groups or disabled individuals who can be considered to be a part of this movement is more difficult. This difficulty arises because many groups who might easily be categorised from an 'outsider' perspective as being a part of a movement network do not appear to see themselves as firmly connected to the disability movement. It is at this point that it should be stated that it is not the intention of this research to consider the history of the disability movement, but rather to provide a 'snap-shot' of the contemporary movement. It is the position of this thesis that in order to remain focused on the particular research aims of this project, emphasis should be given to a comparison between the definitions of the contemporary movement

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[1] In this way, the author is making no distinction between episodes of collective action such as the disability rights campaigns/movement of the 1970's and more contemporary expressions of collective action by disabled people. According to this somewhat 'loose' framework for defining a social movement, the fact that the nature and basis of collective action may alter somewhat, over time, does not mean that successive action by a recognised collective should not be considered to be a part of a larger phenomenon – a social movement.

provided by key academics in the field and the evidence collected within this research regarding the *actual* nature of the movement. This is not to deny that a consideration of the development of the disability movement over time is an interesting one, or that this history is of no relevance to this research. The history, however, of the formation and subsequent tensions between the Disablement Income Group, the Disability Alliance and the Union of Physically Impaired Against Segregation (UPIAS), for example, has been well-documented by authors such as Oliver (1990, 1996) and Finkelstein (1993b). The important point about the history of the disability movement in relation to this research, however, is that in the UK, the development of the social model of disability by organisations such as UPIAS has been closely linked to a range of disability rights campaigns carried out by the movement. It is precisely such campaigns that, amongst other issues, have called for the funding of organisations *of* rather than *for* disabled people.

Oliver's (1997) definition of the disability movement as being constituted *only* by organisations *of* disabled people, not organisations *for* disabled people, therefore reflects the campaigns of the disability movement of the past and present[2]. In the light of this tension, and on the basis of Oliver's definition, it was, therefore, decided that only groups run by disabled people themselves would be contacted about this research. As a final point, however, it is important to state that this research did not take as its starting point Oliver's tendency to equate the disability movement with the constituent member groups of the BCODP[3]. This decision was made on the basis of pre-existing links within the field which informed this author that the BCODP does not encompass all groups run *by*

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[2] That this issue of the need for disability organisations to be run *by* disabled people not *for* disabled people remains central to the campaigns of the disability movement is shown by criticisms directed against the Disability Rights Commission:

> The Disability Rights Commission (DRC) was a positive outcome of Labour's review of disabled people's rights, to help to enforce the DDA. However, the commission is not the voice of disabled people - commissioners are appointed by the government, not by disabled people, and some bodies who should consult disabled people consult the DRC instead, believing that is sufficient. (Rickell, 2003: <http:www.guardian.co.uk/comment/story/o,3604,1053066,00.html> viewed on 08/02/04)

[3] British Council of Disabled People.

disabled people, *for* disabled people and that there is considerable debate amongst disabled people surrounding the importance of this organisation. Further discussion surrounding the nature of the groups contacted about this research will be provided in chapter 2.

Overview of chapters

Chapter 2 Methodology

This chapter considers the various theoretical, ethical and practical issues surrounding the empirical aspects of this research. From a theoretical perspective it is argued that this research is 'critical-abductive' in approach. The nature of 'critical-abductive' research is discussed with particular reference to the similarities and differences between the approach and that of grounded theory and critical theory. This chapter also considers the ethical dilemmas encountered during the process of this research, particularly those relating to the role of a non-disabled researcher engaging in disability research. In terms of practical issues, the final section of chapter 2 provides discussion relating to such matters as the use of focus/discussion groups, the management and analysis of data and the process of feedback to respondents.

Chapter 3 Citizenship

This chapter aims to provide a critical outline of those theories of citizenship that relate most clearly to the focus of this research. It is also the aim of this chapter to introduce the most contemporary debates within the field that will then be considered in more depth as they relate to the findings of this research, in chapter 7. The chapter begins with a critical appraisal of the ancient and classical theories of citizenship. Particular attention is given within this section of the chapter to the work of Hobbes, Locke and Rousseau since the influence of their ideas upon subsequent theorising has been profound. The discussion then moves on to consider the Conservative Neo-Liberalism of Nozick and Hayek, and the Neo-Republicanism of authors such as Arendt, Barber and Oldfield. The second section of this chapter considers the modern or Social-Liberal theories of citizenship provided by Rawls, Marshall and Berlin. This section highlights the importance of Berlin's work to citizenship theorising and argues for greater consideration of his work by sociologists working in this field. The final section of this chapter provides a critical outline of the most contemporary theories of citizenship. The pluralist accounts of Kymlicka and Young are considered in this section of the chapter, as is Habermas' reflexive approach and Mouffe's more post-structural account. The chapter concludes with a reflection upon the future of citizenship theorising and introduces the argument in favour of a more embodied notion of citizenship.

Chapter 4 Disability in Society, Today

This chapter aims to provide the reader with an overview of the position of disabled people in society, today and of the theorising that has sought to explain the experience of disability. The first section of this chapter provides the reader with an overview of the current state of theorising on disability. The work of Parsons and Goffman is considered as an important precursor of more contemporary theorising. The somewhat different theoretical approaches taken by medical sociology and disability studies are then discussed. Having introduced the main theoretical approaches to disability within the first part of this chapter, the aim of the second section is to consider the empirical evidence to support the widely accepted notion that disabled people occupy a position in society that is characterised by discrimination and disadvantage. Given the extent of this empirical evidence, however, it would be impossible within the confines of this chapter, or thesis, to adequately consider all issues. For this reason, two key areas have been chosen, and it is hoped that these will, when considered together, provide the reader with an overview of the current position of disabled people within society. These two areas are: equal opportunities: and the 'coming out' of disability.

Chapter 5 Social Movements

This chapter begins by considering what this author considers to be the most important early, or first phase social movement theories. This 'first phase' can be divided into an American and a European tradition. The first phase of the American tradition centred on the Collective Behaviour approach to social movements, and is best exemplified in the work of Herbert Blumer. The first phase theories in the European tradition are less clearly associated with particular theorists but can be broadly termed a Social Democratic tradition and can be sub-divided into Weberian and Marxist approaches. These approaches will be briefly discussed before a consideration of what is meant by the notion of the '1960's watershed' and what effects it has had upon subsequent theorizing. The second section of this chapter then aims to provide the reader with an overview of the 'second phase theories'. This second phase of theorising can also be divided into American and European traditions. In the American tradition, post-1960's theorizing has been dominated by the Resource Mobilization theories. It is argued within this chapter that the Political Process theories should be considered as being a part of this resource mobilization approach and therefore, these theories are also considered at this point. In post-1960's Europe a number of related theories emerged based around notions of identity, defence of the 'lifeworld', values and culture. These approaches can be rather loosely termed as the 'new' social movement theories and the work of the key authors in this field, Touraine, Habermas and Melucci are considered in turn within this section.

The chapter concludes by considering the future for social movement theorising and proposes that there are two important inter-related questions that are, as yet, unresolved within social movement theorising. The first question relates to the appropriateness of the idea of '1960's watershed': *what was so fundamentally different about the movements that came after this 'watershed' in comparison to those that came before?* The second question relates to understanding the nature of 'unrest': *has the nature of unrest really moved so significantly away from older concerns with structural inequalities as to render the older social movements theories largely redundant?* Possible answers to both of these questions are proposed within the concluding section of this chapter. An even more critical analysis of certain theories introduced within this chapter will then be made in relation to the findings of this research, within chapter 7.

Chapter 6 Findings

This chapter sets out the key findings of this research as they relate to the following major issues: structural issues; disabling attitudes-enabling identities; disability culture; and the disability movement. As previously stated, one of the central aims of this research has been to provide a platform for the voices of disabled people and it is in this chapter that these voices are most apparent, for respondents are quoted extensively. The analysis that forms part of this chapter then forms the basis for the more theoretical consideration of the findings in chapter 7.

Chapter 7 Reconsidering Theorising on Citizenship and Social Movements in the light of Disability

This chapter considers the appropriateness of the modern/contemporary theories of citizenship in the light of the findings of this research and proposes that a consideration of the 'struggle' faced by disabled people can illuminate useful links between citizenship theorizing and current approaches to social movements. Particular attention is given in this chapter to the important links between the work of Berlin, Habermas, and Mouffe; to the value of Ellison's ideas about 'proactive and defensive engagement'; and to Turner's 'sociology of the body'. The chapter concludes by proposing that a synthesis of the ideas of these theorists may provide the starting point for a new understanding of citizenship and the process of engagement, according to an understanding of 'personhood' as *fragile and contingent.*

Chapter 2

Methodology

The aim of this chapter is to consider the various practical, theoretical and ethical issues surrounding the empirical aspect of this research. For reasons of clarity, the chapter is subdivided into three sections as follows:

1. **Theoretical Issues**
   The first section will consider the theoretical basis of the research. Discussions upon the *abductive* approach taken by the research and other ontological and epistemological issues will be considered in this section.

2. **Ethical Issues**
   The second section will consider the ethical dilemmas encountered during the process of this research, in particular those issues faced by a *non-disabled* researcher when undertaking disability research. This section will also include some critical reflections upon the process of the research.

3. **Practical Issues**
   The final section will consider some of the practical issues of the research, namely: the use of focus/discussion groups; the management and analysis of data; and the process of feedback to respondents.

Theoretical Issues

The main aims of this research have been:

- *To elicit the views of a number of disabled people who are members of disability organisations, upon a range of issues related to the concept of 'citizenship'.*

- *To allow their opinions to become a part of the ongoing debates surrounding the concept of 'citizenship'.*

Initially, grounded theory appeared to be the most suitable research strategy to employ in order to achieve these goals. There are however, some well documented limitations to the grounded theory approach in terms of its reliance upon *inductive* reasoning. These limitations will be discussed later in this chapter. In the light of the criticisms directed at grounded theory, however, an alternative approach was sought. After considerable investigation, the *abductive* research strategy was thought to be a *preferable,* if not entirely unproblematic, alternative. The abductive research strategy stems from the work of C.S.Peirce (1867/1960), although the extent to which this research relies upon more contemporary versions of his model should be stressed. For Peirce, abductive research relies upon a certain type of intuition on the part of the researcher in which he/she observe the world with appropriate categories which arise from the internal structure of meanings. In other words, Peirce argued that when a researcher analyses data it is not necessary or desirable for every possible explanation to be explored. Time constraints mean that if a piece of research is to be completed, it is not always possible to falsify every possibility. Instead, Peirce argued, abductive research involves the observation of evidence by minds furnished with *appropriate ideas,* and therefore, the minds of a trained sociologist will tend to make different judgements than those of individuals who are not trained sociologists. In other words, the abductive method is not about hasty thinking, or about being completely naïve to such things as previous research in the field.

For Peirce, abductive inferences take the following form:

A) all counters from bag X are green
B) these counters are green
C) therefore these counters are from bag X

As he admits, however, such reasoning is not always logically valid. Further, critics have commented that it is very difficult to see how Peirce's definition of abductive inferences can be applied to social science reasoning since human beings are not inanimate objects, but have *feelings*. Peirce's definition does not include room for the question "*how do the green counters feel?*" since this would clearly be ridiculous. When the objects being studied are human beings, however, such a question is key to the validity of the research. More recently, therefore, the idea of abductive reasoning has moved on from Peirce's definition and has been redefined as meaning the '*inference to the best explanation*' (Lipton, 1993). This type of abductive reasoning can be applied more easily to sociological investigation and it is this definition of abductive reasoning that applies to this research, for it is the contention here that all that can ever be achieved in sociology is the development of *probable* explanations for social phenomena. In this way, the abductive research method rejects the positivism of both deduction and induction.

Within Sociology the abductive approach is evident in the work of Mead and Dewey, within phenomenological and ethnomethodological research and within other approaches that use interpretivistic ontological and epistemological elements such as feminist research and critical theory. Blaikie (1993) has most recently defined the sociological version of abductive research thus:

> *(...) the process used to produce social science accounts of social life by drawing on the concepts and meanings used by social actors and the activities in which they engage.* (p.176)

This is an approach, therefore, that gives a central place to the views of the 'insiders' and as such has clear ontological implications for it rests upon an understanding of the social world as being *that which is perceived and experienced by its members from the 'inside'*. The abductive research strategy therefore rejects the notion that the researcher's role is to impose 'outsider' views upon the data. This stance must also, therefore, have some clear epistemological implications. In particular, since much activity in social life is taken-for-granted and is not reflected upon by actors, it is not easy to see how *meaningful* knowledge can result from observations of such mundane occurances. Blaikie

(1993), has, however, proposed that meaningful knowledge can result from the abductive approach providing that the following method is utilised:

Everyday concepts and meanings

provide the basis for

Social action/interaction

about which

Social Actors can give accounts

From which

Social Scientific descriptions can be made

From which
Social Theories can be generated

OR

And understood in terms of
Social Theories or perspectives
(Blaikie, 1993: 177)

Figure 2a.

In other words, this is a method of research that begins by seeking to encourage actors to reflect upon their activities and thus 'give accounts' for their actions. For Blaikie (1993) the role of the researcher is then to transfer these accounts into 'social science descriptions'. At which level, he claims, it is perfectly legitimate to conclude the research. Equally, however, much abductive research will go on to a second level, to form social theories from the data or to relate the findings to existing perspectives.

The process of this research echoes Blaikie's model, and advances to the second level, for it seeks to compare findings from the research with existing perspectives on citizenship. In so doing, it points to the need for renewed theorising in this area. Having stated the above, however, this may give the misleading impression that the research was *theory led*. This is an important point because to follow the abductive approach, as this research attempted to do, is to follow a carefully ordered method, with *theory* only entering into the final, and optional level. In this respect, the abductive research approach does rely upon methods developed by *inductive* research such as grounded theory. It should be stated, however, that there are some important distinctions between the two approaches.

The term 'grounded theory' normally refers to theory that has been developed *inductively* from a dataset. If grounded theory is done well, it is claimed that the resulting theory should be valid at least in terms of fitting one set of data perfectly. Key to this approach is the idea that the researcher should enter the field as an almost 'naïve' data gatherer (see also Kvale, 1996) in order to avoid running the risk of becoming constrained by the existing perspectives. To embark upon a piece of grounded theory research is therefore, to begin by observing and noting the observable social phenomena occurring within a given context. The researcher will, however, rapidly begin to identify key issues. As categories and themes become clearer, so some almost subconscious analysis may occur within the mind of the researcher, at the same time as the process of data collection continues. This may impact upon the nature of the research as it unfolds. According to Glaser and Strauss (1968), who are widely acknowledged to be the founding fathers of the grounded theory approach, there is also a process in the development of the theories that result from this data collection. Initially, they claim, *substantive theories* emerge, which are seen to be appropriate to the particular context being studied. Eventually, however, the process of theorising from the data will result in *formal theories,* which possess a higher level of generality and which can be applied to more than one substantive area.

There are, however, some important problems with this type of thinking. Firstly in relation to the idea that 'facts speak for themselves' and that it is possible for a researcher to stand back from observed events as a neutral/naive observer, critics of the approach have suggested that since all observation involves *interpretation,* that it will, therefore, always be theory-laden to some extent.[1] Abductive research whilst employing some of the *methods* of inductive research in terms of data collection and coding (as will be discussed later in the practical issues section)

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[1] For further discussion on this see Balihar Sanghera's website:

differs from the inductive method because it does not claim that it is either possible or desirable to be completely 'naïve' when gathering date in the field. Drawing on this abductive approach, it is the argument here, therefore, that in reality, most researchers will be familiar to some degree with previous research that has been done in the area and that to be intuitive requires the researcher to make use of a pre-existing 'vocabulary' of understanding which they then bring to bear on the findings. Rather than suggesting an alternative to the inductive approach, therefore, the question posed by this research is whether it is ever possible to be entirely 'naïve' when engaging in social research? In other words, is the inductive method ever really possible?

Critics of the inductive approach have also pointed out that no matter how confident we might feel about the correlation between observed events we can never entirely conclude the nature of the causality. This problem means that it will always be difficult to establish a logical way of determining the true validity of universal statements from particular statements, or as grounded theorists would term it, a formal theory from a substantive theory. This issue has not been adequately tackled by grounded theorists. In the light of this, the abductive approach's reliance upon '*inference to the best explanation*' is useful because it allows for the transformation of a substantive theory into a formal theory whilst at the same time making no claims to a *definitive* explanation. That having been said, it is not the argument here that the abductive method produces theory that will always be easily disputed, for the strength of this process is that at all times the theory is intimately linked to the data.

With such a firm connection to the data, there is also one other important benefit to researching in this way: unless the researcher develops overly abstract terms for recurring themes the resulting theories should not prove to be inaccessible to the social actors in question. This is an important point when the research being carried out involves working with vulnerable or disadvantaged people, as in this thesis. Since it was considered to be ethically important that this piece of research be of use to disabled people and accurately reflect their 'voices', an abductive research strategy was thought to be the most appropriate.

Establishing some somewhat unfocused, initial aims was the first stage of the process of this research. As previously stated in chapter 1, these aims were: *To elicit the views of a number of disabled people who are members of disability organisations, upon a range of issues related to the concept of 'citizenship'; and to allow their opinions to become a part of the ongoing debates surrounding the concept of 'citizenship'.* The next stage was to use these broadly defined aims to develop an interview framework with which to loosely structure dialogue, in this case in the form of group discussions, with members of a number of disability organisations. This framework took the form of a series of questions that were sent in advance to each of the participating organisations. The questions were wide-ranging in style from fairly straightforward to more abstract and were essentially unfocused with regard to particular issues.

The questions aimed to encourage discussion on a variety of issues, all of which, it was initially believed, might bear some relation to the wider citizenship debates. The research did not begin, however, with any underlying preconceptions concerning which aspects, if any, of the citizenship debates would of greatest relevance to disabled people. Indeed, in the covering letter that accompanied the questions it was made clear that these questions were only meant to be a guide to the discussion, and only indicated the general area of the research. *Please see Figure 2b for examples of some of the questions sent to groups.* [2] *Please also see the appendix for copies of the full list of questions and covering letter.* At the start of each group discussion it was also made clear that respondents were encouraged to pick out those questions that most interested them. Alternatively, if, having understood the general area of interest, respondents wished to suggest other questions or issues for discussion, this was also encouraged. The power to identify key issues was, therefore, given to respondents, and their identification of these issues as 'of importance' is considered to be central to the claim that *meaningful knowledge* had been produced within this research.

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[2] The actual layout of the questions that were sent in advance to participating organisations was slightly different in terms of providing space for any answers and using a larger typeface. The version sent to participating organisations can be found in the appendix.

Figure 2b.

Section B

1. What would you say was the central function/s of .... for example, group support/campaigning etc?

2. What would you say were the central hopes/aims of your organisation?

3. Has your organisations been involved in any campaigning, for example, for rights for disabled people? If "yes", could you give me any examples?

4.a. Would you say that campaigning is a significant part of the function of your organisation?

b. If the answer to the previous question is "no" – what reasons do you have for working in alternative ways?

5. What do you regard as the major achievements of your organisation?

Section F

4. Is there such a thing as a 'disability identity'?

5. If there is a 'disability identity', what kind of image exists of disabled people and what is it like to experience this identity?

6. Is there such a thing as a 'culture of disabled people'? Do you find this a realistic concept?

7. Is it helpful/useful to talk about a 'disabled culture'? If so, why? If not, why not?

Following the first round of group discussions at six disability organisations, held between late August 2000 and early February 2001, initial analysis of the transcripts highlighted one key theme arising from each of the discussion, this related to the idea of a 'disability identity'[3] and how this was linked to such issues as the 'self', language, respect, the nature of rights being claimed by disabled people, and a disability culture. At this point in the research some initial analysis of the data took place. The methods used in this analysis will be discussed later in this chapter. A paper was written at this time, and was given at the *Seventh International Conference on Alternative Futures and Popular Protest,* held at the Manchester Metropolitan University. This was an important stage of the research because it resulted in a clear focus being established for a second round of group discussions with two of the organisations that had expressed a wish to engage in further dialogue.

After the first round of group discussions one further issue also arose and this concerned the absence from any of the participating organisations, of disabled people from ethnic minorities, Deaf/deaf people, or people with mental health issues. This absence led to inevitable questioning of whether this was a chance occurrence, or whether such individuals were, for some reason, not a part of the disability movement. Since the most striking theme arising from the first round of group discussions surrounded the issue of identity, it was important to investigate whether the absence of these individuals from disability organisations was connected in any way to the idea of the 'disability identity'. It was considered important to establish whether the absence of such individuals was because they did not feel themselves to be welcome within the disability movement, or because they did not regard themselves to be disabled people. Since research time was limited, it was decided that further investigation would be made into the apparent absence of Deaf/deaf people[4] from such disability organisations. To achieve this, a letter and series of questions was posted onto the web-based mail group:

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[3] The following definitions are used throughout this research:
'Disability identity' – is used to denote the political identity of disabled people that is key to *disability politics.*
'Disabled identity' – is used as a shorthand for: 'those who have been categorised or labelled as having a disability'.

[4] Throughout this research, the word 'deaf' is used to refer to those people who experience the physical impairment of deafness, but who do not regard themselves as being a part of the culture of Deaf people. The word 'Deaf', therefore, refers to those individuals who aspire to British Sign Language usage and its related cultural heritage.

"Deafmail". (*Please see Figure 2c for the list of questions and the appendix for a complete copy of the "Deafmail" posting.)*

Figure 2c.

"Deafmail" questions:

Are Deaf people *disabled*?

Are Deaf people a part of a disability movement? If "no", could you tell me why this is so? If "yes", do you personally feel a part of a disability movement?

Do you feel a part of a Deaf community? If "yes", how is this different from your experiences within the hearing community?

Is there a Deaf identity and/or a Deaf culture that is different from those of hearing people?

Have any important improvements been made in the lives of Deaf people in your lifetimes? What do you feel has brought these changes about?

Are there any improvements that need to be made in the lives of Deaf people and how could these be brought about?

Do you have any concerns for the future in relation to the lives of Deaf people? What could we do to stop these things happening?

How do you see the new developments in technology effecting Deaf people?
For example, advances in knowledge surrounding genetics?

The second stage of group discussions, and the collation of the responses to the "Deafmail" questions, took place between late February 2001 and the end of April 2001. This marked the end of the process of data collection. The next part of the research was to review all of the data gathered and to advance the analysis of the findings beyond that undertaken after the first round of interviews. As in the early analysis this took the form of gaining familiarity with the text of the group interviews, establishing social science descriptions of the key issues arising form the discussions and then relating this to existing citizenship theories. In the case of this second phase of analysis, however, this process was more thorough. In this respect, therefore, the process of this research clearly echoes Blaikie's model of abductive research in that it moved from social scientific descriptions, to an attempt to understand the findings in relation to existing perspectives. When, however, at the completion of this more thorough analysis, it was found that none of the existing perspectives adequately fitted the data, some tentative steps were taken towards developing a new theory. The data resulting from this research has clearly demonstrated that there is a need for a more fluid and dynamic understanding of citizenship in relation to the experiences of disabled people. Chapter 6 provides a more detailed explanation of the particular findings of this research. In the concluding chapter, however, some tentative steps have been taken towards more formal or universal theorising, since it is proposed that there is a need for a more fluid and dynamic understanding of *personhood* as the basis for citizenship.

The last part of the research involved a process of feedback to each of the participating groups. In each case, either a transcript, or detailed minutes from the meeting, or *both*, depending upon the wishes of the group members, was sent to each organisation. *Figure 2d provides further details of these minutes and transcripts.*

Figure 2d.

Groups for which transcripts were written and length of transcript:

Disability Action South Lakeland *Transcript*: 9,264 words
Disability Association Carlisle and Eden *Transcript*: 14,126 words

Lancaster Disablement Information and Support Centre
Transcript meeting 1: 8,723 words
Transcript meeting 2: 5,995 words

Deafmail responses transcript: 10,391 words

Groups for which minutes were written and length of minutes:

Sheffield Forum of People with Disabilities
Minutes Meeting 1: 2,568 words
Minutes Meeting 2: 2,792 words

Arthritis Care Support Group Carlisle *Minutes*: 1,936 words

Group for which minutes <u>and</u> transcript were written and length of these documents:

Speaking Up For Action
Minutes: 2,045 words
Transcript: 11,615 words

This was then followed by the sending of a document outlining the key findings of the research, and in some cases by a further 'informal' visit to each group in which the findings were discussed. Whilst this final aspect of the research may at first glance appear to be more of an issue of ethical good practice, there is one other important reason for engaging in this process. As previously stated one of the important advantages of using an abductive approach is that because such research relies upon tapping into 'lay' accounts of attitudes to, and experiences of citizenship, and maintains a firm link with this data at all times, then the resulting theories should not and *ought* not, be inaccessible to the respondents. In this manner, it was hoped that the respondents would consider the research to be *valid at the level of meaning* and in this way the research would have 'emancipatory' properties.

Having stated the above, however, it is important to make a clear distinction between the approach taken in this research and that of the form of 'emancipatory research' often employed within Disability Studies. Critical theory has greatly influenced Disability Studies' preference for social theory that has been generated by research and is so interlinked with social practice, that the truth or falsity of the theory can be partially determined by whether it can be transformed into action. In other words according to the model of emancipatory research often employed within Disability Studies, for research to be emancipatory, it must affect praxis within the marginalized group. It is the argument here, however, that in order for a piece of research to have 'emancipatory' properties, such an outcome in terms of praxis is not necessary.

There are some persuasive arguments that suggest that it may be wrong to judge emancipatory knowledge only in terms of the pragmatic criterion of contribution to praxis. For Alvesson and Sköldberg (2000):

> *Identifiable outcomes in this respect – have people managed to free themselves from constraints? has suffering been abolished – may not be a good criterion for assessing the value of knowledge, as the latter's relationship to social action and practical accomplishments are never simple or straightforward. An insightful study does not necessarily affect praxis in a distinct way. (p.126)*

Further, Alvesson and Sköldberg (2000) suggest that it might be possible to achieve a minimal version of critical research according to which research may not have entirely 'failed' in terms of critical theory.

> *A possible role for critical theory – as an example of a problem-identifying, questioning, research position – could be to counteract any (...) unconscious reinforcement of existing society's hold over thinking. Critical self-reflection thus has a limited emancipatory purpose, which is more about trying to prevent research from contributing to dominance and less about directly overcoming it.* (p.129)

It has been the aim of this research to fulfil these criteria as set out by Alvesson and Sköldberg. It is for this reason that it is proposed that the term *critical-abductive*, may be a legitimate description of this research.

Ethical Issues

As previously stated, there has been much discussion within Disability Studies about the need for research in this field to be *emancipatory*. There appears to be widespread agreement that a new and improved research strategy is needed within the field, since disabled people themselves have highlighted the historically important role that disability research has played in the oppression of disabled people (Barnes, 1996). Indeed, some disabled people have "*constructed their experience at the hands of traditional, non-disabled, researchers as 'research victims'*." (Lloyd et al, 1996: 305). The expression of such experiences has provided a clear imperative for the development of more ethically sound research practices. There is less agreement, however, surrounding the form that this ethical disability research should take. Indeed, as a series of articles within the past 6/7 year's editions of the journal *Disability and Society* demonstrate, the issue of how best to engage in ethical disability research is not easily resolved and can be a highly emotive subject both for disabled people as research subjects and for researchers in this field.

In the light of the emotive and important nature of these debates, it would be impossible to avoid engaging in some discussion surrounding the central issues as they relate to this research. The following section of this chapter will consider these issues. The ethical section will then conclude with brief statement surrounding the adherence of this research to the British Sociological Association's "*Ethical Guidelines*"[5] and "*Guidelines for Non-Disablist Language*"[6].

The 'Independent Researcher' and the issue of emancipatory outcomes

In 1996 an article by Colin Barnes appeared in the journal *Disability and Society*, it was entitled: "Disability and the Myth of the Independent Researcher". In this article Barnes considered whether it was possible, or more importantly *desirable*, for researchers in the field of disability to remain independent from the aims of the wider disability movement. He concluded that:

> *If disability research is about researching oppression, and I would argue that it is, then researchers should not be professing 'mythical independence' to disabled people, but joining with them in their struggles to confront and overcome this oppression. Researchers should be espousing commitment not value freedom, engagement not objectivity, and solidarity not independence. There is no haven or middle ground when researching oppression: academics and researchers can only be with the oppressors or with the oppressed.* (Barnes, 1996: 110)

In calling for this 'partisan' approach to disability research, Barnes echoes much of the writing of Mike Oliver on the emancipatory research paradigm within Disability Studies. For Oliver (1992) disability research, in addition to consulting seriously with disabled people, must seek to address the mechanisms for influencing policy. Unless research in this field is linked into policy-making structures so as to influence outcomes directly, then there is a risk that the research may constitute an abuse of involvement for the disabled people who have participated in the project. Oliver is quite clear in his belief that disability research must advance beyond merely providing information that informs decision-making, to a position in which it provides the basis for important shifts in power. He is equally clear in his belief that good disability research must not be about the advancement of the career of the researcher, but rather about changing the lives of disabled people.

In this regard, Barnes and Oliver have provided a powerful argument in support of an approach to disability research that owes much to the Critical Theory research paradigm outlined in the first section of this chapter. Their views have not, however, gone unchallenged. During 1996, again in the journal *Disability and Society*, two articles appeared, both of which expressed the authors' concerns with the out-and-out rejection of independence within research. In the first of these articles, Mike Bury (1996) countered some aspects of Colin Barnes' notion that academics must either be with the oppressors or with the oppressed. For Bury, to strive for independence does not mean that the researcher must possess a complete absence of commitment or accountability. Indeed, he argues that independence can mean quite the opposite, for many social researchers may be very committed to revealing social inequalities, the successes or failures of certain social policies, or disparities in power. Remaining 'independent' for Bury (1996), however, means that there must "*always be room for argument and counter argument, and crucially for researchers, to reveal matters that may be uncomfortable, for specific interest groups and even those funding the research.*" (p.112) He goes on to argue that:

> *The idea that a particular section of the disability movement should control the research agenda on a 'you are either for us or against us' basis as the final comment in Colin's article implies, sounds like a thinly veiled threat. For example, research on representative samples of disabled people might reveal that relatively few subscribe to the 'oppression' theory of disability, or find it relevant to their everyday experiences. Or research might reveal that activists identify with it more than others. (...) would Colin object to see negative as well as positive findings emerge from such research?* (Bury, 1996: 113)

Bury's fear that an 'orthodoxy' was being established within Disability Studies was echoed by Tom Shakespeare (1996), in the second of the 'opposing' articles. In his article Shakespeare writes with candour about his own research and admits to engaging in research practices and to possessing certain views that many within Disability Studies would fine 'challenging'. He begins by questioning the notion that there needs to be a formalised connection between Disability Studies and the disability movement. He highlights the fact that in the case of lesbian and gay studies the connection between the discipline and the lesbian and gay political movement has been much less formalised, and indeed there has been dissent amongst some academics in the field from the 'orthodoxy' of the movement. What has been vital, however, to the development of lesbian and gay studies, is, according to Shakespeare, that whilst commitment has been clear, accountability has been more diffuse. Relating this to Disability Studies, Shakespeare (1996) states that in his opinion "*there is a difference between accountability to one's research subjects, and accountability to the disability movement or specific organisations within it.*" (p.249) Further, Shakespeare (1996) states that:

> *"I have major reservations with the concept of emancipatory research (...) I am cynical about the possibility of research achieving major change (...) Ideas clearly have a role, but actions decide the day, and while it is possible to make the research process more balanced, grandiose claims for its revolutionary potential seem to me to be over-optimistic. Furthermore, whilst few would now argue in terms of objectivity, a notional independence and balance is still seen as critical to the academic endeavor. Given the political context, there is little point in developing progressive research which is rejected out of hand by government and media alike as being contaminated by ideological prejudice (...) academics cannot be perceived to have axes to grind."* (p.252)

At first glance this statement might appear to be a rejection of the emancipatory approach to research on the basis of some fairly practical concerns, i.e. that research that is perceived to be partisan will not have as much influence upon policy makers. In fact, Shakespeare clearly has some more profound difficulties with the notion that praxis must always be an essential part of disability research. He comments that he does not think that all research should be judged on instrumental grounds. Whilst he does not believe that researchers should have *carte blanche* to "*parasite disabled people's experiences and develop careers on the back of disabled people's lives*" (Shakespeare, 1996: 253), he nevertheless defends the rights of researchers to undertake research and to develop theory for its own sake. Equally, he also rejects the idea that for research to have emancipatory outcomes, that the findings must, therefore, be accessible and immediately comprehensible to disabled people. According to Shakespeare, if Disability Studies is to truly engage in a sociological understanding of disability it will have to make use of complex ideas and analyses which may be quite difficult to grasp. It is important he believes, to acknowledge within theory the "*often complex, nuanced and difficult*" (Shakespeare, 1996: 252) nature of social reality. Social research cannot always be therefore, simple and transparent in order to facilitate praxis. In arguing thus, Shakespeare is clearly at odds with Barnes and Oliver who have suggested that the only legitimate role for disability research is to produce knowledge that can be easily used by disabled people to challenge disablism within society and bring about positive changes in their lives.

With regard to this research considerable effort was made to follow the guidelines for good research practice as set out by authors such as Barnes and Oliver. For example, as already discussed, this research did consult seriously with disabled people and aimed to represent their views fairly; the respondents were given the opportunity to ask questions about the research and to identify key issues that they wished to discuss; feedback was given at each stage of the research to provide respondents with the opportunity to revise, or add to their existing comments; a more informal and less tightly structured interview technique was utilised in order that respondents should be enabled to truly speak out about issue in their lives; the comments of respondents have been reproduced in this thesis verbatim, and have been given a prominent position within the findings chapter; the author has remained accessible and accountable to research respondents through-out the research.

Finally, with regard to the nature of the theory generated by the research, and in contrast to Shakespeare's view, a stance was taken that as far as possible, the majority of respondents must be able to understand the theories resulting from the research and even more importantly, how the theories were generated. It was thought that the first stage of this process was to ensure that all participating organisations received a record of their meeting. This was important because it allowed respondents to consider what had been their responses to the research questions, and to draw their own conclusions about how their views might inform the research. In the second document sent to each organisation, in which the findings of the whole research was outlined and in which verbatim quotations from many respondents have a prominent position, it was hoped that each respondent would be able to see how their views 'fitted into' the overall conclusion. The feedback process will be considered in more depth later in this chapter.

Despite these important aspects of the research, however, certain aspects of this project do not seem to fit directly within the emancipatory approach as set out by Barnes and Oliver. Whilst in the initial stages of this research this was a matter of some concern, by the end of the research this concern was less about the potential for criticism of the research and more about the need to question some of the existing research 'orthodoxies'. As has already been stated, this research does not have the clear emancipatory outcomes as described by Oliver (1992), since it is not tied into policy-making structures. In the light of what might be viewed by authors such as Oliver as a failing on the part of this research, Tom Shakespeare's reservations concerning the emancipatory approach to disability research and his subsequent defence of research which seeks to 'develop theory for its own sake' is, at first glance, reassuring, for he offers a way out for researchers who are finding it difficult to identify clear emancipatory outcomes in their work. One of the arguments put forward in this research, however, is that it is not always necessary to seek this way out. Indeed, whilst I share Shakespeare's unease concerning the orthodoxy within disability research, it is possible to argue that his analysis of the alternative is not entirely convincing. Arguably, no sociological theory is, or should be, only of value in itself.

Sociologists have long prided themselves on their critical role in society. As Giddens (1993) has commented:

> *No sociologically sophisticated person can be unaware of the inequalities that exist in the world today, the lack of social justice in many social situations or the deprivations suffered by millions of people. It would be strange if sociologists did not take sides on practical issues...* (p. 23)

The history of sociology demonstrates that understanding differences, concern with social inequalities and/or the potential for social change, are major and honourable parts of what sociology is *about.* Whilst much of this sociology is not tied directly to the formulation of a particular policy, that is not to say that sociological theory has no influence upon society. Within Disability Studies itself, to deny the importance of the development of theory that is not policy related, would be to deny the important influence of such theories as Goffman's "Stigma" and Douglas's "Purity and Danger" to understandings within this field. It can be argued that with knowledge comes understanding and having a clearer understanding of the status quo must surely provide a more solid basis for empowerment.

In relation to this research it has always been a central aim of the project to ensure that the disabled people involved in the research should emerge from the process in a more powerful position in that they would be able to use the understandings and knowledge gained from the research to both define and then act upon their own objectives. Whilst Shakespeare, therefore, in speaking out against some of the orthodoxies of disability research has given considerable support to calls for a much needed degree of flexibility within disability research, he may not have been entirely correct to assume that the development of theory unrelated to policy can never be accommodated within emancipatory research. It is an interesting reflection upon the power that key academics in a field can possess in shaping research practices, that an equally well-known author such as Shakespeare should construct an argument that proposes an *alternative* to the prevailing model of emancipatory research, but does not advance to questioning whether or not there may be more flexible understandings of the emancipatory research paradigm itself. As previously discussed within this chapter, writers such as Alvesson and Sköldberg (2000) have suggested that there might be a minimal version of emancipatory/critical research. It is the argument here that this research can legitimately be termed 'emancipatory' on the basis of Alvesson and Sköldberg's model.

Who can do disability research?

The issue of what constitutes a legitimate emancipatory outcome for research, however, was not the only dilemma that needed to be resolved within the process of this research. It was, in many respects, however, the least complicated problem to overcome. The final issue has proven more difficult to address. The first aspect of this issue concerns the uneasy relationship between the researcher as a member of the academic community and disabled people as an oppressed group. Despite disagreeing to an extent upon the desired outcomes of disability research with regard to praxis, both Oliver (1996) and Shakespeare (1996), as already mentioned, have made clear their dissatisfaction with research that has been carried out essentially in order for the researcher to achieve career advancement. The first aspect of this issue, therefore, is *who the researcher is with regard to motive?* This is clearly an issue within this research, for their can be no doubt that the desire on the part of the researcher to achieve a PhD has been an important factor. Arguably, however, some aspects of this ethical dilemma can be overcome so long as the research findings remain of some value in themselves.

The most insurmountable problem that occurs when undertaking disability research as part of PhD is that by necessity, unless secondary data analysis is being used as the basis for the research, the sole responsibility for the collection of the data and the authorship of the thesis lies with the PhD student. The second aspect of this issue, therefore, surrounds the relationship between researcher and research subject and *who has been in control of the research*? In the case of PhD research, control over the research tends to lie with the researcher since abdicating research responsibility would, ethically speaking, necessitate joint authorship. This does not allow for what Humphrey (2000) has described as 'the equality proviso' to function within the research, a process defined as involving everyone becoming co-researcher and co-researched, or as already stated, the eventual abdication of the researcher's role as 'researcher'. Since the equality proviso is held by many to be key to ethical disability research this author must remain uneasy surrounding this issue. It would seem that the only position that can be taken with regard to this matter is to admit to the shortcomings of this research with regard to the equality proviso, to propose that some flexibility be allowed into the PhD process of the future, to allow for such uneasy asymmetries in power to be minimised, and finally, to hope that the attempts made in other ways during this research to act in accordance with the guidelines for good research practice in this field, will be noted. It is of some comfort to this researcher that well respected authors in this field (for example, Zarb, 1992) have acknowledged that the pathway to 'ideal' emancipatory research is going to be long and hard and that along the way research will be carried out that will be considered to be less than ideal in one or more respects.

The final aspect of this issue is, however, quite the thorniest. Over the past few years a heated debate has been going on within Disability Studies surrounding the role of non-disabled researchers within the field. The final aspect of this issue is therefore, *whether non-disabled researchers are welcome within the field?* It is clearly important that it is stated that the author of this thesis is not a disabled person. As a non-disabled researcher in this field it would, therefore, have been unethical to ignore this important insider/outsider debate. The following section provides an overview of the key positions within this debate and how it relates to this research.

To be true to the insider/outsider debate within Disability Studies, it must be stated that the issue of the role of non-disabled researchers within the field is only part of a wider debate about the role of non-disabled people within the disability movement as a whole. The reason why the issue of research ethics enters this debate is due to the focus upon the importance of the emancipatory research paradigm and the assumption that this methodology implies the need for empathy based upon shared experiences between the researcher and respondents and a partisan focus upon praxis as the desired outcome of such research. This last issue has been discussed in some depth earlier in the chapter, and will not be restated here. What has not been discussed, however, is the important question that arises from the prevailing model of emancipatory research, namely, to what extent it is necessary/desirable that:

> *If empowerment is to equate with an emancipatory approach, then reciprocity between researcher and researched must come to mean the exchange of like with like – women engaging in feminist research, disabled people in disability research.* (Lloyd et al, 1996: 306)

In two articles, Fran Branfield (1998, 1999) sets out her argument that it is essential that Disability Studies does not become "*hijacked and reappropriated by non-disabled people.*" (1998: 144). She has commented that:

> *Disability studies is a subject for disabled people who are, precisely, its subjects, the people who make it; it is our affair. Disability studies are also a subject for non-disabled people; what it is should obviously concern them. They have to learn to make it their affair, to carry it through into their lives, but it must be understood that support and participation are not the same.* (Branfield, 1999: 402)

In both articles what is key to Branfield's argument is the maintenance of the dualism non-disabled/disabled, oppressor/oppressed. Not everyone within Disability Studies, however, shares Branfield's view. Barnes (1992a), who in many respects one would expect to share Branfield's opinions, in fact offers a somewhat confusing argument, which, it can only be supposed, must reveal his unease with regard to Branfield's position. He states on the one hand that:

> *(...) logic dictates that if a researcher is to empathise with those being researched then it follows that their life history must be as near as possible to that of the people being studied.* (Barnes, 1992a: 117)

but on the other hand that:

> *I am not convinced that it is necessary to have an impairment in order to produce good qualitative research within the emancipatory model (...)* (Barnes, 1992a: 121)

Other writers have offered more direct opposition to Branfield's position. Duckett (1998), whilst not being dismissive of Branfield's views, does ask where such views will take Disability Studies? He perceives that it is a "*particularly oppressive theoretical position she leads us towards, one that mirrors the oppression experienced by disabled people.*" (Duckett, 1998: 625) He further argues that maintaining such binary discourses is what sustains segregation. Branfield, he argues, may feel that this can be overcome by turning the tables on such binaries by privileging the historically disempowered group, but "*this would* *be shifting the focus of oppression whilst leaving the process of oppression intact."* (Duckett, 1998: 625-6) Duckett then goes on to argue that clear-cut distinctions between disabled and non-disabled people are too simplistic and that differences within the disabled population must not be ignored for they bring into some doubt the assumption that the distinction non-disabled/disabled equates automatically to oppressor/oppressed. Duckett's position is one that is echoed by Humphrey (2000) who has commented that this dualism can be used to support the idea of a 'ghetto' of/for disabled people.

For Humphrey, the idea of the 'politics of experience' in which only those with a lived experience of a particular form of oppression can possess the necessary prerequisite for understanding that oppression, can be taken too far. If pursued too far, Humphrey claims, it would mean, for example, that only those with spinal injuries would be able to undertake research with people with spinal injuries and so on. This, she claims would lead to the isolation of groups and an inability to develop a more "*inclusive civil rights agenda or a more overarching theory of disability.*" (Humphrey, 2000: 72) Humphrey (2000) has also warned that maintaining this dualism can:

> *(...) militate against a recognition that many currently non-disabled people have been and or will become disabled in their lifetimes, that many carers and some professional service providers are also disabled people, and that the disabled identity may have been constructed in a way which limits its inclusiveness.* (p.70)

In many respects this quotation from Humphrey is key to this research because it echoes the theoretical position taken within this research towards the idea of citizenship and disability. As will be discussed in the conclusion to this thesis, a more fluid and dynamic understanding of citizenship as 'personhood', in which the identity of every individual is seen to be vulnerable and contingent may provide the best way forward for understanding and changing attitudes towards many historically oppressed groups. What is implied by this theoretical stance, therefore, is that what is needed on the part of the researcher is not to possess the identical experience of oppression as their research subjects, but rather, to be constantly aware of the vulnerability of their own personhood. In transcending one's own fairly conditional identity it is possible to add to calls for the end of a range of oppressions without directly experiencing those oppressions. Thus, echoing much of the anti-racist and feminist approaches to research, a researcher does not have to be black to recognise and deplore the injustice of apartheid or more widespread racism, and following the same argument, the non-disabled researcher does not need to be disabled to appreciate the second-class citizenship experienced by disabled people. The argument put forward by this research, therefore, is that non-disabled people can and should engage in disability research so long as they maintain reflexivity at all times with regard to their motives, their own identities and their research practices.

Some final comments:

Finally, it was an important part of this research to respect the physical, social and psychological well-being of respondents and to ensure that their confidentially and anonymity be maintained at all times. It has been the intention of this research to abide by the British Sociological Association's "*Ethical Guidelines*" throughout the process. In relation to the correct use of language, the position taken by this research is that, wherever possible, the terms used are those that have been identified by respondents as carrying the most respect. Where differences of opinion arose the British Sociological Association's "*Guidelines for Non-Disablist Language*" was used to identify the most widely accepted terms.

Practical Issues

The purpose of this final section of the chapter is to describe the practical methods employed during this research in the process of gathering, analysing and giving feedback on the empirical data. The following section is divided into four parts, the first three of these are, as suggested by Berg's (1989) schema, *subject information, data collection and setting* and *analysis*. The final, additional, part will consider the *process of feedback*.

Subject Information

Key points:

- Who were the respondents?
- How were they selected?
- What information were they given about the research?
- What were they told about their participation?
- Were there any groups/individuals who refused to take part and why (if known)?

In relation to the questions 'who were the respondents?' and 'how were they selected?' the reader is referred back to chapter 1 in which these issues are considered in some depth. To summarize the argument made there, however, it was decided that an appropriate starting point would be to follow Oliver's (1997) definition of the disability movement as being constituted *only* by organisations *of* disabled people, not organisations *for* disabled people. For this reason, only groups run by disabled people themselves were contacted about this research. This research diverges in one respect from Oliver's definition, however, for it rejects the tendency on the part of Oliver and others to equate the disability movement with the member groups of the BCODP. Personal experience within the field suggested to this researcher that the BCODP does not encompass all groups run by disabled people, for disabled people, and therefore, whilst it is clearly a very important umbrella organisation, it cannot be equated with the movement.

Since it was thought that it would be useful to include within the research organisations from a number of different geographical settings, the following areas were initially chosen: London; the cities of South Yorkshire, Lancashire and Manchester Region; and Cumbria. All groups which met the criteria as set out above, and which were located in one of these locations, were contacted with a short letter. In this letter the focus of the research and the level of involvement required on the part of respondents was made clear. The letter also contained a brief statement regarding the ethical position of the research and provided an opening for any interested groups to contact the researcher to ask any questions before they considered becoming involved in the research. A slightly different style of letter, but with a similar content, was sent to any groups who had as members, people with a learning disability. In writing this letter and in all correspondence with people with learning disabilities, an effort was made to use a style in keeping with the material produced by the organisation "People First" and the Joseph Rowntree Association's "Plain Facts" series. (Both research letters can be viewed in the appendix.) In all, nineteen organisations were contacted, but only six organisations were found to be either suitable or willing to be involved in the research. The final spread of groups covered the following areas: Sheffield, as a large, industrial city; Lancaster, as a smaller city with a more rural hinterland; and the whole of Cumbria, as an essentially rural area.

There were a number of reasons why thirteen of the organisations contacted did not become involved in the research. In some cases, despite numerous efforts, the organisation could not be contacted. It was a sad reflection upon the state of funding for many disability organisations that several groups that were contacted were either in the middle of major upheaval due to changes in funding, or had ceased to exist due to complete lack of funds. In addition, after further contact, some groups were found to be unsuitable for inclusion within the research because they did not have a cohesive 'membership' as such and it was considered important that the organisations included within the research were those whose membership met regularly. This was considered to be important for two reasons, firstly, because it meant that arranging group meetings was less complicated, and secondly, because participating members of group discussions were familiar with interacting with one another. The last point was thought to be important in the light of the fact that many disabled people have had personal experience of oppressive research practices, and many other disabled people remain wary of research in general. It was therefore hoped that holding discussion groups amongst groups of individuals who were familiar with one another would give respondents confidence.

Finally, there was also some direct reluctance on the part of some organisations to becoming involved with the research. In some cases this took the form of 'stalling', in which a group never finally agreed to becoming involved, no matter how many times they were contacted. Sometimes it was suspected that this stalling may have been due to the effect of gatekeepers. Since there was often no direct way to contact the individual members of an organisation other than through their central office staff, there was always a risk that key members of staff would make a decision regarding the research on the basis of their own motives and would not consult their members. One group, however, did directly respond to the research letter and explained that they were not willing to participate in the research because, as an organisation, they had made a decision not to support research being carried out by non-disabled people. (*Please see Figure 2e for a list of the 13 organisations that were initially contacted but did not subsequently become involved in the research. Figure 2e also gives details of the reasons why each group did not become involved in the research.*)

Figure 2e.

Name of Organisation	Details **All groups were contacted between March 2000 and January 2001. Details below relate only to the position of groups at that time.**
CHANGE, London	**Despite repeated correspondence final date for contact never given by group – this mainly due to organisation moving offices at time of research and other upheavals.**
Spinal Injuries Association, London	**Despite repeated correspondence and**

	by their request the sending of a set of questions for council members to consider, no further response was received.
Action Disability Kensington and Chelsea, London	Despite repeated correspondence final date for contact never given by group.
Forum for Living of Young Disabled People (Floyd P), London	Despite repeated correspondence and by their request the sending of a set of questions for members to consider, no further response was received.
National League of the Blind and Disabled, Greater London	No reply to research letter. Published phone number no longer existing. Unable to contact group.
DAN Leeds and Yorkshire	Published phone number no longer existing. Unable to locate group.
DAN North West and Manchester	Published phone number no longer existing. Unable to locate group.
Ideas in Motion, Liverpool	Despite repeated contact with group and attending, at their request, a conference run by the group, final date for contact never given.
Down to Earth, Bolton	Organisation had ceased to exist.
Greater Manchester Coalition of Disabled People	Group declined to be involved in research being carried out by a non-disabled researcher.
Ankylosing Spondylitis Group, Cumbria	Organisation unsuitable.
Your Rights Your Voice, Cumbria	Met group to discuss becoming involved in research but shortly after, group ceased to exist due to lack of funding.
Allerdale Disability Association, Cumbria	Organisation unsuitable.

The response from this organisation raised an important question for the research: *to what extent were those organisations that agreed to becoming involved in the research, representative of the feelings of all groups within the disability* *movement?* This issue of was of wider importance, in the light of the fact that not only might there be differences in attitudes between participating and non-participating groups, but also that the process of gaining access to research groups took the form of 'opportunity sampling' i.e. the groups that became involved in the research were those that agreed to participate and were based within one of the chosen areas. Such 'opportunity' sampling, whilst proving necessary, was not considered to be entirely *ideal* by this author because it did not guarantee the inclusion of a cross-section of the different substantive groups that form the disability community. The importance of these different substantive groups should not be underestimated since, as will be discussed later in this thesis, there is evidence of a hierarchy of privilege and power within the disability community, with *working age, white, academically gifted, so-called 'able-disabled' men* being in the most privileged positions.

On a positive note, the participating groups in this research did include organisations of people living with a particular condition/illness that radically reduces their physical 'ability' (Arthritis Care Support Group, Carlisle), an organisation of people with learning disabilities who experience difficulties intellectually (Speaking Up For Action), as well as several groups of disabled people living with a range of physical impairments, some of whom might be considered to be more 'able-disabled'. Further, participating individuals were both male and female and although all adults, respondents ranged in age from mid-twenties to post-retirement.

Noticeably absent from the participating groups, however, were disabled people from ethnic minorities, deaf/Deaf people and people with mental health issues. As has already been discussed, time constraints did not allow for additional groups to be sought from each of these substantive areas, so it was decided to investigate further into the views of deaf/Deaf people. It should be stated, however, that whilst the acknowledgement of the shortfalls of the 'opportunity sampling' method is necessary, it is equally important to stress that in focusing upon *micro-representativeness*, this research was not seeking to be 'definitively representative' of the entire disability community. Thus, the research remains accountable only to the groups and individuals involved. At the same time, however, it was also felt that the groups who had agreed to becoming involved in the research were not so atypical, that insight gained from working with them would be of *no relevance* to understanding the disability movement as a whole. Indeed, since all five organisations involved in the research matched the definition of groups that make up the disability movement as set out by Oliver (1997), in other words they were run *by disabled people for disabled people,* it was concluded that the resulting data would allow for tentative generalisations to be made.

Figure 2f lists the participating organisations and provides a brief description of each:

Figure 2f.

Sheffield groups

1. **Sheffield Forum of People with Disabilities (SFPD):** A 'politically' orientated group of disabled people.
2. **Speaking Up For Action (SUFA):** A self-advocacy group of people with learning disabilities.

Lancaster group

3. **Lancaster Disablement Information and Support Centre (Lancaster DISC):** An organisation acting as a resource for other disabled people.

Cumbria groups

4. **Arthritis Care Support Group, Carlisle:** A support group of people living with chronic arthritis.
5. **Disability Action South Lakeland (DASL):** An organisation acting as a resource for other disabled people.
6. **Disability Association Carlisle and Eden (DaCE):** An organisation acting as a resource for other disabled people.

Having agreed to participate in the research these organisations were then contacted again, as has been described in the first section of this chapter, with more information about the research and a set of questions that it was hoped would provide a framework for the group discussions. As has also already been discussed, it was made clear that these questions were only meant to be a guide to the general area of the research and groups were given considerable flexibility concerning which, if any, of the questions they wished to discuss. Slightly different questions were sent to SUFA since this is an organisation of people with learning disabilities and it was anticipated that some people with learning disabilities might find some of the more abstract questioning, problematic. It is hoped, however, that what can be seen from the questions sent to this organisation is that an effort was made to avoid underestimating the level of abstract understanding that many people with a learning disability do possess. *Please see the appendix for a copy of the questions sent to SUFA.*

Once the questions had been sent out to each organisation, the data gathering then began. Before this aspect of the research is discussed, however, it is necessary to mention two further points. The first point is that, for reasons already stated in this chapter, an additional request for involvement in the research, an explanation of the central aims of the research and a set of questions was posted at the web based mail group "Deafmail". As already discussed, the focus of these questions was slightly different from those sent to the other disability organisations. It is also important to note here that there was only a small response to this posting on "Deafmail" and to date, there have been no responses from members of the Deaf community. Those people who did choose to respond to the research questions all stated that they were 'deaf' and did not see themselves as being a part of the Deaf culture. What conclusions might be drawn from this pattern of response will be considered later in this thesis.

Finally, there is the issue of the second round of group discussions, and how the participating groups were selected, the answer to which is straightforward. Further discussions were held at two organisations that had expressed interest in holding a further meeting to consider, in more depth, the issues raised in their first focus group discussion. With regard to the focus of these discussions, as has already been stated, some initial analysis of the data took place after the first round of interviews and this provided the researcher with an overall impression of the central issues for further discussion. It was not the intention of the researcher to *enforce* a focus for the second meeting however, and instead the transcripts or minutes of the first meeting held at each organisation were sent in advance to each group, in the hope that a review of the previous comments that had been made would provide the basis for a further discussion. This was found to be a successful strategy.

Data collection and setting

- What was the setting for the data collection and what method was employed?

As has already been mentioned, following the posting of a set of questions to each organisation, arrangements were made for a focus group discussion to take place with members of each group. In each case, the organisation itself was responsible for gathering together a number of members for the group discussion, and each group chose a venue for the meeting. The researcher then travelled to that location and the resulting discussions were recorded on audiotape. All respondents were asked whether they agreed to the use of audiotape and were assured that the tape could be switched off at any point, according to their wishes. The same process was repeated for the second round of interviews. This system worked well in all but one case, where on the researcher's visit to an organisation it was announced that a group meeting had not been arranged, but instead a key member of the organisation was willing to be interviewed individually. Whilst this interview at *DASL*, did take place, and data from this interview is included in this thesis, it must be stated that this interview did not benefit from some of the advantages that a group discussion can bring to respondents and to the research itself.

Baker (1999) has identified the following advantages to the use of the group discussion as a method of data collection:

- *Security – individuals may feel less exposed and more comfortable when expressing opinions, if they feel that their opinions are shared with other* *respondents. They may also feel that they need not defend their ideas, but can feel secure in their beliefs.*

- *Snowballing – comments from one person within the discussion group often elicit comments from others.*

- *Spontaneity – since no one person is asked to answer any particular question, then respondents will offer views and pick up upon what genuinely interests them. There is no requirement in a group discussion for everyone to be interested in, or have an opinion upon every question.*

- *Synergism – more ideas and information is likely to flow from a combined interview environment.*

- *Serendipity – discussion groups possess the potential for unexpected 'out of the blue' comments and ideas to emerge.*

- *Speed – the group interview reduces the time needed for single interviews.*

Group discussions, along with other qualitative approaches, can also provide a wealth of insights into experiences, attitudes and beliefs that would be hard to access via quantitative approaches. Further, as Goss and Leinbach (1996) have commented: *"the stories produced in the collaborative performance (...) better reflect the social nature of knowledge than a summation of individual narratives extracted in interviews."* (p.115) It should be noted however, that the definitions above relate to one particular type of group discussion/interview, namely the *focus group*. Gibbs (1997) has usefully explained the difference between group interviews and focus group discussions thus:

> *Group interviewing involves interviewing a number of people at the same time, the emphasis being on questions and responses between the researcher and participants. (...) the key characteristic which distinguishes focus groups is the insight and*

> *data produced by the* *<u>interaction</u>* *between participants.* (section entitled – *What are focus groups?*) (*My emphasis).*

The key to a successful focus group, therefore, is the manner in which respondents interact with one another, asking each other questions and reconsidering their views in the light of the group discussion. In this way focus groups can generate large amounts of valuable and *valid* data within a shorter period of time than is required for many other methods. As has already been discussed, focus groups are also of considerable value where there are inherent power differentials between the researcher and the researched, as was the case in this research between the non-disabled researcher and disabled respondents, because a large degree of control of the discussion is devolved to the respondents.

There are, however, some drawbacks associated with the use of focus groups: firstly, the supposedly 'empowering' aspect of focus groups may not apply for all respondents. Focus groups can be quite intimidating for shy or less articulate individuals. The researcher can do much to combat this problem by creating an atmosphere in which every individual's contributions are encouraged and respected and by using positive and non-threatening body language and terminology. During this research, considerably effort was made by the researcher to facilitate the involvement of every respondent in the focus group discussions. A more intractable problem, however, lies in the possibility that group dynamics, about which the researcher is likely to be unaware, may lead to the 'freezing out' of dissident voices. Such a process may even have meant the prevention of certain individuals from attending the focus group. Since the power to convene the focus group was left to each organisation, there is a real possibility that this problem may have occurred within this research. Whilst it was not possible to resolve the issue of the potential for certain individuals to be excluded from attending the focus group, it was possible to find a solution to the problem of the 'freezing out' of dissident voices during the discussion. At the end of every focus group respondents were given the contact details of the researcher, and were encouraged to get in touch by telephone, email or in writing should there be anything that they wanted to say privately, away from the group. No respondents contacted the researcher in this way, but the option for them to do so was considered to be an important part of the research method.

Other limitations of the focus groups have been summarised by Dwyer (2000: 239) as:

- *The interviewer has less control of a group when compared to an individual interview. It is important therefore to be aware of detours in discussion and attempt to keep the discussion focused.*
- *The data generated can be more difficult to analyse.*
- *The successful negotiation of focus group interviews is often dependent upon the skills of the moderator.*
- *Groups can be difficult to assemble.*
- *Focus groups are said to suffer from a lack of generalisability because samples are small and purposively selected.*

There is evidence of some of these drawbacks within this research, for example, as previously mentioned, it was not always easy to assemble groups. As has already been discussed, however, whilst some of these factors have occurred during this research, not all have been considered to be drawbacks. The idea that the researcher might have less control over the discussion was not considered to be a problem within the research, since, as has already been discussed, attempts to reduce the inherent power imbalance between researcher and respondent had taken the form of giving groups some control over the topics discussed. Equally, the idea that 'micro-representativeness' does not entirely rule out tentative generalisations has already been discussed earlier in this chapter, and is thought to apply to this research. Finally, in relation to the analysis of the data produced by the group discussions, no significant difficulties have arisen during the process of analysis. This last point is probably due to the method employed in the analysis of the data, which was intentionally less structured than is often the case.

Before considering this mode of analysis in more depth, however, a further aspect of the data collection must be mentioned. As has already been discussed at some length, data was also collected via the web-based mail group "Deafmail". The data took the form of a series of emails that had been sent between a number of participants in the mailbase group and the researcher, and the text of these emails was saved. It must be acknowledged, however, that one of a number of key dilemmas associated with the use of web-based communication within research (see BSA's Ethical Guidelines for further details), is the problem that it is often impossible to ensure that respondents are who they say they are. For example, in the case of this research, it has been necessary to accept as a matter of trust that the respondents to the questions posted on "Deafmail" are truly Deaf/deaf people. There are, however, some key benefits to this method of data collection, which it was felt out-weighed the limitations. Firstly, the use of the mailbase enabled the researcher to rapidly contact a very large number of Deaf/deaf people. Secondly, there are benefits to the use of email where respondents may have difficulties with verbal communication. In such cases, email provides a way of interacting with the researcher that is more like a conversation that more formal, written correspondence.

Analysis

After each group discussion, transcripts of the meetings were produced. These transcripts took one of two forms, as agreed with each group. In some cases a verbatim transcript was produced, in others detailed minutes of the meeting were written. In the case of the 'minutes' these were chronologically ordered according to the flow of the discussion and were sufficiently detailed so as to provide a direct reference to everything that was said. This was considered to be important since there was insufficient time within the research to produce both detailed minutes and a verbatim transcript for each meeting, and so for the benefit of the researcher, the minutes needed to represent a clear record of the meeting to accompany the audio recordings. In the case of the emails written by members of the "Deafmail" group these emails were collated to form another transcript. (*Please see figure 2d for details of minutes and transcripts.*)

At this point a decision needed to be made about to how to proceed with analysing the data. This decision was made difficult because there is a lack of clear advice within the literature surrounding the best way to analyse focus group interviews/discussions. How to run focus groups, and the advantages of this approach have been the key themes in the literature in this field. Nevertheless, there does appear to be a predominant approach within the social sciences to the analysis of the data emerging from group discussions, and that is to axial code the data and/or make use of computer packages such as *Nud*ist* to assist in this process.

This approach to analysis was not considered to be appropriate in the case of this research, however, for a number of reasons. Firstly, axial coding, in which categories are related to each other via a combination of inductive and deductive reasoning necessarily involves a process, be it manual or on the computer, of 'cutting and pasting', a process which fractures the text. Catterall and Maclaran (1997) have warned that such an approach runs the risk of failing to capture or even recognize a number of events in the unfolding story of the discussion group. They list in particular the tendency of respondents to make contradictory comments; the tendency for respondents to alter their views during the research through dialogue with others; and the tendency for respondents to expand later upon comments made earlier in the discussion, adding new or even different explanations. They have also identified inadequacies in traditional approaches to coding and in the current computer packages, when seeking to understand the outcomes of *interaction* within the discussion group.

For these reasons, therefore, neither axial coding nor computer-assisted analysis was used during this research. Instead, initial analysis took the form of gaining *familiarity with the text*, something that May (2001) has identified as key to the analysis of all interviews. A process of *annotation of the text*, was the second key method of analysis. Such a method could be termed *informal or open coding*. Catterall and Maclaren (1997) claim that this form of analysis is "*more likely to capture the whole moving picture*" (para.4.4) In practical terms this meant reading and re-reading the scripts and listening repeatedly to the audio-tapes of the meetings in order to make notes about key themes and thoughts about the data. Essentially, whilst reading the transcripts or listening to the tapes the question in the mind of the researcher was: "*What is this about?*" Labels and categories could then be written in the margins of transcripts or minutes. These labels referred to the key concepts revealed within the comments of respondents. For example, such categories included:

- *Disablist Language*
- *The Disability Movement*
- *Disabled Identity/Disability Identity*
- *Ghettoisation/Separatism in the Movement*

Familiarity with the data then allowed not only for key issues to be identified *within* focus groups, but also *between* focus groups. As has already been discussed, the predominant theme of all the group discussions surrounded the issue of *identity* and how this related to the idea of citizenship. As has also been discussed previously, this theme was clearly identified after the initial analysis of the *first round* of meetings and provided the basis for the second two group discussions. Analysis of these final two meetings then took the same form as stated above.

Whilst this informal approach to coding may appear to echo the grounded theory approach, there is, however, one important difference. According to the grounded theory approach, informal coding results in both concrete and fairly abstract categories emerging. The abstract categories, according to this approach, may often emerge out of the minds of the researcher and help to generate theory. Whilst, as can be seen in the list above, many of the categories used in this research were fairly abstract, these categories did not come from the mind of the researcher, but instead arose straight from the data in *abstract form*. This is because the respondents themselves spent considerable time talking about abstract concepts and so there was no need for the researcher to apply abstract categories *onto* the data.

The final aspect of the data analysis was to relate the findings to the existing theories in the field. At this point care needed to be taken in order to avoid over interpretation of the data, and the related risk of distortion. This process was made easier by the spontaneous way in which codes had emerged from the data, as discussed above. It was then quite a straightforward process to write up the findings in such a way as to give voice to the respondents and to remain truly accountable to them. It is hoped that this is what has been achieved within chapter 6.

Feedback

After the completion of this thesis it is envisaged that an outline of the central findings of the research will be sent to each of the participating groups. The first part of the feedback process took place during the analysis of the findings. At that point, a letter of thanks together with either a verbatim transcript or a detailed set of minutes, as agreed, was sent to each organisation. Any comments concerning the documents were welcomed since it was considered to be important that each group approved the record of their meeting. In the case of the group run by people with learning disabilities, they stated that since they regarded their involvement in the research to have been an important example of self-advocacy, that they wished their group discussion to be written up into a report that could be used by the organisation. Such a document was produced and presented to the group for approval. An anonymised version of this report can be found in the appendix.

In addition as part of the process of feedback, one group invited the researcher to give a talk to the group about the initial findings of the research. This invitation was taken up by the researcher.

Concluding comments

It has long been acknowledged that when research is being carried out with/on oppressed groups, there must be transparency with regard to the position of the research/er. Research practices that, no matter how inadvertently, add to the oppression of the research subjects, must be avoided. The aim of this chapter has been to state in some detail, the theoretical, ethical and practical processes that formed part of this research. It is hoped that this chapter demonstrates that self-reflection on the part of the researcher has been an important part of the research process.

Chapter 3

Citizenship

Introduction

> *Duty is the cornerstone of a decent society. It recognises more than self. It defines the context in which rights are given. It is personal but it is also owed to society... It draws on a broader and therefore more accurate notion of human nature than one formulated on insular self-interest. The rights we receive should reflect the duties we owe. With the power should come responsibility.* (Blair, 1995: 5)
>
> *A modern notion of citizenship gives rights but demands obligations, shows respect but wants it back, grants opportunity but insists on responsibility.* (Blair, 1996: 218)

> *Citizenship involves providing for family members, being a loving parent, playing by the rules or looking out for a neighbour in need. It's about having a sense of responsibility, obligation and duty. (Duncan Smith, 2002: quote from speech given at Toynbee Hall on Iain Duncan Smith's first anniversary as Party Leader.)*

> *The purpose of the proposed Equality Act is to extend the life chances of people disadvantaged through belonging to groups discriminated against by British Society. These people have suffered the whiplash of rejection and the knowledge that they are not valued as individuals. To right this wrong, and to make meaningful the concept of citizenship, of living in a civilised society, we need the statutory remedy of true and enforceable equality before the law. (MacLennan, 2000: quoted in Liberal Democrat press release)*

As the above quotations demonstrate, the rhetoric of 'Citizenship' is a favourite tool of politicians. Clearly, for the concept to be so utilised, 'citizenship' must be widely accepted to be *a good thing*! Centuries of theorizing have, however, demonstrated the difficulty in establishing a widely agreed definition about what exactly the notion of citizenship entails. In writing this overview of some of the central academic theorizing on citizenship it became clear that it is difficult, if not impossible, to separate out discussions of citizenship from wider debates surrounding notions such as *democracy; liberty; justice; human rights discourses; the nature of the polis; the nature of the 'self'; identity; 'difference'; and 'struggle'*. It is not possible within the limits of this chapter, or this research to consider each of these areas in depth, as indeed they warrant a fuller account. It is important to note however, that such issues impact greatly upon citizenship debates and at times I will refer to such areas where they impact upon matters under consideration.

To provide a short overview of the structure of this chapter: the first section will briefly consider the major issues resulting from those theories that I have termed the 'Ancient' and 'Classical' approaches. It is not my intention to consider these theories in great depth however, for whilst providing the framework for much, if not all, subsequent theorising, they are increasingly being seen to be redundant in themselves. The second and third parts of this chapter will consider the modern and contemporary approaches to citizenship theory, respectively. Further, contemporary citizenship theorising can be usefully separated into three major categories: the pluralist approach; the reflexive account: and the post-structuralist approach and these will be considered in turn. (The historical framework, as set out above, for considering citizenship theorizing is shown in fig. 3.a)

Ancient and Classical Theories of Citizenship

Theorizing on citizenship has a very long tradition, stemming back to the Ancient Greeks. Indeed, citizenship had its first institutional expression in the Athenian polis between the 5th-4th centuries BC (Faulks, 2000). This long-standing tradition of theorizing has had profound effects upon the manner in which we understand the relationship between the individual and the state/society more generally. In Ancient Greece the optimum relationship between the individual and the state was embodied in the notion of the 'citizen', which literally meant 'member of the state' (Heywood, 1994). For the ancient Greeks, the 'self' was only as robust as the polity to which it belonged. Aristotle stated that citizenship was a core element of what it means to be human. This was a view of the individual that saw each person as intricately interconnected with society. In a manner that appears to echo much of Giddens' (1984) notion of the 'duality of structure', the ancient Greeks viewed individuals and society as each being coterminous of the other.

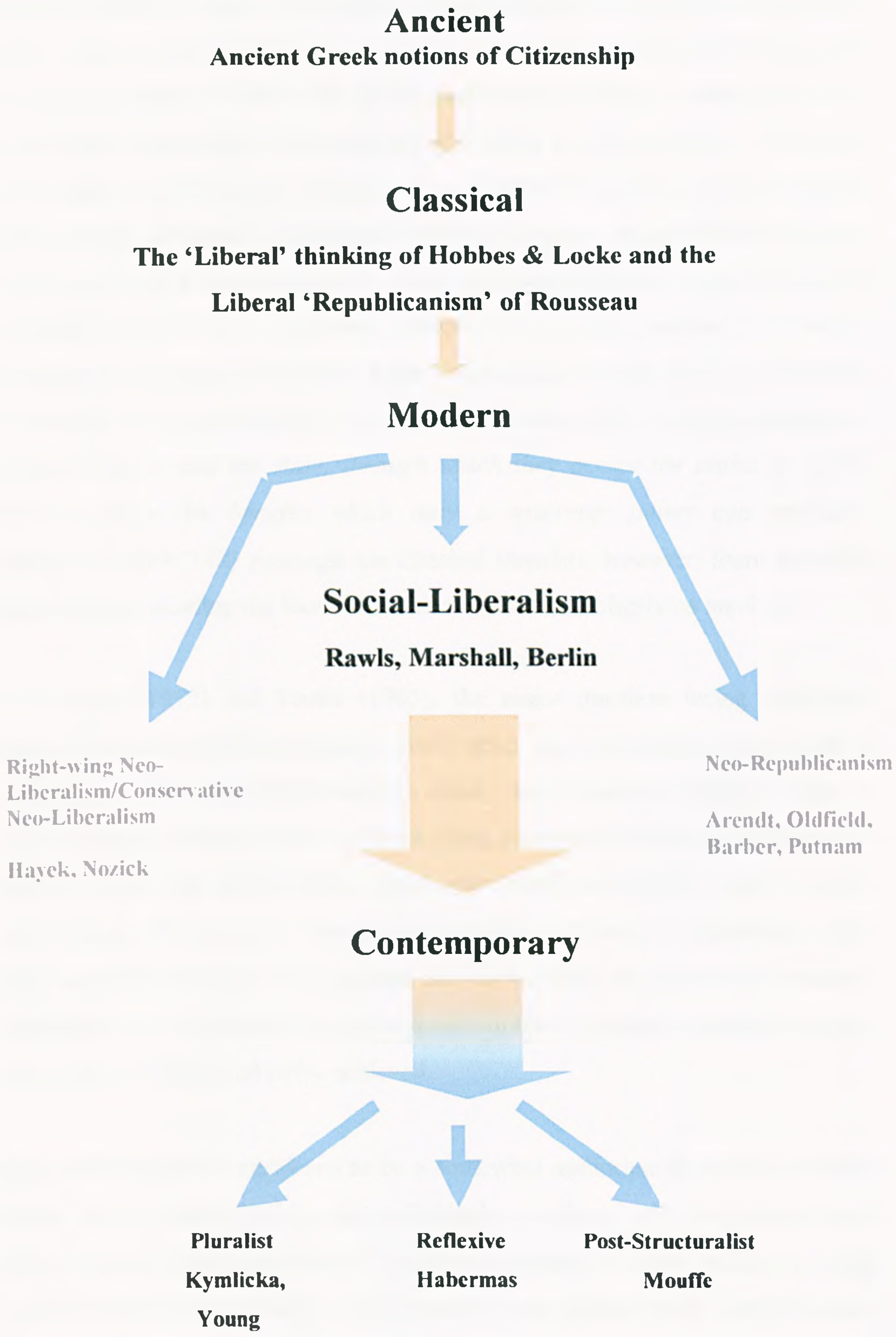
Further, the ancient Greek notion of citizenship is also infused with a morality that considered those who did not live up to the expectations of citizenship to be inherently 'selfish'. For the ancient Greeks, beyond the confines of the household, there was only the polis. McAfee (2000) highlights this fact by noting that the Greek word for someone who is uninterested in public life is 'idiôtês' i.e. an 'idiot', thus the word 'idiosyncratic', which literally means to hold only to one's own self. Aristotle echoed this sentiment when he famously argued that to refuse to take part in the running of a community is to be either a beast or a God! Meier (1990) has also concluded that this sense of morality is key to understanding the ancient Greek notion of citizenship. Meier has questioned why it was that the citizens of ancient Greece worked so hard, often in a military capacity, in their duties as citizens but for so little in return? He concludes that the activity on the part of citizens was partly due to social pressures but also because fulfilling one's duties as a citizen was also thought to make you a better person and as being opposite to acting out of self-interest.

The context in which the notion of citizenship was born, therefore, was the small-scale, organic community of the ancient Greek, and in particular, the Athenian polis. The content and 'depth' of this citizenship was greatly influenced by the fact that it was not a purely public matter. For the ancient Greeks, the values of active citizenship should be internalised within the individual citizen. In many respects, this ancient view of citizenship is diametrically opposed to much subsequent theorising, perhaps most acutely to the classical liberal approaches of Hobbes and Locke. For the ancient Greeks, the self is *"'fleshed out' by the city – that is, the polis brings about a richer subjectivity – and politics is the collective search for the good life."* (McAfee, 2000: 6) This theorising on the 'self' is in stark contrast to the theorising of the classical theorists, particularly of the liberal tradition. Classical theorists considered 'selves' to be substances of sorts, which, may or may not, according to their desires, engage in the polis. Thus whilst the ancient Greeks considered citizenship to be about the combined struggle by citizens for the good life, for the classical, liberal theorists, politics is a struggle *between* citizens in a climate of scarce resourses, and is, therefore, an essentially antagonistic process.

Although it is often stated that the classical theories of citizenship mark the clearest opposition to earlier, ancient theorising on citizenship, this process of change within citizenship theorising in fact began during the medieval period. It is not my intention here to consider this period in any great depth, but it would be wrong to overlook the contribution that Machiavelli, for example, has made to thinking within this field. For Machiavelli, citizenship was not a *manner of being*, but rather it was a process, or a method by which those individuals deemed to be citizens could assert their interests. His notion of protective republicanism was designed to ensure that public order was maintained (Faulks, 2000) and in this respect his work reveals a preoccupation with social order. Such a preoccupation continued to characterise later theories.

The classical models of citizenship did not, therefore, emerge out of a vacuum. Chief proponents of this classical approach to citizenship, Hobbes and Locke, were however, writing in a context that varied greatly from that experienced by previous theorists. One key point about the nature of the ancient Greek citizenship that has not been previously mentioned here, is its inherently *exclusive* nature. Ancient Greece was an agrarian, slave-based society in which inequality had been naturalised: *"citizenship was valued in part because of its exclusive nature and as a mark of superiority over non-citizens whether they be women, slaves or 'barbarians'."* (Faulks, 2000: 18) It was only with the development of the liberal state, the beginnings of which emerged in the late sixteenth century, that citizenship became infused with egalitarian and/or inclusive notions.

Figure 3.a *Changing Theories of 'Citizenship'*



From the seventeenth century onwards, most of the key liberal philosophers who contributed to the classical theories of citizenship were concerned not with notions of self-governance, but with the 'social contract' between each individual citizen and the state. There were a number of different strands of thinking that can be encompassed within this 'social-contractual' tradition, ranging from the *"essentially authoritarian prescriptions of Hobbes to the essentially libertarian prescriptions of Rousseau."* (Dean et al, 1999: 74) The essential element characterising all theories within this tradition however, is an understanding of what is meant by a 'social contract'. At its core this notion rests upon the idea of a 'contract' as a formal agreement between two or more parties, and that by entering into a contract, moral and legal obligations come into play. As Heywood has stated: *"A 'social contract' is an agreement made either amongst citizens, or between citizens and the state, through which they accept the authority of the state in return for benefits which only a sovereign power can provide."* (Heywood, 1994: 148) Amongst the classical theorists, however, there was little agreement surrounding the basis of this contract or the obligations involved.

For Hobbes (1973) and Locke (1965), the major question facing citizenship theory was how political authority could arise out of a society composed of morally free and equal individuals. In short, they concluded that the right to govern rested upon the consent of those being *governed.* Without such agreement between rulers and ruled, Hobbes and Locke feared a barbaric 'state of nature' would result. The pursuit of power and wealth could not go unchecked or the result would be a war of all against all. In the light of such risks, 'rational' individuals would *wish* to enter into a social contract in which an agreed authority would be established and order achieved.

From what might be considered to be a somewhat authoritarian position, Hobbes argued in *Leviathan* (1973) that individuals are faced with the bleak choice between anarchy and absolutism. His central contention, upon which this rather gloomy conclusion is based, is that humans are fundamentally self-interested. The social contract that he envisaged involved the complete surrender of individual sovereignty to a powerful political authority. For Hobbes, whose writing is likely to have been greatly influenced by his experiences of the chaos of the English Civil War, the existence of a state, no matter how oppressive it may be, was preferable to the instability and disorder of the 'state of nature'.

It has been suggested, however, that in so theorising the relationship between the individual and the state, Hobbes in effect nullified citizenship. Critics of Hobbes such as Clarke (1996) have argued that in defending the right of a monarch to possess absolute power, Hobbes' theory terminates citizenship and politics. Instead of providing a model of the relationship between the citizen and the state, Hobbes was in fact producing a model of the relationship between the *subject* and the state. Further, in relation to rights and obligations, Hobbes' view of the citizenship is rather 'thin'. For Hobbes, the state had only one major obligation to the individual citizen, to maintain social order. Conversely, the individual citizen was obliged to obey the state, but had few rights beyond that of living in a socially ordered society.

This is not, however, to negate Hobbes' contribution to theorising in this field. In many ways his theories mark the transition towards more highly developed notions of citizenship. Faulks (2000) identifies four key ways in which Hobbes' work has influenced later theorists. Firstly, unlike the medieval notions of citizenship in which rights were extended to groups, it is the individual that is seen to be in a direct relationship with the state. Secondly: *"Hobbes believed that in terms of their abilities, as well as in their powers to upset the basis of social order, individuals were equal."* (Faulks, 2000: 22) This line of argument provided the basis for the link between citizenship and equality that has characterised subsequent liberal thinking. Thirdly, although Hobbes had a personal preference for a monarchical system, this is not to say that his theory perceives the state and the sovereign as indivisible. Finally, by arguing for the concentration of power in the monarch, Hobbes was arguing for the concentration of the means of violence. This was important because Hobbes was suggesting a break from the feudal notion of divided sites of power.

An alternative, and some would argue, more balanced view of citizenship is to be found in the work of Locke. Locke's conception of the relationship between the individual and the state involved two 'contracts'. The first was essentially Hobbes' 'social contract', in which individuals agreed to sacrifice a degree of their personal freedom in order to ensure social order. The second contract was a 'contract of trust', between a society and its government, in which the government became authorised to protect the natural rights of its citizens. The important point to note here is that for the first time there emerges a sense of the reciprocal nature of the relationship between citizens and state. It is implied in Locke's work that obedience to the state is conditional upon the state fulfilling its side of the bargain.

As was previously discussed, however, this classical liberal approach with its fairly *passive* view of citizenship as a series of rights possessed by the individual, stands in contrast to the more ancient approaches which saw citizenship as being a more *active* process engaged upon by citizens as part of a republic. At this point it is interesting to consider the work of Rousseau (1913) because his Liberal Republicanism is often considered to stand apart from the liberalism of Hobbes and Locke on precisely this basis, that his is a view of a more *active* citizenship. At first glance, Rousseau's theories do seem to be a little more optimistic than those of Hobbes and Locke, particularly with regard to his views on human nature. For Rousseau, in contrast to the views of Hobbes and Locke, government should be based upon active citizenship, what he termed the 'general will', which reflects the common interests of society over the selfish desires of each individual. Rousseau's work is also often considered to represent an important first step away from the liberal tradition's individualistic construction of citizenship since he is clearly concerned with the process by which the desires of the individual can be melded with the needs of the community.

The extent to which Rousseau, however, should be considered as being an important part of the communitarian/republican tradition needs to be considered carefully. Rousseau did not manage to convincingly resolve the issue of conflicting interests. In acknowledging that the individual will have 'selfish desires' he appears to be simultaneously acknowledging that there will be some degree of conflict between the individual's desires and that of the 'general will'. Rousseau, however, side-steps this dilemma by arguing that the 'general will' is synonymous with each individual's 'real' interests. Thus for Rousseau in fulfilling their duties and responsibilities, a citizen is obeying their own 'higher' selves. In this quest to meld the desires of the individual with that of the community, Rousseau arguably negates individual rights. In his famous dictum Rousseau stated that ignorance or selfishness might blind individuals to the fact that the general will embodies the desires of their 'higher selves', under such circumstances it would become necessary to be 'forced to be free'. Critics have pointed to the fact that such ideas seem to be at odds with the notion of government by consent. Ultimately, therefore, despite the apparently optimistic start to Rousseau's theorising, his conclusions point to a much more pessimistic perception of human nature. When Rousseau states that a 'higher' body or intellect, in the person of the 'lawgiver', must determine the rules of a society he is essentially mistrustful of the individual's capacity to determine the future democratically. This last point must bring into some doubt the extent to which Rousseau was really proposing an 'active' form of citizenship.

In essence then, what a consideration of both the classical 'liberal' model of citizenship and Rousseau's Liberal Republicanism provides is a view of a *passive* citizenship. According to Burchell (1995):

> *In the most common form of this story it is explained that with the rise of market society in early modern Europe the (...) 'active' civic ideal was progressively replaced by a (...) 'passive' or 'liberal' ideal which crucially weakened or distorted the vitality of the original civic impulse (...)* (p.541)

Even Rousseau's conception of the citizen, which was, in many respects, an attempt to rejuvenate the ancient model, was a corrupted version of the latter because, in the end, it relied upon an *enforced* return to ancient civic rectitude. Rousseau's model is essentially both anti-libertarian, and utopian. This utopianism in Rousseau's theorising can be seen to have an interesting parallel in the work of Marx. Marx shared with Rousseau a utopian vision of a society in which each individual can achieve his/her 'higher' self. Whist he was heavily influenced by Rousseau, however, Marx did not agree the earlier theorist's work regarding how this 'fully developed' society could be achieved.

> *On the one hand, he notes, Rousseau's version is founded on a conception of a civic space dominated by the sphere of public altruism; on the other hand, the stuff from which Rousseau's citizens had of necessity to be created is the privatised bourgeois self of market society. Famously, Marx's solution to Rousseau's contradiction is the utopia without contradictions: the Communist societies in which the stunted and divided personalities of societies based on the division of labour have at last been overcome. (...) Of course, to replace a contradictory utopia with a utopia without contradictions may be accounted no solution at all.* (Burchell, 1995: 548.)

Marx can thus be criticised for providing an equally unrealistic utopian vision of society. His critique of Rousseau and the 'liberal' model of citizenship is, nevertheless, important because it highlights the classical theorists' failure to engage with the issue of the inequitable distribution of resources. For Rousseau, for example: "*the nature of the authority vested in the state by the general will should at best temper rather than redress the imbalance of power between the poor and the rich.*" (Dean et al: 1999: 75.)

This thorny issue of the extent to which citizenship should aim to reduce social inequality has continued to plague citizenship theorists. Later, 'modern', theorists such as Rawls, Marshall and Berlin have followed on from the 'liberal' tradition of Hobbes and Locke, but have focused specifically upon this problem of social inequality identified by Marx. The general approach taken by these three theorists I have termed Social Liberalism. For these thinkers, a distinction should be made between absolute destitution/poverty and social inequality. In effect, the Social Liberalist approach is an attack on poverty but a legitimation of inequality according to a system of meritocracy. That is not to say that all Social Liberals are concerned to the same extent with these issues, there are some important distinctions between their approaches: Rawls' work is essentially an attempt to re-work social contract theory, whilst countering the Marxist critique *amongst other issues*. The work of T.H. Marshall ([1963] 1998) on the other hand, also acknowledges the inherent tension between an egalitarian notion of citizenship and the economic inequality that is a recognised part of capitalism, but marks a more sustained shift away from the 'liberal' model of citizenship in search of solutions to this problem. It is the argument here and in chapter 7, however, that it is Berlin's work that represents the most convincing and subsequently influential Social-Liberal approach because of his concern with issues of *pluralism.*

Whilst the Social-Liberalist approach to citizenship has proven to be the most influential in terms of contemporary theorising, precisely because of its focus upon the issue of inequitable outcomes, that is not to say that all theorists have agreed that social inequality should be a concern within citizenship theorising. Indeed, almost at the same time as the Social-Liberal approach was being developed, two rival approaches emerged, the first being Conservative Neo-Liberalism and the second being Neo-Republicanism. Whilst it is not my intention here to go into any great depth on either of these approaches since they have had significantly less impact than Social Liberalism, it would be wrong to over-look these theories completely for they both provide interesting arguments in opposition of the idea that social issues should be allowed to impact on the civil sphere.

Conservative Neo-Liberalism is to be found in the work of authors such as Hayek (1944) and Nozick (1974) and whilst it is tempting to suggest that this approach has not been of long-term significance theoretically, that is not to say that there have been no real consequences of the approach on peoples' lives. The Thatcher government of the 1980's was highly influenced by what might be considered to be the more 'populist' form of this Conservative Neo-Liberalism, namely the 'New Right'.

The dominant characteristic of the Conservative Neo-Liberal approach is an intense opposition to the idea of social rights. Hayek (1944) believed that inequalities affecting an individual's private life are both inevitable and desirable within a free-market-economy. Democracy, he believed, had certain useful properties but it should only be allowed to function in those areas of life that are not determined by the market. Nozick (1974) took this one step further, stating that any attempt to seek social justice via democratic means, is an infringement of civil rights. The state should act only as a 'night-watchman', providing security, but in the most inconspicuous way possible and it should not be directly concerned with the material welfare of its citizens since this would inevitably mean that it was interfering in relation to the market's role as distributor of resources.

Before moving to consider Neo-Republicanism, however, there is one final point that should be raised concerning Conservative Neo-Liberalism and that is that it is often claimed by those who adhere to the principles of his approach that it is based upon a form of citizenship akin to Rousseau's vision of 'active citizenship'. Setting aside the whole issue of whether or not Rousseau's model is really one of active citizenship, there are also reasons to question Conservative Neo-Liberalism's credentials with regard to active citizenship. As previously mentioned, successive Conservative administrations of the 1980's and 1990's drew heavily upon this Conservative Neo-Liberalism. Repeated attempts were made by the government at this time to reduce the state's role in the funding and provision of welfare for its citizens in an effort to redefine the state in accordance with Nozick's 'night-watchman' principle. Further, the idea of an 'active citizen' who was both individually and socially responsible and for whom state help was only a 'last resort' was an idea favoured by Margaret Thatcher ([1988] 1989) and Douglas Hurd (1988). The 'active citizen', it was claimed, would take responsibility for themselves and for their families. Beyond this, philanthropic activities were also encouraged in order to reduce the need for the state to provide for the welfare needs of the less fortunate (Hurd 1988, Thatcher, [1988] 1989). At the same time, active citizenship also became associated with the consumer culture. To be an active citizen meant asserting one's rights within the market as *consumers*, with such an ideology applying even to public services.

The central problem with this approach, however, was that it both ignored and at the same time exacerbated the problem of material inequality. Individuals who failed to live up to the ideals of active citizenship were increasingly stigmatised as being either 'work-shy' or part of Charles Murray's (1994) 'underclass' if they failed to take responsibility for their own welfare, or 'second order' citizens if they failed to act in a philanthropic manner for the welfare of all (Dwyer, 2000). The Conservative Neo-Liberals overlooked the fact that many disadvantaged groups did not have the resources to fulfil the responsibilities of 'active citizenship'. As will be discussed later in this chapter, this approach stands in stark contrast to the approach taken by the Social-Liberals who whilst not proposing an entirely egalitarian system of equality of outcome, certainly envisaged a considerably larger role for the state in guaranteeing those universally held rights that made such inequalities more tolerable and which *enable* active citizenship.

A truer sense of active citizenship is to be found in the Neo-Republican approach. This approach also cites Rousseau's republican ideas as inspiration and believes in the importance of commitment and participation in public life. The main difference between Conservative Neo-Liberalism and the Neo-Republican approach, however, is that the Neo-Republicans reject the idea of the private pursuit of interest that so characterises the New Right accounts of citizenship. For authors such as Arendt (1958) rather than self-interest, what is actually at stake is *public interest.* At the heart of this approach is a fairly radical theory of citizenship as participation in the public domain of civil society, the challenge being to "*preserve as much of the autonomy of the political field as possible, to prevent politics from becoming privatistic or statist.*" (Delanty, 2000: 33) In relation to the issue of social inequality what this approach is therefore arguing is not that social inequality does not exist, but rather that the social issue should not intrude upon what must be a purely political domain.

Active citizenship, for the Neo-Republicans is about participation not just rights and duties. This was the central idea of authors such as Arendt (1958) and later, Oldfield (1990) and it was most powerfully expressed in Barber's (1984) idea of 'strong democracy'. Democracy, he claims, must be taken out of the hands of the elites and given back to citizens: "*(...) strong democracy transforms conflict. It turns dissensus into an occasion for mutualism and private interest into an epistemological tool for public thinking.*" (Barber, 1984: 151) A slightly less radical approach is taken by Putnam (1993) who claims that the value of participation in civil society is not the ability to overcome conflict, but is instead, to promote the values of trust, commitment and solidarity that allow democracy to flourish (Delanty, 2000).

Critics of this approach have suggested however, that the problem with all of the Neo-Republican theories is that they underestimate the level of conflict that occurs within civil society on the basis of different identities and social inequalities and which must bring into some doubt the idea that solidarity is something that can be easily achieved. To this extent the approach may be somewhat utopian. There are, arguably, more profound difficulties with the approach however, and these stem from the Neo-Republican notion that citizenship should best be viewed as a commitment to achieving an *unspecified* common goal. The first problem is that in stressing the need for citizens to commit to participation some Neo-Republicans advocate fairly authoritarian measures to ensure citizens do actually participate. Oldfield (1990) states that it may be necessary for the citizen to be '*shamed, disciplined and sometimes terrorised into living "civic virtue" (...)*' (p.47) By arguing thus, Oldfield opens himself up to the same criticisms that have been directed at Rousseau for negating the rights of the individual. The second problem is that the Neo-Republicans prioritise the actual process of participation over the substance of the common goal. Thus, whilst it is undoubtedly true to say that this approach represents an important precursor of later models of citizenship as 'engagement' (Ellison, 1997, 2000), the Neo-Republican view of citizenship fails to adequately theorise the nature of the rights being actively sought. The reliance upon somewhat substantive rationality within, not just the Neo-Republican approach but also wider citizenship theorising, is something that is only now being seriously reconsidered. As McLeod (1998) has commented from a philosophical perspective: "*The typical noninstrumentalist position, by contrast, would be that* *for the action in the conclusion to be one it is rational for the agent to perform, it must serve an objective it is rational for the agent to pursue (...)*"(paragraph 1) As will be discussed at some length later within this chapter and in chapter 7, understanding the nature of the *contested citizenship* is key to understanding the nature of participation.

Modern/Social-Liberal Theories of Citizenship

Rawls

Since the publication of his work entitled "A Theory of Justice" in 1971, John Rawls' ideas have inspired many subsequent theorists, whether they are sympathetic or critical of his theories. Rawls' credentials as 'torch-bearer' of the liberal tradition of citizenship theorising, stems from his continuing use of the classical liberal theorists' idea that the 'social contract' is at the heart of social order. Rawls significantly diverges from earlier theorising, however, in two regards. The first is with regard to the extent to which he considers the liberal concept of a society based upon a shared state of 'higher being' in which true happiness for all is the desired goal, to be achievable. The second is with regard to his concerns with social justice and egalitarianism.

To understand Rawls' notion of citizenship it is vital to consider his discussion upon the rights of free and equal individuals, which forms the central part of his theory of social co-operation. The central aspect of his theory is the idea of 'justice as fairness':

> *In justice as fairness, social unity is understood by starting with the conception of society as a system of co-operation between free and equal persons. Social unity and the allegiance of citizens to their common institutions are not founded on their all affirming the same conception of the good, but on their publicly accepting a political conception of justice to regulate the basic structure of society.* (Rawls, [1985] 1998: 70)

There are several key points arising from the previous quotation. Firstly, for Rawls, the notion of 'justice as fairness' is not intended to be a comprehensive moral doctrine, but rather a method for achieving an over-lapping consensus. Rawls ([1985] 1998) rejects the earlier liberal idea that all rational and well-informed individuals will have the same sense of what constitutes the 'good'. 'Justice as fairness': *"must allow for a diversity of doctrines and the plurality of conflicting, and indeed incommensurate, conceptions of the good."* (p.54) Having said this, however, Rawls was faced with the problem of how such diverse goals could be attained though co-operation and yet still benefit all?

To solve this problem Rawls employs a somewhat abstract political theory of democratic citizenship in which 'political justice' is the desired goal. To begin with, Rawls hypothesises a situation in which people have to assume a 'veil of ignorance' in which they must not know the true nature of their position in the inherently unequal society. Having assumed this 'veil of ignorance', and the imaginary position of equality, individuals will *"evolve from their basic intuitive ideas of cooperation in a democratic society a framework of political justice."* (Shafir, 1998: 7) The resulting concept of political justice, or 'social contract', is made up from two principles:

> *(1.) Each person has an equal right to a fully adequate scheme of equal basic rights and liberties, which scheme is compatible with a similar scheme for all. (2.) Social and economic inequalities are to satisfy two conditions: first, they must be attached to offices and positions open to all under conditions of fair equality of opportunity; and second, they must be to the greatest benefit of the least advantaged members of society.* (Rawls, [1985] 1998: 56)

Rawls also states that (1) takes priority over (2). Thus, the first stage of 'justice as fairness' will always be to ensure that the basic liberties of all have been safeguarded and that the rights of the least advantaged should always be the main consideration in a just society. After this, principle (2) can be viewed as the 'difference principle' and amounts to a call for a meritocratic society in which there is equal opportunity to be *unequal*, providing that any resulting inequalities work to the advantage of the least advantaged members of society. I would suggest that this marks Rawls' response to criticisms directed towards the earlier liberal thinkers in respect of their failure to take sufficient account of the inequalities that characterise capitalist societies.

The second part of Rawls' political theory of democratic citizenship is concerned with the notion of identity. As Shafir (1998) has noted, Rawls makes a distinction between an individual's private and public identity:

> *Since rights are attached to an individual's public identity as a free and equal citizen and not to one of the features that determine her identity, such as religion or nationality, she is free to change her view of the good life (eg. convert from one religion to another) without being deprived of these rights.* (p.8)

This distinction between public and private identities allows for the toleration of diversity and for the emergence of an overlapping consensus despite oppositional doctrines. Here again, however, Rawls' theory rests upon his notion of the *reasonable* individual, for in order for this over lapping consensus to be sustained, citizens must take into account the need for co-operation and must not make excessive demands.

It is this final point that has provided the basis of much of the criticism that has been directed against Rawls' theory. Most critics of Rawls have highlighted the normative nature of his theory and have questioned his faith in the ability of *rational* individuals to co-operate on the basis of mutual respect. Rawls himself acknowledged this problem with his approach in later work (see Rawls, 1993), but by the time he came to re-consider his position, the issue had been 'taken over' somewhat by the more pluralist/multiculturalist perspectives. To highlight a further problem with Rawls' approach, I would add that his definition of co-operation appears to rely upon a notion of *competency*, a term that is far from un-problematic:

> *(...) since we wish to start from the idea of society as a fair system of co-operation, we assume that persons as citizens have all the*

> *capacities that enable them to be normal and fully co-operating members of society.* (Rawls, [1985] 1998: 60)

The implications of this notion of competency will be re-considered in chapter 7.

Marshall

Although it is not my intention to say much more about this notion of *competency* at this point, it is interesting to note that it also underpins much of the theorizing of T.H. Marshall. T.H. Marshall was greatly influenced by the writings of Alfred Marshall, the economist. Alfred Marshall provided a very similar definition of citizenship to that of Rawls, in the respect that he regarded citizenship to be a status that expressed the ability, or the competence to be a member of society. This definition was to greatly influence the writings of T.H.Marshall ([1963] 1998) who wrote that:

> *(...) societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspiration can be directed.* (p.102)

Turner (1986) has pointed out that in many respects Marshall's work fits comfortably into a liberal democratic tradition, particularly with regard to Marshall's emphasis upon equality of opportunity whilst at the same time promoting universally held rights as the way of making the resulting inequalities of outcome, more tolerable. Evidence for this is to be found within "Citizenship and Social Class" in which Marshall ([1963] 1998) makes clear his faith in the capacity of education as the basis of a meritocracy:

> *The right of the citizen in this process of selection and mobility is the right to equality of opportunity. Its aim is to eliminate hereditary privilege. In essence it is the equal right to display and develop differences, or inequalities; the equal right to be recognised as unequal. (...) the final outcome is a structure of unequal status fairly apportioned to unequal abilities (...)* (p.109)

Further, he states that the status differences that result from this educational meritocracy can be regarded as legitimate in terms of citizenship, provided that 'they do not cut too deep'. It is his level of concern for those experiencing poverty, however, that marks his theory as significantly different from earlier liberal theories.

> *In the work of Marshall, the concept (citizenship) was developed to answer a problem in liberalism. In capitalism, liberal values were successful in emphasising freedoms and individualism, but there was no easy answer to critics who pointed out that the classic freedoms (...) were ineffective tokens for the majority of the population who lived in poverty.* (Turner, 1993a: 176-7)

Marshall was, therefore, concerned with protecting individuals from the vicissitudes of capitalism. He believed that by developing the concept of citizenship at both a practical and a theoretical level, it might be possible to remove or reduce some of the inequalities generated by the capitalist market system. As authors such as Dwyer (2000) and Mead (1997) have highlighted, however, what clearly indicates that Marshall was not a social democrat as is often claimed, is that he was not 'about' social reform in a Marxist respect. Marshall's intention was only to moderate the worst excesses of capitalism through the promotion of the idea of citizenship and in so doing to only modify, rather than remove, the social class system. As Mead (1997) has commented: *"In part, equal citizenship compensates for social inequality and makes egalitarian social reform less imperative."* (p.198)

Having stated Marshall's overall aim, however, the question of how he thought that his notion of citizenship would achieve the goal of protecting individuals from the vicissitudes of the capitalist system, remains. Marshall began his theorizing by an historical analysis of the development of citizenship. According to his theory, there are three major components of citizenship, namely, civil, political and social rights. In his essay "Citizenship and Social Class", Marshall ([1963] 1998) demonstrated how over the centuries these three elements of citizenship have developed at their own pace and often disproportionately, to the extent that *"it is only in the present century (...) that the three runners have come* *abreast of one another.*" (p.95) Thus, the 18th century, according to Marshall was characterised by the development of *civil* rights; the 19th century by the development of *political* rights; and the 20th century by the development of *social* rights.

It is not my intention here to go into very great depth surrounding Marshall's definitions of civil and political rights since his understanding of these rights did not differ from widely held understandings of these terms. In brief, however, civil rights for Marshall, included such things as liberty, freedom of speech, equality before the law and the right to own property. Political rights amounted to universal suffrage and more vaguely, the right to access the decision making process. It was his concept of 'social rights' that really represented his contribution to citizenship debates, however, and moved citizenship theory beyond more 'historical' definitions of citizenship.

According to Marshall ([1963] 1998) then, the basis of his notion of social rights stemmed back to the older Poor Law (pre-1834) which was the "*last remains of a system which tried to adjust real income to the social needs and status of the citizen and not solely to the market value of his labour...[But] by the Act of 1834 the [new] Poor Law renounced all claim to trespass on the territory of the wages system, or to interfere with the forces of the free market.*" (Marshall, p.99-100) So, the 19th century had actually marked a backwards step with regard to social rights. In fact, according to Marshall, the Workhouse and the minimal social rights that remained post-1834, became detached from the status of 'citizenship' because paupers forfeited their civil right of freedom (in practice), and, by law, they lost their political rights on entering the Workhouse. In addition, according to Marshall ([1963] 1998), a profound sense of 'stigma' clung to poor relief and "*expressed the deep feelings of a people who understood that those who accepted relief must cross the road that separated the community of citizens from the outcast company of the destitute.*" (p.100)

For Marshall, then, the advent of proper social rights, which began to emerge in relation to education in the late 19th century and with the 20th century welfare state, were vital steps in countering the attack upon social rights that had occurred in the 19th century, and an important advancement in the notion of citizenship. Indeed, his vision is somewhat utopian in this regard for, to use his much quoted comment, Marshall ([1963] 1998) believed that social rights represented: "*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.*": (p.94) This rather 'woolly' definition of social rights has been criticised for its lack of clarity with regard to the levels of economic welfare and security envisaged. Marshall (1972) however, did clarify his position by stating that a distinction should be made between absolute destitution/poverty and social inequality. In effect, he argues, his approach is an attack on poverty but a legitimation of inequality according to a system of meritocracy. Arguably, therefore, it is not the 'woolliness' of Marshall's definition of social rights that is the problem, but rather the manner in which he apparently overlooks major power differentials within society that affect individuals' chances of success, and which, therefore, bring into some doubt the idea that we live in a meritocracy.

Equally importantly, however, Marshall's theory has also been criticised as having normative connotations, for the notion of a 'civilised being' carries implications for an image of an 'ideal citizen'. This point will be considered in more depth within later sections of this chapter and within chapter 7. In addition, Delanty (2000) has usefully identified a further 5 major challenges to Marshall's concept of citizenship. Firstly, there is the challenge of cultural rights. Writers such as Kymlicka ([1995] 1998) and Young ([1989] 1998, 1990), to name but two, have highlighted those types of exclusion that cannot be accommodated within a model of social rights. Such discussions have led to the development of 'the politics of difference'. Secondly, there is the challenge of globalisation and 'multiple modernities'. As Delanty (2000) comments, drawing upon Mann (1987): "*(...) there is no singly developmental logic by which citizenship unfolds along a historical trajectory.*" (p.18) The worldwide experience of citizenship has been very diverse. Thus, for example, in the USA social rights have been slow to develop, whilst in the former USSR there was a strong recognition of social rights. As Delanty highlights, the irony is that totalitarianism is not incompatible with social rights, take for example the experience of Chile under the rule of Pinochet. Marshall's framework for considering the development of civil, political and social rights can be considered therefore, to be flawed once applied outside of the UK. Further, as Roche (2000), has highlighted, whilst not rejecting out-of-hand the continuing relevance of Marshall's analysis as a point of reference, nevertheless, globalisation can be seen to have led to the current crisis in a number of national welfare states, thus bringing into question the manner in which Marshall's notion of social rights can be sustained:

> *Firstly globalization tends to generate unemployment, and thus simultaneously raises the cost of welfare while undermining the tax base necessary to pay for it. Secondly although globalization depends to a significant extent on national and internationally based social compacts, arrangements and cohesion, (particularly between classes association with power in the realm of the state and the economy and their hegemonic influence over subordinate classes and groups), nonetheless it stimulates forces which are destabilizing and destructive of these national and international social orders."* (p.13-14)

Thirdly, Marshall largely ignored the importance of participation as a dimension of citizenship. Citizenship, it has been argued, is not simply a strategy of the ruling classes with which to control the masses. Citizenship can be an empowering concept and has precisely come about due to centuries of popular protest and mobilisation. Giddens (1982) has also criticised Marshall on this point stating that: "*The extension of citizenship rights in Britain as in other societies, was in substantial degree the result of the efforts of the underprivileged to improve their lot.*" (p.171) This is an important point because it suggests that on many occasions the notion of citizenship may underpin/form the basis of social movement activity and as such must be considered as a 'contested concept'. This issue is one of considerable current interest and will considered in more depth in chapter 7.

Fourthly, there is the challenge posed by the de-coupling of citizenship and nationality. Marshall's notion of citizenship was dependent upon a firm link existing between the nation and the state. For Marshall, the state provided and guaranteed rights, whilst the nation was the focus of identity. Today, according to Delanty, we live in a 'global age' in which this link can no longer be assumed. The development of regional governments has caused a shift in sovereignty downwards whilst simultaneously, trans-national developments such as the EU have shifted governance upwards, away from the nation-state. The need for re-thinking the 'social' aspect of citizenship, in particular in the light of these changes to the national, transnational, and in the British case, most centrally the European dimension, has been clearly identified by a number of authors, but most notably by Roche (1987, 1992, 1995, 2000) and by Turner (1993a). Turner particularly focuses on the issue of international human rights. As an additional point here, it has been argued that Marshall's explicit link between citizenship and the nation state has also negatively impacted upon many ethnic groups and has, in the case of the UK, led to a racialised notion of 'Britishness'. Tariq Modood (1992) has said that:

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

Finally, Delanty points to the confluence of public and private spheres. Marshall assumed that there would be separation between these two zones, equating as he did the 'private' with social class and 'public' with the state. For Delanty (2000) this was a highly reductionist stance for:

> (...) *there is more to civil society than the culture of entitlements and the administrative welfare state does not entirely absorb the public sphere, which also contains informal networks of organisation and mobilization..* (p.20)

Further, Lister (1997a/b), has argued that in maintaining a false public/private dichotomy, Marshall's work has been a factor in the continuing oppression of women. Marshall's concept of citizenship relied upon the ideal of full male employment and overlooked the important role women play in supporting the welfare system and the market economy via unpaid domestic work and the provision of care for many of the vulnerable groups in society, such as elderly people and children.

To Delanty and Lister's challenges to Marshall's theory can also be added the argument put forward by Offe (1984), that Marshall's notion of the social rights of citizenship have merely acted to buy off dissent and as a form of crisis management for capitalism. Whether this is a correct interpretation of the intentions underpinning the construction of the welfare state is unclear. It would certainly seem that the welfare state has not alleviated inequalities to the extent that Marshall envisaged. Further, authors such as Oliver and Heater (1994) have highlighted the conflict between social rights and civil/political rights. For Oliver and Heater, civil and political rights are 'first generation rights', being residual in nature. As such, they do not conflict with the underlying values of the capitalist system, indeed they have at times been vital to the success of this system. Social rights, however, are seen as being 'second generation rights' and ensuring that the necessary financial resources are made available to meet the costs of these rights is largely a matter of political will. Barbalet (1988) has argued similarly, pointing to the conditional nature of social rights and questioning whether such rights can truly be regarded as citizenship rights.

Having stated these criticisms, however, it is only right to also note that twenty years after writing "Citizenship and Social Class", Marshall (1981) did respond to at least some of his critics. In this later lecture he focused upon power and rights and was essentially concerned to establish which types of rights would best prevent the rise of authoritarianism. To briefly summarise his argument: he believed that political rights could be easily undermined, and that social rights had not been designed for the exercise of power at all, but instead reflect the strong individualist element in society in which individuals are best viewed as consumers and not as actors. It is only civil rights that, according to Marshall, truly relate to the individual as 'actor'. Such rights, Marshall argues, are internalised by each individual at the early stages of socialisation. These civil rights then permeate the social body making them very difficult to attack and these rights can then be used to create groups, movements, associations and as the basis of social and political pluralism (Isin and Wood, 1999).

Marshall went on to usefully theorize power in relation to the civil rights movement in the USA. He concluded that the powerlessness of Black people in the USA was not only due to lack of rights, but also that the manner in which Black people possessed power, made them powerless. According to Marshall then, what the leaders of the Civil Rights movement were calling for was "*not for power over or redistribution but rather an effective share in the total power of society, which we may now call the politics of recognition.*" (Isin and Wood, 1999: 31) According to Marshall (1981): "*The goal is a new kind of society, truly multiracial or, should that prove impossible, then, some would say, composed of independent and equal racial communities.*" (p.150) In this way, Marshall appears to have anticipated much of the debate over multiculturalism and the politics of difference, themes taken up most notably by Kymlicka ([1995] 1998) and Young (1990).

Berlin

Marshall's later thinking with regard to the US Civil Rights movement resonates clearly with a lesser-known aspect of Isaiah Berlin's work. It seems strange that the work of Berlin (1958) is only very occasionally considered by sociologists, considering that his 1958 lecture "Two Concepts of Liberty" has very clear implications for citizenship theorizing. Berlin's (1958) first form of liberty he defines as *negative* liberty:

> *I am normally said to be free to the degree to which no human being interferes with my activity.* (p.7)

His second form of liberty he terms *positive* liberty, and he defines this as deriving from the "*wish on the part of the individual to be his own master.*" (Berlin, 1958: 16) Although at first glance this form of liberty may not sound very different from Berlin's definition of negative liberty, his subsequent discussion of the two concepts results in a more distinct account. It becomes clear that by positive liberty Berlin was intending the notion of resource systems that enable social actors to engage in *active* citizenship where they would otherwise be constrained. This point is of considerable importance because for the first time within the liberal tradition, Berlin acknowledges fully that such things as lack of material resources can radically reduce the ability of individuals to engage in active citizenship. It is easy to see, therefore, how it can be argued that Berlin's concept of positive liberty both requires and underpins the idea of a welfare state and advances considerably beyond Marshall's quite minimal social rights.

The aspect of Berlin's (1958) work that seems to me to be most interesting, however, is not one of his two famous concepts of liberty but a lesser known concept that he defines at the end of his work "Two Concepts of Liberty", albeit somewhat indistinctly, as "*the desire for recognition*" (p.43). In part VI of this work, Berlin considers the 'search for status' and the following discussion, it seems to me, represents Berlin's theorizing upon the 'self'. Curiously, Berlin's (1958) theorising here is highly reminiscent of the symbolic interactionist perspective of authors such as Mead:

> *(...) I am a social being in a deeper sense than that of interaction with others. For am I not what I am, to some degree, in virtue of what others think and feel me to be? (...) My individual self is not something that I can detach from my relationship with others, or from those attributes of myself that consist in their attitude towards me. Consequently, when I demand to be liberated from, let us say, the status of political or social dependence, what I demand is an alteration of the attitude towards me of those whose opinions and behaviour help to determine my own image of myself.* (p.41)

What Berlin (1958) appears to be arguing here is that what those who are oppressed are demanding is not simply freedom of action, or equality of social and economic status/opportunity, the importance of which he does not overlook, but the right to be regarded as "*fully human*" (p.42). In a very interesting article on the writings of Berlin, Gary Reed (1980) discusses the importance of this third, somewhat 'hybrid' form of freedom and uses the idea of the 'stranger' to explain the concept:

> *A free person is then one who is a member of the kin; not a stranger. A second metaphor introduces the idea of liberation, of making free, by speaking of a person born a stranger as if he had grown up with the kin. This metaphor enables people to do by choice what at first only nature could do by birth: make a person free. A liberated person is one who is no longer a stranger, whether a stranger within (a slave) or without (an enemy). At this stage simple release of a stranger from captivity is not yet called liberation, making free; a former captive remains a stranger unless by admission to membership he is made free.* (p.371)

Although the terminology here may seem somewhat removed from present day concerns, the idea that an "*unappropriated stranger is simply a slave without a master*" (Reed, 1980: 372) can, I suggest, be usefully employed when considering the position of many disadvantaged, stigmatised or exploited groups within society.

The other useful aspect of Berlin's theorising on this third form of liberty, is the manner in which he critiques the normative and monistic tendencies of other neo-liberal thinkers such as Rawls. Berlin considered other neo-liberals to have relied too heavily upon universalistic definitions of *'what is right/good'* and in so doing had failed to resolve the dilemma of what happens when people disagree about what constitutes the *right or good.* For writers such as Gray (1995) and Galipeau (1994), it is precisely this rejection of the universalistic philosophies favoured by other liberal thinkers, that is the basis of Berlin's unique and important contribution to the field.

For Berlin, the idea, as found in the work of both Rawls and Marshall, that there can be a universally accepted image of 'ideal citizenship' against which *"all human projects should contribute or tend, and against which they might be evaluated"* (Gray, 1995: 8) is flawed, for as Kenny (2000) has written: *"The principle of incommensurability suggests that there is no external standard, no 'super-value', according to which values can be rationally ranked."* (p.1028) It is in this way that Berlin introduces the idea of 'value-pluralism' and because of this, I would suggest, his work should be seen to be, to an even greater extent than that of the later Marshall, an important precursor of more contemporary accounts of citizenship. Berlin's work will be considered again as it relates to the findings of this research, in chapter 7.

Contemporary Accounts of Citizenship

The Pluralist/Multicultural Accounts

In the traditional liberal conception, as has already been discussed, citizenship is seen to be the embodiment of universalist ideals. In this conception of citizenship, all individuals who can legitimately claim to be citizens of a state are supposed to possess equal rights and equal responsibilities. For pluralist thinkers, however, this notion of citizenship can act as a "*powerful exclusionary discourse*" (Faulks, 2000: 83), and needs modifying if it is to be sustained within plural societies. The general approach taken by the pluralist thinkers is, therefore, that in addition to individual rights of citizenship, special group rights are also required. What is less clear is the extent to which some of the chief proponents of this approach to citizenship theorising agree about the form that this pluralist citizenship should take. Chief amongst the pluralist thinkers are Will Kymlicka and Iris Marion Young, for this reason I have chosen to focus my attention upon their work. This is not to say, however, that they are the only theorists working within this field, the work of Pakulski (1997) and Stevenson (1997a/b), for example, is also of importance. Nevertheless, Kymlicka and Young are widely held to have made the most powerful contributions to this approach. Both Kymlicka and Young take as the basis of their theorising a critical stance towards the universalist notion of citizenship. Both theorists perceive that in pluralist societies it is essential to consider group rights within the citizenship framework. Whilst proposing a relatively similar critique of universalist notions of citizenship, there are differences, however, between the models of citizenship employed by Kymlicka and Young. The next section of this chapter will provide a critical appraisal of their separate approaches.

Kymlicka's defence of group rights is, he claims, firmly rooted in a liberal conception of citizenship. In support of this statement he has developed a multiculturalist perspective that requires social institutions to be reformed in a manner that allows for the "*accommodation of the cultural distinctiveness of multiple ethnic groups in a single state.*" (Shafir, 1998:18) Such a perspective demands that the rights that have previously been bestowed only upon the individual citizen, as in liberalism, be extended to groups as well. This, Kymlicka claims would lead to a *differentiated citizenship* and should be seen as an extension of, rather than a threat to the liberal conception of citizenship.

To this end, Kymlicka proposes that there are three types of differentiated citizenship: in particular he states that it is important to distinguish between the closely related *representation rights* and *polyethnicity* and the altogether different, *self-government rights.* For Kymlicka ([1995] 1998), group representation rights generally take the form of a demand for inclusion by disadvantaged groups:

> *Groups that feel excluded want to be included in the larger society, and the recognition and accommodation of their 'difference' is intended to facilitate this. (...) It has always been recognized that a majoritarian democracy can systematically ignore the voices of minorities. In cases where minorities are regionally concentrated, democratic systems have responded by intentionally drawing the boundaries of federal units, or of individual constituencies, so as to create seats where the minority is in a majority. Proponents of special representation simply extend this logic to nonterritorial groups who may equally be in need of representation (for example, ethnic minorities, women, the disabled.)* (p.169)

Similarly, according to Kymlicka, demands for polyethnic rights most often take the form of requests for special rights to facilitate the participation of certain groups within the mainstream of society. Kymlicka cites, as an example, the case of Sikhs who wished to join the Royal Canadian Mounted Police but who faced problems because they were not allowed to wear turbans as part of their uniform. Modifying an institution such as the Royal Canadian Mounted Police in order to allow Sikhs to integrate into them as fully as possible is, according to Kymlicka, an important step in preventing Sikhs from withdrawing from mainstream society. Further, according to Kymlicka ([1995] 1998): *"the fact that these men wanted to be a part of the national police force or the national military is ample evidence of their desire to participate in and contribute to the larger community."* (p.170) Thus, in Kymlicka's opinion, group representation and polyethnicity can promote social integration and political unity.

His third form of differentiated citizenship, *self-government*, poses, he believes, a more "*serious challenge to the integrative function of citizenship*". (Kymlicka, [1995] 1998: 174) The basis of his fear is that demands for self-government suggest a desire to weaken the notion of a permanent, unitary, 'macro' level political community. In other words, demands for self-government are very different from demands for representation rights, in which it is seen that certain groups are disadvantaged within the political community, or polyethnic rights, where there is a need to see the political community as culturally diverse. Instead, calls for self-governance suggest that there is more than one political community within one state. Such multination states, Kymlicka argues, are inherently unstable, since the tendency towards secession will always be strong.

This is not to say that Kymlicka is entirely opposed to secession, however, for he believes that where it is viable it may be desirable. In this he draws upon J.S. Mills' argument that a stable liberal democracy will be based upon a nation-state, with a single national culture. Nevertheless, he claims that it may not always be desirable where the minority group would have problems developing a viable nation-state. In such cases, a way of holding such a multi-nation state together, must be found. Unfortunately, as Kymlicka himself admits, it is not easy to find such a solution. He does consider, however, that the basis of unity within states is likely to be dependent upon the development of a particular form of sentiment amongst citizens. These sentiments would take the form of a desire to be united, but at the same time to remain respectful of the deep diversity that constitutes their state. It must be said, however, that although Kymlicka claims that he is not falling into the trap of proposing an overly legalistic definition of citizenship which neglects more socio-cultural factors, in calling for the development of certain 'sentiments' on the part of citizens, he does appear to be clinging somewhat to the normative and monistic liberal notion of a *common citizenship* so usefully critiqued by Berlin.

I think that the problem must rest upon Kymlicka's definitions of culture and identity. Although he begins his theorising on differentiated citizenship by acknowledging that culture need not be tied to membership of a national group, as previously mentioned with regard to representation rights, his subsequent theorising on the possible ways of maintaining unity in a multi-national state, suggests that he has become preoccupied with the idea that the choices citizens make are meaningful only in the context of the nation (Faulks, 2000). In theorising thus, Kymlicka is clearly being far too reductionist of the complexity of culture, for the idea of a national culture often stands in tension to social cleavages that can occur within one nation, such as class, gender, sexuality and so on.

Further, there is a fundamental flaw in Kymlicka's understanding of culture *per se*, for it is not as concrete a phenomenon as his theory suggests. Kymlicka makes some rather questionable assumptions about the nature of culture. The first is that he tends to essentialise cultural *difference* between groups of people. There are undoubtedly, differences between all people, but the manner in which society manipulates the concept of 'difference' in an essentialist manner in order to categorise some groups as 'other', needs to be problematised. In the first part of his theorising, for example, where he talks about the idea of representational rights, Kymlicka appears to be making the assumption that differences such as gender or dis/ability are necessarily based upon cultural differences. Whilst a shared sense of cultural identity may be the basis of the formation of *many groups*, it need not be the basis of *all groups*. Equally, to assume that any group exists on the basis of only one, predominant identity trait, is to essentialise both the nature of group formation and to be reductionist of the complexity of 'identity'. As Fierlback (1998) has commented:

> (...) *to assert that one simply knows that another person is defined predominantly by their culture or specific group traits rather than other factors seems as oppressive as refusing to believe that cultural characteristics are important at all.* (p.99)

The further problem with Kymlicka's approach is that in proposing group rights in a differentiated citizenship, he fails to tackle the problem posed by complex cultures. Where cultural groups *do* exist not all are as distinct and unified as Kymlicka appears to suggest. The culture itself may show differences according to such as factors as class, or gender. This issue and the contribution of Bourdieu's to theorising on this point will be considered in more depth in chapter 7. Equally important, however, and only touched upon by Kymlicka, is the problem posed by any 'illiberal' cultures that involve cultural practices that disadvantage particular members of the cultural group. Kymlicka fails to explain how he believes it to be possible to achieve a multicultural unity based upon shared 'sentiments' when the cultural practices of one group are fundamentally in conflict with the practices of another.

As previously stated, in many respects the goal of Iris Marion Young is very similar to that of Kymlicka in that she seeks to critique those theories of citizenship that have tried to suppress group differences. She differs from Kymlicka, however, in that she does not seek to develop a modified liberalist approach to citizenship, but instead rejects the earlier approach entirely. Central to Young's approach is the argument that the universalistic sense of citizenship that had underpinned liberalism "*by separating the public sphere of 'reason' from the private realm of 'desire' and the body, elevates the dispassionate notions of 'collective interest' and 'equal citizenship' as expressed in the idea of the 'civic public' over and against the particularised interests that comprise the aspirations of groups and individuals.*" (Ellison, 1997: 705) The result of this liberalist approach to citizenship, Young claims, has been to suppress or deny the differences between groups in the public realm and instead to demand of each citizen the denial of their very identities when exercising their rights and duties. In other words, as Faulks (2000) has commented, Young perceives liberalism as standing "*not for equality between different individuals but the domination of the* *ideal of equality over difference: the diversity that characterises society is sacrificed in the name of an abstract and unattainable conception of citizenship.*" (p.85)

According to Young this insistence on the part of the liberal thinkers that equality and liberation can only be achieved by ignoring differences has had three oppressive consequences. The first consequence of this liberal approach has been a focus upon a process of *assimilation*, in which formerly excluded groups are brought into the mainstream. So influential has this idea been, that it has largely gone un-challenged, even by other pluralist thinkers such as Kymlicka. For Young (1990), however, assimilation "*always implies coming into the game after it has already begun, after the rules and standards have already been set, and having to prove oneself according to those rules and standards.*" (p.164) Needless to say, it is the privileged groups that determine these standards. In so doing, however, they genuinely consider themselves to be determining a culturally neutral ideal of common humanity. This is clearly not the case, for norms determined by the dominant group will always be culturally biased. This then, according to Young (1990), is the second problem with the liberalist approach to citizenship for "*the ideal of a universal humanity without social group differences allows privileged groups to ignore their own group specificity.*" (p.165) This, according to Young, leads to the final oppressive consequence of liberalism. The tendency to denigrate any groups that fail to live up to the supposedly neutral, but in fact culturally biased standards as set by the privileged group, in turn can lead to "*an internalised devaluation by members of those groups themselves. (...) The aspiration to assimilation (thus) helps produce the self-loathing and double consciousness characteristic of oppression.*" (Young, 1990: 165)

The answer to these problems, according to Young, is to reject assimilationist ideals entirely and to embrace instead what she terms the 'politics of difference'. This new politics would, she argues take the form of a rejection of the "*appropriation of a universal subject position by socially privileged groups*" by which they force "*those they define as different outside the definition of full* *humanity and citizenship*." (Young, 1990: 169) Echoing Goffman's notion of 'stigma', Young proposes that the root cause of this tendency on the part of the dominant group to essentialise difference, is their fear of making the boundaries permeable between themselves and those they determine to be 'others'.

For Young the alternative to this essentialised notion of difference is a notion of difference as 'variety'. In this way group differences can be seen to be merely functional means of comparison between groups, with dominant groups such as white people being seen to be just as *specific* as Black people, men as women, homosexuals as heterosexuals and so on. The other important aspect of this new form of politics, Young argues, is that it is also a contextualised understanding of difference. According to this argument, depending upon the groups compared and the context, differences may become more or less salient. Young (1990) gives the following example:

> *(...) in the context of athletics, health care, social service support, and so on, wheelchair-bound people are different from others, but they are not different in many other respects. Traditional treatment of the disabled entailed exclusion and segregation because the differences between the disabled and the able-bodies were conceptualised as extending to all or most capacities.* (p.171)

In many respects, therefore, the great value of Young's work is that it provides us with this basis for a more fluid and contextualised notion of difference. There are, however, some problems associated with the manner in which Young then sets about utilising her understanding of difference to develop a model of democracy. She states that:

> *I assert, then, the following principle: a democratic public should provide mechanisms for the effective recognition and representation of the distinct voices and perspectives of those of its constituent groups that are oppressed or disadvantaged. Such group representation implies institutional mechanisms and public resources supporting (1) self-organization of group members so that they achieve collective empowerment and a reflective understanding of their collective experience and interests in the context of the society; (2) group analysis and group generation of policy proposals in institutionalised contexts where decision*

> *makers are obliged to show that their deliberations have taken group perspectives into consideration; and (3) group veto power regarding specific policies that effect a group directly, such as reproductive rights for women, or land use policy for Indian reservations.* (Young, 1990: 184)

Whilst this may at first glance appear to be an appealing notion of democracy, it would seem, however, that it is based upon a number of questionable assumptions.

Taking her second point first, since in some respects it is perhaps the least problematic, is would nevertheless seem likely that she is being overly optimistic here. Many disadvantaged groups have already had experience of "*decision makers (being) obliged to show that their deliberations have taken group perspectives into consideration*", but have found that this 'consultation' takes the form of mere 'rubber stamping'. This is a point that will be returned to later in chapters 6 and 7 in relation to the findings of this research. In defence of Young's ideas, however, it can be argued that there is nothing intrinsically wrong with her notion of consultation, it just needs to be put into proper effect.

Point (1) in the schema is more problematic, however, for it is clear that Young believes that the self-organisation of group members in order that they achieve collective empowerment is both possible and desirable. Although the work of Bourdieu will be considered in more depth in chapter 7, it is important to note at this point that much of his work on the nature of groups appears to contradict Young's work. Firstly, according to Bourdieu (1987), no matter how many resources are available to a number of individuals occupying similar positions, it does not necessarily follow that they will mobilize as a group. In other words, simply because a number of individuals can be identified by others as being 'similar' in some way, does not mean that they can be *categorised* as a group or a community. Secondly, although Bourdieu would probably agree with Young that where groups *have* mobilized, they gain collective empowerment, he perceives risks associated with this process. He highlights the fact that in the process of becoming such a 'practical group', chief advocates or spokespeople emerge. He concludes that a paradox then arises, for whilst an individual who so identifies themselves with a group becomes empowered and gains recognition, they are at the same time relegating their individual powers to those who claim to speak on behalf of the group. Collective empowerment may, therefore, mean individual disempowerment.

In relation to point (3), here Young clearly falls into the same trap as Kymlicka. Giving powers of veto to groups in relation to policies that directly affect them can be a positive step. It may, however, allow for the continuance of practices and behaviours on the part of minority groups that may be regarded as illiberal by the majority. Both Kymlicka and Young fail to explain how this potential conflict could be overcome. This may not be unintentional on their parts, however, for ultimately, problems such as this must rest upon ethical dilemmas that are not easily resolved. For example, there is an important debate currently taking place in the world of genetics between geneticists who would like to find ways to eliminate congenital deafness, and some Deaf people who oppose the development of such technologies on the grounds that such moves are akin to genocide.[1] Whilst it is not my intention to go into any depth on this matter since it warrants significantly greater attention than can be afforded here, it is nonetheless important to highlight how giving Deaf people the right to veto moves to eliminate congenital deafness, immediately sets up a dilemma in relation to the rights of the unborn child to *not be born deaf.* In the light of such continuing debates, it is the argument here that theories that bypass ethical dilemmas need to be reconsidered.

Having stated the above there is, however, an even more problematic assumption underpinning the idea of the 'politics of difference'. The problem is that Young (1990) relies upon the idea of the social group as culturally determined: "*A social group is a collective of people who have affinity with one another because of a set of practices or way of life.*" (p.186) The problem is that whilst Young does admit that other collectives can and do exist on the basis of other factors, these

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[1] For more information on this debate please see: <http://www.deafgene.info/designer.htm> and related links.

she terms interest groups and ideological groups, she does not believe that such groups should be allowed specific representation. The reason for this can only be that Young is prioritising cultural issues over any other. The tendency on the part of Young to focus primarily upon issues of cultural recognition and in so doing fail to give sufficient attention to issues of redistribution, for example, has been highlighted by writers such as Nancy Fraser (1997) who states that social inequality must still be considered to be one of the key impediments to a true democracy. This aspect of Young's work will be considered again in relation to the findings of this research in chapter 7.

It is not entirely surprising, therefore, given the significance of some of the problems associated with the pluralist account of citizenship, that alternative approaches have emerged. I have chose to focus upon two alternatives to the pluralist account. The first approach I have termed a 'reflexive' account of citizenship, and is most clearly articulated in the work of Habermas. This theory has been developed to counter the tendency on the part of some pluralist thinkers, such as Kymlicka, to focus upon citizenship as being based upon nationally held, shared 'sentiments'. This approach highlights the effects that globalisation/cosmopolitanism has had upon the notion of citizenship and calls for a more "*reflexive transformation of existing national conceptions of group membership.*" (Delanty, 2000: 65) The second account is probably best termed 'post-structuralist', and is to be most notably found within the work of Mouffe. This approach has been developed to challenge the pluralist assumption that "*individual persons can have singular, integral, altogether harmonious and unproblematic identities*" or that "*collective identities as based on some 'essence' or set of core features shared by all members of the collectivity*" (Calhoun, 1994: 13).do actually exist

The Reflexive Account of Habermas

Habermas' contribution to the citizenship debates begins with his work on the political realm, where he distinguishes between the 'lifeworld' and the 'system'. Habermas developed the distinction between these two zones of action within the second volume of his "Theory of Communicative Action". McAfee (2000) usefully defines Habermas' notion of the 'lifeworld' and the 'system' thus:

> *(...) the lifeworld (...) consists of the background assumptions, cultural norms, expectations, and meanings that we use to interpret and make sense of our experience and to co-ordinate our actions with others. The system on the other hand, is society conceptualised in terms of the division of labour and functions into separate spheres of actions and goals (e.g., the banking system, the political system, the educational system), each with its own predetermined ends and selected means for achieving them.* (p.85)

Habermas (1984) then went on to integrate these two concepts into an analysis of society in which society is seen as both a "*system that has to satisfy the conditions of maintenance of socio-cultural lifeworlds*" and a "*systematically stabilized nexus of action of socially integrated groups.*" (p.xxix) Even as he so theorized, however, he simultaneously identified an increasing trend towards the differentiation, or what he termed the 'decoupling' of the lifeworld and the system. Habermas saw this as being the inevitable outcome of Modernity. In particular, he saw this passage to Modernity as being characterised by the move away from more traditional forms of society towards a society characterised by various aspects of life becoming increasingly independent of the normative structures in society, such as traditions, culture and kinship.

In some ways, Habermas perceived this move towards Modernity to be a good thing, for it had ended the authoritarian traditions and conventions that had previously governed society and led to a more rational society of 'postconventional' morality. Habermas did not consider this move to be without risk, however, for these changes rendered the lifeworld vulnerable to colonisation by the system, as reasoning previously only appropriate to systems is applied to social life. The result, Habermas feared, was that Modernity has not made society more just. McAfee (2000) summarises Habermas' concerns thus:

> *While the prerogatives of citizenship have been expanded to more and more people, the tasks of citizenship have been distorted into*

> *the role of consumer. Likewise, capitalism has not made the labor-for-wage relationship better in any real way, instead it has transformed the identity of worker into that of consumer. The colonization of the lifeworld turns citizens into clients and workers into consumers, thereby minimizing opportunities for overcoming capitalism's and Modernity's injustices.* (p.88)

Despite such theorizing, Habermas was not entirely pessimistic about Modernity, for he saw the rise in communicative rationality and the existence of the 'new' social movements to be precisely *about* challenging the manner in which the lifeworld is encroached upon by the system. In this respect Habermas' work has had profound influence upon social movement theorizing, particularly upon the work of writers such as Touraine and Melucci.

In his work, subsequent to "The Theory of Communicative Action", Habermas has sought to further develop the notion that certain mechanisms can prevent the system encroaching upon the lifeworld. What Habermas calls for is the re-kindling of democracy, in which the will of the people guides public policy. In particular, Habermas states the need for 'discoursive democracy', which he perceives to be a deliberative process within public communication. In other words, Habermas believes that the solution to the previously stated problems of Modernity is to foster the right conditions so that public opinion can have public influence. In contrast to his earlier work however, Habermas has now somewhat re-stated his position, for whilst he still largely locates discoursive democracy within the communicative domain that is the public sphere, he also locates it in the "*partly institutionalised political culture of civil society.*" (Delanty, 2000: 41)

The idea of a discoursive democracy has not gone unchallenged, however, for the question of how a consensus can be reached within a heterogeneous society remains. Feminists such as Meehan (1995) have highlighted the fact that the aim of consensus actually closes off many of the differences that characterise society. Habermas countered these criticisms by stating that such problems can be overcome by the 'public use of reason'. Delanty (2000) has commented that Habermas' notion of 'discursive democracy' seeks to:

> *(...) render positions reflective. (...) To adopt the public perspective is to accept a third-person perspective, which is neither the perspective of the opponent nor one's own vantage point. The public perspective is the genuinely intersubjective perspective, reducible to neither self nor other.* (p.42)

Thus, Habermas' notion of consensus differs from that of Rawls, for example, because it does not rest upon the normative assumption that decisions can be made on the basis of an overlapping sense of the 'common good'. In fact, Habermas rejects this idea and states that in complex societies characterised by cultural pluralism, it cannot be taken for granted that a background consensus exists. In Habermas' (1998) notion of consensus, therefore, it is not assumed that different parties will necessarily reach an overlapping consensus, but rather that a reflexive position can be reached that looks for the critical appropriation of both positions.

I would suggest, however, that Habermas' position is equally, if differently normative in approach, when compared with the work of more liberal thinkers, such as Rawls. Many Feminist writers reinforce this criticism of Habermas' work, for example Fraser (1989) who has highlighted the fact that Habermas fails to adequately theorize the notion of *power*. Differentials in the power possessed by different groups will affect the degree of autonomy they possess within the public sphere. Attention, therefore, must be paid to the 'pre-discoursive' space. Thus, whilst Habermas' work has been highly influential within contemporary citizenship theorizing, particularly with regard to his theories of communicative ethics, other aspects of his work are more contentious. In particular, the question of the extent to which this reflexive position can realistically be achieved from within a society characterised by a large number of social cleavages and related power differences, continues to be a major issue within the citizenship debates.

It seems to me, however, that the great strength of Habermas' theorising lies less with the fine details of how this discoursive democracy could be made to work in practice. The strength of his theory lies instead in the manner in which he locates this discursive democracy largely within the state, whilst simultaneously rejecting the idea that this citizenship is in itself necessarily rooted in a particular cultural community. I think that he is also right to reject the idea, as seen in the work of Kymlicka, that certain 'shared sentiments' need to be developed by citizens. Indeed, Habermas is clear when he states that since each individual possesses multiple 'selves', that the idea that uniform cultural communities ever exist, must be placed into some doubt.

For Habermas, all that is needed is a shared sense of obligation between members of a polity that is solely political, and in no way cultural. This, he claims, would take the form of minimal shared identity, a kind of 'common denominator commonality' that is based only upon the legal frameworks as set out within the constitution of a state. In this way, it seems to me, Habermas is paving the way for a more cosmopolitan notion of citizenship. Indeed, he states: "*Only a democratic citizenship that does not close itself off in a particularistic fashion can pave the way for a world citizenship (...)*" (Habermas, 1996: 514) In this way, borders at every level, between neighbourhoods, regions or states, are seen as only existing for administrative purposes, not as barriers between 'us' and 'them'.

By de-coupling the notion of citizenship from nationality or cultural heritage in this way, Habermas (1996) (see also Habermas, 1992) is thus providing a way of integrating states, as is happening within the EU, for example, on the basis of a shared civil society, rather than a shared sense of culture. Further, by uncoupling nation-state and citizenship discources, there is more of a chance that citizens will sense that their responsibilities reach beyond their immediate locality (Faulks, 2000), from the local to the global.

The Post-structuralist Approach of Mouffe

Again in the work of Mouffe, the essential focus is democracy. Mouffe's vision of democracy is one that sees the tension between universalism and particularism, not as something that needs to be resolved, but rather as constitutive of the democratic process itself. As in the later work of Habermas, in which he proposes that the individual is best understood as having multiple selves, Mouffe perceives the social agent as an ensemble of subject positions. In other words, Mouffe's notion of 'citizenship' rests upon her understanding of the identity of the subject as being; "*always contingent and precarious, temporarily fixed at the intersection of those subject positions and dependent on specific forms of identification.*" (Isin and Wood, 1999: 11)

Since Mouffe is a feminist writer, she is essentially talking about feminist politics, nevertheless, her thoughts can easily be applied to other groups. Thus her rejection of what she regards to be the essentialist idea that certain qualities or functions that are commonly associated with women are central to women's identity as women, can be applied to many other groups engaged in 'struggle'. Equally useful is her idea that ultimately, there is no need to hold to any kind of essentialist concept of identity in order to make political action possible or to support any kind of democratic politics. Indeed, according to Mouffe, what feminists should be doing is seeking to find a common cause with other groups that have been denied the democratic ideal of equal citizenship, thus as McAfee (2000) states: '*The goal, for Mouffe, is for such oppressed people to join together as a "we" to gain hegemony over "them", all those oppressors.*' (p.118) Thus, in relation to her conception of citizenship, Mouffe is suggesting that "*radical democratic citizens depend on a collective form of identification among the democratic demands found in a variety of movements: women, workers, black, gay and ecological as well as other oppositional movements.*" (Isin and Wood, 1999: 11)

In this way, she proposes that the way forward is to develop a 'radical and plural democracy', in which there is a non-essentialist conception of the subject, and identity is seen to be determined by identification with groups rather than as an essential property of the subject (Mouffe, 1993). Thus, for Mouffe, politics will always be a 'struggle', an antagonistic process between such groups. Focusing thus on groups, Mouffe does not support the idea of the 'self-regarding individual' of liberalism, nor does she believe that an allegiance to the 'common good' is possible, no matter how desirable it may be. This leaves her with the central problem, however, of how to then theorise a concept of citizenship that does not perceive individual liberty to be incompatible with the political community.

Mouffe's answer is to reconsider the *nature of the polis*. She draws upon the work of Oakeshott (1975), who makes the distinction between *universitas* and *societas*. In the former, the polity is composed of individuals with a shared *purpose*, in the latter, the polity is seen to be composed of individuals with shared *interests*. Mouffe proposes that her notion of a 'radical democracy' is best understood as a radical *societas*, in which conflict and antagonism play a crucial part. In other words, in Mouffe's view, individuals cannot be considered to be peacefully pursuing their interests, but should instead be considered to be engaging with each other over the meaning and definition of their common interests. There will never be, therefore, a homogenous unity in such a societas, for there will always be a need for an 'other'.

The form of citizenship arising out of this definition of a radical societas, is one that is clearly opposed to the more classical approaches to citizenship theorising. For Mouffe, the citizen is neither the passive possessor of rights, as in the work of Hobbes for example, or someone who agrees to submit to the rules prescribed by the 'general will', as Rousseau proposed. Instead, Mouffe (1992) proposes that this notion of citizenship is best understood to be "*not a unitary subject but as the articulation of an ensemble of subject positions, constructed within specific discourses and always precariously and temporarily sutured at the intersection of those subject positions.*" (p.237) The existence of these multiple subject positions has already been documented in many movements demanding democratic, citizenship based rights, for example, in the Black, gay and ecological movements.

Mouffe's work has not gone un-criticised, however, particularly with regard to her tendency to label any theory that takes identity categories seriously, as 'essentialist'. In relation to Mouffe's attacks on what she regards to be essentialism within feminism, many feminist theorists would counter her criticisms by stating that they are not talking about a supposed female *essence*, but rather about the manner in which women have been historically, socially and culturally *constructed.* McAfee (2000) has stated that it is important to distinguish between essentialism and nominalism:

> *Are we talking about women de re or women de dicto? Is it a matter of what woman is in herself or of what she is called? Of how she is 'naturally' versus how she's been constructed socially? Many feminists are careful to make distinctions between, for example, what a women is biologically and what she is taken to be culturally.* (p.119)

Nevertheless, it can be said that the importance of Mouffe's work lies, not in its attack on essentialism, but rather in the manner in which it highlights the inadequacies of any theory that takes a particular aspect of a person's identity and claims that it is more pertinent than any other.

Conclusion - future developments?

This chapter has sought to provide a critical overview of some of the key citizenship theories that have been developed over time, from the ancient to the contemporary accounts. As I think is clear from the discussion, it is debateable to what extent any of the existing models account for the nature *of*, or provide a realistic ideal *for*, the citizenship of 'Later Modernity'. In the complex and often unstable world of Later Modernity, whilst much cannot be said with certainty, I would argue that the following can be held to be widely apparent. Firstly, it is no longer possible to talk about a sense of citizenship that is 'universal'. Secondly, understandings of citizenship based upon the idea of 'national communities' must also be placed in some doubt. Thirdly, whilst rejecting universalistic understandings of citizenship, it is equally impossible to develop a theory of citizenship that relies upon developing the recognition of a stable set of 'differences'.

Whilst the development of theory within this field must be on-going, some existing models have gone further than others in providing the basis for future theorising. What I take from Berlin, Habermas and Mouffe, in particular, is a sense in which citizenship is still about social engagement, and in particular that it is still firmly linked to democracy and the struggle for a common goal. Further, what is common in their approaches is an understanding of citizenship as being about the development of new forms of social and political practices that are themselves the result of the formation of new social alliances across a range of different 'communities'. That understanding the *process* of engagement is key to developing a new theory of citizenship is a new idea proposed by Ellison (1997, 2000). Further discussion of the work of Berlin, Habermas, Mouffe and Ellison can be found in chapter 7.

There are however, some new contributions to the citizenship debates that advance beyond the traditional parameters of citizenship theorising and into realms that have not previously been considered by theorists in this field. The idea that has remained unquestioned for so long, that citizenship is connected with *competence*, is now being deconstructed by authors such as Jenkins (1998) and Silver (2002) and this marks an important step in terms of understanding the 'citizenship' experiences of many disadvantaged or stigmatised groups. More central to the argument in this thesis, however, Jenkins (1998) has called for an understanding of the 'materiality of identity'. In this respect his views clearly resonate with those of feminists such as Ruth Lister (1997a) who has shown how traditional approaches have relied upon a *disembodied* notion of citizenship. For such theorists, the rights and responsibilities that are part of being a citizen cannot be divorced from an understanding of the importance of the body.

In terms of 'bringing the body' back into sociology Foucault's (1979) work has clearly been highly influential, if equally greatly criticised, for in writing about the body as a site of power, he grounded what may seem at first glance to be fairly esoteric theorising on materiality, in the actual, everyday processes of power. As previously mentioned in relation to Lister's work, such ideas have been usefully taken up and modified by feminists. One branch of feminism has been particularly influential in this regard however, and that is the theorising of postmodernist/poststructuralist feminists such as Butler (1993). Butler (1993) states that:

> *(...) what constitutes the fixity of the body, its contours, its movements, will be fully material, but materiality will be re-thought as the effect of power* (p.2)

As part of this re-thinking of materiality, Butler (1995) calls for a questioning of the ways in which certain paradigms serve to disempower and erase that which they seek to explain, '*effecting a violent reduction of the field to the one piece of text*' (p.37). Such theorising has clear implications in terms of challenging the social model of disability and the work of authors such as Oliver (1996), who as will be discussed later in this thesis, perceive that the inclusion of 'impairment' in theorising on disability, runs the risk of diluting the social model's potential in terms of praxis. Using the arguments put forward by Butler, to truly challenge discourses of power in terms of disability, it is important to understand that 'impairment', whilst having an undeniable, basic, biological definition, is also imbued with diverse social meaning (Fawcett, 2000).

In terms of citizenship theorising *per se*, however, it is Turner ([1996] 2000) who has most famously developed this connection between a Sociology of the Body and citizenship. In order to break with this earlier theorising he proposes a Sociology of the Body which requires consideration of the following:

> *1. an elaborate understanding of the basic notion of embodiment, which would be a method of systematically exploring the complexity of the body in terms of its corporality, sensibility, and objectivity;*
>
> *2. an embodied notion of social agency in the theory of social action and a comprehensive view of how body-image functions in social space;*
>
> *3. a genuinely sociological appreciation of the reciprocity of social bodies over time – that is, an understanding of the collective nature of embodiment;*

> *4. a thoroughly historical sense of the body and its cultural formation;*
>
> *5. a political understanding of the body in relation to governance, with special reference to what we might term corporeal citizenship, namely sexual regulation and surveillance of bodies by state legislation on reproductive technology, abortion, adoption, and parenting.*
> (Turner, [1996] 2000: 487)

He then uses his sociology of the body to develop an embodied understanding of citizenship as *personhood*, where each person is both *seen as*, and is *aware of*, their own vulnerabilities. How he does this and the implications of his theorising will be considered in more depth in chapter 7. Ultimately, however, Turner (1993a/b) proposes, along with some other key thinkers (Soysal, 1994, Delanty, 2000), that there are now good grounds for suggesting that another discourse, that of human rights with is foundation in understandings of the de-centred and contextualised self, may provide the most sustained challenge to the idea of citizenship, and may indeed, mark the end of the concept entirely. The extent to which Turner provides a convincing alternative to the notion of citizenship will also be considered in more depth in chapter 7.

Chapter 4

Disability in Society, Today

Introduction – a brief history of theorising on disability

Prior to the 1970's to have an impairment was regarded as a 'personal tragedy' and this thinking existed not only within the wider public sphere but was also a major influence upon service providers and policy-makers. As Barnes et al (1999) have commented, these prejudices and stereotypes had profound and unfortunate effects upon the lives of disabled people:

> *It seemed to dictate a life as a passive 'victim' characterized by social exclusion and disadvantage, and by dependency on assistance from family and friends and a 'safety net' of state welfare benefits and services.* (p.10)

Curiously however, despite social science's history of exposing social inequalities, the position of disabled people in society had generated little research and had prompted almost no theoretical interest. Further, during the 1970's strong objections began to emerge against the small amount of research and theorising that had taken place during the 1960's, most notably in the work of Parsons on the sick-role and Goffman on stigma.

Parsons and Goffman

For Parsons (1951), for a society to function properly all of its members must play their appropriate roles. Health is viewed as the 'normal' state and is linked to optimum capacity. In contrast, illness is regarded as being akin to a form of social deviance since it is a disruptive and 'abnormal' state. Since illness along with deviance of all types is viewed as a threat to the smooth functioning of the system, it must be managed and controlled. The first part of this management of illness, Parson's termed the 'sick role' which he perceived to be a form of sanctioned social deviance, controlled and managed by the medical profession. For Parsons, power imbalances between doctor and patient are necessary to serve the interests of society and such relationships are entirely benign.

As previously stated, however, Parsons' work and his notion of the sick-role have been heavily criticised. Firstly, it has been argued that the sick-role is an 'ideal type' which, whilst being of some benefit when seeking to understand acute illness, does not relate as successfully to the experience of long-term or permanent impairments/conditions. Secondly, this sick-role theorizing has been criticised for failing to take a more critical stance towards the role of doctors and other therapeutic professionals. The sick-role model tends to assume that the role of these health care professionals is to seek to 'normalize' the disabling consequences of a particular illness, in a manner that clearly reflects the psychological notion of 'adaptation'. As Albrecht (1992) has commented, this "*idealised process seems too facile*" (p.74). Many disabled people have rejected this perceived role of the health care professional, claiming that it has led to them being treated as objects and being manipulated against their wishes into abnormal lifestyles. Further, Oliver (1996) has proposed that such thinking is the result of the 'psychological imagination' and rests upon assumptions made by non-disabled people about what it is like to have an impairment.

This notion of illness as a form of social deviance is also to be found in the work of Goffman, although he elaborated the idea rather differently. In his famous work "Stigma", Goffman (1968) broadly defines the term as 'abominations of the body' and goes on to list as examples such things as physical deformities, differences according to 'race' or religion and faults of character. In each case, the notion of the 'normal human being' becomes a normative system for grading those who are perceived to have a 'stigma' and for categorising them as being 'not quite human'. Goffman then went on to consider how people seek to manage their 'spoiled identities', for example, how people with an acquired disability manage their re-identification, or how those with a more visible 'stigma', *the discredited*, differ from those with a less visible 'stigma', *the discreditable*.

The current consensus within Disability Studies appears to be that in moving theory on from Parsons in this way, Goffman's work must be considered of considerable value. Equally, however, it is clear that Goffman's work has left Disability Studies with a number of important questions which are yet to be adequately resolved, such as: "How far can disabled people resist the process of becoming 'stigmatised'?" "To what extent can individuals create their own identities?" and "When both intellectual and physical differences are equally visible, why do such differences possess such contrasting meanings?" (Barnes et al, 1999)

Critics of Goffman, however, have highlighted the following: on the one hand Scambler and Hopkins (1986) have proposed that there is evidence to suggest that the 'felt' stigma or anxiety of disabled people may, sometime, be greater than the actual discrimination experienced. On the other hand, Gussow and Tracy (1968) and Ablon (1981) have argued that theories that focus upon such things as anxiety may be providing an inaccurate, 'doom and gloom' account of stigmatised identities. Indeed, Booth and Booth (1994) provide evidence to suggest that negative labels and being treated as 'sub-human' can sometimes be rebuffed. In the light of such complexity, Goffman's account must be viewed sceptically.

"Enter the two main contenders" – Medical Sociology versus Disability Studies

After Parsons and Goffman, two fresh approaches to the sociological understanding of illness/disability emerged partly, at times, as a result of further development of their ideas, but also resulting from those criticisms of their work previously stated. The first approach is that of Medical Sociology which has sought to develop an interpretative account of illness that moves away from those definitions of impairment that have been established by the medical professionals, and to explore instead the symbolic and material interactions between the disabled individual and wider society. Research in this area began by considering such things as the interactional difficulties experienced by people with chronic illness (Strauss and Glaser, 1975). The focus of Medical Sociology then moved on to consider such things as the range of financial, medical care based and employment barriers facing people with chronic illness. From such research emerged the notion of the 'handicapping' environment.

More recently, the emphasis in Medical Sociology has been upon the active way in which disabled or chronically ill individuals adapt and make use of various coping strategies in order to gain control over their lives. Key to this research have been the terms *coping* and *competence*. Medical Sociology has highlighted the manner in which disabled people strive to retain a sense of their own competence. Such research has also been concerned with the ways in which both lay and professional attitudes towards disabled people, can radically constrain disabled people's abilities to make use of a number of central coping strategies.

For Jenkins (1998), a contextualised understanding of personhood is central to understanding the notion of competency since the competence of an individual is always, to some extent, determined by their performance with regard to an arbitrary and culturally determined selection of aptitudes. This is not to say, however, that Jenkins is denying the reality that (in)competence can, and does, reside at least in part in the physiology of embodied persons. Indeed, one of the strong points of Jenkins' approach is that he does not ignore such things as the effects of impairments. He does, however, stress that we need a *social* framework in which to understand these issues.

Writing from a Bioethics perspective, Silver (2002), has made a useful link between theorising such as Jenkins' on competence and how understandings gained through such analyses can be used to further the rights of individuals in terms of autonomy. For Silver, competency rests upon the notion of autonomy. Thus, to be competent one must be autonomous. The problem then arises that traditional approaches to autonomy tend to focus upon its instrumental rather than intrinsic properties. According to Silver, medical professionals have tended to focus upon the instrumental properties of autonomy alone, thus avoiding the potential moral problems that can emerge when a person's intrinsic autonomy clashes with what the medical professional considers to be their 'best interests'. Silver (2002) proposes that instead of focusing on the instrumental properties of autonomy in this way, that instead: "(...) *the standard of competency we ought to employ is as follows: is the person making her own decisions, is she shaping, however well or badly, her own life. If she is, she is competent, because she can be autonomous.*" (p.462)

In other words, Silver states, we need to reject the notion of 'relative competence'. This notion of 'relative competence' is clearly akin to Jenkins' notion of the arbitrary and culturally determined nature of competence. Silver (2002) then takes this critique of relative competence one step forward, however, by commenting that:

> *I would argue that no amount of these relative incompetencies should amount to rendering a person incompetent in the sense that we are discussing: incompetent to make decisions that normally everyone has a right to make. That sort of competency should not depend on your ability to make a decision well, but on your ability to make it at all.* (p.464)

What is new and thought provoking about Silver's approach therefore, is the way in which he links the issue of competency with autonomy and ultimately with human rights discourses.

Currently, however, some new and even more contentious strands of theorising have emerged from within Medical Sociology. The phenomenological approach, as usefully described by Hughes and Paterson (1997), has been viewed by many within the field of disability as striking at the very heart of the Social Model of Disability, the model which dominates Disability Studies. This phenomenological approach to disability reflects the wider trend within Sociology over the past 10 years, in which the 'body' has been rediscovered and 'bodiliness' has increasingly been seen to be centre-stage. The phenomenological approach to disability considers there to be an important link between this sociology of the body, and theorising on disability and calls for an 'embodied' notion of disability. Drawing upon the work of both Bryan Turner (1984, 1992, 1994, 2000) and

Terence Turner (1994), this approach proposes that the Cartesian compartmentalism that had led to the separation of impairment and disability, be abandoned in favour of a "*realignment between body, self and society.*" (Bendelow and Williams, 1995: 156)

In this respect, this trend in Medical Sociology was somewhat overdue, for, some thirty years previously, Merleu-Ponty (1962) commented that social action is not only intersubjective, but also intercorporeal. Further, within the field of disability itself, writers such as Jenny Morris (1991) had complained that the Social Model of Disability denies the existence of pain and affliction, experiences that are truly 'embodied'. Nevertheless, this phenomenological approach to disability remains as yet little more than an important strand within Medical Sociology, and is strongly opposed by many within Disability Studies[1]. The basis for the opposition to this approach is, in many respects, understandable, for as will be discussed in the following section, many disabled people consider references to 'bodiliness' as being inextricably linked to the idea of 'suffering', which is, in turn, linked to the personal tragedy model of disability. This model has been widely accepted to be disempowering and victim blaming.[2] The challenge for theorists who favour the phenomenological approach to disability is, therefore, to overcome such fears and to persuade people that:

> *A phenomenological approach to suffering in which the reversibility of impairment and disability made it possible to think of suffering as a concept which reflected the mutual engagement of pain and oppression may be a way of reflecting the fact that disabled people do suffer. However, at the same time, by foregrounding the concept of oppression, suffering is removed from its connotative association with a charitable response to tragedy. To recast suffering as a dialectical concept on the threshold between pain and oppression not only politicises the medical, but exposes the disablist basis of the charitable response.* (Hughes and Paterson, 1997: 336)

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[1] For example, see Finkelstein (1996) who argues that to consider impairment is to dilute the effectiveness of the Social Model.

[2] See Swain and French (2000) for a useful discussion on the disempowering aspects of the 'tragedy model'.

It will be interesting to see whether such an important new development will bring about the end of the historical division between Medical Sociology and Disability Studies. Certainly, there is already evidence that several writers from Disability Studies are trying to break away from key orthodoxies of the field and some interesting connections between their work and the phenomenological approach to disability will be discussed later in this chapter. The major issue that continues to divide Medical Sociology from Disability Studies, is, however, the extent to which the material world disadvantages disabled people. Whilst many medical sociologists consider Disability Studies to have provided an over-socialised image of disability that does not move beyond 'outdated' Marxist accounts (Bury, 1997), writers within Disability Studies have criticised Medical Sociology for failing to engage with the material world and the manner in which material difficulties disadvantage many disabled people.

For Disability Studies, the central focus of research in this field must be upon the barriers and constraints placed upon the lives of disabled people by a 'disabling' society. The central inspiration of this approach has been the 'Social Model of Disability', the origins of which lie firmly within the campaigns by disabled people against discrimination and material disadvantages during the late 1960's and into the 1970's. Probably the first step was taken by Hunt (1966) who highlighted the way in which powerful groups within society categorise disabled people as abnormal and in so doing perpetuate the notion of disability as both a personal tragedy and as something to be greatly 'feared'. Further, he exposed the ways in which disabled people are perceived as being economically useless. Hunt then went on to become a key figure within the wider disability movement, since he was central to the formation of UPIAS[3], an organisation that was run *by and for* disabled people and which maintained a very critical stance towards those organisations that were merely run *for* disabled people.

In 1976, UPIAS published "Fundamental Principles of Disability" in which the organisation made it clear that it is 'society' (sic.) that disables people with impairments. Whilst it would not be true to say that this publication denies the

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[3] Union of the Physically Impaired Against Segregation.

reality of impairment, nevertheless, the focus is upon the manner in which 'society' increases the dependency of disabled people and prevents them from participating equally within the economic and social sphere. This notion of disability as a form of social oppression then became the dominant theme within Disability Studies and is clearly the precursor of the later more materialist accounts of disability provided by Abberley, Finkelstein and Oliver amongst others.

For Abberley (1993), work on disability can be usefully compared to research undertaken on the subjects of sexism and racism. This focus upon the notion of social oppression led Abberley to conclude that it is social relations that create the material disadvantages that, in addition to impairment, generate disability. What is less well developed in Abberley's work, is a picture of *who* it is that is supposed to be benefiting from the oppression of disabled people. He is clearly edging towards a Marxist account of disability, referring as he does to 'capitalism' as being the victor when it comes to the social oppression of disabled people, but he takes this little further.

Finkelstein, on the other hand, provides a much more developed materialist account of disability. For Finkelstein (1980), disability can be viewed as a social problem that is directly linked to changes in the mode of production. His theory rests upon the idea that changes in technology are key to understanding changing attitudes towards disability. Thus, it was only with the advent of industrial capitalism that disabled people became excluded from the workplace. New technology meant that disabled people could not 'keep up' and this became the basis for segregation. This idea is clearly echoed in the work of Oliver (1990), although he is considered to have advanced the concept somewhat, to produce the most highly developed materialist account of disability. For Oliver:

> *(...) definitions of disability, as of other perceived social problems, are related both to economic and social structures and to the central values of particular modes of production. He explains the emergence of the individualistic and medicalised approach to disability in terms of the functional needs of capital, especially the need for a workforce that is physically and*

> *intellectually able to conform to the demands of industrialization. But it is not simply the mode of production which precipitated the development of personal tragedy theories of disability, but also the 'mode of thought' and the relationship between the two.* (Barnes et al,1999: 84)

By this, Oliver is suggesting that it was not simply the mode of production that altered during the process of industrialisation, but also that there was an important shift in ideology. He proposes that the first ideological shift, towards individualism, was brought about by the growth of the free market economy and the spread of wage labour. The second ideological shift he considers to be the medicalisation of the mechanisms of social control, which led to the development of the concept of 'able-bodiedness', a standard against which 'normality' can be judged.

The strength of this Social Model of disability has been, therefore, to give "*disabled people the confidence to campaign for rights in a way that was uncompromisingly based on social oppression.*" (Campbell, 2002: 473) Further, in maintaining a clear focus upon the manner in which disability is socially produced, this model has moved away from bio-medical models and towards an understanding of disability in terms of current debates on citizenship/social exclusion. So powerful has been the emancipatory capacity of this model, however, that criticising the approach is something that has been viewed as highly contentious.

Nevertheless, there are some important criticisms of the Social Model that do need to be addressed. Oliver's account, for example, has been criticised for failing to consider adequately the very different experiences of disability and for ignoring the role of impairment in the disabling process. Pinder (1997) highlights what is the central problem in this field, namely that the Social Model of Disability is not just an academic model, but has been the central feature of disability politics since the 1970's. For Pinder (1997) the central tension is "*between the search for clear-cut, univocal messages crucial for the success of any political movement, and the necessarily more complex and subtle reality of peoples' lived experience.*" (p.304) Shakespeare and Watson (1997) admit that there has been a great reluctance on the part of key writers in Disability Studies to address the issues of impairment, for example, because it is seen to weaken the Social Model. They state that: "*Debates are necessary, and recognising difference within the disabled community is overdue.*" (Shakespeare and Watson, 1997: 299) Furthermore, they comment that the tendency within the disability movement to silence dissent in favour of "*marching to the beat of a single drum*" (Shakespeare and Watson, 1997: 299) should be resisted. What is ironic, however, is that their overall conclusion demonstrates exactly the same attitude that they are criticising:

> *Obviously individual disabled people may not always agree with the radical agenda or analysis, just as individual women have often not supported feminism. But this does not mean that disabled activists, any more than feminists, are wrong. (...) We suggest, therefore, that while academics and activists can debate amongst ourselves, our main efforts must be to fight for a social model analysis in society as a whole, and to take the insights and evidence we have gathered into other disciplines and areas of public discussion. Rather than putting energy into internal arguments, we need to challenge the continuing complacency of the intellectual establishment, and to win the battle for a social model understanding of society and our lives.* (Shakespeare and Watson, 1997: 299)

This attitude is perhaps, understandable considering the emancipatory emphasis that has been placed upon the Social Model and the extent to which many disabled people have gained strength from the concept. Shakespeare and Watson, as key figures within Disability Studies are, no doubt, highly conscious of the fear that is felt by many disabled people when faced with the possibility that the Social Model might be weakened. As Shakespeare (1992) has commented: "*to mention biology, to admit pain, to confront our impairments, has been to risk the oppressors seizing on evidence that disability is really about physical limitations after all.*" (p.40)

Despite these fears there is a growing body of literature within Disability Studies that does openly question the predominant doctrines of mainstream Disability Studies. The earliest critiques of mainstream Disability Studies arose during the early 1990's when Feminist writers such as Jenny Morris (1991) highlighted the fact that accounts of disability tended to be male dominated and constructed. Morris, along with a number of others, have written convincingly about the 'double disadvantage' faced by disabled women which results in them being placed in a worse position, economically, socially and psychologically, than either disabled men, or non-disabled women. This critique was later extended to consider Disability Studies' failure to adequately theorise the position of Black disabled people and other minority groups such as gay and lesbian disabled people.

Such issues have become the 'hot topics' in Disability Studies and have been key to current debates surrounding the issue of impairment and the body, which are echoed in some of the current trends in Medical Sociology, as previously discussed. The work of authors such as Begum (1992) and Harraway (1991) have been particularly influential. Begum's notion of the 'dominant body ideal' and how this leads to the construction of defective bodies, and Haraway's (1991) related idea that *"(n)either our personal bodies nor our social bodies may be seen as natural."* (p.10), have greatly supported the argument made by disabled feminists that the experience of impairment must be included in any analysis of disability. There is therefore, a growing awareness within Disability Studies that the Social Model provides a picture of the body as having no history, and of impairment as being entirely opposite to disability because it is not socially constructed. As Hughes and Paterson (1997) have commented, this dominant model must be questioned for it:

> *"also posits a body devoid of meaning, a dysfunctional, anatomical, corporeal man obdurate in its resistance to signification and phenomenologically dead, without intentionality or agency."* (p.329)

There are, therefore, two key challenges facing Disability Studies today, the first being the need to theorise the 'body' adequately from a disability perspective. The second challenge is overcoming the resistance to such theoretical developments by key figures within the field. Both Oliver (1995, 1996) and

Finkelstein (1996) have argued forcefully against the idea that understanding the 'body' is key to understanding *disability*. For them, considering the body and impairment 'fudges' the critical issue of causality and the source of disability. That is not to say however, that either theorist entirely ignores the issue of impairment, Oliver (1996), for example, calls for a Social Model of impairment to stand alongside the Social Model of disability. His argument is that, whilst non-interchangeable, these two models might together produce a social *theory* of disability. Ultimately however, whilst his argument here may seem appealing, it nevertheless perpetuates the distinction between impairment and disability. In addition to this theoretical opposition to placing the 'body' at the heart of theorising on disability, other writers have claimed that such an approach reduces the opportunity for political and cultural praxis by disabled people. Barnes (1999) has commented that the new trend in theorising, which he believes arises from the liberal arts and cultural studies, "*seems to be written by a particular sort of academic luvvie who write mainly for themselves and other academics rather than for a wider audience: consequently, it is replete with obscure and esoteric jargon, virtually inaccessible to all but the most dedicated of readers and, most importantly, politically benign and pragmatically irrelevant.*" (p.580)

In the light of such resistance to the idea of an embodied notion of disability from within Disability Studies it is unclear, therefore, whether significant advancements in this theorising will occur from within this field, or whether such ideas will find more fertile ground within Medical Sociology. What is clear, is that in both Medical Sociology and Disability Studies there is a significant and growing minority of authors who are keen to move beyond materialist accounts and to acknowledge the value that contributions by a range of theorists in the fields of semiotics, critical theory, post-structuralism, feminism and phenomenology can make to understandings of disability. Some of these issues will be considered in more depth as they relate to the findings of this research in Chapter 7.

The 'reality' of life for disabled people

Whilst the aim of the first part of this chapter was to provide an overview of the main theories of disability, the aim of this next section is to consider the empirical evidence to support the widely accepted notion that disabled people occupy a position in society that is characterised by discrimination and disadvantage. The body of research that has been carried out on the lives of disabled people is large and encompasses most, if not all, areas of experience. Given the extent of this research, it would be impossible within the confines of this chapter, or thesis, to adequately consider all issues. For this reason, two key areas have been chosen, and it is hoped that these will, when considered together, provide the reader with an overview of the current position of disabled people within society. These two areas are: equal opportunities: and the 'coming out' of disability.

Before considering the first of these areas, however, it must be stated that care must be taken when using the term 'reality' when describing the lives of disabled people, for there is a risk that in describing a collective reality for all disabled people, the wide variety of experiences of disability are reduced to some sort of common denominator (Corker, 1999). With this risk in mind, an effort has been made to avoid universalising the experience of disability and wherever is appropriate, to mention differences.

Equal opportunities

Whilst the issues relating to equal opportunities for disabled people are wide ranging, injustice within the following spheres appear to have generated the most anger amongst disabled people, and are the most well documented:

- *Education*
- *Income and employment*
- *The inaccessible environment*
- Family life

Education

It is widely accepted that *historically*, children with perceived impairments have been socialized in such a way as to foster low self-expectations of success in education or in work:

> *Besides perpetuating the age old myths and ignorance surrounding both impairment and disability, the special school system consistently fails to provide disabled school leavers with the skills and confidence necessary for adulthood in a world increasingly geared towards the needs of a mythical non-disabled majority.* (Barnes, 1997: *introduction*)

Groups of disabled people calling themselves 'survivors of the special school system' have argued forcibly for the complete abolition of the special school system and their calls have not gone entirely unheeded. The current drive towards 'mainstreaming' is precisely because of a growing acceptance by government and educationalists that the special school system disadvantaged/s disabled children.

In terms of evidence to support these claims, it is clear that the educational attainments of young people who have gone through special needs education are indeed considerably less than for the average student in mainstream education. As a consequence, disabled children leave school with fewer qualifications and skills than their non-disabled peers. For example, Thomas (1997) found that just 4% of pupils in special needs schools attain grades A-C at GCSE. These findings have been explained in a number of ways: partly, it is suggested, it is due to the fact that children who have been labelled as having 'Special Educational Needs' (SENs) experience a much narrower curriculum than their non-disabled peers. It is also thought to be because special need schools enter less than a third of pupils for GCSE's. Finally, whilst it might be tempting to argue that lower attainment is due to a lesser ability on the part of pupils, there is also evidence that the low expectations of teachers constrains the performance of disabled children.

Interestingly, despite such evidence there have been arguments in favour of special needs education. These arguments have come not least from many parents and some disabled young people. In particular, Deaf people and their organisations have consistently argued in favour of schools for the Deaf. They argue that Deaf children require regular contact with their Deaf peer groups and Deaf adults as role models, in order to combat oppression and to develop a strong and positive self-identity. According to such Deaf organisations, forcing Deaf children into mainstream education denies them access to the Deaf community and Deaf culture. Arguing from a more materialist standpoint many other parents and disabled children have stated that they consider special needs education to be preferable to mainstreaming on the basis that only special schools and the teachers in such establishments have the necessary facilities and training required for educating disabled children. Such groups have also argued that too often only 'lip service' is paid to the integration of disabled children into mainstream schooling, with the result that such children find themselves educationally and socially isolated.

As previously stated, however, 'inclusive education' is now the favoured approach to educating children with special educational needs. The moves towards mainstreaming began as far back as 1978 with the publication of the Warnock Report. This report was a direct response to early criticism that was directed against the special school system and was important in that it argued for special needs provision within mainstream schooling. The 1981 Education Act and subsequent legislation clearly built upon the Warnock Report, but according to many critics, was imperfect in certain key respects. Firstly, pupils with severe learning disabilities remained apart from mainstream schooling; hearing and visually impaired children were largely excluded from the new initiative; and finally, the increased costs involved in providing mainstream schooling for children who had been labelled as having SENs resulted in a tendency on the part of Local Education Authorities (LEAs) to avoid statementing too many children, allowing some children genuinely in need of support to 'slip through the net'. The later 1993 and 1996 Education Acts did seek to address some of these issues and to promote more clearly the idea of an inclusive policy, but doubts have continued surrounding the extent to which all the issues have been resolved.[4]

Some critics have suggested that such problems demonstrated that the government, despite appearances, was not really giving sufficient support to mainstream schooling for disabled people. It is certainly the case that education as an issue was omitted from the Disability Discrimination Act 1995. Critics of the government's actions at that time suggested that whilst it may have been true that key policy makers shared with many parents of disabled children a concern that mainstream schooling may disadvantage some disabled children, it was also the case, however, that there were concerns surrounding the effects that integration may have upon mainstream schools, particularly in the light of the increased importance of performance indicators and league tables of educational attainment.

Since 1995, however, some major advances have taken place in terms of 'mainstreaming'. In 1998, the Labour Government announced an increase in resources for inclusive education as part of its Action Programme for Special Educational Needs. There are now two main sources of government funds for inclusion, the Schools Access Initiative and the special educational needs element of the Standards Fund. £220 million is being made available through the Schools Access Initiative over the period 2001-2004[5]. In 2001 the government also introduced the Special Educational Needs and Disability Discrimination (Amendment) Act, which set out the responsibilities of Primary, Secondary, Further and Higher Education institutions to engage in non-discriminatory practices in terms of disabled students and to further the inclusion of disabled people into non-segregated educational settings. This act also made clear the responsibility of the teacher-training agency to ensure that an awareness of the needs of disabled children is an integral part of teacher training.

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[4] Personal experience as a teacher within the secondary school system leads this author to believe that the problem of children who have special educational needs 'slipping through the net' is a continuing issue because of some LEAs' attempts to reduce their published figures of numbers of children considered to have such needs.

In the same year, an investigation into the Schools Access Initiative was carried out for the 'Within Reach' campaign for inclusive education run jointly by Scope and the National Union of Teachers (NUT). This investigation found that 65% of schools felt that students with special educational needs were making more rapid academic progress whilst within mainstream schools[6]. This report in combination with other campaigns by the NUT, suggests that teachers are now much more in favour of inclusive education than they have been in the past.

In the light of this increase in funding, improved legislature and the apparently supportive attitudes of teachers, the CSIE[7] has stated that the only real remaining barrier to inclusive education is a continuing lack of commitment to transfer funds from segregated to mainstream settings by certain LEAs. In a report published on their website[8], the CSIE states that whilst the national percentage of 5-15 year olds in special schools across England has fallen from 1.39 % in 1997, to 1.32 % in 2001 (part of a slow, but steady trend towards inclusion), there are worrying variations in approaches to placing disabled students according to LEA:

> *In 2001, for example, a disabled pupil in* ***Manchester*** *was more than seven times as likely to be placed in a segregated special school than a child in the London Borough of* ***Newham*** *(...) which has actively pursued a policy of inclusion for 18 years (...) A group of 41 out of England's 149 LEAs actually increased their percentages of pupils in special schools between 1997-2000.*
> (CSIE: http://inclusion.uwe.ac.uk/csie/stats02.htm)

Clearly, therefore, whilst major improvements have occurred in terms of mainstreaming in some English regions, disabled children in certain areas remain disadvantaged.

There is one further debate surrounding mainstreaming that has yet to be resolved, however, and that surrounds the *evidence* to support the idea that disabled children and other children with special educational needs do make better educational progress within mainstream schooling. Clearly, as the NUT

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[6] "Within Reach 3: An Evaluation of the Schools Access Initiative." (2001) downloadable from the NUT website at:

[7] Centre for Studies on Inclusive Education.

report suggests, many teachers believe that such children are benefiting from being a part of a mainstream school, but there is as yet little hard evidence to support this belief. A recent report by the Audit Commission entitled "Special Educational Needs. A Mainstream Issue" (2002) stated the following:

> *In contrast to the national focus on attainment, little is known about the outcomes achieved by children with SEN. A lack of monitoring of their achievement and a lack of performance measures make it difficult to recognise the good work in many schools, or to identify where children are poorly served.*
>
> *Schools feel pulled in opposite directions by pressures to achieve ever-better academic results and to become more inclusive. National performance tables and targets fail to reflect the achievement of many children with SEN. Government needs to find a way of recognising and celebrating the achievements of these pupils and their teachers, often against considerable odds."*
>
> (p.41)

Of course, since the publication of this report, the government has introduced a 'value-added measure' in secondary school tables and will be introducing the same measure for primary schools from 2003. This measure is intended to show the progress of students between key stage 3 and GCSE/GNVQ examinations and key stages 1 and 2. Whilst this is clearly a step in the right direction, it still does not give detailed enough information on the particular progress of children who have been statemented as having special educational needs. Thus, whilst substantial improvements to educational provision for disabled children and young adults have been made, particularly over the past few years, it would appear that there are still issues that need to be addressed.

Income and employment

In October 2000 the Joseph Rowntree Foundation published a report, written by Tania Burchardt, entitled "Enduring economic exclusion: disabled people, income and wealth." In the current political climate characterised by a second term of a New Labour government (a government which prides itself on being a champion of social justice) the findings of this report make for uncomfortable reading. As Fig.4a clearly shows, employment rates amongst disabled people remain low, at around 40%, a figure that is about half the level of employment for non-disabled people.

Fig.4a ***Employment rates of disabled and non-disabled men and women*** ***(NB. 'figure 1' in title of graph refers to position in original report)***

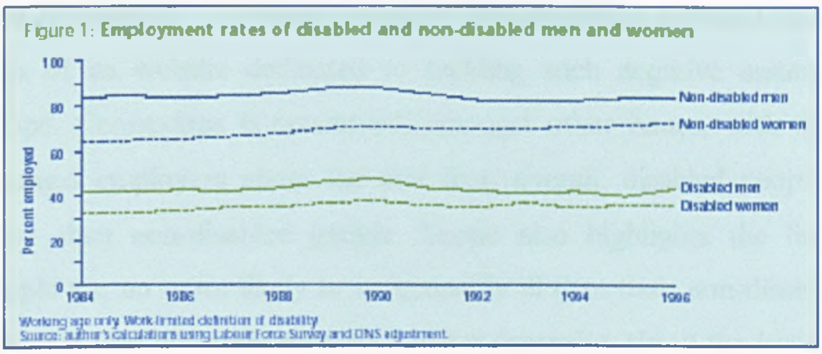
Figure 1: Employment rates of disabled and non-disabled men and women

Working age only. Work-limited definition of disability
Source: author's calculations using Labour Force Survey and ONS adjustment.

From Burchardt,T (2000) (JRF Findings) *Enduring economic exclusion: disabled people, income and wealth* viewed on the JRF Website: 18.01.03

In 1999, disabled people made up half of those who were unemployed but who said that they would very much like to work. Yet, even after allowing for the fact that some disabled people cannot, or do not wish to be employed, non-disabled people are still four times more likely to gain employment than disabled people. Maintaining employment after becoming disabled is another area where disabled people experience major disadvantages. Each year around 3% of those in work become 'limited in daily activities', of whom approximately half also report disability within the following or subsequent year. Of these, one in six lose their employment in the first year after becoming disabled. Given that disabled people make up a large and growing percentage of the working-age population, between 12 and 16% depending on the definitions used, this means that a significant number of individuals are being discriminated against.[9]

By means of explaining this situation, it is tempting to point to the smaller proportion of disabled people who have good educational qualifications and to

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[9] Figures from Burchardt,T (2000) (JRF Findings) *Enduring economic exclusion: disabled people, income and wealth* viewed on the JRF Website:

argue that this makes many disabled people less attractive to potential employers. It is undeniable that this may often be one of the factors influencing rates of employment amongst disabled people. There are other factors, however, for example, it is well documented that many employers make negative assumptions about disabled people in terms of perceiving them as unreliable workers. The damaging impact of this assumption upon the job prospects of disabled people is well recognised. The young persons' careers advice service Connexions[10] has an area of its website dedicated to tackling such negative assumptions, as does Scope. Connexions is concerned, amongst other issues, with raising awareness amongst employers about the fact that, overall, disabled people have less sick leave than non-disabled people. Scope also highlights the fact that disabled people are no more likely to be generally ill than their non-disabled colleagues[11]. Scope is also currently running a major campaign about the issue of employment for disabled people entitled: "Ready, Willing and Disabled". The slogan for this campaign, which is shown below in fig.4b, stresses the fact that it is not only disabled people who lack qualifications who are disadvantaged within the labour market, but also those who have qualifications which should put them on an equal footing with many non-disabled people:

Fig.4b[12]

Ready, Willing and Disabled

10 GCSEs
2 A-levels
1 degree
114 job applications
24 job interviews
1 disability
0 job

The basis of this campaign is a survey into the attitudes of employers to disabled people, and the results, as documented by Daone and Scott (2003), demonstrate the persistence of certain negative assumptions about disabled people as workers. The survey found that 19% of employers said that the fact that they had never

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[12] Daone, E and Scott, R (2003) *Ready, Willing and Disabled - Executive Summery and Recommendations for Employers* Viewed at:

worked with a disabled person before, and so did not know what to expect, would prevent them from employing a disabled person. A further 11% of employers said that they would not employ a disabled person because their clients or customers would not want to be served by a disabled person.

There have been many attempts to explain this persistent discrimination faced by disabled people in the labour market. The dominant approach within Disability Studies, however, has been to employ a materialist framework when understanding this problem. Wolfensberger (1989) suggested that the social construction of disability and dependence is a covert function of the 'human service industries'. According to his argument, whilst the stated purpose of institutions such as the education system and the health care system are to rehabilitate people back into the community, their hidden agenda is to create and sustain large numbers of dependent and devalued people in order to secure employment for others. In other words, the social construction of disability functions to keep disabled people out of the labour market and thus reduce competition for jobs.

Wolfensberger's work was not as radical however, as the assessment of the situation provided by some earlier British authors such as Hunt (1966). In analysing the position of disabled people in the labour market, Hunt similarly proposed that disability should be viewed as a social construction of capitalism. Disabled people, he argued, become the 'unfortunates' who cannot benefit from capitalism and are perceived as 'useless' because they cannot work. As a consequence, disabled people are marked out as a minority group and placed in a similar position to other oppressed groups such as Black people or homosexuals, because, like them, they are regarded as being 'different'. Hunt concluded that industrial capitalism increased prejudice against disabled people and that this prejudice in turn expresses itself in discrimination and oppression. Hunt's view was later echoed in the work of Abberley (1997) who highlights the important role that work plays in the process of social *inclusion*. Abberley, however, went on to develop a somewhat more nuanced approach than Hunt, writing that it would seem that historically, the rights of the human 'being' have come second to the universalising of human 'doing'.

The importance of the work of theorists such as Hunt and Abberley, has been to propose an understanding of the position of disabled people within the labour market in terms of both material considerations and cultural perceptions. Their views that the cultural perceptions of disability are not only the result of the material inequalities characteristic of industrial capitalism, but are also some of the central mechanisms by which such inequalities are maintained, is clearly supported in the work of Colin Barnes (1992b). Barnes (1992b) provides extensive evidence for institutional discrimination, which he claims comprises a "*complex system of hostile environments and disabling barriers*" (p.1). He highlights, amongst others, such issues as:

- Medical screening – despite some occupational health expert's scepticism regarding the value of such screening, such tests remain central to a large number of employers' recruitment procedures. The historical link between doctors and disabled people has perpetuated the widespread belief that impairment is the same as illness. Employers generally associate ill health with poor performance and excessive absenteeism, they are therefore wary of employing people with a history of illness, and by association, people with impairments.
- 'Vital abilities' – the majority of employers continue to describe most of the work in their establishments as unsuitable for disabled people to undertake, especially in relation to what they describe as the 'vital abilities' required to do the job. Since the need for many of these so-called 'vital abilities' would not stand objective analysis, this must be viewed as another example of the discriminatory attitudes of employers.
- 'Appearance' – Jones and Longstone (1990) discovered that 10% of all vacancies displayed in Jobcentres stated that applicants were required to be of 'clean and tidy' or of 'generally good' appearance. Many disabled people are significantly disadvantaged in this regard either because they are unable to afford a 'smart' set of clothes suitable for an interview, or

> because for some disabled people their 'unconventional' body shape makes sourcing suitable clothing a problem. Such difficulties should be understood by employers and taken into account when considering a disabled applicant, but in reality the problem is exacerbated by the emphasis that many male employers place upon the physical attractiveness of prospective employees. Morris (1989) found that some employers in the service sector felt that the sight of a disabled woman disturbs some clients.
>
> Based upon Barnes (1992b)

What is clear from Barnes' list however, is that materialist accounts, whilst important, cannot entirely explain the position of disabled people in the labour market. When, for example, Barnes considers the impact that some disabled peoples' 'non-conventional body forms' may have on their job prospects he is clearly pointing to evidence of the power of *stigma.* It would seem likely therefore, that whilst materialist 'dual market' theories may well provide a major explanation for the position of disabled people in the labour market, especially during times of high unemployment, other factors must also play a part in perpetuating discrimination against disabled people during times when the job market is more buoyant. The impact of stigma and other processes by which disabled people and disabled bodies are deemed to be 'abnormal' will be considered again in chapter 7.

These major barriers facing disabled people who wish to *enter* the labour market are not, however, the only employment problems facing disabled people. For disabled people who do work there is also the issue of underemployment and the particular problems associated with sheltered employment. All to often, the only type of work that is available to disabled people is poorly paid and requires only low skills. Such underemployment is undemanding and is both psychologically and financially unrewarding. People who have been labelled as having 'severe' impairments often experience this problem most acutely. For such individuals, it is often the case that the only work available is in sheltered employment, in organisations such as Remploy. Such workers are some of the poorest wage earners in the country.

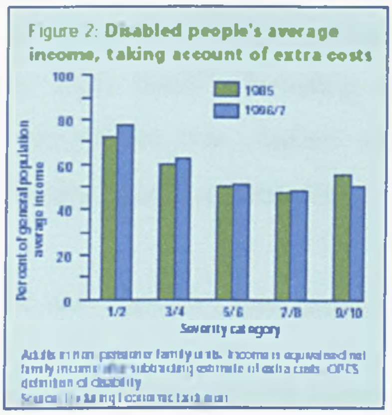
In the face of such problems, the British government has historically opted for a fairly minimalist and voluntaristic policy response. Of those initiatives that have existed, few have been rigorously enforced. For example, enshrined in the 1944 Disabled Persons (Employment) Act, is the requirement that all employers of twenty or more employees must employ a 3% quota of disabled people. The failure of employers to support this quota has been largely ignored by successive governments. Indeed, there have only been 10 prosecutions since the quota was introduced, the last case having been brought in 1975 and with the maximum fine for employers remaining unchanged from the level set in 1944 of £100 (Barnes et al, 1999). To make matters even worse, much against the wishes of disabled people, the quota scheme was entirely abandoned in 1994. In addition, new initiatives have often been criticised for being ill-conceived. The new policy initiative of the 1990's, the move away from sheltered employment and towards 'sheltered placements' in mainstream places of work, for example, has been greatly criticised for exacerbating the problem of underemployment, doing little to combat employer discrimination and for failing to improve the chances for disabled people to move into 'proper' mainstream employment.

In addition, the Disability Discrimination Act 1995, heralded by the government as one of the most advanced anti-discrimination legislation documents is fundamentally flawed in relation to workplace discrimination. Whilst the Act does cover issues relating to recruitment, terms of employment, promotional opportunities, training and dismissal procedures, unlike the legislation pertaining to 'race' and sex discrimination, discrimination against disabled people is only illegal if it is 'unreasonable'. As Roulstone (2000) has commented: "*The belief that the power of employers is substantially countervailed by the DDA has to be acknowledged as untenable.*" (p.440)

Critics such as Roulestone (2000) have also suggested that even the most welcome new development, the New Deal for disabled people, is unlikely to deliver the enhanced employment opportunities envisaged, since the underlying power relations of employment remain largely unchallenged. Heenan (2002), however, has questioned Roulestone's critique of New Deal, suggesting that whilst it may not be a *perfect system*, there are, nevertheless, many positive aspects of the scheme. She demonstrates through empirical research with disabled respondents that there are many disabled people for whom the scheme has made a real difference to their lives. Thus, whilst the disadvantaged position of disabled people in terms of the labour market remains, small steps in the right direction are being made in relation to the lives of some disabled people.

One of the most profound and persistent implications of this injustice faced by disabled people with regard to the labour market, however, can be seen in relation to the average incomes of disabled people. Figure 4.c clearly demonstrates that disabled people remain poor in relation to the general population. What is also clear from these figures is that the greater the severity of impairment, the lower the income. This situation persists despite a number of specific benefits such as the Disability Living Allowance and other additional tiers of benefits that have been put in place with the aim of reaching further down the impairment severity scale. Whilst such policies have contributed to a substantial decrease in the numbers of disabled people in the bottom tenth of the income distribution, nevertheless, it is still clear that those with the most severe impairments remain significantly disadvantaged and in real terms were less well off by 1996-7 than they had been in 1985 (Burchardt, 2000).

Fig. 4c. ***Disabled people's average income, taking account of extra costs*** *(NB. 'figure 2' in title of graph refers to position in original report.)*



From Burchardt,T (2000) (JRF Findings) *Enduring economic exclusion: disabled people, income and wealth* viewed on the JRF

Positive developments have not, therefore, been sufficient to counter the wider trends towards inequalities both between disabled people and in relation to disabled people's position in society as a whole. Indeed, the continuing disadvantage experienced by many disabled people in terms of income is part of a wider problem facing the UK. In terms of international comparison, the expansion of social security systems and/or safety nets in most countries has mitigated, to some extent, the observed trend of increasing income inequality over the past 20-30 years. When compared internationally, for example with other countries within the EU, Australia, Canada Japan and the United States, the UK, however, has seen a below average increase in growth of social security transfers as percentage of GDP (1979-around 1994), despite a continuing increase in income inequality. Other countries with a below average growth rate include: Australia, Germany, Ireland, Italy, Japan, the Netherlands, Switzerland and the United States. Countries with an above average rate of growth in social security transfers include: Canada, France, and the four Nordic countries (Caminada and Goudswaard, 2000). In many respects these figures are not surprising given the fact that the Scandinavian welfare model, for example, acts within a market economy in which inequalities in income distribution and the concentration of wealth and power are allowed less free play than is the case in the UK and elsewhere. It is difficult to avoid reaching the conclusion that despite having a more 'left-wing' government, UK social security policy continues to be influenced by a more conservative neo-liberalist ideology. Thus, despite the current government's increased targeting of social protection benefits to those in the most need[13], including many disabled people, overall, income inequality continues to rise, further disadvantaging socially excluded groups of which disabled people are but one.

The Inaccessible environment

Appropriate and decent housing is something that most people feel should be a basic entitlement in society, but changes in UK government policy have led to a virtual 'ghettoisation' of lower income groups. Government spending on the education and health care systems has risen by over 30% since 1981, but the reverse is true for investment in housing. Policies such as the last Conservative governments' 'Right to buy initiative' and privatisation schemes, have greatly reduced the availability of socially rented housing, leading, according to some commentators to a housing crisis[14]. Disabled people have been particularly affected by this housing crisis because their position as one of the lowest income groups in society means that they are often reliant upon socially rented housing. The reluctance on the part of private landlords to offer accessible homes and the pressure that this is putting upon local authorities to provide suitable housing has been acknowledged by the government, and yet they have done little to encourage either public or private house builders to build to accessible standards. The result is that the development of 'special needs' housing has been insufficient and uneven.

Over the past 25 years, the number of local authority 'completions' (or approvals to build) of wheelchair-adapted homes in England has decline dramatically. This is largely due to the transfer of housing stock to Housing Associations, and the 'right to buy' initiative. At the same time, there has been a modest, if uneven,

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[13] Please see :
"Expenditure on social protection benefits in real terms by function, 1990/91 and 2000/01." 18/09/03
[14] Please see the current UNISON campaign: "Hands Off Our Housing":

increase in the provision of accessible housing by housing associations. As Harris et al (1997) have discovered, however, the problem has been that there is evidence to suggest that a mismatch between tenants and housing association dwellings has resulted in only a quarter of wheelchair adapted homes actually being occupied by a wheelchair-user, whilst over half of wheelchair-using tenants are living in non-wheelchair-adapted dwellings!

Apart from the issue of housing, disabled people also face considerable barriers within the wider built environment. Disabled people's requirements are poorly articulated and/or represented in the design or development of the built environment, a problem that is largely explained by the fact that UK planning legislation is weak and is often not enforced properly. By way of explanation for this, social geographers have pointed to the socio-spatial construction of inaccessible environments, whilst many within sociology have recognised that life and society are not only constituted in time and history, but are also located, contextualised and reproduced in space. Kitchen and Law (2001) talk about the 'landscapes of exclusion' faced by disabled people, which are created by "*particular power geometries and shaped by notions of citizenship and social justice.*" (p.287) In an earlier article, Kitchen (1998) draws upon Imrie (1996) when he comments that:

> *Environments that exclude disabled people are rarely 'natural'; they are produced through individual social interactions combined with state policy, building regulations, and architectural and planning practice.* (p.346)

Kitchen (1998) identifies the following as examples of implicit or thoughtless designs that contribute to the 'landscape of exclusion': steps with no ramp; cash machines that have been placed too high on walls; inaccessible out-of-town shopping centres; disabled toilets becoming storerooms; and obstacles being placed so as to block accessible entrances. Kitchen's (1998) conclusion is that as an active constituent of social relations, space is socially produced to exclude disabled people in two main ways: firstly, spaces are currently organised to keep disabled people 'in their place'; secondly, spaces are social texts that convey to disabled people that they are 'out of place'. Kitchen's argument is reinforced by the work of Imrie and Kumar (1998) whose research demonstrates that many disabled people feel estranged and oppressed by facets of the built environments and generally feel powerless to do anything about it. Whilst there have been some recent amendments to building regulations to acknowledge disabled people's rights to access public buildings, the inaccessible built environment remains a major barrier to the inclusion of disabled people into society.

Finally, a key part of this inaccessible environment which cannot be overlooked, is the problem disabled people face in relation to transport. In 1989 the Disabled Persons Transport Advisory Committee (DPTAC) estimated that between 10 and 12% of Britain's population experience problems with the "*unfriendly features of the transport environment*" (DPTAC, 1989: 1) Over the intervening 10 years improvements to the transport environment have been taking place, not least due to the immense efforts in campaigning that has been undertaken by many key disability organisations (eg. Direct Action Network). Nevertheless, change has taken place slowly and even though the Department of Transport now fully supports the principle of accessible public transport, it is likely to be many years before such things are commonplace.

Family life

The final issue to be considered within this section is that of family life for disabled people. For most people, the family is one of the central, if not *the central* institution in their lives. It is only fairly recently, however, that family life for disabled people has attracted the attention of social researchers. What research has been done in this area has broadly concluded that the presence of a disabled person within the family has profound implications for the relationships and opportunities of the family as a unit. Such broad conclusions can be misleading however, for the issues relating to the family lives of disabled people are very complex and the diversity of experiences both between individuals and groups cannot be ignored. Further, such conclusions can be misleading if they focus upon the disabled member of a family as the 'problem' and fail to consider how the low level of service provision for disabled people may be compounding the problems faced by many disabled families.

Over the past twenty years the position of the disabled family has undergone a number of radical changes associated with exposure to a range of factors, the most important being the move away from institutionalisation and the drive towards *care in the community*. Few disabled activists or commentators have questioned the ethics behind such a change; the reality of community care has, however, been more problematic. In general, local authority social services, especially those for physically disabled people have received low priority in comparison with other user groups. The focus of local authorities, according to writers such as Hudson (2000), has been more upon the deinstitutionalisation of people with a learning disability and upon concerns surrounding the needs of the increasing numbers of frail elderly people. Given this low priority accorded to services for physically disabled people, it is inevitable that a range of problems have been identified. Hudson (2000) has identified these problems as including: a lack of strategic interagency work in terms of planning, information and assessment for people with physical disabilities; service users have not been regularly and actively involved in planning services strategically for the community or for themselves as individual users; poor levels of information available to service users about services.

These final two points made by Hudson surrounding the lack of control experienced by disabled people in relation to the services that impact upon their lives, is echoed by other authors such as Priestley (1999) and Wood (1991). Wood (1991), a disabled writer, has attacked the philosophy of community care as it is set out within the White Paper "Caring For People". He claims that this approach to community care emphasises 'care' over concepts like choice or control. Priestley (1999) shares Wood's view stating that: "*the construction of disability as dependency has been a recurrent and pervasive feature of community care policy making.*" (p.44) He further highlights how some authors in this field have gone so far as to argue that the surveillance of disabled people, particularly disabled women, by professional groups as part of community care, can be understood in Foucauldian terms as *disciplining* and *controlling*. Under such analysis, community care takes on an almost *sinister* aspect.

Having stated these broad criticisms of community care the aim of the following section is to consider how such issues impact upon different types of disabled family. The first type of disabled family exists where there is a disabled child. Over the past twenty years there has been a major trend towards disabled children living with their families, not within institutions. Today, less that 2% of all disabled children live within institutions (Smyth and Robus, 1989). Whilst few would argue against such moves, the distress caused by institutionalisation being well understood, such a trend has not always been matched by the necessary increase in support available to these families. It seems unethical to talk in such terms, but it is nevertheless the case, that the situation for many disabled families is now exacerbated by the increased life expectancy of many severely disabled children. There are clearly some serious moral issues that need to be addressed by all those who determine policy and resources in this area, for if such increases in life expectancy are to be the source of great joy, then adequate funding must be given to the already stretched community based services in order that they can adequately support families.

The result of such service inadequacies is growing strain within the disabled family, particularly upon mothers. As with all 'caring' much of the responsibility for looking after disabled children within a family falls to the mother. Whilst many women find the role of caring for a disabled child rewarding, many others find the role very stressful, especially if the child's impairment takes the form of often being ill. In such a situation, the physical and emotional effort involved in day-to-day parenting is extended beyond what would normally be expected. This problem is exacerbated by the apparent lack of childcare for disabled children. In a recent survey carried out by "Contact a Family", an organisation for families with disabled children, 1000 of the 1,870 parents who responded stated that they had had to reduce their hours or give up work altogether because of childcare problems[15]. The current government's recent introduction of 'flexible working' from April 2003, as part of The Employment Act 2002, may help to alleviate some of these problems. According to this new initiative, employers must consider requests for such things as flexitime, home working, term-working, and job-sharing, *fairly* and are only able to refuse if there is a clear business reason. Ultimately, however, the onus is on employers to be 'fair' and so there may still be a battle to persuade employers to back the new initiative. In addition to this new strategy, improvements to the availability and affordability of childcare for disabled children are still needed.

Whilst the effects upon family life that result from having a disabled child can vary depending upon the family's existing circumstances and networks of support, more often than not disabled families find themselves very much alone. Research by Glendinning (1986) found that:

> *Parents consistently pointed out how the onus lay with them to initiate such contacts as and when they felt they needed to. This often causes them considerable difficulty (...) Parents were reluctant to be seen to need help, and were unsure about how that expressed need would be judged by professional or administrative officials.* (p.13)

The fear of being perceived by service professionals as having failed as parents can, therefore, act to perpetuate the isolation of the disabled family.

Where the picture may at first glance seem 'rosy' as in families where informal care seems to be succeeding and parents are determined to look after and protect their disabled child, there is evidence that siblings of the disabled child may suffer from unintentional neglect. In the worst cases, where informal care is not succeeding, McCormack (1992) reports that the extra stresses faced by disabled families have resulted in increased levels of family breakdown and divorce, certain families faring particularly badly: the divorce rate amongst UK couples with children with learning disabilities, for example, being 10 times the national average. Further, it is a sad fact that disabled children are still more likely to be

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abandoned than non-disabled children, have considerably less chance of subsequently being adopted and even more disturbingly, evidence suggests, are more at risk from the dark side of family life in the form of physical and sexual abuse.[16]

For disabled adults, family life is often no easier. It is well documented that disability within marriage can put a major strain upon the relationship. Parker (1993) interviewed married couples where one partner was disabled; such couples indicated their uncertainties about giving and receiving support, in particular, with personal tasks. She further suggests that providing intimate care is harder for those who are in a close sexual relationship or where sexual relations have been restricted by a disability. Feminists have suggested that these problems are experienced by women most acutely, as part of the relationships of surveillance, subordination and control that operate not only within the public domain, but also within the private domain of the family. Analysing the disabled family in this way, feminists have suggested that even when actions are construed by the dominant party to be about 'love' for the disabled individual, those actions may have more to do private patriarchy (Barnes et al, 1999).

Women may also be more disabled than men in comparable situations in another key respect, that is, with regard to the ways in which they are de-gendered. It has been widely recognised that service providers tend to give a lower priority to the needs of disabled women in general terms, but where service provision does exist it tends to be designed in ways that replace women's role within the family, instead of empowering them to retain control of domestic arrangements. Further, one of the most basic rights of womanhood is the right to reproduce, but both historical and contemporary attitudes towards disabled women as mothers, suggests that society is unsure about whether to grant disabled women this basic human right (see Kallianes and Rubenfield, 1997).

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[16] Please see NSPCC Information Briefing February 2002: Miller, D (2002) "Disabled Children and Abuse" NSPCC Practice Development Unit. Downloadable from website:

Fears have been expressed surrounding what is perceived by many to be the *risk of childbearing* to disabled women in terms of exacerbating their impairments or in terms of transmitting their impairments to a child. This second point has become an even greater issue in the light of recent technological advances such as genetic counselling and prenatal screening. Such attitudes place a great pressure upon prospective disabled parents. Even more stress, however, is felt by those disabled people who do become parents. Disabled women have highlighted the enormous pressure placed upon them to be 'good enough mothers' not only by health and social welfare professionals, but also by family and friends. As has already been mentioned, this pressure can be understood in Foucauldian terms as a system of discipline and control, in which disabled mothers experience greater surveillance than their non-disabled peers.

With regard to mothering and parenting more generally, people with a learning disability undoubtedly experience this surveillance most acutely. While disabled women who do not have a learning disability feel the pressure to prove themselves to be 'good enough' mothers, more often than not people with a learning disability are denied even the opportunity to prove their *competence.* Parents with a learning disability are widely considered to lack the skills required to ensure the well-being and development of their children. This is a view that has persisted despite some strong evidence from authors such as Booth and Booth (1994, 1998) to suggest that such black and white thinking must be avoided:

> *Our research challenges such a summary judgement by showing that child outcomes cannot be predicted on the basis of their parents' label alone. Some children (...) become well-adjusted adults who make their own way in society and bring up families of their own. Others (...) are corralled into a melancholic and shrivelled existence. Understanding their stories means looking beyond the capacities and limitations of their parents.* (Booth and Booth, 1998: 101)

Verdict – inequalities of opportunity

What is clear from the discussion above is that systematic inequalities continue to exist between disabled and non-disabled people in each of the major public spheres – education, employment and in relation to issues of access. What the previous discussion also demonstrates, however, is the extent to which public attitudes towards disabled people impact upon the private world of the disabled family. Further, when considered in its entirety, what the research discussed above clearly demonstrates is that moral issues surrounding what kinds of lives are valued within a society and are considered to be worthy of inclusion within the 'mainstream', continue to structure the lives of disabled people. In the final part of this chapter, the ways in which disabled people and groups have themselves been challenging these issues through such things as the disability identity, the disability movement and disability culture will be considered.

The 'coming out' of disability

The fact that disabled people are devalued and stigmatised by society has been well documented by a large number of authors (see Karpf 1988, Morris, 1991, Ross, 1997), but arguably, chief amongst these authors are Colin Barnes and Tom Shakespeare. Barnes (1992c) provides one of the most powerful analyses of this process of stigmatisation through his discussion of the disabling imagery used by the media. According to his argument, such images as they appear in films, books, in the press and on television, form the "*bedrock on which the attitudes towards, assumptions about and expectations of disabled people are based.*" (Barnes, 1992c: 19) For Barnes (1992c), these disabling images include:

- The view of the disabled person as a 'curio'
- The view of the disabled person as a 'super cripple'
- The view of the disabled person as an object of ridicule
- The view of the disabled person as a burden
- The view of the disabled person as their own worst and only enemy
- The view of the disabled person as incapable of participating fully in community life
- The view of the disabled person as an object of violence
- The view of the disabled person as sinister and evil
- The view of the disabled person as sexually abnormal

Perhaps the most profound and frequently occurring disabling image, however, is that of the disabled person as pitiable and pathetic. For Barnes, this entirely negative view of disability is recurrent in all media depictions of disability and is key to perpetuating the myth that disability is synonymous with suffering. According to his analysis, such a view of disabled people succeeds in focusing attention upon the medical aspects of impairment whilst diverting public attention away from the social factors that disable people. Further, such attitudes towards disabled people are revealed, Barnes claims, by the frequent use of patronising and offensive language such as 'the plucky' and 'the brave', or the 'victim' or 'unfortunate' to describe disabled individuals.

Most interestingly and controversially, perhaps, Barnes also identifies one final disabling image, that of the disabled person as 'normal'. Whilst he admits that in some respects the appearance of such images in the media recently is an important step, he nevertheless identifies three risks associated with this imagery. Firstly, in emphasising 'ability' not impairment, such images essentially deny the reality of impairment and undermine the positive disability identity which many disabled people are seeking to celebrate. Secondly, there are limits, Barnes claims, to this notion of disabled people as 'normal', for after all, 'normal' people are rarely dependent upon the goodwill of others in order to survive. Thirdly, the focus of this new approach within the media tends to be about stressing the 'normality' of certain individuals with impairments, rather than questioning how society *disables.* Thus, for Barnes even seemingly positive new developments in public attitudes towards disability can in fact be little more than a re-packaging of familiar attitudes.

Shakespeare echoes Barnes in his belief that disabled people remain devalued and stigmatised within society and most recently he has been tackling the issues raised by advances in medicine and genetics. For Shakespeare (1998), the problem with the 'new genetics' is that it fails to consider impairment as part of the human condition. Instead, according to Shakespeare, such new technologies further disadvantage disabled people by perpetuating the idea that disability is a purely medical problem which can and should be dealt with in purely medical terms, so avoiding the issue of the social construction of disability. Further, as he also highlights, there are some major ethical dilemmas associated with seeking to eliminate disability, for the underlying logic to such an approach must be that *a disabled person's life is not worth living.* Whilst there are clear implications of this in terms of disabled people's rights to life, the other effect of such attitudes is to further disadvantage those individuals who acquire a disability in their lifetimes.

> *The drive to use genetic and obstetric techniques to remove disabled people from the population fails to consider the millions of people developing impairments as a result of accident or disease during the life-course. Resources would be better spent on creating an inclusive and barrier-free society, and promoting the civil rights and independent living of disabled people. Society should value disabled people, alongside all human life.* (Shakespeare, 1998: 679)

Given therefore, that the dominant culture is replete with these disabling images, the challenge for many disabled people has been how to develop counter images and values which are empowering and which promote the idea that society should value people with impairments. The following discussion will focus upon two main areas: firstly, issues relating to disability identity politics; and secondly, issues relating to the thorny question of the extent to which disabled people can be considered to be a part of an alternative culture, in opposition to mainstream culture.

Disability identity politics

In 1996, a very interesting chapter by Susan Peters appeared in Len Barton's (Ed.) "Disability and Society: Emerging Issues and Insights." In this chapter, Peters (1996) examined the current state of the politics of the disability identity and concluded that there is no 'positive' identity of disability:

> *People with disabilities have largely assimilated these tarnished images in society and the academy. Accepting the idea that we are the Other, we continue to search for ways that will garner our acceptance in 'mainstream' society – mostly through political*

> *strategies and legal mandates – while at the same time denying our personal and multiple identities.* (p.219)

Yet, only one year later, in 1997, Gilson et al wrote:

> *The transformation from tentative affirmation of disability identity to proclamation of disability pride reflects the increasing importance of self-determination. A confident, positive disability identity within a broad, inclusive disability community has emerged. The benefit to disabled people to determine and relate their own stories is increasingly evident.* (p.16)

Clearly there is little agreement surrounding this issue of a positive disability identity.

Of those who share Gilson's view, Shakespeare (1993), Morris (1991) and Oliver (1990, 1997) are probably the best known authors. All three authors see the development of a politicised disability identity as having the potential to bring about radical improvements in the lives of disabled people. Such thinking has led both Shakespeare (1993) and Oliver (1997), to make the not unsurprising link with new social movement theorising, Oliver in particular claiming that the "Disability movement *is* a New Social Movement!" (my italics). Shakespeare and Oliver's new theorising, however, whilst of considerable interest and importance in furthering our understanding of the disability movement is as yet not fully developed and herein lies the problem. It is difficult to avoid concluding from some of Oliver's work that his personal desire to see the disability movement as a new social movement is clouding his academic judgement somewhat. In an earlier paper written with Gerry Zarb ([1989] 1997) Oliver analyses the extent to which the disability movement is a new social movement and concludes that: "*the disability movement can, indeed, be considered as part of a new social movement* ***generally.***" (p.207) (my emphasis) The word 'generally' is important here, however, for although clearly hoping to persuade the reader that the disability movement is a new social movement, Oliver and Zarb do admit that it does not share one of the four major characteristics of a new social movement. In relation to the idea that new social movements are characterised by 'post-materialist' or 'post-acquisitive' values being given precedence over those concerned with income, material needs or social security, Oliver and Zarb ([1989] 1997) state:

> *Whilst it is certainly true that the disability movement is concerned with issues relating to the quality of life of disabled people, it is also true that many disabled people still face material deprivation as well as social disadvantage and the movement is centrally concerned with this. It would be inaccurate to attempt to characterise the disability movement as stemming from a middle-class, disabled elite concerned only with their own quality of life (...)* (p.206)

In other words, the disability movement's concerns with some of the persistent social inequalities discussed earlier in this chapter, cannot be denied, and must bring into some doubt the notion that the disability movement is a new social movement. Indeed, Erevelles (1996) makes it quite clear that these post-materialist/post-structural values and disability make an "*uneasy alliance*" (p.523). In response to the post-structural idea that privilege should be given to the 'space of the discoursive' in order to produce many empowering possibilities, Erevelles (1996) points out that many disabled people have argued that these:

> *(...) imaginative meaning systems within discoursive spaces do not in any way alleviate the real material limitations that they face on a daily basis – material conditions that have caused many of them to live lives of extreme poverty.* (p.524)

Setting aside this issue of whether the disability movement is a new social movement, there do seem, however, to be a large number of authors who share the view that fashioning a positive collective identity for disabled people is both a major part of what the disability movement *is* and *should* be about. Barnes et al (1999), for example, have commented that;

> *Disabled people's self-organisation challenges the myth of passivity and the objectification of disabled people. Disabled people, like children, are meant to be seen, and not heard; they are meant to be grateful, not angry; they are meant to be humble not proud. In challenging all these preconceptions and discriminatory ideologies, the movement is making progress*

> *everyday, even before attaining its central political objectives.* (p.178)

There is evidence, however, to suggest that the disability movement in the UK has not been entirely successful in developing this positive identity and group consciousness across the disabled population as a whole. One of the key stumbling blocks has been the division that exists between groups of individuals with different impairments. Whilst some authors have suggested that these divisions have largely been established arbitrarily by charities and traditional welfare organisations, others, for example Priestley (1995) have proposed that these differences are very real and cannot be ignored. For Priestley, the tendency on the part of many of the key players in the disability movement, has been to emphasise commonality over difference. This, he warns is unwise for:

> (...) *it is clear that all social movements based (necessarily) upon a commonality of interests run the risk of alienating individuals and groups with unique personal experiences. In the present context, unique personal experiences of impairment may often be perceived as more immediate and important than the commonality associated with disablement as a form of social oppression.* (Priestley, 1995: 159)

In particular, Priestley draws attention to what he considers to be the legitimate concerns of many disability groups with special interests such as ethnicity, gender or sexuality, that their special interests may be perceived to be 'optional extras' to the *common experience* of disability. Priestley's point is taken further by Vernon (1999) who argues that so-called 'simultaneous oppression' or 'double jeopardy' has often been alleged to be the unique experience of a *minority* of disabled people. In fact, according to Vernon, the experience of simultaneous oppression, is key to understanding disability itself, since the majority of disabled people are not a homogeneous mass of disabled, white, heterosexual, middleclass, young men!

For Vernon, it is essential that the disability movement avoid making the assumption that other forms of oppression, for example, sexism, have already been 'taken care of' by other movements. She points to the growing literature which shows that disabled people experience racism (Begum, 1992, 1994, Sharma and Love, 1991 and Stuart, 1992, 1993, 1994.); sexism (Fine and Asch, 1988, Morris, 1989, 1991, 1996, Lloyd, 1992); heterosexism (Corbett, 1994, Hearn, 1988); ageism (Zarb and Oliver, 1993, MacFarlane, 1994); and class inequality issues (Priestley, 1995). She then highlights the manner in which different forms of oppression can interact, for example, for many disabled people, their socio-economic or class position can have profound effects upon their options as a disabled person with regard to lifestyle. To make matters even worse for such groups, Vernon (1999) claims: "*Being black and disabled can sometimes mean that you are neither fully accepted in the black community nor in the disabled community.*" (p.395) This is a potential problem for all groups experiencing simultaneous oppression, and is, seemingly, yet to be adequately considered by the disability movement. Indeed, Fawcett (2000) drawing upon the work of Nancy Fraser (1995a) states that focusing on disability as 'difference' can in itself be used in a normative way to 'gloss-over' pervasive differences between disabled people, for example, between academically able physically disabled people and individuals with learning disabilities.

Fiona Williams (1996), however, again from a feminist perspective, suggests that whilst the above is undoubtedly true, it may sometimes be expedient to engage in the temporary 'fixing' or 'freezing' of differences in order to achieve key political and strategic goals. The challenge for the disability movement, however, in its quest to 'freeze' divisions within the disabled population even temporarily for political purposes, is to find an agreed disability identity behind which people are prepared to unite. Warren (1999) has commented:

> *(...) while users may be united by shared experience of forced dependency and a common goal of empowerment, it cannot be assumed that individuals agree about the identity to adopt in order to fight for that goal or the path of the battle: for example, some people reject the term 'disabled' as a stigmatising label, others object to the degree of emphasis placed on physical access by the disability movement.* (p.123)

In the light of this absence of solidarity amongst disabled people, it unclear what form the battle for disabled people's citizenship rights is truly taking.

A disability culture?[17]

The debate surrounding the existence of a disability culture reflects this uncertainty with regard to disability identity and the disability movement. The debate is also made considerably more complex due to academic disagreements surrounding the whole notion of *what is meant by culture*. Perhaps the most useful definition of culture, however, is provided by Raymond Williams (1980, 1981), who has been very influential within the field. For Williams, culture has two main aspects: firstly, the known meanings and directions into which members of a culture are socialised and which represent the traditional aspect of a culture; secondly, the new observations and meanings, which are offered and tested by a group, and which represents the creative aspect of a culture. Thus, for Williams, the significance of cultural practices and representations such as those in the media and other art forms, is that they are often one of the key ways in which a culture is created and maintained, whilst always providing opportunity for change.

The key point here, however, is that whilst Williams does stress the importance of forms of representation, he does not equate 'culture' with the 'arts'. This is important when considering the disability culture, because it would be a mistake to equate the disability culture, with the Disability Arts Movement. Undeniably, the Disability Arts Movement has played a very powerful role in communicating

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[17] Readers may note that no reference is made within this section to the particular experiences of those people with congenital hearing impairments who self-define as Deaf, rather than deaf, who use Sign Language and who consider themselves to be a part of a cultural minority. This omission was not unintentional. Clearly the Deaf culture does constitute a separate culture on the basis of a shared language and Deaf people's arguments in favour of viewing them as a cultural minority analogous to other minority ethnic groups is convincing.

The reason why this group has not been considered in more depth within this chapter, however, is because Deaf people have long resisted identification as disabled or impaired people and this has proved to be a major stumbling block to developing links between Deaf people and the disability movement. Since this is a very specific issue applying to only a very small proportion of the disabled population, and does not reflect the views of the many deaf people who do not identify themselves with the Deaf culture, or who do clearly define themselves as disabled people, it was not considered necessary to go into any depth with regard to this debate. For those who wish to know more about these issues, however, a good introduction to the debate has been provided by Mairian Corker (1998).

the distinctive history, skills, customs, experiences and concerns of disabled people, which many people consider to be a distinctive lifestyle. The key question, however, is whether this distinct lifestyle expressed by Disability Arts truly represents a distinct disability culture?

There would appear to be two approaches to theorising disability culture, and there are some key problems with each. Firstly, there are those who consider disability culture to be about challenging the cultural representations of disability that exist within mainstream culture in order to achieve for disabled people the equal respect and value that is given to other members of society. Such a position with regard to disability culture clearly perceives that such cultural practices are not only about tackling stigma, but in so doing are also about increasing the equality of opportunity and outcomes for disabled people.

Whilst not denying the importance of such cultural challenges to mainstream prejudice, the question of whether such cultural strategies represent true cultural difference is a thorny one. Chapters 6 and 7 will consider this issue in greater depth. It is important to note here, however that such issues have also led some people to question who actually belongs to the disability culture. Clearly, individuals who aim to become assimilated into the mainstream 'normal' world would not choose to identify themselves clearly with the disability culture, but there are also other groups, for example, people with a learning disability or a mental illness, who may also find that their cultural membership is unclear. Gilson and Depoy (2000) have highlighted the way in which the question of who can be a part of the disability culture is a constant source of tension. They suggest that individuals within the disabled population may find themselves positioned against one another as political advantage is sought. This is hardly the basis for a shared cultural context.

The second approach to disability culture is similarly problematic. For many of the authors in this field, Oliver and Morris being key examples, disability culture is about 'celebrating' disability as 'difference'. This notion of celebrating difference is very much connected with the idea of the positive 'disability identity', and as such is equally contested. For many, it is problematic to speak of 'disability pride' and the 'celebration of difference' in relation to the lives of people whose impairments are painful, debilitating or even fatal. Whilst many people in this field would agree that the quality of life of many disabled people is gravely affected by social factors, medical factors cannot be ignored and in the light of the diversity of experience with regard to impairment, it would seem overly optimistic, if not insensitive, to talk about celebrating disability across the disabled population. The tendency on the part of a number of key theorists in this field to ignore the very real reasons why some disabled individuals may feel unable to celebrate their difference is one of the key problems facing disability theory today.

Perhaps much of the discussion above can be summarised by saying that one of the key problems facing those who consider there to be a disability culture is the extent to which they perceive this culture to be 'exclusive'. For many commentators, there is a growing risk that in the manner in which key figures are defining disability culture, a 'confining social identity' (Gilson and Depoy, 2000) is being created for disabled people. Whilst on a positive note establishing such clear cultural boundaries may create *belongingness*, they may also create *symbolic incarceration.*

Conclusion

As the various sections of this chapter demonstrate, despite some major improvements in the lives of disabled people, systematic structural inequalities between disabled and non-disabled people remain, as do the persistent negative attitudes towards people with impairments. Such prejudicial attitudes may themselves be responsible for confirming many of these traditional patterns of inequality.

Despite this gloomy conclusion, there is some hope for the future with regard to the position of disabled people in society. Advances in Medical Sociology and Disability Studies, emancipatory research paradigms, and the collective power of disabled people in challenging the dominant views on disability, have already brought about some important changes in the lives of disabled people. In the future it is to be hoped that such progress will continue, and that Disability will be recognised by disabled and non-disabled people alike as a civil rights issue. Whether or not we will ever witness the true 'coming out' of disabled people is questionable, however, for as has been discussed in the later sections of this chapter, the ways in which issues such as impairment, gender, ethnicity, sexuality affect experiences of disability have created divisions within the disabled population, significantly weakens the notion of a collective disability identity or culture.

Chapter 5

Social Movements

Introduction

Setting aside the debate regarding the term 'post-modernity', few social theorists would disagree that over the past century, society has undergone a wide variety of changes that when considered cumulatively bring into some doubt the idea that we inhabit a 'modern' society. For example, 'struggle' and unrest are no longer focused within a homogenous 'working class'. Instead, divisions within the socio-economic groupings and blurring of the boundaries between groups have become widely understood resulting in a questioning of the whole notion of 'class'. What has come to be known as Late/r Modernity is now characterised by a variety of forms of unrest that can alternatively be seen as either resulting from the breakdown of 'class' as the major social cleavage, or as further hastening the decline of class-based 'politics'. Issues relating to gender, sexuality, 'race', dis/ability, ecologism, and a wide variety of other belief- and value-based systems have now come to the fore. The proliferation of such social groupings at first glance appears to make the idea that we live in a 'movement society' increasingly plausible. The term must be used with caution however, since it is unclear whether any agreement has been reached regarding whether or not all movements within a 'movement society' are based upon this proliferation of unrest, or what are the central factors necessary to transform a 'struggle' into a 'movement'.

Nevertheless, there can be seen to have been two broad traditions of social movement theorizing, roughly equating to an American and a European tradition (see Fig.5.a). Further, the 1960's proved to be a watershed with regard to theorizing in this field and led to a break with traditional views on social movements. Those theories developed before the late 1960's I have termed 'First Phase Theories' and those that came after, the 'Second Phase Theories'. This chapter will begin by considering the First Phase Theories. The first phase of the American tradition centred on the *Collective Behaviour* approach to social movements, and, I would argue, is best exemplified in the work of Herbert Blumer. For this reason, I will begin by considering Blumer's contribution to social movement theorizing. This is not to say, however, that the collective actor approach was the *only* first phase American theory. It would be wrong to overlook completely the structural-functionalist perspective of Parson's, for example. This approach has been heavily criticised however, for regarding collective movements as irrational actors, and collective action as being solely the product of malfunctions of the social system. This approach, other than being the subject of much, later criticism, particularly by Oberschall (1973), has not subsequently developed into a major strand of social movement theorising. It is for this reason that this approach is not considered in any greater depth within this chapter.[1]

The 'First Phase Theories' in the European tradition are less clearly associated with particular theorists. Instead, European social movement theory has taken many forms, but can, nevertheless, be broadly termed a *Social Democratic* tradition and can be sub-divided into Weberian and Marxist approaches. These approaches will be briefly discussed before a consideration of what is meant by this notion of the '1960's watershed' and its effects upon subsequent theorizing.

I will then move on to consider the 'Second Phase Theories'. In the American tradition, post-1960's theorizing has been dominated by the *Resource Mobilization* theories, and I include within this category the *Political Process* theories. Within this America tradition, the work of Oberschall, Tilly and Tarrow is particularly central, so these theorists will be considered in some depth. In post-1960's Europe a number of related approaches emerged based around notions of *identity, defence of the lifeworld, values and culture.* I have rather loosely termed these approaches the 'New' Social Movement theories. These

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[1] For readers who may be interested to read further about this approach, please see: Parsons (1961, 1969); Smelser (1963); and Eyerman and Jameson (1991).

theories are most clearly articulated in the work of Touraine, Habermas and Melucci and their theories will be considered in turn within the chapter.

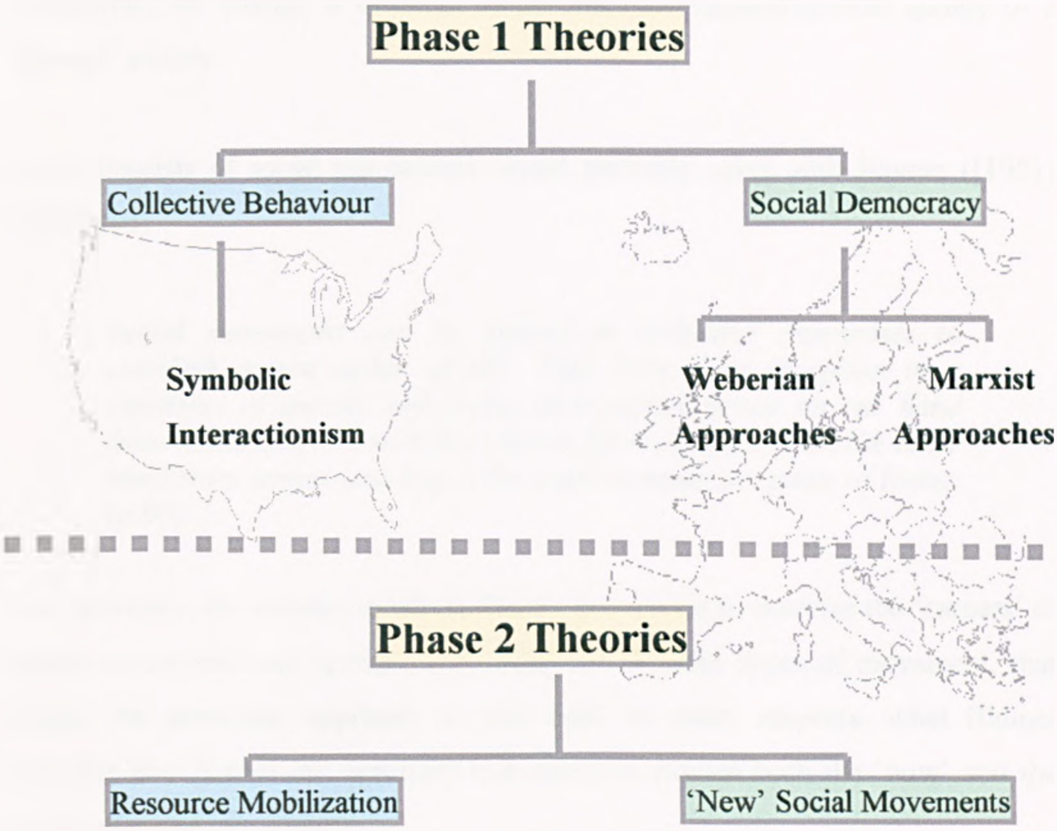

Fig. 5a

Phase 1 Theories

Collective Behaviour – The American Tradition

Blumer – symbolic interactionism

The *Collective Behaviour* explanation for social movements originates within the Chicago School and is probably best exemplified in the work of Herbert Blumer. Blumer was interested in the symbolic production and construction of identity and saw social movements as being about producing new norms and solidarities. Social movements, according to his theory, are strongly linked with the value systems of a society and are as such, an integral part of any 'normal' society. That is not to say that social movements are not about change, but that their role as catalysts for change is essential to the inherent transformational quality of a 'normal' society.

Most theorists of social movements would probably agree with Blumer ([1951] 1995) that:

> *Social movements can be viewed as collective enterprises to establish a new order of life. They have their inception in a condition of unrest, and derive their motive power on one hand from dissatisfaction with the current form of life, and on the other hand from wishes and hopes for a new scheme or system of living.* (p.60)

It is, however, the manner in which Blumer proceeded to theorize the 'careers' of social movements and produce a typology of different types of movement, that signals his particular approach to this field. In many respects, what Blumer provides is a 'joined up' approach that seeks to explain both the 'how' and the 'why' of social movements.

Implicit in Blumer's work is a focus upon the individual actor and issues of identity. Blumer was clearly concerned with social movements as examples of collectivities, the identity of which are simultaneously structured by individual members, and yet also structure the lives and identities of those members. He identified three major types of social movement, and these he termed the '*general social movements*', the '*specific social movements*' and the '*expressive social movements*'. To begin with the last, the distinguishing feature of expressive movements is that they do not seek to achieve structural objectives. Expressive movements are not about social change. The tension and unrest out of which these movements emerge is not focused upon a particular objective, but rather takes the form of some kind of expressive behaviour. Nevertheless, these movements are not without effect, for some of this expressive behaviour may have *"profound effects on the personalities of individuals and on the character of the social order."* (Blumer, [1951] 1995:77)

Blumer identifies religious movements and 'fashion' as two examples of expressive movements, with fashion probably being the most 'expressive' in nature and thus most clearly distinguished from a specific social movement. In particular, Blumer states that fashion differs from other movements in that it does not develop into a 'society'. This is an important point because it establishes Blumer's ([1951] 1995) over-arching view of general and specific social movements, that they are *"societies in miniature"* (p.76). Thus, fashion does not have a social organization, or develop a form of 'we-consciousness', instead it provides the means for expressing dispositions and tastes and in crystallizing these tastes, fashion constructs a common subjective life. This common subjective life is what Blumer describes as a 'Zeitgeist', and is a part of the development of a new social order.

In contrast, according to Blumer, general and specific social movements are *fundamentally* about social change, although they differ in the extent to which they are organised about their goals. General social movements are constituted by gradual changes in the values that people possess. Blumer termed these changes 'cultural drifts' and suggested that in particular, they took the form of changes in the way that people conceptualise themselves. Where there has previously been acceptance of the status quo and inertia, people begin to perceive infringements to their rights and privileges and they develop new opinions with regard to what they consider their entitlements to be. These new opinions are largely based upon individuals' hopes and dreams and the development of such ideas effects the way in which people look upon the reality of their own lives. As people come to form new conceptions of themselves, so they increasingly find a disjuncture between how they see their 'true selves' and the actual positions in which they find themselves. For Blumer this change in sense of 'self' explains how people come to experience dissatisfaction where before there was none.

The chief characteristic of general social movements, is therefore, *vagueness*, for *"these new images of themselves, which people begin to develop in response to cultural drifts, are vague and indefinite; and correspondingly, the behaviour in response to such images is uncertain and without definite aim."* (Blumer, [1951] 1995: 61) As a result, Blumer considers the efforts of such movements to be 'groping' and as moving only slowly towards their goals. Further, Blumer saw these social movements, of which he identified the women's movements as an example, as structurally unorganised with no clear leadership or membership. Instead, such movements consist of unconnected individuals engaging in the struggle in a wide variety of loci.

According to Blumer, all social movements begin as general social movements, but whilst some remain uncoordinated, others develop into *specific social movements*. A social movement can be considered a 'specific social movement' once it possesses a well-defined objective or goal, has organization and structure and has a recognised leadership and membership. Again, emphasising the importance of theorizing the individual when considering social movements, Blumer states that the membership of specific social movements is characterised by the development of what he terms 'we-consciousness', in which the individual senses that they are no longer struggling alone. This has clear implications for notions of shared identity and solidarity.

Although stating that specific social movements are distinguished from general social movements by higher levels of coordination, Blumer sees a 'career path' or continuum along which these movements will pass over time, becoming increasingly organised and solidified over the lifetime of the movement. Several key processes are seen to occur during this development process and Blumer identifies the role of *agitation*, the development of *esprit de corps*, and the degree of morale within the movement.

The role of *agitation* is most important during the early stages of a specific social movement, although Blumer states that it may persist in a more minor form during later stages of development. Agitation results in the awakening of people and creation of new impulses and ideas that make for restlessness and dissatisfaction. Agitation cannot work however, where there are insufficient pre-existing grounds for disquiet. Agitation relies upon the pre-existence of some sort of injustice, discrimination or abuse, and seeks to encourage people to challenge the 'taken-for-granted'. Alternatively, agitation works well where people are already discontented or restless but where they are either too timid or do not know what to do. Agitation gives people courage and the means to change things.

Esprit de corps, as defined by Blumer, is probably the most important aspect of specific social movements since it determines who is an *insider* and who is an *outsider.* Further, according to Blumer, 'in-group/out-group relations' are never neutral, and it is an essential part of the development of the social movement that the *outsiders* are demonised as *enemies.* Esprit de corps is also developed through such things as informal fellowship in which individuals within the movements get to know one another and through common sympathy and a sense of intimacy the individual gains a sense of status and social acceptance. This 'fellowship' is a particularly uniting factor since, according to Blumer, it is often the case that individuals who become members of social movements have experienced prior loneliness and alienation. Involvement in ceremonial behaviour such as rallies, parades and demonstrations further enhance the individual's sense of vast support, and parading in numbers gives the individual a sense that both they and their views are important.

Yet, Blumer claimed that a specific social movement cannot survive on esprit de corps alone. Morale is also central to the maintenance of solidarity, especially in the face of adversity. To survive over time, the members of specific social movements must be sure of the rectitude of their aims and that the achievement of their goals would result in a near utopian state of affairs. Further, members must have faith that the movement will eventually achieve its goals. This faith is essential if momentum is to be maintained even through the hardest of struggles. This faith is shored up by the development of 'sacred' texts, by having leaders who are viewed as 'saint-like' and by developing myths surrounding such things as the inhumanity of one's opponents.

Finally, ideology plays a part in maintaining morale, and is particularly important when a movement faces clear opposition from outsiders for it provides, amongst other things, a clear statement of the objectives of the movement, a critique of the status quo, against which the movement is struggling, and a body of 'defence doctrine' that justifies the actions of the movement. According the Blumer this ideology takes two forms, academic and populist. Populist ideology within a movement makes the more academic forms of the ideology more readily comprehensible. The relationship, therefore, within a movement between the academic and more general members of the movement is key to the success of a specific social movement:

> *To be effective (...) the ideology must carry respectability and prestige – a character that is provided primarily by the intelligentsia of the movement. More important than this, however, is the need of the ideology to answer to the distress, wishes, and hopes of the people. Unless it has this popular appeal, it will be of no value to the movement.* (Blumer, [1951] 1995:73)

This issue will be considered again in relation to the findings of this research in chapters 6 and 7.

For Blumer ([1951] 1995), the manner in which all these aspects of a specific social movement come together to gain supporters, keep hold of supporters and reach the objectives of the movement, depends upon the particulars of the situation and the nature of the movement: "*For, tactics are always dependent on the nature of the situation in which the movement is operating and always with reference to the cultural background of the movement.*" (p.73)

The value of Blumer's theorizing, quite apart from the breadth of explanation he provides, is, therefore, the way in which he outlines a new way of theorizing social movements as a form of collective behaviour. In emphasizing the potential for social creativity that can be found within such behaviour, Blumer provided one of the first 'positive' theories of social movements. Blumer's contribution is also vital in the respect that he highlights the context specific nature of social movements, an issue that is still key to social movement theorizing. Blumer's theories in this field have therefore, clearly been highly influential, and came to dominate the study of social movements until the late 1960's.

Social Democratic Approaches – The European Tradition

At the same time as the *Collective Behaviour* approach was being developed in the United States, in Europe, other approaches were emerging. Of key importance in explaining the differences between the European and American traditions is the fact that European societies have been more traditional and class based that the society of the United States. In addition, according to Eyerman and Jamison (1991), the European, *Social Democratic* tradition was more philosophically informed than the *Collective Behaviour* approach, with the two major and competing theoretical interpretations arising from the work of Weber and Marx.

For Marx, society was comprised from a "*moving balance of antithetical forces that generate social change by their tension and struggle*." (Coser, 1971: 43) Thus, social struggle was at the heart of social progress. The main actors in this social struggle, according to Marx, were the economic classes whose interests conflict. Thus, this 'political' conflict between the classes becomes more acute as more and more changes occur to their relative positions during the process of economic development, and as increasing consciousness of their interests emerges within each class (Tansey, 1995). Most importantly, according to Marx, the result of these contradictions and tensions within capitalism, is the development of a class-consciousness within the *oppressed classes*, that by banding together in collective action, will seek to over-throw the dominant class.

Much subsequent Marxist theorizing on social movements within this first phase, European tradition of theorizing has echoed Marx's views on collective action and has tended to view social movements with some anticipation. Such approaches have considered social movements to be signs of a forthcoming collapse of the existing, capitalist order within society. For many Marxists, then, social movements possess the potential for social change, and the image of the collective actor is that of the "*self-activating class*" rather than the faceless mass (Eyerman and Jamison, 1991: 16). The theories within this branch of Marxism have tended, therefore, to focus rather more upon what these movements represent, and what potential they may have for creating social change. It should be stated, however, that this somewhat 'Leninist' approach has not been the only line of thought within this tradition. Some Marxist approaches have attempted to retain a critical distance from the Leninist model. Even so, they still tend to emphasise the importance of politics and to reduce social movements to their political expression (Melucci, 1996). In short, all Marxist accounts have tended to be less concerned with *why* social movements emerge, or *how* they take shape.

In contrast to Marx's hopeful and positive views on social movements, Weber viewed such things as crowds and mass movements with some concern, preferring to see them as necessary, but transitory factors in social transformation. Weber's classification of social stratification was rather more complex than that of Marx and suggested a more pluralistic basis for social conflict (Coser, 1971). Weber rejected Marx's vision of a society polarized into the 'haves' and the 'have-nots' and in so doing provided a more complex analysis of power in society. Although Weber did agree with Marx that economic power is the predominant form of power in many modern societies, he saw power existing on other bases. One example Weber provides is the power that exists within bureaucracies, but more crucially for theorizing on social movements, Weber also perceived power to be the chance of an individual, or a group of individuals to achieve their goals through joint action, even against the opposition of others.

This aspect of Weber's work on social movements is somewhat misleading however, for it suggests a more positive view of social movements than Weber perhaps intended. This point is addressed in the work of Michels (1959), Weber's friend and confidant. Michels saw the life-cycle of social movements as a process in which charismatic leadership became routinized and there was the establishment of bureaucratic institutions. This maturation of social movements in which previously dynamic social forces became routinized into stagnant, topheavy institutions, was seen to be a necessary part of the life-cycle of social movements in modern society. This notion of the institutionalisation of mass movements became known as the 'Weber-Michels model' and has led to considerable debate. Indeed, Eyerman and Jamison (1991) claim that the *Resource Mobilization* approach to the study of social movements emerged, at least in part, as an alternative to the 'Weber-Michels model'.

These two major approaches, stemming as they do from the work of Weber and Marx, appeared to be most strikingly opposed to each other during the early part of the twentieth century, when the issues resulting from the emergence of 'modernity' were most acutely felt. During the past century however, social democracy, exemplified by the development of the welfare state, achieved a central role in society. Weberians and Marxists agreed that social movements appeared to have moved to the very core of society. This notion of the institutionalisation of 'movement' was to be greatly challenged during the 1960's however, and the events of this period instigated a radical re-think of social movement theory.

1960's 'watershed'

On August 28, 1963, between 200,000 and 500,000 people marched on Washington D.C. in what has been dubbed the "March on Washington for Jobs and Freedom". This protest culminated in the now famous "I have a dream" address by Martin Luther King Jr. (Giugni, 1999). This famous mass mobilization was one of many during the period and these widespread protests raised some serious questions for theorists of social movements. Della Porta and Diani (1999) identify these major issues as being:

> *(...) questions of a practical nature, relating to the evaluation of emerging forms of social and political participation, and the response to them. (...) Furthermore, actors engaged in the new conflicts (youth, women, new professional groups and so on) could only partly be characterized in terms of principal political cleavages of the industrial societies. It was even less appropriate*

> *to view these actors in terms of class conflicts, which certainly constituted the principal component of these cleavages.* (p.2)

Initially, theorists attempted to explain the 1960's movements relying upon earlier approaches, such as the collective behaviour theories, or the social democratic ideas. The result of such theorizing was to continue to view social movements as being the products of such things as 'alienation', the actions of social deviants or misfits, 'relative deprivation', or status inconsistencies. In short, as Stryker et al (2000) have commented:

> *(...) social movements were viewed largely as the products of unbridled affect, of non-rational and irrational wellsprings of action. Social movements were taken to be anything but well-considered responses to legitimate concerns about real but oppositional interests.* (p.2)

Since many social movement theorists were, and continue to be, active participants within social movements, it was not entirely surprising therefore, that there was considerable opposition to this view of social movement activity as being 'irrational'. Out of this opposition to the existing theories emerged what I have termed the 'Second Phase Theories', namely, in the United States, the *Resource Mobilization* and the closely related *Political Protest* models, and in Europe the 'New' Social Movement theories. A consideration of these 'Second Phases Theories' forms the next section of this chapter.

Phase 2 Theories

Resource Mobilization and Political Process – the changing face of the American tradition

Up until the 1970's much social movement theorizing had drawn heavily upon Blumer's work, but from the 1970's onwards this social psychological approach to theorizing social movements was heavily criticised. A major critique of the Collective Behaviour approach came via *Resource Mobilization* theory and the work of the major proponent of this approach, Oberschall. Equally important however, was the *Political Process* model of Tarrow and the critique of the *Collective Behaviour* approach put forward by Tilly, whose theories appear to fall somewhere in between the *Resource mobilization* and the *Political Process* models.

In many respects, it is very difficult to define the distinguishing features of these two approaches, so akin are they to each other. Both theories see social movements as being about well-organised, purposeful, rational action. In so emphasising organizational and political factors, social psychological variables are de-emphasised within both models. In addition, according to both theories, it is unnecessary to focus the theoretical explanations of social movements upon the structural tensions or conflicts that have prompted the protest. The focus of this social movement theorizing is, therefore, more upon the 'how' and 'when' of social movements rather than the 'why'.

Oberschall

Oberschall drew upon the concept of 'resource management' which had been introduced by Charles Tilly in his early work. Tilly (1978) had provided a new basis for the analysis of mobilization, counter-mobilization, the struggle for power and the manner in which individual resources could be utilized for achieving collective group goals through the process of conflict. Although Tilly, as will be discussed subsequently, went on to modify his own theories to the extent that they no longer belong entirely to the *Resource Mobilization* tradition, he did provide an important starting point for the development of this approach by Oberschall.

For Oberschall (1973), social conflict arises out of the dynamic relationship between mobilization and social control.

> *Mobilization refers to the processes by which a discontented group assembles and invests resources for the pursuit of group goals. Social control refers to the same processes, but from the*

> *point of view of the incumbents or the group that is being challenged.* (p.28)

Further, social structures, according to Oberschall, can be analysed according to how resources are managed and allocated in the process of pursuing a group goal. For example, Oberschall cites the experiences of the Black Power Movement and other such civil rights movements as examples of the problem that negatively privileged groups face when trying to mobilize their meagre resources for the pursuit of their group goals. He then theorizes the extent to which external support can make up the resource deficits of such movements. Oberschall (1973) also provides a useful analysis of the Hungarian Revolution of 1956, and in so doing demonstrates how a *"shared culture, national sentiments, and historical tradition can be rapidly converted into a resource base for conflict, even in the face of an authoritarian regime."* (p.29)

In other words, Oberschall provides us with a clearer understanding of what kind of things can be utilized as 'resources' by a movement. Finally, Oberschall states that participation, leadership and ideology within a movement can all be analysed according to cost-benefits and resource allocation. His approach does, therefore, tend to stress the instrumental bases for the various actions, interactions and relationships that occur within social movements. In this respect, and the manner in which Oberschall makes use of such notions as risk/reward ratios, the influence of economics upon his theorizing, is clear. Indeed, Oberschall himself states that injecting some economics into theorizing upon social movements was his intention.

Overall, however, the most important aspect of Oberschall's development of *Resource Mobilization* theory is, as Melucci (1996) has commented, the idea that: *"In order for a protest movement to form, common sentiments of oppression or an identification of a common enemy will not suffice; there must also be a minimal organizational base and leadership."* (p.291) It is this notion of the necessity of pre-existing networks of social-ties that provides the starting point for the theorizing of Tilly.

Tilly

For Tilly (1993), social movements should not be theorized or spoken about as 'groups' "*thence assigning (them) a continuous life resembling the natural history of an organism.*" (p.4) Social movements can be distinguished from organizations proper, belief-systems and even individuals by the manner in which they *do not* possess self-reproducing 'natural histories' according to which they form, flourish, undergo change and eventually disappear. Instead, Tilly (1993) proposes that social movements are best viewed as resembling:

> *(...) dragons living continuously somewhere in the social underground, but emerging recurrently from their labyrinths to stomp around roaring.* (p.6)

In other words, social movements do not arise from the ether in some mysterious manner, instead they depend upon pre-existing groups and networks such as voluntary associations, fronts, federations and others. Echoing the *Resource Mobilization* model, Tilly sees these networks as resources that can be mobilized by key players in a movement. Although denying social movements a life cycle similar to that of an organism, Tilly (1993) does state that the actions of these key players or 'political entrepreneurs' brings coherency to strategic interaction. In particular, Tilly highlights the role of 'social movement specialists' in co-ordinating collective action, consistently publicizing the struggle engaged upon and influencing the routine behaviour of supporters, rivals and those observing the movement.

Tilly, although echoing much of the *Resource Mobilization* model in the manner in which it rejects social psychological explanations for social movements, does take from the Collective Behaviour model of social movements, a belief in the context specific nature of such movements. Further, echoes of the *Collective Behaviour* approach, in particular Blumer's notion of *esprit de corps* and *morale,* can especially be seen in the work of Tilly (1993, 1999) when he identifies the manner in which solidarity is reinforced within movements by such things as slogans, banners and other "*identifying devices*" (Tilly, 1993: 12). It is at this point, however, that the two models begin to diverge, for Tilly considers such techniques to be 'auxiliary activities', being of only secondary importance to his quite programmatic notion of mobilization. In addition, Tilly rejects two more elements of the *Collective Behaviour* approach, namely the idea of 'career paths' or what he terms the 'standard life histories' of social movements and the related concept of a social movement as an *organism* that appears to be implied by this approach.

Essentially, Tilly takes a programmatic approach to theorizing social movements. This programmatic approach is best exemplified in his notion that social movements function according to the following multiple:

Numbers x Commitment x Unity x Worthiness

(Tilly, 1999: 261)

For a social movement to succeed as a political force, it must be able to show evidence of each element. Providing that none of the four elements falls to zero, at which point the movement would lose its standing as a political force, a deficiency in one area can be compensated for in another. As an example of this 'scorecard' schema, Tilly cites terrorism and in particular ostentatious self-destruction as being a characteristic strategy of small sections of divided movements. In this example, the small section of the movement would be demonstrating high levels of *commitment* and *worthiness*, and thus compensating for a deficiency in *numbers*.

Further, according to Tilly, additional coherency is given to a movement when it interacts with outsiders, particularly those in powerful positions. A series of strategic interactions will become viewed as a coherent social movement when those in power and other third parties, react to this series of struggles by treating them as "*successive manifestations of the same phenomenon.*" (Tilly, 1993: 6) The relationship between the powerful and social movements is a complex one however, for whilst it is often the case that the powerful are the objects of claims made by social movements - and possess therefore, an inherent desire to undermine social movements - they may also at times become activists, at least to a degree, if it proves politically advantageous.

Thus, Tilly's perspective on social movements provides the starting point for Tarrow, for Tilly (1993) concludes that social movements will vary according to four main factors: the nature of the claims being made; the prevailing political opportunity structure; the shared understandings of the participants; and the social structure from which members are drawn (p.19). It is Tilly's second point regarding the effects that the nature of the polity can have upon the development of social movements that provided the basis for Tarrow's theorizing.

Tarrow

In general, Tarrow's aim was to understand which characteristics of the political system influence the growth of less institutionalised political actors, in the course of what he termed 'protest cycles' (Tarrow, 1989). Della Porta and Diani (1999) have commented that:

> *The 'political process' approach succeeded in shifting attention towards interactions between new and traditional actors, and between less conventional forms of action and institutionalized systems of interest representation. In this way, it is no longer possible to define movements in a prejudicial sense as phenomena which are, of necessity, marginal and anti-institutional, expressions of disfunctions of the system.* (p.10)

Tarrow views social movements as part of the 'normal' functioning of the political system and yet stresses the context specific nature of social movements. In both these respects, Tarrow also echoes the ideas of Blumer and the *Collective Behaviour* approach. For Tarrow, the most important context is the 'political opportunity structure' in which the movement exists.

The concept of the 'political opportunity structure' is central to Tarrow's theorizing on social movements. His central argument is that individuals join social movements in response to political opportunities that have arisen and then through the process of collective action, they go on to create further political opportunities. In conceiving of social movements as being firmly linked with the polity in this way, Tarrow (1994) is arguing that as far as the outcomes of the actions of social movements are concerned, although movements nearly always conceive of themselves as being external to the key institutions, nevertheless, collective action "*inserts them into complex policy networks, and, thus, within the reach of the state.*" (p.25)

Tarrow's second central concept is the notion of 'contention by convention'. According to Tarrow, the theory of collective action had become somewhat preoccupied with the problem of how individual actors become mobilized to achieve group goals. For Tarrow, this traditional focus is misplaced, for there is nothing particularly problematic about collective action *per se*. Instead, the problem needing analysis is the manner in which collective action is sustained:

> *Movements do have a collective action problem, but it is social: coordinating unorganized, autonomous and dispersed populations into common and sustained action.* (Tarrow, 1994: 9)

Social movements partly solve this problem by responding to political opportunities using established forms of collective action. In this respect, Tarrow (1994) draws upon the work of Tilly:

> *Tilly observes that people cannot employ routines of collective action of which they are ignorant; each society has a stock of familiar forms of action that are known by both potential challengers and their opponents – and which become habitual aspects of their interaction.* (p.19)

According to Tarrow, however, although social movements do draw upon these established forms of collective action, the question of how this action is co-ordinated and sustained remains. For Tarrow, *mobilizing structures* are necessary for activating and sustaining collective action. Existing institutions often represent these mobilizing structures. Tarrow cites the work of Aldon Morris (1993), in which Morris demonstrated that the origins of the Civil Rights Movement in America were bound up with the role of the Black Churches.

Tarrow also makes links with the work of Melucci, who highlights the role of movement networks in creating the collective identity of movements in Italy. Tarrow's work, therefore, represents an important link between the American and European traditions.

'New' Social Movements – the changing face of the European tradition

There are three major proponents of the *'New' Social Movement* theory, Touraine, Habermas, and Melucci. In many respects the theories of Touraine and Habermas are very similar, they remain, however, quite independently influential. Melucci's work draws heavily upon the work of both Touraine and Habermas, although he is more critical of Touraine. For the purpose of comparison, therefore, these theorists will be considered in the order, Touraine, Habermas, Melucci.

Touraine

For Touraine, social movements are the result of the general crisis of modernity. Two major problems face modernity, the first involves issues of social order and the second is concerned with issues of instrumental action. Touraine raises the question of how social order is possible within societies that are entirely defined by their capacity to *change*. Capitalism, for example, is characterised by its capacity to destroy old forms of production in order to make way for newer forms. For Touraine, the result of this process is a society that is characterised by anomie, uprootedness and a tendency to subordinate all aspects of individual and collective life to economic interest. According to Touraine, anything that cannot be expressed in monetary terms is destroyed by this process of modernity.

Touraine also states that the so-called triumph of instrumental action has failed to lead to a balance between individual interests. Touraine (1987a) states that "*in a highly mobilized or modern society, power and domination are everywhere...*" (p.208). Here the influences of Foucault's (1979) work on power are clear, for Touraine is clearly drawing upon Foucault's notion of the diffusion of systems of normalization and of cultural and social control. Thus, modernity has been characterised by the subordination of the individual to the impersonal laws of rationality, which has in turn, increased the power of the elites.

According to Touraine, this crisis of modernity has inspired two particular types of social movement. The first are the neo-communitarian movements, which seek to defend cultural identity. The second are the anti-modernist movements, which seek to resist mass production and to defend personal aesthetic or moral experience. The key point, however, according to Touraine, is that neither type of movement calls for the triumph of particularist over universalist values, or vice versa. Instead, the focus of the 'new' social movements is on the production or defence of the *subject*, be it the individual or collective:

> *We do not defend minorities' rights because they fulfil a specific function or try to increase the level of social integration; we defend directly the right of a given group to assert its own identity, while fifty years ago we would have been more universalistic, more integrationist, fighting against obstacles to the assimilation of minorities (...)* (Touraine, 1987a: 211)

Further, in his work entitled "An Introduction to the Study of Social Movements" (1985), Touraine makes it clear that for him, social movements are only one form of social conflict, but that they are defined precisely by their preoccupation with making claims for the recognition of the other as *subject*. In other words, for Touraine (1985), "*the concept 'social movements' only refer(s) to conflicts around the social control of the main cultural patterns.*" (p.760)

Having established what he regards these new forms of conflict to be *about*, Touraine, goes on to develop a somewhat complex schema for both defining 'new' social movements in a given situation, and to a certain extent, explaining *how* they function. For Touraine (1985), social movements are defined by the relationship between conflicting actors and the stakes of their conflict. Thus the action of social movements can be seen to involve three components: firstly, the identity of the actor (*i*), secondly, the definition of the opponent (*o*), and thirdly, the stakes or cultural totality which define the field of conflict (*t*) (Touraine,

1985. Prioetto, 1995). A social movement is thus defined as the relationship ***i-o-t*** and represents a quite complex vision of social action since it depends upon sustaining relations of creative tension between all of the three fundamental components (Proietto, 1995).

All three of these factors – ***i-o-t*** - are bound together in the same social world and express the central conflict of a particular type of society. It is in this respect, that Touraine's theorizing on social movements is most ambitious, for he places his theorizing on social conflict right at the heart of his general social theory. Using the concept of *historicity*, which is defined as the interweaving of a system of knowledge, a type of accumulation and a cultural model (Della Porta and Diani, 1999), Touraine identifies four types of society: agrarian, mercantile, industrial and 'programmed'. Touraine prefers the concept of a 'programmed' society to the term 'post-industrial society', but in many respects, the two terms mean the same thing. For Touraine (1987b), a 'programmed' society is characterised by the "*production of symbolic goods which model or transform our representation of human nature and the external world.*" (p.127) The basis for power in such a society therefore, becomes the control of information and these cultural resources. Echoing Habermas' notion of the colonisation of the lifeworld and the system, Touraine is therefore arguing that:

> *Mobilizations by social movements address, therefore, the defence of the autonomy of civil society from the attempts of public and private technocratic groups to extend their control over ever-widening areas of social life.* (Della Porta and Diani, 1999: 46.)

Thus, Touraine's theorizing has been concerned with social movements as both central to and the result of, transformations in modernity. His theories have been highly influential, but have not gone un-criticised. This is a point that will be considered later in this discussion.

Habermas: social movements at the seam between the 'lifeworld' and the 'system'

Definitions of 'new' social movements see these movements acting within a broadly defined socio-cultural sphere (Pakulski, 1997). 'New' social movements in comparison with older movements have been viewed as being concerned with redefining culture and lifestyle rather than structural reforms (Martell, 1994). In defining social movements thus, these theorists clearly echo the work of Habermas (1981) when he says that:

> (…) the new conflicts are not sparked by *problems of distribution,* but concern the *grammar of forms of life.* (p.33)

For Habermas there is a paradox at the centre of modernity and this paradox concerns the nature of the relationship between what he terms the 'lifeworld' and the 'system'. Habermas' conclusion to "The Theory of Communicative Action" (1987) is bleak, for he sees the 'lifeworld' as being threatened by the 'system'. Habermas (1987) feared that reasoning that is only appropriate to the "*formally organized domains of action*" (p.403) would take over those functions of social life that should belong to communicative action. This is what Habermas meant by the 'colonisation of the lifeworld' and it is this understanding that made him question the notion that Modernity has made society more just.

This is not to say, however, that Habermas has entirely given up on the notion of Modernity as a 'good thing'. In fact, Habermas sees the role of the 'new' social movements as being an essential mechanism for preventing and working against the encroachment of the 'lifeworld' by the 'system'. Whilst the 'colonization of the lifeworld' makes workers into *consumers* and citizens into *clients*, thereby minimising the opportunities for overcoming Modernity's injustices, the 'new' social movements seek to break and restructure these redefinitions. (Habermas, 1981. McAfee, 2000.) Further, Habermas (1981) sees the 'new' social movements as being motivated by the unease members experience as a result of the "*culturally impoverished and unilaterally rationalized praxis of everyday life.*" (p.36) Resistance, according to Habermas (1981), takes the form of placing a high value on the 'particular' and is intended to encourage the "*revitalization of buried possibilities for expression and communication.*" (p.36)

Habermas (1981) is therefore, painting a picture of the 'new' social movements as existing at the "*seam between system and lifeworld*" (p.36) His call, is for nothing less than the re-kindling of the promise of democracy and in so doing ensuring that the 'system' be made less autonomous and more accountable to the 'lifeworld'. In this respect, Habermas' work can be seen to provide an important precursor of theories of 'engagement', such as that proposed by Ellison (2000), which seek to forge a link between sociological understandings of social movements and sociological understandings of citizenship. According to Delanty (2000), it is precisely this view of social movements, as existing within the 'meso-level' of society, between the micro- and the macro- levels, that is key to understanding contemporary citizenship and democratic transformation. Roche (1995) echoes this when he says that:

> (...) *the new sociology of citizenship could be said to have much in common with the sociology of citizenship movements.* (p.188)

Roche's use of the term 'citizenship movements' is interesting because it suggests that the essential characteristic of contemporary social movements is that 'citizenship' is their project, it is what they are truly *about*. This link between citizenship and social movement theorising will be considered in more depth within chapter 7.

Clearly, therefore, Habermas has greatly influenced the development of social movement theories. It must be noted however, that whereas many 'new' social movement theorists continue to draw heavily upon Habermas' early work, in which the role of such movements is seen as being to prevent the colonisation of the lifeworld by the system, Habermas himself has moved on. In comparison to the ideas set out in his work "The Theory of Communicative Action", Habermas (1996) has more recently viewed the role of social movements rather differently. In this work he considers law to be central to radical politics and views social movements as embracing the state domain to a degree, whilst maintaining a firm link to civil society. In other words, Habermas considers it possible for social movements to exist at both the macro- and the meso- level. In some respects this is not too great a departure from his earlier theorizing, it merely demonstrates the difficulties associated with attempting to answer the questions of 'why', 'when' and 'how' of social movements.

Melucci

Melucci, whilst drawing considerably upon Touraine's work, also provides a clearly articulated critique of Touraine's notion of 'conflict' and 'identity'. For Melucci (1996), Touraine, failed to adequately distance his theorizing from earlier definitions that portrayed social conflict in an overly deterministic manner. The problem for Melucci (1996) is how to "*explain conflict in terms of social relations without turning it into a primal dimension.*" (p.45) Melucci also criticises Touraine for failing to adequately deconstruct the notion of identity. For Touraine, identity is taken as a given, whereas Melucci views identity rather differently. Melucci, although preferring the term 'potential for individualization' to 'identity', nevertheless views this as a process upon which action is entirely dependent. This critique of Touraine is central to the development of Melucci's own theorizing in his field, for he begins by reconsidering the basis of social conflict and then goes on to establish *how* collective action occurs.

Melucci (1985, 1989, 1994) begins his theorizing by drawing upon the work of Habermas and the notion of the colonisation of the lifeworld, claiming that the role of the 'new' social movements is to oppose the excessive intrusion of the state and the market into the realm of the individual and to protect each individual's identity from the manipulation and control of the system (Della Porta and Diani, 1999). In other words, for Melucci, the 'new' social movements are about reacting against the colonisation of the lifeworld by the system. Indeed, Melucci (1989) has commented that: "*among my criteria for defining a social movement is the extent to which its actions challenge or break the limits of a system of social relations.*" (p.38)

For Melucci, the idea of the 'colonisation of the lifeworld' is intrinsically linked to the notion of 'complex societies'. In this respect he echoes the work of Foucault (1970, 1979, 1980a, 1980b) in the way that he perceives complex societies as being characterised by a homologation of behaviour patterns, brought about by the manipulation of the information and cultural codes which form the basis of communication and consensus. For Melucci the present is characterised by society's capacity for intervening in the production of meaning. Areas that had previously escaped control and regulation are no longer free from interference by the system. Melucci (1989) suggests that these areas may include "*self-definition, emotional relationships, sexuality and 'biological' needs*" (p.45). At the same time, however, Melucci states that there is a parallel demand from the lifeworld for some control to be measured over the conditions of personal existence.

In firmly linking notions of the lifeworld and the system to theorizing on social movements, both Habermas and Melucci are placing considerations of social movements at the heart of social theorizing, for their theories strike at the very centre of the agency/structure debate. In the work of Melucci, this is most clearly demonstrated by his theorizing on the notion of 'identity'. Melucci suggests that the concept of 'identity' is increasingly redundant and that a consideration of the 'potential for individualization' is of greater value. He defines this 'potential for individualization' as involving on the one hand the possibilities for an individual to have control over the conditions of their action, and on the other hand the expropriation of these "*self-reflexive and self-productive resources by society itself.*" (Melucci, 1989: 48) For Melucci, social movements are *about* challenging the powers that seek to control these social resources.

In seeking to redress this balance between the lifeworld and the system, agency and structure, social movements, Melucci (1985) claims, are striking at the very heart of society's accepted 'truths':

> (...) *movements question society on something 'else': who decides on codes, who establishes rules of normality, what is the space for difference, how can one be recognized not for being included but for being accepted as different, not for increasing the amount of exchanges but for affirming another kind of exchange?* (p.810)

What is sometimes less clear within Melucci's work, however, is the extent to which he acknowledges that the redistribution of material resources may still be a *central* aim for many social movements. In a later work, Melucci (1989) does not appear to be completely rejecting the idea that social movements are still about addressing structural inequalities, but he makes it clear that he only sees this as *one aspect* of the aims of social movements, for they are about:

> (...) *more than the affirmation of new rights and the demand for equality. (...) also claims the importance of difference, the need for alternative codes which demand recognition. (...) urge that everyone can be recognised as different.* (p.56)

Having established what social movements are *about*, however, Melucci is more concerned with the 'how' of collective action. He claims that a form of 'political reductionism' has characterised the views of researchers in this field, he cites Tilly and Tarrow as examples. According to Melucci, both Tilly and Tarrow have engaged in quantitative studies of social movements and in so doing, have considered collective events as discrete units of analysis. This research, according to Melucci, has produced some useful data concerning the *product* of diverse relationships and the goals of action. This, however, is a constructivist view of social movements, focusing as it does upon the outcomes of collective action, rather than upon *how* that action is produced. For Melucci (1989), this emphasis upon the effects of action can become unhelpful if it ignores the "*creation of cultural models and symbolic challenges inherent in the 'new movements'.*" (p.45)

In seeking to explain the 'how' of collective action, Melucci considers social movements to be positioned outside the established boundaries of political systems, in what he terms 'social spaces' (1989, 1993, 1996). These social spaces exist as a result of forms of behaviour that do not 'fit in' with the system, for example, conflict, deviance and 'cultural experimentation' (Melucci, 1989). According to Melucci (1993), on the one hand these social spaces prevent social movements from becoming institutionalised and on the other, they ensure that society is able to institutionally process the issues and conflicts arising from the goals and meanings of the social action undertaken by social movements.

Although focusing upon the 'how' of social movements, nevertheless in viewing the area in which social movements operate as a new, and valuable "*'sector' or 'subsystem' of the social*", Melucci (1996: 3) stresses the important role of social movements in preventing the system from closing in upon itself. In this way, Melucci (1985) is stressing the transformative nature of 'new' social movements, for they force the ruling groups to innovate and to include in the decision-making process, groups which have previously been excluded. Melucci (1993) also makes a valuable link with notions of power, when he states that social movements: "*expose the shadowy zones of invisible power and silence which a system and its dominant interests inevitably tend to create.*" (p.190) This is an idea that has been developed by Foweraker (1995) who also makes an important link to citizenship theorising in that he envisages social movement activity as being *about* citizenship, which in turn is *about* challenging these systems of power in defence of group rights. The issue of the connection between citizenship theorising and social movement theorising will be considered in more depth within chapter 7.

Conclusion – the future for social movement theorizing?

From this discussion, it seems clear that whilst there are many differences between the various approaches, there are also continuities. Two major questions, however, remain and these, it seems to me, represent the fundamental issues yet to be resolved within social movement theorizing. Firstly, it would seem that it is now time to re-look at the social movements of the 1960's and ask again, what was so fundamentally different about these movements from those that came before? One of the most apparent 'differences' between many of the social movements that existed pre-1960's and those that came after the '1960's watershed' is the fact that from the 1960's onwards social movement activity has been seen to be more 'successful'. For example, early movements such as the Chartists and the Jarrow Hunger marches were largely unsuccessful. There is a sense, however, in which such movements as the Greenham Common protests and the Black Power movement, for example, have really 'changed the world'. The important question, therefore, is whether social movements themselves have changed or whether the protest environment in which they take place has altered, thereby affecting the ability of protest to bring about change?

From the literature it is clear that theories that emphasise the 'newness' of the 'new' social movements rest upon notions of the crisis of modernity and the dawn of post-modernity. These are contested concepts, however, and need to be used as the basis for theorizing only with extreme care. Without a doubt during the past forty years society has undergone radical transformation, but there appears to be little consensus surrounding the key aspects of this change. Whilst Melucci (1996) is clearly one of the theorists responsible for introducing the concept of the *'new' social movements* into sociological debate, he is, however, concerned about the arid debate that he considers has ensued between supporters and critics of 'newness'. For this reason he is anxious that in debating the validity of the term 'new' social movement, theorists in this field do not lose track of the fact that contemporary social movements are signalling that radical transformations *are* occurring to the reality in which we live. The first challenge then, for theorists in this field, is to rise above this sterile debate about 'old' and 'new' social movements and to consider them afresh in the context in which they now exist.

One way forward may be to forge stronger links between citizenship and social movement theorising. It is the argument in this thesis that this may prove to be effective because understanding the way in which citizenship has changed over time is key to understanding the social and political environment in which social movements act. Understanding the nature of contested citizenship is also likely to be key to understanding social movements. For example, if, as writers such as Stevenson (1997a/b) suggest, 'cultural citizenship' is the basis of social movement activity, then the second phase European theories of social movements, with their focus upon such things as values, culture and identity, may well provide the key to understanding conflict today. Touraine (1985) is clear that citizenship as 'identity' has become central to social movements but is equally certain that without the full recognition of the other as subject, calls for the acceptance of difference, specificity and identity can lead to ghettoisation and intolerance. Further, he fears that whilst this now 'anxious' search for identity may result in new definitions of social 'norms', there is also a risk of an individualism that excludes successful collective action.

If, however, there is evidence to suggest that more structural inequalities may also be a central part of this process of engagement, then it may be necessary to return to some of the older explanations for social movements. The possibility that this may be the case raises a further challenge for any future theorizing on social movements, for if we can no longer completely disregard the earlier, 'First Phase Theories' as explanations for *why* social movements exist and what they are *about,* perhaps we need not see these two phases of theorizing as incommensurable in other respects. Cohen (1985) offers a starting point for tackling this challenge when she writes that:

> *Of course, one cannot evade the fact that the striking feature of the contemporary (...) situation of movements is heterogeneity. The old patterns of collective action certainly continue to exist. In some movements, they may even be statistically preponderant. It would thus be futile to speak of the new identity of the movements. Since all movements are complex phenomena, however, heterogeneity itself cannot be the unique aspect of contemporary contestations. Instead, it is the thesis here that some identities, implying specific forms of organization and struggle within the contemporary movements, are new in the sense just indicated, and that there are good reasons to consider these to be of major significance.* (p.665)

She proposes a more critical consideration of the relationship between collective action and identity as the basis for future theorizing on social movements. Thus, in her model, social movements are viewed as having a fragile composition, often being fragmented and composed of individuals with diverse opinions and interests. This model may well provide a starting point when considering contemporary social movements, for it acknowledges diversity of *aim* and *action* within one movement.

The idea that social movements may possess diversity of aim and action according to the social and political environment in which they exist is an idea that forms the basis of Ellison's (2000) work on 'defensive and pro-active engagement'. In many respects, his ideas echo Cohen's but he has advanced further in theorising the link between these processes of engagement and citizenship theorising. His work is therefore, of central importance to the argument within this thesis and will be considered in more depth within chapter 7.

Chapter 6

Findings[1]

The specific purpose of the first section of this chapter is to consider the key findings of this research. To this end, the qualitative data[2] presented has been grouped according to four main categories or themes. These themes are as follows:

- Structural Issues
- Disabling attitudes-enabling identities
- Disability Culture
- The Disability Movement

Structural Issues

In relation to this research, 'structural issues' are those that relate to the *access to*, and the *nature and experience of* certain key resources, such as education, employment and the built environment. In relation to this research, a distinction is drawn between these issues and more subjectively defined issues of public attitudes towards disabled people (in the form of disablism) or the private identities of individual disabled people, although the manner in which the two

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[1] Since respondents in this research are being kept anonymous, quotations in this chapter have been coded as 'members of a particular group'. In excerpts in which more than one member is speaking the quotations have been coded according to the order in which the respondents speak – i.e. member 1 for the first speaker and so on. There is no connection between the coding of each excerpt, so the code 'member 1 of DaCE' for example may refer to more than one individual according to the particular excerpt. This is part of a system of coding which aims to avoid accidentally identifying certain individuals. In the case of the Deafmail respondents, the coding 'respondents 1/2/3' does refer to the same individuals throughout this section. This was considered to be justifiable since the membership of Deafmail is extensive and the respondents replied privately to my questions, therefore making it unlikely that other users of Deafmail will easily identify them.

[2] **Key to organisations as follows:**
SUFA = Speaking Up For Action
SFPD = Sheffield Forum of People with Disabilities
Lancaster DISC = Lancaster Disablement Information and Support Centre
DaCE = Disability Association Carlisle and Eden
DASL = Disability Action South Lakeland
Arthritis Support = Arthritis Care Support Group, Carlisle

can inter-relate is important. The initial point to make here is that respondents clearly identified a number of structural issues that were affecting their quality of life and life chances. Further, in many cases when asked a variation upon the question: “What, if any, barriers or problems are disabled people facing today?”, there was a marked tendency on the part of respondents to identify structural issues only, or else before any other issues.

Respondents highlighted the key problems facing disabled people as being the perpetuation of dependency and their exclusion from the ‘ideals of citizenship’. They stressed the role of the state and/or society in relation to this problem:

Member of Lancaster DISC: *"(...) I think that there is a kind of hypocrisy, that is, that the state is working towards making disabled people more dependent. As the state cuts back on provision, disabled people can become more dependent on others - which I don't think is the way it should be because it really burdens others. We are getting back to 'cap in hand'."*

Member of DACE: *It's also about the circumstances being created which allow you to be a good citizen.*

Angharad: *So you have to be enabled to be a good citizen in some way?*

Member of DACE: *Participation is a big element of it - isn't it? If you can't actually participate fully in society, how can you even be a good citizen really?*

Respondents frequently highlighted issues relating to experiences of schooling and in the workplace and of the types of barriers faced by disabled people in these two spheres. Respondents who chose to comment upon segregated special needs education were unequivocally critical of this type of education provision for disabled children. The following comments clearly echo the critique of segregated education provided by many authors within Disability Studies and provide strong support for the view that this type of educational provision can greatly limit the educational achievement of disabled children:

Member of Lancaster DISC (re. special needs education): *I don't know whether they think that it is best to encourage you to aim low, so that you don't then get disappointed (...)*

Member of DACE: *Well, my first school was (...) a private school and I learnt more there up to the age of 11. Then I went to a special school and I'd found that children there were just being (...) they didn't know anything! They weren't being taught anything (...) the staff just thought well, you know, they've got disabilities, they can't do this, they can't do that, we'll just get them through a day - and that was it. I just hated it. I know that there are still places like that.*

The logical assumption that might be drawn from these types of comments might, therefore, be that disabled people favour inclusive, mainstream education. In this research, however, the issue of mainstream education was not discussed in sufficient depth to draw any clear conclusions. The following excerpt from one group interview nevertheless suggests that whilst in favour of mainstreaming, some disabled people are gravely concerned about the way in which lack of sufficient resources may be disadvantaging disabled children in mainstream schooling:

Angharad: *How would you set about building a more inclusive society? How does one do it?*

Member of Lancaster DISC: *I think you start in school, in (...) all the schools - inclusive education.*

Angharad: *Rather than segregated?*

Member of Lancaster DISC: *Yes.*

Worker at Lancaster DISC: *Only if they give enough money. Without the money actually people suffer....*

Member of Lancaster DISC: *(*agrees with worker*) in the long run.*

What can be concluded from the findings of this research is that disabled people clearly believe that major structural barriers still exist within the sphere of education, even where advances such as 'mainstreaming' have been taking place. Some respondents also made important connections between what they considered to be these major barriers within education and subsequent barriers within the field of employment.

> **Member of DACE:** *(...) disabled people are still not encouraged to apply for jobs and to try and move into employment. (...) I mean, we have an education system discouraging people in their future development.*

What is clear from this last quotation is that the disabled people in this research supported the idea that the attitudes of those involved in the education of disabled people have tended to restrict the job prospects of young people. This is particular quotation goes one step further than this, however, for the respondent here is equally definite in their belief that the education system has been *actively discouraging* the future development of disabled people.

Other important comments on the issue of employment came from respondents who are members of Speaking Up For Action (SUFA), a self-advocacy group for people with learning disabilities. In the first quotation one member expressed his feelings about his experience of trying to gain access to employment:

> **Member of SUFA:** *It's like when you go for jobs isn't it (...)? You just tell 'em you've got summat wrong with you - then they don't want to know at the end of the day...they treat you like scum in jobs.*

In the second quotation, another member of SUFA who had gained employment within a sheltered workshop highlights the vulnerability of many disabled people once they are within the field of employment:

> **Member of SUFA:** *I'm fed up with it.* (sheltered workshop) *(...) Staff treat people like kids. There are two staff always picking on me - "Comb you hair!". It happens a lot* (there). *I don't like it. They're picking on me.* (Distress)

What these two comments demonstrate is that according to the participants in this research major structural barriers still exist to the full employment of disabled people and to their fair treatment by employers. That these problems persist despite changes to legislation to try to enforce equality of opportunity is something that frustrates many disabled people as is clear from the following quotation:

Member of DACE: *(...) almost everything at the moment I would say had some sort of barrier-creating effect (...) I mean, why something for instance as* (changes to) *employment practices, why that hasn't had a significant effect in terms of increasing the employment of disabled people is quite hard to understand.*

In addition to issues relating to education and employment the respondents in this research also highlighted other areas where they perceived major structural barriers. Many respondents commented upon the need for improvements to services in order to maintain their own independence, members of SUFA stated that seeking to improve service provision was one of the key functions of their organisation:

Member of SUFA: *I think SUFA wants to make services better for people with learning difficulties - Social Services, Health Services, the Police Services, all of them need up-grading really.*

Other members of SUFA expressed their desire to have more choices in relation services which impacted upon them and to be more involved in decision making about their own lives. Having a voice in consultation processes with service providers was an issue that other respondents raised throughout the research. Clearly there was a feeling that in the past too many decisions had been taken about the lives of disabled people with no reference to the views of this 'client' group:

Angharad: *What other factors or ways can improvement be made in the lives of disabled people?*

Member of DACE: *In the ways services are provided - giving people greater opportunity (...) to exert their own independence, to have greater control over how services are provided, greater choice in the type of services that are available to them...creating a situation where disabled people themselves are making decisions or influencing development, so that what is available relates a bit more clearly to their actual...not just their*

needs, but their wants, their desires, their feeling about that. (...) I suppose to a certain extent, there's a certain idealism in that, but it's something we should work towards (...)
Angharad: *(...) What would you say were the barriers? (...)*

Member of DACE: *(...) Oh the obvious one is that disabled people aren't a priority in terms of (...) elements of consultation - being involved. If you don't have enough disabled people working for an organisation, and you're not consulting with disabled people, how can that organisation, therefore, be in touch with what disabled people feel or what they need?*

That this lack of consultation can be explained at least in part by the Medical Model of Disability and the traditional power of professionals over the lives of disabled people, was clearly identified by two respondents:

Member of Lancaster DISC: *(...) professionals - there are a lot of people making a lot of money out of knowing what's best for people like us. (...) I mean, it is **you*** (to another group member) *who is a stroke victim, and **I** am a **cerebral palsy sufferer**. (...) **They** haven't got it.*

Excerpt from a discussion at SUFA - the questions at this point of the discussion are being asked by SUFA's support worker:
Worker: *Do you think that in (...) those organisations and groups that are for people with learning disabilities (...) people with learning disabilities don't get their say?*
Member: *Yes, Mencap does that.*
Worker: *They don't let people have their say? Are there any other groups like that where people can't have their say?*
Member: *Yeah - in Social Services you can't...*
Worker: *I'm thinking about something that you said earlier* (name) *about the Down's Syndrome Association?*
Member: *They were talking **about** people with Down' Syndrome...*
Worker: *Who should have been doing the talking?*
Member: *They don't know about it really.*
Worker: *Who should be doing the talking more?*
Member: ***Us! Give us a chance!***

What is clear from both of these excerpts is that the power of professionals over the lives of disabled people persists both in the state and the voluntary sectors and regaining power over their lives is something that many of the respondents identified as being of great importance to them. Further, some respondents also highlighted the problem of tokenism within existing consultation processes:

Worker at Lancaster DISC: *They'd much rather you didn't actually say anything! They want you to be there, but not to be awkward!*

Member of Lancaster DISC: *It's a rubber-stamping thing isn't it?*

In addition to these issues of professional power and lack of consultation, disabled people in this research also routinely highlighted the barriers that they faced in relation to transport and the built environment. What became clear from the discussions was that most respondents considered the inaccessible environment to be if not the only barrier, certainly one of the *key barriers* facing disabled people today. Indeed, when asked about key issues facing disabled people, the inaccessible environment was by far the most frequently mentioned problem. The following quotations demonstrate the views of some respondents on this issue:

Member 1 SFPD: *(...) independent living shows how the public environment could be made accessible, also mainstream services for disabled people such as supermarkets allowing their staff to assist disabled people with their shopping. I believe this is what the disability movement is about, and I do feel part of that.*

Member 2 SFPD: *There is still great scope for improvements in the lives of disabled people. Transport is one area where this is evident. The provision of community transport can enable a disabled person to travel a realistic number of times a week at an affordable price, but true equality, civil rights and the disability movement demands that disabled people should be able to catch a bus at any time.*

Member Lancaster DISC: *Everyone thought it was awful that in South Africa when black people weren't allowed to use the buses for white people. But because someone cannot walk and cannot physically get on a bus, that's acceptable. I don't look at it in that way.*

Member 1 DACE: *But people cash in on disability as well - (...) we went to Blackpool the other weekend and we found a hotel that has wheelchair* *access, but we paid double for it because it had a lift and it had wheelchair access. Everywhere else we 'phoned, yes, they had steps, stairs, couldn't get up to the first floor and yet this Hotel had everything and (...) because of it they know people would have to got there, so they put the price up.*

Member 2 DACE: *You felt that you were exploited?*

Member 1 DACE: *Yes. I think people are exploited.*

Member DACE: *It isn't just about the physical environment, it's about people getting around as well. How many buses in Cumbria are actually accessible for disabled people? I think there's two in Carlisle, or something.*

Another comment which was not made directly in relation to this topic of the inaccessible environment, but is nevertheless very revealing was made by a respondent in answer to the question: "What do you personally gain from being a part of this organisation?". In this quotation, the respondent is highlighting the fact that her experience of arthritis has made performing many tasks within the home difficult. For this respondent, one of the key benefits of the organisation of which she is a member is the sharing of knowledge between members about how to overcome these problems:

Member of Arthritis Support: *(...) if you can't do something in the house, people will tell you how they got round it.*

Clearly this is an issue that relates to the inaccessible environment since many of the difficulties mentioned in the wider discussion from which this comment was taken relate to the design of homes, equipment, consumer good such as jars of food and so on. Interestingly, this particular group took a somewhat less 'political' stance towards the problem of the inaccessible environment, seeing it as a problem to be faced and for which solutions must be found, rather than as something that they considered to be inherently unjust.

In addition to this interesting difference between groups, two other important differences must also be highlighted within this section on structural barriers. The first relates to key differences in experiences between physically disabled people and people with learning disabilities with regard to opportunities for independent living. For many disabled respondents with physical impairments, independent living was an 'ideal' which could be achieved given the appropriate support. The main issues, for these respondents was the funding shortfall in this area and the lack of availability of carers, these two issues being closely linked as is shown in the following excerpt:

> **Member of DASL:** *Independent living is a limited thing too - they've changed the rules for that now.*
>
> **Angharad:** *Really?*
>
> **Member of DASL:** *Yes - because they've actually run out of the funding available. (...) It's also very difficult to recruit carers because unemployment is quite low and those are the sorts of jobs that people go into when unemployment is high because...*
>
> **Angharad:** *It's not the best paid job?*
>
> **Member of DASL:** *No - and it's not the nicest job in the world either...and the employment services are forcing people to do the job, so they're doing it not because they want to but because they have to. (...) whereas, if you made it lucrative enough you'd be able to recruit your own personal assistant or carers for example. But the Independent Living, I think it was the pre-1993 rules, it was almost, the ceiling was almost limitless, whereas now they've capped it to a certain amount each week.*

The view of this respondent is quite clear - shortfalls in funding are the major barrier to independent living.

This was not the case for many of the respondents who had learning disabilities. The desire to 'have my own flat' was something that many of the respondents at SUFA mentioned as a 'hope or dream' but there was little sense that this goal was achievable for most members of this group. Discussions at SUFA also highlighted the fact that whilst attempts have been made to support 'quasi'-independent living for people with learning disabilities within small group homes, these living arrangements fall short of the 'ideal' of independent living. In the following excerpt from a discussion at SUFA one of the members of this group describes his experiences of living in a group home and the stress that this way of life causes him:

Excerpt from a discussion at SUFA:

Member: *I like being treated with respect*

Angharad: *Are you not treated with respect?*

Member: *Yeah - I do, but sometimes I'm always getting blamed in that house sometimes. (...) I try to keep out of trouble...*

Worker: *I think that's something about living together - with a group of people. Sometimes you're bound to fall out (...)*
(...)

Member: *She's* (member of shared household) *always like that, she takes it out on other people as well (...)*

Worker: *Who sorts it out then when it happens?*

Member: *We have to sort it out. So I say to her - now come on* (name), *you can stop this you know.*

Worker: *And do you sort it out in the end?*

Member: *Every time I say something she gets a face on. (...) And she storms out of the kitchen, bangs on the door on the wall - made a right mark on it and went upstairs.*

The second issue relates to differences within groups between the views of members with regard to the importance of structural barriers in their lives. In the following excerpt from a discussion held at Lancaster DISC, what became clear is that there are some important differences of opinion regarding what is the central function of the organisation. Whilst the excerpt may not be the most 'profound', it is the only example of a discussion between members of a focus group on the topic of 'social exclusion'. One member of the group clearly states that the aim of the organisation should be to combat social exclusion and to help to build a more inclusive society. The responses of the other members of the organisation to this comment are most interesting:

Angharad: *Okay - so the central hopes and aim of the organisation - what might they be would you say?*

Member 1 Lancaster DISC: *To help build a more inclusive society.*
(...)

Angharad: *Right...to build a more inclusive society you think that's a central part?*

Member 2 Lancaster DISC: *I'm not sure whether that is actually in the constitution. I think maybe it's lurking somewhere in that scatterbrain of yours* (to member 1).

Angharad: *Would you say that it should be in* (the constitution)? *(...)*

Member 2 Lancaster DISC: *Yes.*

Member 3 Lancaster DISC: *But that is the ultimate aim, but slightly smaller than that - I mean, our aim is to given disabled people as much information, confidence, advice to live as independently as they want to live.*

The first comment by member 2 about the 'scatterbrain' of member 1 was clearly this individual's *spontaneous* reaction to the idea that the chief aim of the organisation is to build a more inclusive society. It was apparent at this point in the discussion that member 2 did not consider social inclusion to be a central aim of the organisation, although when asked whether it should be a part of the formal constitution of the organisation, member 2 agreed that it should. To what extent this second statement of agreement reflected a genuine feeling is unclear, it is possible that member 2 felt in some way obliged to agree given the current 'political' importance of the term 'social inclusion'. Most revealing however, is the comment made by member 3, which goes some way to explaining why it might be that the organisation as a whole has not embraced the idea of 'social inclusion'. Member 3 clearly indicates that 'social exclusion' is a part of a much bigger agenda, somehow 'beyond' the smaller, and more 'everyday' aims of the organisation. These everyday aims member 3 identifies as 'information, confidence and advice' about independent living. Combining this comment with knowledge about the functioning of this organisation it is clear that member 3 is talking about advice regarding how to overcome structural barriers such as income inequalities, housing difficulties, employment issues and access issues.

It seems to me that it can be logically inferred from this final comment, that for this member of the organisation, 'social inclusion' is about more than combating these types of structural barriers. Indeed, I would suggest that the use of the term 'ultimate' suggests that 'social inclusion' is viewed by this member at least as an almost *utopian* goal and one that does not reflect the everyday operations of the organisation. The main conclusion that may be drawn from this excerpt, seems to be that not all disabled people feel able to engage in the sort of truly emancipatory politics that is suggested by member 1's comments about an 'inclusive society'. It would seem therefore, that whilst not denying that there are wider issues of participation, identity and acceptance, some disabled people are still choosing to focus their efforts upon helping disabled people to remove or bypass certain key structural barriers in society.

This final point is reinforced by the comments of another respondent from a different group who admitted that fighting against the numerous structural barriers that remain, took up so much of the organisation's time, they were unable to engage in wider emancipatory action:

Member DASL: *(...) about being a bit more proactive and probably a bit more militant and probably raising awareness - we're so bogged down in doing what we're already doing that we find we haven't got time to do anything else.*

To conclude this section of structural issues, therefore, what the evidence from this research suggests is that for many disabled people these structural issues represent some of the major, if not ***the major*** disabling factors in society:

Member SFPD: *The environment and services - these are the two things that disable me most.*

Disabling attitudes – Empowering Identities?

Whilst, as discussed previously, the majority of respondents identified structural barriers as being at the heart of their experience of disability, discussions relating to disabling attitudes, language and identity also formed a major part of most discussions. Indeed, many respondents demonstrated that they had very strongly held views on these matters.

Several respondents described what they considered to be disabling attitudes and behaviours within society. The attitudes they described were those held by non-disabled people and ranged from unconscious acts that disempower disabled people through their unintended consequences, through widely held but influential misconceptions about certain impairments, to openly prejudiced attitudes and actions. The following excerpts point to the key power imbalances that exist between all non-disabled and disabled people. What is clear from these quotations is that such power imbalances can occur even in seemingly caring or close relationships such as between friends, and persist in the field of medicine where despite years of awareness raising, medical professionals continue to focus too heavily upon impairment and in so doing exacerbate the problem of disability.

Member of Arthritis Care: *Well, I was out and I was struggling, and I never told her, my best friend at work - it was my own fault because I ordered pizza and I couldn't cut it! And she took my plate off me - and I was mortified! Really, really mortified! - and I was: "Oh please don't do this!" - and she was doing it and I was holding on to the plate. And she really thought she was being helpful.*

Member Arthritis Care: *(...) I think it was about September that my daughter came and said "we'll go to shop mobility in Carlisle!" - so I tried a chair and I felt awful! I really did! Because (...) people were talking to* (name of husband) *as if I was invisible, and I was someone, you know, who was just there.*

Member Lancaster DISC: *You get so that you can't talk as a friend to a doctor, they're just interested in you as a medical condition.*

Respondents also highlighted the problem of negative assumptions that many non-disabled people make about disabled people. At one end of the scale respondents highlighted the very disempowering effects that such assumptions can have:

Member of Lancaster DISC: *Even now it happens that people come in assume that because there's an able-bodied in the office and assume that they're in charge.*

Member of SFPD: *I was sitting next to a women, she got on the bus at the Sheaf Market and she said "Oh you're blind aren't you! My daughter's blind, and she's just had a baby! Isn't it <u>wonderful</u> what they can do!"*
(...)
I was on a train once, going to Swansea from Paddington and there was an old lady, and do you know I still can't believe this story, but it happened - and I knew she wanted to talk to me, and we'd gone through Reading and Bristol and we were nearly in Cardiff and then she said - "Young man, would you like a chocolate biscuit?" So I was doing my social bit and I said "Oh Thank you!" and she placed this silver wrapped biscuit in my hand and there was silence whilst I unwrapped it and just as I was about to eat it, she said: "No, stop!" and I said "Why, what's the matter?" and she said: "I didn't mean you to eat the biscuit, I just wanted to know if you knew where your mouth was!". I couldn't come back from that one, I just sat there chewing the biscuit. (...) I think she must have been in her eighties. It happens all the time and the reason for it is, we're basically excluded. I mean, I think she grew up in a school for nice 'gals' somewhere and probably they had a few Black girls - but only the very rich ones and I think she'd never met a disabled person and I don't think she regarded me as being a human being, I think she regarded me as an organism that she could experiment with (...)

Whilst such assumptions of incompetence clearly need to be challenged very seriously, at the other end of the scale respondents at SUFA highlighted the even more disturbing beliefs that some people hold about disabled people, in this case people with a learning disability, that they are dangerous and 'deviant':

Member of SUFA: *I'm not bad, but some people think I am. I don't think much of them!*

Member of SUFA: *(...) more able-bodied people are frightened of us.*

Worker at SUFA: *(...) what other words have people used to describe people with learning disabilities?*

Member 1 SUFA: *'Funny Farm'*

Worker at SUFA: *Funny Farm?*

Angharad: *From the Funny Farm?*

Member 1 SUFA: *Yeah - 'cos that's what they said about us at College, 'cos we used to work at* (name) *farm - and they used to say "Oh, here they are from the Funny Farm."*

Member 2 SUFA: *People call us mental as well.*

Angharad: *Mental?*

Member 3 SUFA: *Nutter!*

According to another respondent, such attitudes are both demonstrated and perpetuated by the media. In this excerpt the respondent highlights the way in which disability is portrayed by the media in terms of crisis and incompetence:

Member of DACE: *But it's the same with I mean, there are other things like on TV. Disabled people only really appear on specific disability related programmes and that becomes a bit of an extreme because they focus, I mean they do, they focus on the more extreme issues related to disability. It's not like disabled people are present in all programmes. But I suppose this is something Black people would have said a lot more a few years ago and things started to change - but they're still saying it aren't they? And it's definitely not happening with disabled people! I mean it's usually 'issue' things that come up - if it's in the media it's like, you know...*
(...) it'll be like, a women being pregnant and then she becomes blind and "Ah! How will she cope with that?". You know! And then it becomes a crisis and disability tends to be related to crises in the media and not about people like us just living their lives really.

The role of the media and the importance of preconceived ideas about the nature of disability was also considered by several other respondents during discussions about the transition from a non-disabled to a disabled identity[3]. The following excerpts demonstrate the power of disablist attitudes, and as will be discussed at greater length later, also show how understanding the extent to which most non-disabled people hold these views can help explain subsequent differences between the attitudes of those individuals with acquired as opposed to congenital impairments:

Member of SFPD: *I used to work as a physio. in a rheumatism clinic and I think that my patients found (...) because they'd been able-bodied and probably their Mum or their Granny or their Dad had had arthritis before them, and when they were able-bodied they were really scornful (...) then when it goes around and comes to them, they've still got those attitudes but now they're looking at themselves like that.*

Angharad: *(...) is it important to re-identify (...) disabled people (...) in a more positive light - do you see that as something important?*

DASL Member: *Yes. You see prior to my accident, I was as guilty as anybody of all the stereotypical images of what disabled people are. It wasn't because I really felt like that, it was because every time you see someone on the telly, in a wheelchair, they were always stupid or something like that - you never saw them in a positive way.*
(...)
You know the Tom Cruise film - the Vietnam one, when he's in the wheelchair. Again it's always about him becoming disabled, but never actually integrating or being a part. And I was as guilty as anybody else. (...) I was ignorant, like the majority of people are, of the whole disability issue - totally ignorant of what it meant, of who the people were. It's like I said, I always thought that anybody in a wheelchair, they were brain-damaged or something like that (...) and that was the perception I had at the time. It was only when I became disabled myself that my whole attitude changed.
(...)

Respondents also talked extensively about what being disabled meant to them in terms of their identities. On the whole, the majority of respondents did not

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[3] Please see footnote 3, chapter 2 for definitions of the two terms 'disabled identity' and 'disability identity'.

perceive their disabled identity as something that was positive, or something that they felt proud about. Most of the respondents felt that their disabled identity had been imposed upon them. Of those who did not seen their disabled identity as a negative thing, nevertheless, they did not see it as something positive, simply as a 'fact' to be lived with. The following comments exemplify the large number of comments made on this topic throughout the research:

Member of Arthritis Care: *I think other people have to put the label on you* (disabled) *- I don't think that I could say myself that I'm disabled. (...) I feel that it's not my decision.*

Member of Arthritis Care: *I think you come to accept it because you have to use it when you are claiming for this, that and the other. You accept that you've got that label.*

Member of SFPD: *We are all individuals with our own identity who have in common that we are depersonalised by barriers including attitudes.*

Member of SFPD: *(...) having part of your person not working is essentially negative. It is possible to be proud of achievements as a disabled person. To be proud to be disabled was not a concept that found support here.*

Angharad: *Is there such a thing as a 'disability identity' and if there is, what is the image that exists - what is it like to experience it? You said that "I'm a disable person!" with some...well, was it pride?...*

Member of Lancaster DISC: *It was just a statement. But I think that on a practical basis, I might have needs - because of my disability - but that's a fact, not...it shouldn't be a problem. If I go into a pub and a buy a lemonade, and I want to sit at a table because I'm disabled, then I need to get someone else to carry the lemonade - it's a fact - but it shouldn't be a problem.*

Angharad: *When you became disabled, did you feel that you had gained a new identity?*

DASL Member: *Definitely yes, without a doubt, yes.*

Angharad: *Was it a positive identity or...?*

DASL Member: *From a personal point of view - no, it's not. There are some positive things about it - but from a personal view point I would say probably* *less than 5% - I can think of 95% more reasons of not being disabled than being disabled. (...)*

Curiously, in addition to these comments, which must bring into some doubt the idea of a positive 'disability identity' and the notion of 'celebrating' disability, some respondents expressed their reluctance to accept the 'label' of disability at all. Considering that each of the respondents were key members of a disability organisation their position in relation to this issue of identity is obviously complex:

Member of DASL: *I don't always see myself as disabled (...) The only time I see myself as disabled is when someone else is having to do things for me that I can't do for myself - or I'm in bed and I obviously can't get up. And I do feel vulnerable. And I do - I am aware that I become, more passive because you are so vulnerable.*

Member 1 of Dace: *I get as much help as I can but I don't call that being disabled, sorry.*

Member 2 DaCE: *Well I'm just thinking, I feel pretty normal you see. (...) I don't think of myself as disabled - I am, but I don't think like that.*
(...)

Member 1 DaCE: *I used to hate being called blind!*

Angharad: *Did you? What did you prefer?*

Member 1 DaCE: *I don't know - I probably didn't want to be called anything.*

Angharad: *Right - which goes back to what you* (to Member 2) *were saying - (...) that you don't want to particularly be, or feel the need to be identified as a disabled person?*

Member 2 DaCE: *I know other people think I am, but I personally just think just "I'm one of you". I just have a mobility problem (...) I'm me you see!*

Member 3 DaCE: *It's having a label isn't it? People seem to think that we should be labelled.*

Member of SUFA: *We just don't want to be labelled like jars!*

The important point here is that in the case of each of these respondents, the impairment that forms the 'visible' sign of their disability was clear. It is often assumed that there is a greater tendency on the part of individuals with so-called 'hidden' disabilities to seek to avoid being labelled as disabled. The findings of this research show that this is not the case and individuals with what might be considered by many non-disabled people to be 'profound impairments' also wish to avoid being termed 'disabled'.

Another assumption that does not necessarily need to be completely rejected but which does need to be considered more carefully, is the idea that there are fundamental differences in terms of identity between people with congenital as opposed to acquired disabilities. Broadly speaking, the findings of this research do support the idea that individuals with acquired disabilities have particularly negative views about their disabled identity and find the transition to such an identity very traumatic:

Member 1 of Arthritis Care: *I mean, the moment I was diagnosed, I burst into tears and said to the doctor, "Oh no! I'm going to have funny hands!" and I mean I was in agony! I couldn't turn my wrists over I was in such pain, but all I could think about was that I was going to have these funny hands!*

Member 2 Arthritis Care: *I thought the same about being in a wheelchair - I though: "Oh my god! I'm going to be in a wheelchair!"*

These comments clearly demonstrate, as discussed earlier, the ways in which negative attitudes towards disability possessed prior to disablement, can greatly effect the experience of transition from a non-disabled to a disabled identity. Other respondents commented upon the long-term effects that this transition can have upon the extent to which an individual engages in the 'politics of disability':

Member of DASL: *Hmmmm...I think that the important thing as well is whether a person has become disabled as a result of an accident or whether they were born with a disability. I imagine that you'd probably get* *completely difference answers from both. (...) So from a cultural point of view, I think you're going to have two cultures within one...where people are coming from...because they've not had life experience of not being disabled...whereas I have.*

Angharad: *And you think that that has an effect on how you identify yourself now?*

Member DASL: *Yes, (...) I think that's actually why I'm not so militant - I'm not vocal, angry, bitter, bothered about terminology.*

Member 1 Lancaster DISC: *Well, I've said before that* (other member of group) *is on that side of Disability where you have to change society, the rest of us are - we have to cope, we have to put up with things as they are and this is what we've got and we've got to do something with it.*
(...)
Where (other member of group) *would say "This is not acceptable", I would tend to say "Well, whether or not it's acceptable, this is the position and how do we get out of it?"*

In the second of the two quotations above, the member of Lancaster DISC being discussed is an individual with congenital disabilities and the member voicing these opinions is an individual with an acquired disability.

There were occasions during this research, however, when individuals made comments, or debated with each other on this topic in such a way as to demonstrate that broad generalisations must be avoided and the complexity of identity issues must always be acknowledged. One respondent with a congenital impairment stated that the difficult transition towards acceptance of a disabled identity is something that he has also experienced:

Member of SFPD: *It is not just people who have acquired disabilities - I'm still going through it.*

Equally interesting was a discussion that took place in Lancaster DISC between two respondents, one with an acquired disability and one with a congenital disability. In the following excerpt from this discussion the two respondents consider the differences between their identities. What becomes clear is that member 1 feels that member 2 possesses a more positive identity as a disabled person and is better adjusted to life as a disabled person. Member 1's comments reinforce the general findings of this research in terms of indicating the uneasy transition from non-disabled to disabled identities. This discussion is even more revealing however, because the comments made by member 2 clearly bring into some doubt the idea that individuals with congenital impairments have more positive identities as disabled people. This is not to say, however, that member 2 is indicating that he does not feel positive about his identity as a disabled person, for his argument is rather subtler than that. Member 2 suggests that the special needs education he had received attempted to impose upon him a certain kind of identity that he considered to be essentially negative. His subsequent rejection of this negative identity and development of a more positive 'disability identity' was, therefore, not something that developed naturally because of the congenital nature of his disability, but rather from his own determination and emancipatory thinking:

Angharad: *Would you say though that you had chosen your identities as 'disabled people' - or do you feel that you have been labelled by society?*

Member 1: *Oh its been put on me entirely...yes...(...) I do wonder though, whether there is a difference between us - you've* (to respondent 2) *been disabled all your life and me...I wondered that?*

Angharad: *So how do you think - what is it like, if I may ask you, to experience that change of identity?*

Member 1: *Well, this is it...you see, I think that I do rather think that it was imposed on me...whereas, you* (to respondent 2)*...it seems to me - have had an identity of your own all your life.*

Member 2: *No - not really, because...I think that at my former college, a lot of the pupils were more ready to accept what society had marked down for them...they were more likely to accept the expectations.*

Angharad: *What were the expectations would you say?*

Member 2: *Basically, to go to special school and to go to local day centre and to live in some sort of local sheltered housing. That is what is available...*

(...)

Member 1: *You know...I'm shocked, in big levels about you* (to respondent 2) *saying about disablism and about this identity thing...because you've developed your own....whereas I had one forced on me!*

Member 2: *Well, I didn't choose mine!*

Member 1: *Yes you did!!*

Angharad: *Okay, okay! How about me suggesting that what you are saying is that for you* (to respondent 1) *your identity pre-existed your disability...whereas for you* (to respondent 2) *your disability is very much a part of your sense of identity?*

Members 1 and 2: *Yes!*
(...)

Member 1: *(...) this is one of the problems you just have to get used to...you see, when you become disabled, it just happens like that* (with a click of a finger) *and it took me a year to get used to it. And I think that in that year I had to develop my own identity...which came with my own reasons for wanting to be alive...It is a terribly confusing time.*

Angharad: *Yes...this is what I've heard in other groups too - that to go from a non-disabled identity to a disabled identity, is very difficult.*

Member 1: *Yes, and it is what a lot of people just can't deal with...you know the people who have strokes who are 70 or 80, and are so used to living an active life...they just can't adapt...whereas I had to adapt.*

Angharad: *Yes, you were young...*

Member 1: *I was 34....I had to adapt, or go under...and take on a new identity.*

Excerpt from discussion at Lancaster DISC.

What the previous excerpt, in connection with the whole of this section of the chapter shows, is that very few respondents considered their disabled identity to be something entirely positive and several of the respondents clearly felt that their identity as disabled people was a negative factor in their lives, or something that they wished to reject, challenge or avoid. It is important at this juncture, however, to stress that whilst the findings of this research do bring into some question the idea of a positive 'disability identity' and the notion that disabled people are 'celebrating the disability identity', this is not to say that respondents entirely rejected the idea of striving for a more positive representation of disability in society.

Two respondents described how they used humour as a way of disrupting people's negative attitudes towards them:

Member of SUFA: *Yeah - someone says: "There then you nutter!" I said to them: "If I'm a nutter, they would be salted nuts!" And that way I got them back! If I fight back they don't like it.*

Member of DISC: *(...) the first time I went into the Biker's Pub in Lancaster, I said "Hi! I'm Wobbly* (name)*!" and after that, you know, that ended any kind of taking the piss! That meant that they had no chance to say "Bugger Off!", you know...*

Whether in defining themselves in these humorous ways these individuals are truly finding a positive 'disability identity' is unclear. There are echoes of the idea of 'defensive identities' here. Nevertheless, the actions of these individuals do represent a definite rejection of the negative attitudes in society.

In another discussion, respondents at Lancaster DISC, felt that one of the key functions of the organisation was to promote a positive image of disabled people:

Member 1 Lancaster Disc: *(...) I think it also shows that disabled people can actually do it and we can be seen in a quite a positive role within the local community.*

Member 2 Lancaster DISC: *I actually think that is very important...too often disabled people are seen as incapable. There are not many positive roles out there.*

They were also keen to reject the use of certain terms such as 'invalid' to describe disabled people because of its connotation of not being '*valid*'. Members of other organisations involved in this research put forward similar arguments against the use of derogatory language:

Member of DACE: *A lot of language had a derogatory connotation didn't it? And I presume if you are trying to change things in society then I suppose a very obvious change is language, because it's something that we use and is around us all the time. If you are trying to educate, if you are trying to change, language is perhaps the most obvious way.*

Of particular note was the issue of the use of the term 'sufferer' when describing individuals with certain impairments. Some of the respondents at SFPD explained why they disliked the term:

Member 1: *I don't like to be described as an 'MS sufferer'. (...) 'a person with MS'.*

Angharad: *What is essentially wrong with this term? (...)*

Member 2: *I have a great problem with the way that society sees disabled people - they also actually assume that because we've got some sort of disability that we are all suffering, you know. (...) But it's like everything, when someone get's depressed because of their disability then they'll see themselves as suffering then. But in general I would say it's how general society sees the disabled person, rather than how the disabled person sees themselves.*

Clearly for these respondents, the use of the term 'sufferer' was derogatory and negative. It should be noted at this point, however, that as with most issues considered during this research, not all respondents agreed with the views of the members of SFPD and there was diversity of opinion even within organisations:

Member 1 Arthritis Care: *I don't think there's anything wrong with it* (term arthritis sufferers)

Member 2: *Because we do suffer don't we?*

Member 3: *I mean, I would say "I suffer from..." not "I've got..."*

Member 4: *I think that if people say we're sufferers, it makes us sound like victims.*

Member 5: *Half of it is that we do want to feel in charge - it has to be our decision. I mean, now and again it's nice to have a bit of sympathy, or empathy.*

This diversity of opinion occurred on a number of other occasions during the research in relation to the importance of language as a way of positively 're-identifying' disabled people. For example, at Lancaster DISC, comments by respondents demonstrated that although they did not deny the importance of using respectful terms when talking about disabled people, they nevertheless felt that there was a limit to the importance of language when seeking to improve the overall lives of disabled people:

Angharad: *Okay - well the next issue is about how you prefer to identify yourselves (...) I'm thinking (...) about which expression is more acceptable: 'disabled people', 'people with disabilities' and so on...?*

Member 1: *Oh, I think you are moving onto 'political correctness' now!*

Angharad: *Well, do you have any feelings about it yourself?*

Member 2: *I just find it quite ironic that there is so much discussion that is a waste of time...it has been 'academicised'. Unless the position of disabled people in society changes, saying which word is most appropriate is just tokenism.*
(...)
(...) if you look at words like "spastic" or "Mongol", you know - then they are medical in origin. And so until we move away from seeing people in that way, and instead see people in a more positive light - then any name will become an abusive word. I mean I can imagine it in the playground now, instead of saying that someone is "spastic", they're saying "do you have a disability?"!

Worker at Lancaster DISC referring to a statement made by another member of the group (member confirmed this statement): *That's the central problem (...) isn't it? - I don't care what you call me - as you said to* *someone when they asked you about the language of disability - you can call me a cabbage if you like, just give me the money, basically.*

On the other hand, at DaCE, another respondent thought that campaigns relating to the use of language were a vital part of the struggle to improve the lives of disabled people:

Member of DaCE: *It's preferable that people either worry about it or think about it* (language) *than...even if they don't always get it right...than if they don't think about it or think it's not important.*
(...)
But that's why, in a sense, the language becomes a kind of, not a flag-ship, but it's almost like something that stands out. If you can't change that, if you can't start to change attitudes, how do you get the support to change the other things that you need to change?

Angharad: *So you think you need to change attitudes first?*

Member of DaCE: *It works both ways, sometimes other things get, are put in place that start to change attitudes. Like a lot of people's language in terms of 'race' wouldn't have changed unless there was a lot of publicity or a lot more awareness of equal opportunities and using terms that are non-discriminatory developed* (then) *in terms of 'race'.*

On one level these differences are quite profound, in that for Lancaster DISC achieving improvements in relation to the language of disability runs the risk of being a mere sop in relation to the major structural barriers still facing disabled people. The respondent at DaCE, however, sees structural and attitudinal barriers as closely interlinked, and that, therefore, disability campaigns need to have a dual focus. The differences between the respondents here should not be over-emphasised however, because the comments from both groups essentially convey the same message: that the key struggle facing disabled people is still to demolish structural barriers. Their views differ surrounding the notion of the extent to which changing the language of disability can help in this struggle.

This is a critical finding for this research because it highlights again, that even when the disabled respondents in this research talk about the need for changes in attitudes and language, they are not aiming to achieve cultural or identity based rights but rather, necessary structural changes to their lives. These findings must bring into some doubt the idea that a unified and positive 'disability identity' is at the heart of all disability campaigning. These findings also have clear implications for the notion of a disability culture. This issue will be briefly considered in the following section.

Disability Culture

During this research, very little evidence emerged to support the idea that a celebration of a separate 'culture of disability' is occurring widely amongst disabled people, with the possible exception of the limited number of people involved with Disability Arts. Most respondents showed some degree of uncertainty surrounding the idea of a disability culture. The only cultural difference that was clearly identified by a number of the respondents in this research was the issue of the acceptable use of non-politically-correct language amongst disabled people in humorous contexts. Whilst several of the respondents suggested that this probably represented the disability culture, I think that it is questionable to what extent this use of humour amounts to an entirely separate 'culture'. The following excerpts typify the comments made on this issue:

Member DaCE: *It's hard to see that* (disability culture) *existing in very broad terms, in terms of disability as a whole.*

Angharad: *Is there such a thing as a 'culture of disabled people'? Do you find this a realistic concept?*

Member SFPD: *Yes, but it is not well developed. (...) Not many cultural icons. We have our heroes and villains and jokes - some of the elements of culture, but we are fundamentally different to other cultures in that you can be proud to be a woman, proud to be black, proud to be gay - but having a part of your person not working is essentially negative.*

Member DASL: *(...) I think that there is a culture of disability.*

Angharad: *Right - so how would you describe that then?*

Member DASL: *(...) for example, we tend to talk in a different language with each other than we would do with someone who is not disabled...because there is affinity (...) we can use the terms that are not PC and get away with it. (...) we can crack Christopher Reeve jokes and that...*

The real difficulty, perhaps, when considering cultural aims as the basis of the disability movement appears to be the assumption that there is some 'essential' cultural *difference* between disabled people and non-disabled people, and that disabled people are culturally united. Whilst the members of Lancaster DISC largely echoed the quotations above, again identifying humour as an example of disability culture, one respondent at this organisation made the following comment:

Member 1 Lancaster DISC: *It's funny...non-disabled people...if for example...in town, in a meeting area, if you are in a wheelchair, people expect you to have much more affinity to someone else in a wheelchair...and you might do...*

Angharad: *But no more than anyone does to anyone else?*

Member 1 Lancaster DISC: *Quite.*

Evidently then, this respondent is not entirely convinced by the idea of a homogenous disability culture that unites all disabled individuals.

During the research, some respondents also openly voiced concerns about the activities of those engaged in Disability Arts, who they feel are 'ghettoising' disabled people by celebrating cultural 'difference' in a manner that is exclusionary:

Worker at Lancaster DISC: *It's a bit like when we went to this Art's meeting, you know, what I call the Disability Arts Mafia - DAM! - sorry! - (...) they are getting too separatist (...)*

Member 2: *Which I hope doesn't happen because I think it will split the movement.*

Such fears are clearly related to wider issues of separatism within the disability movement that will be considered in the next section of this chapter. Before moving onto consider the disability movement, however, it is also important to note one further point about the issue of the disability culture. In the research questions sent in advance of each group discussion, there was a question about disability culture, yet, despite having raised this issue with each group no respondent chose to focus upon or talk at length about the question. Whilst this issue of a disability culture clearly requires a fuller investigation than was possible within this research, what I suggest can be concluded is that, at present, the number one focus of many disability organisation is the dismantling of structural barriers; identity issues are an important but somewhat confused secondary issue; whilst *cultural issues* have yet to reach the main agenda in many organisations and may never reach this position.

The disability movement

In their 1999 book "Exploring Disability. A Sociological Introduction" Barnes et al state the following:

> *It is a sign of the maturity and confidence of the disabled people's movement that disabled people are able to celebrate difference, and work together to create and discuss images of their own choosing.* (p.207)

The purpose of this section is to consider the extent to which the evidence from this research supports this statement. The first thing that can be said with some certainty is that as shown in the previous discussion, there was a large degree of opposition to the idea of 'celebrating difference' amongst the respondents in this research. Equally, the respondents in this research expressed views in complete contrast to this quote from Barnes et al in two other respects:

The first problem arises in relation to the idea of the disability movement being characterised by disabled people 'working together'. Several respondents highlighted the major divisions that exist between disabled people, as demonstrated in the following quotations:

> **Member of DaCE:** *The other thing which is quite important, which we've been doing recently is trying to pull disability organisations through-out Cumbria together as a group, as a network, but that's very difficult. They're all really suspicious of each other and won't work together.*
> *(...)*
> *(...) one of the things we feel at the moment is that we don't have particularly strong links with the Deaf community for instance. And I don't think that's necessarily just to do with us - it's that the Deaf community is quite self-contained as well (...).*
> *(...)*
> *(...) it's very fragmented the whole thing, that's why this idea of a movement is very difficult to come to terms with sometimes.*

> **Member of SFPD:** *Now when we set up the forum we lost all the able-bodied representatives of charities like The Spastics Society - as they were then - (...) the Multiple Sclerosis Society, the Polio Federation and all those, but we also lost a lot of disabled people from those organisations who didn't want to join the 'common pool of disability' they wanted to just stick with their impairments. Now, we said, that basically the barriers we're fighting apply to everybody - to some in one area more than others...regardless of their impairments, but maybe - I feel sure that this is an inadequacy in the social model, because it doesn't place sufficient, it doesn't pay sufficient attention to the specific consequences of specific disabilities and it thinks that everything can be massed together. So in a way they were right and we were wrong and in another way, we were right and they were wrong! And we actually had huge animosity from other disability groups, because when disabled people become empowered what we do is to attack each other first - I think because we see each other as weak and disempowered like ourselves and so really fairly easy targets - but useless target! We should be taking our fight outside to the people who actually erect the barriers.*

During the course of the research other aspects of discussion also highlighted the fragmented nature of the disability movement. Divisions on the grounds of impairment became apparent, the major issue being the reluctance on the part of those with physical impairments to associate themselves with people with a learning disability or a mental health problem, although this is usually explained with regard to the limits of the professional knowledge of the organisation:

Member of Lancaster DISC: *Because none of us have a learning disability it would be very unfair of us to try to advise someone with a learning disability, depending on the inquiry. There are also quite a few organisations who deal with people with mental health problems and people with learning disabilities, so it is quite often better to signpost (...) or getting in touch with the particular organisers because they've got the expertise on whether it be mental health or learning difficulties which we do not possess.*

There were some comments made, however, which show how pervasive certain images of people with a learning disability or a mental health problem can be, even amongst disabled people. In the following quotes, one respondent demonstrates the fear she has in relation to people with a mental health problem; the other respondent in talking about people with a learning disability suggests that forbearance is necessary when including such individuals:

Member of DaCE: *If you don't know them* (persons with a mental health problem) *you don't quite know what they're going to do (...)*

Member of Arthritis Care: *And we're all very tolerant aren't we?* (of persons with learning disabilities)

Whilst in many respects neither of these comments were extremely disablist in tone, nevertheless it may be that such views represent a major barrier to the development of an inclusive and cohesive disability movement.

Divisions on the basis of illness/disability were also apparent during the research. Some of the members of the Arthritis Care Support Group, Carlisle felt that understanding their experiences of pain was important because it helped to explain their apparent lack of politicisation:

(Issue being discussed - the group's lack of connection with the disability movement.)

Member 1 Arthritis Care: *I think we're all quite laid back aren't we?*

Member 2 Arthritis Care: *But surely it's the pace of life we have to lead that makes us like that?*

Member 3 Arthritis Care: *My achievement is getting through the day!*

Another respondent from SFPD, although more personally politicised also highlighted this issue of illness and disability:

Member 1 SFPD: *I actually, personally, have - and still do to a certain extent - question whether I'm really part of it* (the disability movement) *actually, because of my impairment - because my impairment involves being ill.*

Member 2 SFPD: *You're not a 'fit paraplegic'?!*

Member 1 SFPD: *Exactly! Because I think the disability movement when it started out wanted to distance itself from people who are ill - so I sometimes feel that, okay, I'm part of it when I feel reasonably well - but when I don't feel well I don't feel part of it.*
(...)
I agree quite strongly with what GLAD (Greater London Association of Disabled People) *have said - they talk about the need to bring impairment into disability (...)*

What is important at this point is the manner in which this respondent identifies the underlying issue here, the inclusion of the experience of 'impairment' into definitions and understandings of disability. This respondent went on to discuss at some length her own uncertainties with regard to her position as a disabled person. She explained how, because it is unclear whether a person who is long-term 'ill', such as herself, can be a part of the disability community, she had found it difficult to confidently identify herself as a disabled person. Friends and colleagues had rejected the idea that she was disabled, and when the point came when she herself felt that she could accept and embrace the 'disability identity', she then felt rejected by some elements of the disability movement. She stated how she felt that the work of Jane Campbell exemplifies the attitudes within the movement which have made her feel excluded:

Member SFPD: *She said, if somebody is ill then they deserve sympathy but that's different from disability. And I think the BCODP embodies some of that kind of attitude.*

This issue is important to this research because it demonstrates that even when an individual may be keen to embrace the 'disability identity' and to be included in the disability movement, dominant figures and dominant ideologies within the movement may actually exclude that individual.

The other important division that emerged during this research was the difference between the level of 'politicisation' of disabled people who live in the larger cities and traditionally more industrial areas, and disabled individuals living in more rural or isolated areas. In terms of the groups involved in this research the following organisations were city based: SFPD; SUFA; and Lancaster DISC. The following organisations were based in more isolated rural areas, and this includes Carlisle which, although having official 'city' status is an essentially rural centre and groups based there draw their members from the surrounding rural areas: Arthritis Care Support Group, Carlisle; DaCE; and DASL.

Whilst respondents particularly in SFPD and Lancaster DISC spoke in some depth about their feelings about being a part of the disability movement, respondents in the more rural based organisations considered themselves to be somewhat removed from the movement:

Member of DaCE: *We kind of live outside that world for the moment (...) in terms of voluntary sector organisations I would say Cumbria is still behind, lags behind especially (...) the urban areas. But is that about pace of development? It would be quite surprising to see a rural area moving well in advance of an urban area because of the way they can organise - they've got a smaller area, they can pull people together far more easily.*

Angharad: *Do you feel a part of the disability movement?*

Member of DASL: *I don't, no.*
(...)

Angharad: *What is the major reason why there isn't a disability movement then do you think?*

Member of DASL: *I think it's difficult to mobilize people, and motivate because you spend so long...one thing that seems to go hand in hand with disability - and I'm not talking for everyone - is an element of depression, you know, feeling flat..."I can't do anything as a single voice" you know - there's not enough of us in the local area - whereas if you are in Bradford, or somewhere with a high concentration of a particular ethnic group who can go along an lobby their MP - well, I always struggle to get 20 people to help...*

Angharad: *So it's isolation?*

Member of DASL: *To come out and shout...yes, the feeling of isolation...it might not be particularly isolated...*

Angharad: *But you feel that you are?*

Member of DASL: *Yes, but you feel a lone voice a lot of the time...and then you become accepting of things that you should never really accept.*

These discussions would suggest that there is a rural/urban divide between disabled people in terms of the activities of their organisations.

The final, and perhaps most important issue that divides disabled people, and which was greatly evident in this research, is the extent to which individuals envisage a separatist movement. As has already been discussed within the methodology, all of the groups participating in this research were run by and for disabled people, and all place limits upon the involvement of non-disabled people. None of the groups, however, excluded non-disabled people *entirely.* In most of the groups there were non-disabled workers, and some groups chose to include a non-disabled worker in their group discussion. At DASL and Lancaster DISC, helping the carers of disabled people is included in the work of the organisation:

Member of DASL: *Well, because carers have needs as well.*

Several respondents also expressed their concerns surrounding moves being made by one of the most important disability organisations, the BCODP towards a '100% disabled' rule, whereby all member groups should be run entirely by disabled people, with no non-disabled people on their management committees:

> **Member of Lancaster DISC:** *I think they* (BCODP) *may be going too far for DISC's liking.*
>
> *(...)*
>
> *I've already said my biggest concern about the '100%' issue is that RADAR*[4] *will look like a more reasonable option!*
>
> ---
>
> **Angharad:** *(...) I don't know if you are aware that there are moves within some organisations to become, totally, 100% controlled by disabled people. Is that a positive step, is it something you could see...*
>
> **Member of DASL:** *It's a negative step! I don't think...it's segregation again isn't it?*

In a related comment, a respondent at DaCE expressed concerns over the extent to which separatism in general, both in terms of the 'disability identity' and within the disability movement, is a positive step:

> **Member of DaCE:** *But there are situations where, for whatever reason, whether it's social, political or both, people do need to identify together and form some sort of grouping. And it may be more appropriate in certain circumstances or localities than it is in others. (...) In a political sense that is - there may be greater strength, well, some people may feel there's greater strength in grouping with a clear identity to put forward (...) ideas (...)*
>
> **Angharad:** *So you can see times when people would need, or want to identify themselves, firmly, as 'disabled'?*
>
> *(...)*

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[4] RADAR stands for the Royal Association for Disability and Rehabilitation. RADAR's constitution currently states that there must be sufficient disabled members of the association for them to have a controlling vote. RADAR does not, however, exclude non-disabled people from becoming members. Implied in the comment of this respondent, however, is a criticism of RADAR that goes beyond the issue of membership of the organisation. Unfortunately, this respondent did not enlarge upon this comment and so the exact details of the wider criticism of RADAR implied by this comment, is unknown.

Member: *There may be. How far they could do that successfully and in terms of separating themselves off completely - creating a totally separate identity is very difficult because as I said earlier, we live in a mixed society. (...) So there is a danger in grouping (...) that also allows the wider, non-disabled society the opportunity (...) to say, well,* ***"There they are, that group - let them get on with it!"***

To return to the original quotation from Barnes et al (1999) the evidence of all of these different divisions between disabled people and between different disability organisations must bring into some question the idea of a unified disability movement in which disabled individuals are 'working together'. Equally, as the previous discussion demonstrates, the implications of these important divisions between disabled people must surely mean that the idea of a 'mature disability movement' must also be questioned. Several respondents commented on the fact that they considered the disability movement to be in its fairly 'early stages':

Member of SFPD: *My feeling is that it is realistic to talk about a disability movement but it is still very young and it is not coherent and it is in danger of falling apart.*

Member of Lancaster DISC: *(...) if you look at when the suffragettes started, they were just a handful of 'extreme' women. (...) They did not represent, you would not have said that they were a 'Woman's Movement.' (...)*

Angharad: *Would you say it was as embryonic as that? - that the Disability Movement is in a very embryonic stage in that case then?*

Member of Lancaster DISC: *Yes, I mean, maybe not at the very beginning.*

Angharad: *No.*

Member of Lancaster DISC: *But a long way off any kind of movement.*

In the light of such fragmentation and the agreed lack of maturity of the disability movement the question of what kind of movement and what it means to be a part of the existing movement was an issue much discussed between respondents. In terms of locating the movement, discussions at SFPD and Lancaster DISC revealed that although respondents were unquestionably of the belief that the BCODP was a major part of the disability movement, that it could not be said to *be* the disability movement:

Member 2 of Lancaster DISC: *(...) I think the closest we've got to a movement is the BCODP. (...) But it's a long way off being a movement, simply because the numbers don't add up.*

Member of Lancaster DISC: *Well, we are quite willing to leave it* (BCODP) *if necessary.*

Angharad: *Yes? So you don't think...we can't equate the Disability Movement with the BCODP?*

Member of Lancaster DISC: *No.*

Worker at Lancaster DISC: *I should think that nine-hundred and ninety-nine percent of disabled people have never heard of the BCODP.*

Member 1 of SFPD: *I'm against being hide-bound by one organisation. The BCODP is not the movement.*
(...)

Member 2 of SFPD: *There are some remarkable individuals within the British Council and I wouldn't deny that, but I think this organisation's had the belief that the British Council is the B-end and that's it.*

In saying such things, these respondents were aware that they were going against some of the orthodoxies of Disability Studies that place considerable emphasis on the BCODP as the site of the movement. This is a key point because quite a part from the issue of which organisation is the most important within the disability movement it also raises the issue of what does it mean to be a part of the movement? Is it necessary to be affiliated to any organisation to be a part of the disability movement? Here again, there were interesting differences of opinion between disabled people as demonstrated by this excerpt from a discussion at Lancaster DISC where the issue of what constitutes involvement in the movement was debated:

Member 1 Lancaster DISC: *But if you get from the house to the pub and people see you, you are immediately representing disabled people.*

Member 2 Lancaster DISC: *I hope not!*

Member 1 Lancaster DISC: *Oh I hope you are - well, I hope people will stand in the street and go "Oh look! There's* (Name) *on his bike, going to the pub like a normal human being!"*

(...)

Member 2 Lancaster DISC: *(...) but if the BCODP hadn't set up, change wouldn't even have begun yet,*

Worker at Lancaster DISC: *Um...you think change wouldn't have begun if the BCODP hadn't set up? You see, I don't think they're as important as that - I think they're important amongst disabled people like you, but as 90% of disabled people will never have heard of them and 90% of the public - more than 90% of the public - won't ever of hear of them...*

Angharad: *No?*

Worker at Lancaster DISC: *They are so small as to be non-existent. But what does make a difference is people everyday going out - like...*

Member 1 Lancaster DISC: *Yes!*

Worker at Lancaster DISC: *Like you going to the pub, like you doing what you do, like people going to meetings. Those are the people who make the difference, not the BCODP shouting.*

The idea that a broader definition of what constitutes involvement in the disability movement is needed, was echoed by another respondent from DaCE:

Member of DacE: *(...) So, it is strange isn't it - with saying we don't think there's a great, necessarily a movement, and it is giving the impression that we're not particularly political in a sense - especially with a big "P"! Yet at the same time, we've got involved in a disability organisation - why aren't we involved in a childminding organisation! You know what I mean?*

To conclude this section of analysis, therefore, it is plain that there are problems with the views of certain leading academics and activists in this field on the coherence, location and functioning of the disability movement. Whilst the evidence from this research does not, overall, bring into doubt the existence of the disability movement, it does suggest that the definition of the disability movement provided by mainstream Disability Studies may not be entirely accurate. Before embarking, within the following chapter, upon a more theoretical consideration of these findings, there is, however, one final section to this chapter:

Deafness and disability

As previously explained within the methodological chapter, during the process of the research an issue arose surrounding the absence from any of the participating organisations, of Deaf/deaf people, or people with mental health problems. This absence led to inevitable questioning of whether this was a chance occurrence, or whether these groups were, for some reason, not a part of the disability community. Since the most striking theme arising from the first round of group discussions surrounded the issue of identity, it was thought to be important to establish whether the absence of such individuals was because they did not feel themselves to be welcomed within the disability movement, or because they did not regard themselves to be disabled people. Since research time was limited, it was decided that further investigation would be made into the apparent absence of Deaf/deaf people from such disability organisations. To achieve this, a letter and series of questions was posted onto the web-based mail group: 'Deafmail'. In this section, the findings of this part of the research will be considered.

Before considering the comments of the three Deafmail respondents it is important to note one key fact about each of these individuals: that each identified themselves as 'deaf' or 'deafened' and made it clear that they were not a part of the 'Deaf' community.[5] Despite the fact that 'Deafmail' is a mailbase

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[5] Throughout this research, the word 'deaf' is used to refer to those people who experience the physical impairment of deafness, but who do not regard themselves as being a part of the culture of Deaf people. The

group used by both deaf and Deaf people, no Deaf individuals chose to respond to the research questions posted on this website. Therefore, whilst it is not possible to gage the views of the Deaf community on these matters, it may be possible to surmise from this absence of response that the Deaf community either did not wish to address the issue of their association with the disability movement, or simply did not find the question of 'disability' relevant to their experiences. Either way, what can be concluded is that there is some uncertainty about whether Deaf people are, or wish to be, a part of the disability community/movement.

That these key divisions between deaf/deafened and Deaf communities exist, is something that all of the respondents identified, but was most clearly explained by respondents 1 and 2.

Deafmail respondent 1: *I do not feel part of the Deaf BSL community. I've my deaf friends from boarding school* (name of school) *but do not identify with Deaf culture or feel I am part of a linguistic minority. This is despite having spent several years in the London Deaf scene and having Deaf boyfriends.*

Angharad: *Is there a Deaf identity and/or a Deaf culture that is different from those of hearing people?*

Deafmail respondent 1: *Yes, but I don't identify with it. It is about as accessible to me as a culture like Australian aborigines or African Bushmen.*
(...)
I wish the Deaf world would stop bickering and in-fighting. Deaf BSL users look down on SSE deaf people and the deafened. It's just stupid. We all need to accept that everyone is different. (...)
I do feel excluded from the Deaf Community. And yes I did expect to become part of it. When I left school, I started going down the deaf club and learnt to sign - but never felt accepted. In London I was very involved in the Deaf world for about 4-5 years but gradually grew to feel that my face didn't fit and that the way I saw life was different. So I just started fading out of the picture. Incidentally two school friends, who are both fluent in BSL and who have been very involved in the Deaf community, both say they don't feel they are 'real' Deaf people.

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word 'Deaf', therefore, refers to those individuals who aspire to British Sign Language usage and its related cultural heritage.

Deafmail respondent 2: *The Deaf have their own identity and culture based on their use of BSL. The deafened do not have a separate identity or culture. (...)*
As things are at present, I have absolutely no wish to be part of the 'D' community. It is a very bitchy and back-stabbing group. People within it seem to take offence very quickly because they are unaware of the nuances that one can place on one's voice to create irony or something else. (...)
*I would very much like to see the different sections of the deaf (i.e. *ALL* sections of the deaf community) to find common ground. That is achievable as we do co-operate within the Telecommunications Action Group (TAG). But I very much doubt whether we'll see agreement on all issues that will allow us to be presented as a homogeneous group of people.*

Clearly these divisions run deep and are the basis of some conflict between groups of deaf/Deaf people.

In relation, however, to the question of whether deaf people are 'disabled' and whether they consider themselves to be a part of the disability movement, there was less agreement between the respondents. All respondents said that they did identify themselves as disabled people. The interesting point about their comments, however, is that they define their disability only in terms of impairment. This suggests that these respondents may not be as aware of the social model of disability as some of the members of the disability organisations that took part in this research.

Angharad: *Are deaf people disabled?* (Respondents all replying to same question.)

Deafmail Respondent 1: *Yes, from my point of view. My ears don't work. Outside the deaf world, only family and 2-3 close friends can understand what I am saying. Of course I'm disabled. But it is a sensory handicap rather than a physical mobility issue.*

Deafmail Respondent 2: *Deafened people like myself are prepared to accept we are disabled since we don't have full access to communication via our auditory senses.*

Deafmail Respondent 3: *In my view absolutely yes but some would not see it that way. Indeed it took me many years before I would recognise the position. It is because the deafness is hidden unlike a physical disability.*

The tone of these comments clearly suggests that for these respondents the disabled identity is something that is essentially negative since it is associated with loss, in this case of hearing. The comments also suggest that these respondents have not *embraced* their identities as disabled people, but rather, it is something that they have come to 'accept/recognise'. That they would prefer not to be deaf and cannot therefore, be seen to be 'celebrating' their deafness is shown by following comments:

Deafmail Respondent 1: *Being deaf is just something that I am. I get on with life and try to live the life I want to have. I'd just prefer not to be deaf.*

Deafmail Respondent 2: *I am aware that Deaf people (i.e. the born deaf) have some concerns that medical progress eg. cochlear implants may eventually lead to the reduction in size of the Deaf Community particularly if Genetic Engineering identified the faulty gene that causes loss of hearing in inherited deafness. Some of the more extreme Deaf campaigners see medical advances as a means of committing genocide on the Deaf Community. I hasten to add that is NOT my view nor the view of the majority of deaf people but some people genuinely do hold that belief.*
(...)
I would personally welcome advances in genetics that led to deafness being eradicated. No one who has not been deaf themselves will be aware of how isolating the problem can be.

Clearly these types of view echo the rejection of the idea of a positive 'disability identity' expressed by some members of the disability organisations that participated in this research. Interestingly, the final comment from respondent 2 above about genetics, stands in stark contrast to the concerns of some leading disability activists and academics in relation to this matter. Whilst it must be stated that the attitudes of these individuals towards such issues as advancements in genetics may not represent the views of all deaf people, and certainly cannot be said to represent the views of the Deaf community, such opinions must not be ignored by mainstream Disability Studies. That such 'diverse' opinions have been largely ignored with Disability and Deaf Studies is something that respondent 1 clearly identified:

Deafmail Respondent 1: *Nearly all social science work is around Deaf language and culture, you don't often get anything analysing the world of those who have hearing loss and the divisions between the deaf.*

Further, respondent 2 expressed how powerless he felt in relation to his views on genetic engineering when faced with the powerful opposition to these new technologies being voiced by key activists and academics in the field:

Deafmail Respondent 2: *I think it will be difficult to put forward reasoned debate to those who are opposed to genetic engineering. I think we have to reluctantly accept their viewpoint.*

This comment highlights some important disparities of power between leading figures in the field and 'ordinary' deaf individuals. This comment also clearly resonates with the views of many of the disabled respondents in the research in relation to the power of dominant voices within a community. Respondent 1 also highlights the tendency on the part of some key figures in the field to hold a 'your either with us or against us' attitude when facing differences of opinion within the deaf community. She talks about the 'exclusive' nature of the Deaf identity and how some deaf people feel that they are not 'real' Deaf people and that they have not been 'accepted' by the Deaf community. She also stresses her own concerns about the way in which some deaf voices have been silenced in favour of the voices of the dominant few and of the negative implications of this:

Deafmail Respondent 1: *One of the reasons I'm not terribly keen on this Deaf Community approach is that it's so limiting. The world is full of hearing people.*

(...)

The Deaf BSL user community is a tiny minority; they just happen to be extremely vocal.

This quotation clearly echoes the views of several of the disabled respondents in this research in relation to fears they had about separatism in the movement and the potential for 'ghettoisation'.

Moving to the issue of the disability movement, having stated that they each felt themselves to be disabled people, these respondents did, however, have mixed feeling about whether they were a part of the disability movement.

Deafmail Respondent 1: *Deaf people are cut off from the disability movement because of the communication barrier. I do, however, identify with the disability movement because the idea is to remove barriers, whether physical or not.*

(...)

If you put me in a room full of people with physical disabilities, I still can't talk to them without communication support. For me, they are hearing people. To them, I am able bodied.

Deafmail Respondent 2: *Some Deaf people are a part of a campaign to obtain recognition of British Sign Language in its own right but would probably not see that as part of a disability movement. Other deafened people are campaigning for equal access to things and do recognise that their campaigns are part of the wider disability movement. I'm not actively campaigning though.*

Angharad: *Do you personally feel a part of a disability movement?*

Deafmail Respondent 3: *I am not as I prefer to work positively in the hearing world (...) I am basically a part of the hearing world.*

Thus, for these respondents the disability movement is not something that they feel strongly connected with. This is interesting considering that during the email correspondence with these individuals, they each mentioned that they were facing the same sort of structural and social barriers identified by many of the members of the disability organisations involved in this research. In the case of respondent 1, the similarities in barriers faced between deaf and disabled people is something that she herself acknowledges:

Deafmail Respondent 1: *Do you know about deaf education? The Oralism versus Total Communication debate?*

Angharad: *Yes (...) - what are your views on this issue?*

Deafmail Respondent 1: *I could go on for hours on this one! To put it very baldly, oralism works fine for kids with enough hearing to support their lipreading and speech. Lipreading is 90% guesswork on its own. But oralism has been implemented as a blanket method of educating ALL deaf children to be as normal as possible. Unfortunately the end result of oralism applied to very very deaf children is nearly always illiteracy (reading age of 7 at most) plus speech no one can understand. There's a parallel here with other disabled children being educated to 'pass' and it not working at all well. Total communication at least means deaf children leave school with language and skills.*

Other respondents commented about public attitudes towards deaf people and experiences in the workplace, and whilst not making the direct comparison with the experiences of other disabled people, such comparisons are nevertheless obvious:

Respondent 2: *There does need to be some education on the part of hearing people to understand how isolating the invisible handicap of being deaf can be. How that can be addressed I am not sure. I know there are several Deaf Awareness Courses but I'm not sure whether hearing people would welcome them if there was some compulsion to attend them. (...)*
People are much more helpful now but I do find that people still have doubts that deaf people can be intelligent and reliable workers.

Respondent 3: *(...) there is still much that could be improved in deaf awareness. (...) The willingness to provide support under the DDA also needs to be pressed. Many public services do not provide or understand the need to provide support. Just imagine being on a railway station when things are going wrong and the screens are not up to date with information. Or on a train and it is getting nowhere, or a flight which is also wandering around the skies because it cannot land (I have had all these). Because I am strong I do not hesitate to ask (but only when really necessarily) but others do not have that strength.*

To conclude this section, it emerged from this part of the research that there is some uncertainty about the position of deaf/Deaf people in relation to the 'disability identity' and the disability movement. This picture is made considerably more complex by the internal divisions between deaf/Deaf people.

Conclusion

This chapter has highlighted the fact that for many disabled people, breaking down structural barriers remains of central importance. Respondents in this research identified a range of problems facing disabled people in the public sphere, for example in relation to the institutions of government and education and in the labour market. They routinely stressed the role of the state and/or society in relation to their disempowerment. In this respect, the views of respondents in this research clearly supported the idea of the 'disabling society'.

In other central respects, however, respondents' comments very often stand in opposition to those key activists and academics who argue for the exclusion of impairment from the social model of disability and who also espouse the idea of a politics of disability based upon a celebration of the disabled identity. Whilst the findings of this research do not bring into serious question the existence of a disability movement *per se*, they do highlight the fractured nature of this collective. Differences between groups of disabled people in terms of impairment have been shown to be key to understanding the somewhat disunited nature of the disability movement. The views of the respondents in this research also bring into doubt the idea that a unified and positive 'disability identity' lies behind all disability campaigning or that the idea of a celebration of a separate 'culture of disability' is part of the main agenda for many organisations.

As will be discussed in the following chapter, it is the argument in this thesis that these findings have clear implications for contemporary theorising on citizenship, social movements and for the approach taken by mainstream Disability Studies to disability politics.

Chapter 7

Reconsidering Theorising on Citizenship and Social Movements in the light of Disability

Introduction

As previously discussed within chapter 3, despite centuries of theorizing, citizenship remains a contested concept. Whilst a widely agreed definition about what exactly 'citizenship' entails remains largely elusive, certain themes reoccur frequently within contemporary theorising. As shown in the discussion in chapter 3, issues of 'identity' and 'difference' are now at the heart of most contemporary citizenship theorising. That these two issues have become of major importance must largely be the result of successful campaigning by a variety of pressure groups. Consequently such things as class, ethnicity, employment status and sexuality are now routinely considered by citizenship theorists and have greatly affected thinking in this field. *Disability*, however, has been largely ignored and yet the findings of this research suggest that this omission may be unwise, for what a consideration of disability tells us does not always sit comfortably with recent citizenship theorizing. Indeed, I would suggest that a consideration of disability related issues is invaluable for it provides useful insights into the shortcomings of many key theories of citizenship and demonstrates the need for on-going theorizing in this field.

The very ancient origins of the citizenship debates have already been discussed at some length in chapter 3. The first thing, therefore, that must be stated is that in this chapter I have chosen to focus on the more modern/contemporary approaches. By this I mean a variety of theories that have been developed post-World War 2 and which move from the frequently criticised, but nevertheless influential Social-Liberal perspectives exemplified in the work of Rawls, Marshall and Berlin, through the pluralist accounts of writers such as Kymlicka and Young, to the reflexive account of Habermas and finally to the post-structuralist critiques provided by authors such as Mouffe.

The second point that should be noted is that it is not my intention within this chapter to revisit the critiques of the various citizenship theories as considered in chapter 3. For this reason, the reader is asked to consider the arguments that have been made there alongside the discussion within this chapter. The aim of this chapter is to relate the necessarily particular findings of this research to key aspects of existing theories of citizenship. These aspects are, therefore, 'selective'.

Social-Liberalist accounts

As previously stated, the Social-Liberal view of citizenship is probably best exemplified in the work of Rawls, Marshall and Berlin. Whilst some might question Marshall's position as a Social-Liberal since he is often considered to be more of a social-democrat, nevertheless, his credentials as a modern proponent of the older liberal tradition have been discussed at some length in chapter 3. It is on the basis of the argument made there, that he is considered within this section.

For Rawls, citizenship is best viewed as a system of co-operation. This system he describes as: rational individuals co-operating on the basis of mutual respect for one another. The first thing to note here, therefore, is that the attitudes of non-disabled people towards disabled people are clearly not always rational. Several quotations from respondents demonstrate the ignorance of, or fear felt by non-disabled people about disabled individuals. Equally, however, divisions between disabled people, for example, between individuals with physical impairments and those with mental health problems, may also be due to fairly irrational beliefs held by some physically disabled people about the 'risks' involved with working with such individuals. In the light of this, and the other divisions that have been demonstrated both within the disability community and in relation to the position of disabled people in wider society, the idea that a system of co-operation exists is clearly problematic.

Of course, it could be argued that Rawls' system of co-operation is still a useful ideal and one that although not currently in place, is nevertheless something that we should be striving to achieve. It could equally be argued, however, that Rawls' theory is essentially *utopian* in that it largely ignores the seemingly 'natural' tendency on the part of human beings to categorise, stigmatise and disadvantage certain groups. Theorists in the area of 'race' and ethnicity, from as seemingly 'diverse' standpoints as the functionalist (Patterson 1963), Marxist (Cox 1970, Miles 1982, 1993) and Weberian (Rex and Tomlinson, 1979) perspectives have all highlighted the fact that conflict is at the heart of society. Further, arguably, when considering the position of disabled people in society, the functionalist views on 'scapegoating', the Marxist theories of exploitation and the divisive impact of 'scapegoating' on the working class, and the Weberian approach to prejudice as a form of ideology which is used to disadvantage a supposedly 'inferior' group, can all be used to question the feasibility of Rawls' notion of co-operation.

In relation to the findings of this research, it must also be stated that there is a problem with Rawls' (1998) account of citizenship in that it rests upon the idea of 'competency':

> *(...) persons as citizens have all the capacities that enable them to be normal and fully co-operating members of society.* (p.60)

There is a great deal here that needs 'unpacking', for the construction of society being put forward here by Rawls is clearly a normative one. It is the argument here that this is also a view of society shared by Marshall in his famous work: *Citizenship and Social Class*. Although the extent to which Marshall was proposing a normative or an empirical outline of citizenship is much debated, it is the argument within this thesis that it was clearly *both*. In this respect the argument here owes much to Delanty's (2000) analysis, for he states that although Marshall's work *"was primarily a description of the development of citizenship in England*" it was *"one that had a strong normative edge to it."* (p.17) This 'normative edge' is demonstrated in Marshall's ([1963] 1998) definition of citizenship as a 'status', for he writes that:

> *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 those rights and duties shall be,* ***but societies in which citizenship is a developing institution create an image of an ideal citizenship against which achievement can be measured and towards which aspiration can be directed.*** (p.102 my emphasis)

The theories of both Rawls and Marshall therefore clearly rest upon an image of an 'ideal/good citizen' against which the achievements of individuals can be measured. This has implications for all groups whose beliefs or actions do not conform to the dominant group's notions of 'normality' or 'civilisation'. Alternatively, such normative views also have implications for individuals or groups who may be unable to 'live up to' this image of 'ideal citizenship', for they are judged to be failing in what clearly amounts to an important aspect of 'personhood'.

Explanations for the concept of 'personhood' and who is termed a 'proper person' and who is *not*, appear therefore, to underlie both Rawls' and Marshall's approaches to citizenship. There is a tendency in such Social-Liberalist accounts, therefore, to view citizenship as a 'status' in which respect is given to those who take up the role and perform it competently. In relation to the position of disabled people in society, as Marks (2001) states, the manner in which society constitutes disabled people as 'racialised others' positions them outside the category of 'personhood' and this impacts upon their perceived competency with regard to citizenship. As has already been discussed in chapter 4, (in)competence must, therefore, be seen as a social construction (Jenkins, 1998). As Goodey (1995) has commented, by defining who is *fit* to exercise the responsibilities of citizenship, citizenship as a concept has traditionally been *about* exclusion. In other words, a viscous circle emerges in that where there is stigma, there is also an assumption of 'incompetence' with regard to citizenship. The implications of this assumption of incompetence then prevent those experiencing this stigmatised identity from achieving those goals associated with being a 'good citizen', thus perpetuating their image as 'failures' within society.

As a society we appear to regard such things as living an independent life, achieving paid employment and 'responsible' parenting as being central to the image of the 'good citizen'. It has been well documented however, by research in the field of disability and within the findings of this research, that many disabled people continue to face major structural barriers when it comes to gaining proper employment, living their lives independently, and having relationships and family lives. Further, in relation to what Marshall clearly believed to be the 'backbone' of citizenship, *education*, the comments of respondents in this research clearly demonstrate that there have in the past been and are still, serious failings in terms of the life opportunities provided by special needs education. Also, as discussed in chapter 4, despite some key attempts to improve the educational opportunities and attainment of disabled children and young people, important questions remain surrounding the success of more recent moves towards 'mainstreaming'.

According to the Social Model of Disability, the reasons why the provision of a range of services for disabled people fail to *enable* disabled people to 'live up' to this image of a 'good citizen', rest upon the views held by non-disabled people about disabled people. The vicious circle previously described thus emerges in the lives of disabled people, for the 'stigma' attached to the identity of a disabled person can be seen to be both the result of, and the reason for, their continuing position in society. The 'stigma' attached to the identities of disabled people with different impairments does differ, and it may be easier to fight against the stigma associated with certain impairment than others, but nevertheless, the assumption of incompetence with regard to citizenship applies to the majority of disabled people, to a certain extent.

Ironically, of course, one of Marshall's other interests, apart from theorizing British citizenship, was the historical and global comparison of different types of citizenship and social structure. When considering the effects of social status upon citizenship he considered the caste system of India and the manner in which it is underpinned by notions of purity and impurity. It is clear that Marshall did not consider the British system of social structure and citizenship as having any similarities to this caste system and yet, it can be argued, perhaps somewhat controversially, that this connection does exist. Shakespeare (1994) draws upon Douglas' (1966) notion of purity and impurity when he comments that: *"When boundaries are breached, and identities seem threatened, behaviour is devoted to re-establishing the fixates, reinforcing categories and power relations."* (p.294) It can therefore be argued, that the manner in which the identities of disabled people have been stigmatised and the fact that their overall position in society is not entirely based upon personal wealth but upon some other more psycho-social reasons, means that the position of disabled people in Britain today bears more relation to the caste system than to the class based analyses that are more usually employed when considering the UK.

In short, what Marshall, like Rawls, did not adequately resolve within his early work, was the problem of *persistent and unjust social inequality*. If citizenship is to be about *justice*, then unequal status must be *fairly* apportioned according to unequal abilities. In reality, power differentials within society ensure that certain groups remain disadvantaged. Images of the 'ideal citizen' may be socially and culturally determined. In a society in which power inequalities exist, it is likely that the dominant group will determine the image of the 'ideal citizen' but in the same way that host societies tend to deny their own ethnic identities, the powerful group are also likely to think that their image of the 'ideal citizen' is non-group-specific. In this way, it can be argued that if the dominant group are non-disabled, middle-class, white men, then the image of an 'ideal citizen' is likely to reflect the characteristics of this, distinct group. The effect of this is to legitimise rather than reduce social inequality as more and more people are seen to 'fail' to live up to the image of the 'ideal citizen' and the 'official' status of equal citizenship then becomes meaningless as it fails to compensate for that social inequality.

This critique of the early work of Marshall, along with the work of the earlier liberals, was advanced convincingly by feminist writers during the 1980's (see Pateman, 1988). It does not tend to be widely acknowledged however, that at about the same time, Marshall re-visited his earlier theorising. In his 1981 work entitled: "Reflections on Power", Marshall discussed the civil rights movement in America and argued that what was being claimed by this movement was not 'power *over*' or 'redistribution', but rather, an effective share in the total power of society. In other words as Isin and Wood (1999) have stated, Marshall perceived such movements as being about the "*power to escape anomie, disrespect and alienation to achieve legitimate goals by the use of legitimate means.*" (p.31) The goal, Marshall believed, was a new kind of multicultural society, or if that should prove impossible, then a society composed of independent and equal ethnic communities. In this way, Marshall quite clearly anticipated the pluralist accounts of citizenship.

Having stated the above, however, it is the argument here that Marshall's dominant contribution to the citizenship debates, no matter how unfair this may be to his wider thinking, is still that of his earlier theorising. Further more, whilst his later work is interesting in the way in which it can be seen as an important precursor of the pluralist accounts, the work of Marshall's contemporary, Isaiah Berlin has clearer pluralist credentials.

Before moving on to consider the work of Berlin and the pluralist thinkers, it must be stated, however, that there are a number of arguments in favour of the idea that there is nothing inherently wrong with this Social-Liberalist definition of citizenship, particularly as it appears in the work of Marshall, and that perhaps what is needed is to ensure that all groups, including disabled people experience full rights in every spheres. For example, in relation to the lives of disabled people, some improvements that could be made to the social sphere have already been mentioned in terms of welfare service provision and education. In addition, as has been well documented elsewhere, improvements within the civil sphere could be made to the Disability Discrimination Act (DDA) with its numerous 'let-out clauses'. Although improvements to the DDA have been made under the current Labour government it will be some time before the legal changes that can be enforced have positive effects in reducing the numerous disabling barriers and discrimination experienced by disabled people.

As was discussed in chapter 6, the importance of enabling disabled people to 'participate' in decision making was identified by respondents in this research. Within the political sphere, access to decision-making processes could be further improved at the most basic level by ensuring that all disabled people can exercise their right to vote. In reality there are several obstacles, in addition to issues of access, that prevent disabled people from participating. Barnes et al (1999) list some of these barriers as: traditional assumptions about disabled people's inability to make independent decisions; legalised barriers such as the Representation of the People Act 1983 that codifies an assumption of incompetence on the part of people with learning disabilities resident in institutions, and only permits such individuals to vote once they have proved themselves capable to do so; finally, the right to be entered onto the electoral register is often determined by the awareness and integrity of those who are 'in charge' of the lives of the disabled person, be that within the family, or in an institution. In addition to voting, more genuine consultation with disabled people on a range of policy issues, in particular issues relating to welfare provision is also needed in combination with an assurance that this consultation advances beyond what respondents in this research described as mere 'rubber-stamping'.

It can be argued, however that the most fundamental flaw in Marshall's definition of civil, political and social rights is that they assume the possession of certain freedoms and powers on the part of each individual 'citizen'. For example, what is *liberty* without *choice*? As is documented in this research, it is often the case that basic choices about their everyday lives are denied to disabled people because they rely upon local authority provision; or they experience, as many disabled people do, a life in poverty; or they have not got the confidence to speak out about their preferences. The growing number of self-advocacy and empowerment based groups of disabled people, akin to those that participated in this research, is a reaction to this historical reluctance by disabled people to speak out about the issues in their lives.

Ultimately, however, despite the appeal of some aspects of Marshall's work, the normative, monistic nature of his famous early work, and that of other Social-Liberal thinking remains a major stumbling block when advancing this concept of citizenship as a way of tackling the inequalities faced by many disadvantaged groups including disabled people. As has already been discussed at some length in chapter 3, this theoretical weakness was clearly identified by Isaiah Berlin (1958), who, although undoubtedly a contemporary of Marshall and a liberal thinker himself, was considerably ahead of Marshall in terms of his theoretical understanding of the need to broadly reject the idea of a universalist definition of 'ideal citizenship' . The great value of his work on value-pluralism is, I believe, largely overlooked by sociologists and this is unfortunate, for it can be argued that Berlin's work avoids many of the pitfalls of other Social-Liberals. It is also proposed here that whilst Berlin's work can be seen as an important pre-cursor of the pluralist accounts of citizenship, his ideas may in fact be more useful than some subsequent theorising. For this reason, a discussion on the value of Berlin's theorising will appear at the end of the following section which considers the pluralist accounts of citizenship.

Pluralist Accounts

Pluralist accounts of citizenship suggest that any contemporary definition of citizenship must include the realm of 'culture' in addition to the *civil, political and social.* For Stevenson (1997a):

> (...) *cultural citizenship can be said to have been fulfilled to the extent to which society makes commonly available the semiotic and material cultures necessary in order to make social life meaningful, critique practices of domination, and allow for the recognition of difference under conditions of tolerance and mutual respect.* (p. 42)

In other words, the recognition of difference is only one part of cultural citizenship. It is also important to guarantee democratic institutions and to provide protection from the excesses of the free market. Nevertheless, the pluralist accounts do appear to place a large emphasis on the *politics of difference*. This would seem to be essential to the development of the concept of cultural citizenship.

Both Kymlicka and Young take as the basis of their theorising a critical stance towards the universalist, normative notion of citizenship. Both theorists perceive that in pluralist societies it is essential to consider group rights within the citizenship framework. The first problem that arises here in relation to the findings of this research however, is the assumption that all disadvantaged groups possess distinct cultural identities. The views of the respondents in this research demonstrate that individuals often have very complicated feelings about their own identities and that not everyone agrees about the existence of cultural differences between supposedly distinct groups. Whilst Young does tackle some of these issues, as will be discussed later, Kymlicka's ideas are somewhat more problematic.

Drawing upon Rawls' (1971, 1996) 'social bases of self-respect' Kymlicka (1991) treats cultural membership as being a precondition for the appreciation of other goods, not as a means of achieving those goods:

> *But cultural membership is not a means used in the pursuit of one's ends. It is rather the context within which we choose our ends, and come to see their value, and this is a precondition of self-respect, of the sense that one's ends are worth pursuing. And it affects our very sense of personal identity and capacity. When we take cultural identity seriously, we'll understand that asking someone to trade off her cultural identity for some amount of money is like expecting someone to trade off her self-respect for some amount of money. Having money for the pursuit of one's ends is of little help if the price involves giving up the context within which such ends are worth pursuing.* (p.192-193)

In other words, in relation to disability, if disability culture is being used to *achieve* ends not as a context within which to *choose* ends then, according to Kymlicka's argument, the idea of a distinct cultural context of disability must be questioned. The evidence from this research suggests that this *achievement-orientation* is precisely what characterises the activities of the disability community. Indeed, there is very little evidence from this research to support the idea that a celebration of a separate 'disability identity' or 'culture of disability' is occurring widely within the disability movement with the exception of the limited number of people involved with Disability Arts[1]. By the end of the research I had found no evidence for a 'culture of disability' that differs from more 'mainstream' culture and instead encountered concerns on the part of some disabled people about those engaged in Disability Arts, who they feel are 'ghettoising' disabled people by celebrating cultural 'difference' in a manner that is exclusionary. As previously discussed in chapter 6, the only cultural difference identified by respondents in this research was the issue of the acceptable use of non-politically-correct language amongst disabled people in humorous contexts. This does not appear to amount to an entirely separate 'culture'.

Further, as the views of several respondents demonstrated, many disabled individuals choose assimilation into the 'normal' world, over the cultural context of disability. In the light of Kymlicka's theorising, the only logical conclusion that can be drawn from the existence of such individuals is that they do not consider their self-respect to be connected with a strong 'cultural identity' as a disabled person. Hence for these individuals, achieving the resources necessary to become assimilated into the 'normal' world, does not mean a loss of 'true' identity. That many disabled people do not feel that the issue of 'trading off' cultural identities in order to achieve resources applies to them is exemplified in the comment made by one respondent: "*you can call me a cabbage if you like, just give me the money, basically.*" (Member of Lancaster DISC, please see ch.6 p.200)

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[1] As has been discussed in chapter 6, it is important to acknowledge that this is not the case for all members of the Deaf community, many of whom consider themselves to be members of a linguistic and cultural minority.

In this way, Kymlicka's analysis does, to a certain extent, assist in the understanding of the position and views of many disabled people, but a problem then arises, for if by his very construction, disabled people cannot be considered to be engaged in the struggle for cultural citizenship, then what alternative theory should be employed to explain the aims of the disability movement? Kymlicka's theorising is clearly of value when considering the citizenship aims of groups that are unambiguously defined by cultural context but further theorising is needed to explain the aims of groups who have no clear cultural context. The need to advance theory in this area is all the more urgent not just in the light of disability, but also because of the increasing importance of the post-modern approaches to 'ethnicity'. Such approaches propose a more fluid understanding of cultural contexts in which certain identities may be 'created' rather than originating in historical cultural contexts. Where the idea of a political 'disability identity' and disability culture were discussed by respondents, there was a clear sense that this represented a form of 'defensive engagement' akin, if not as well developed, to the defensive identities that have emerged amongst some ethnic minority groups in the face of racism (see the post-modernist account of Modood, 1997). The real difficulty, therefore, when considering cultural aims as the basis of the disability movement appears to be the assumption that there is some 'essential' cultural *difference* between disabled people and non-disabled people. Further, whilst there are undoubtedly, differences between all people, the manner in which the concept of 'difference' can be manipulated in an essentialist manner in order to categorise some groups as 'other', needs to be problematised.

Bourdieu's work on the nature of *groups and categories* is very useful here because it represents an attempt to bridge what many have considered to be a major fault line within social theory: "*between an approach which prioritises people's own understandings of their social relationships, and another which looks for and classifies behavioural patterns from a perspective which is outside the context in question*" (Jenkins, 1996: 81). In short, according to Bourdieu, between *subjectivism* and *objectivism.* According to Bourdieu, the subjectivist approach makes the mistake of assuming that individuals can or do classify themselves according to their awareness and understanding of the social world.

The objectivist stance, on the other hand, makes the mistake of assuming that the classification of individuals according to certain criteria, for example, employment, age, gender and so on, will provide an adequate description of groups as they exist in reality. Indeed, Bourdieu goes further in his criticism of objectivity, for not only, he argues, does this approach run the risk of making inaccurate assumptions about the nature of groups, it has also led to the assumption by some scholars that the groups they describe *actually exist.*

This difficulty with objectivism has allowed some theorists to argue that there are no real social differences between individuals. For Bourdieu this assertion is also wrong, however, for whilst it is not an easy task to classify discretely the great variety of individuals that make up the real world, differences do nevertheless exist. He argues that: "*it is possible to deny the existence of classes as homogenous sets of economically and socially differentiated individuals objectively constituted into groups, and to assert at the same time the existence of a space of differences based on a principle of economic and social differentiation*" (Bourdieu, 1987: 3). Bourdieu also proposes that it might be possible to do this by making a distinction between two types of collectivity, the *probable group* and the *practical group.*

In defining these two types of group, Bourdieu is clearly drawing heavily upon Marx's notion of *Klasse an sich* (class in itself) and *Klasse fuer sich* (class for itself), in which potentiality is turned into actuality, a class in itself, into a class for itself, only when individuals occupying similar positions become involved in "*common struggles, a network of communication develops, and they thereby become conscious of their common fate.*" (Coser, 1971: 49) Marx, however, somewhat *assumed* the practical existence of theoretical classes. Bourdieu (1987) questions this assumption and claims that it is only ever possible at the outset, to talk with confidence about the existence of *probable groups*, whose constituent individuals are likely to form networks and mobilize on the basis of their similar dispositions, but may not in fact do so. This is an appealing framework from which to consider the disability movement since its lack of cohesion and 'embryonic' status was well documented by respondents.

Indeed, Bourdieu also provides a useful definition of a *practical group* against which to compare *probable groups*. For Bourdieu (1987), a practical group exists when:

> *(...) there are agents capable of imposing themselves, as authorized to speak and to act officially in its place and in its name (...)* (p.15)

A paradox then arises, for whilst an individual who so identifies themselves with a group may become empowered and gain recognition, at the same time they are relegating their individual powers to those who claim to speak on behalf of the group. There are two clear risks associated with this: the first, is that when groups "*begin to represent themselves as real as opposed to constructed via social struggles, they tend to essentialize properties of individuals that make up such groups by appealing to nature, God or science.*" (Isin and Wood, 1999: 38) Bourdieu, therefore, clearly shares with Mouffe, as will be considered later, a fear that such essentialism ignores the multiple subject positions that characterise each individual. Again, in relation to the findings of this research, Bourdieu's theorising clearly resonates with the concern respondents expressed about the risks associated with embracing a political 'disability identity'. Respondents were clearly worried that such actions might lead to the essentialising of the 'disability identity' as 'other'. They also expressed fears about relegating their individual powers to the more vocal members of the disability movement who claim to speak on behalf of disabled people. In this way, the findings of this research largely support Bourdieu's warning that instead of voicing the legitimate thoughts of their members, group advocates may become an oppressive power within the collective. If Bourdieu's warnings are correct, then this must be a grave concern for citizenship theorists, for they must not rely solely upon the views of group advocates if they wish to understand the nature of citizenship being claimed by a group, but must also consider the views of the group's constituent members.

To relate this discussion to his notion of *habitus*, what Bourdieu is therefore arguing is that whilst the formation of a group does involve the conditioning of members into particular ways of being in, and understanding, the world, more so in fact than members would perhaps be aware, or wish, it is not true that all individuals displaying the same habitus are identical. For Bourdieu, the relationship between the habitus of the individual and the habitus of the group will always be homologous, but not identical. For this reason, the purpose of sociology is not to consider either the individual, or collectivities as seen as concrete groups of individuals, but rather to consider the "*mutual conditioning between group and individual habitus.*" (Bourdieu and Wacquant, 1992: 126-127)

In the light of Bourdieu's theorising, therefore, the fact that it is difficult to apply Kymlicka's notion of 'differentiated citizenship' to disabled people does not mean that the position of disabled people represents the 'exception to the rule', but rather, that it is important to question the idea of 'differentiated citizenship' when applied to any apparently distinct group.

To a degree, Young also assumes greater homogeneity within groups than may in fact exist. She does, however, acknowledge the need for a more contextualised understanding of difference. As has already been discussed at some length in chapter 3, what sets Young apart from Kymlicka is her theorising on the need for a more fluid and contextualised understanding of difference which rejects the tendency on the part of the dominant group to essentialise differences whilst denying their own specificity. Further, Young (1990) points to what she terms the 'dilemma of difference'. She defines this as a dilemma facing some socially excluded groups as they find that they have to deny that they are different from others since citizenship rights are so often based upon the equal moral worth of each individual, and yet simultaneously have to affirm their difference from other groups since formal, equal treatment, has placed them in a position of disadvantage. Young's theorising here, on the construction of difference is useful when considering the position of disabled people: a group, which she herself, in a somewhat rare move by a citizenship theorist, actually considers. Her argument, that depending upon the groups being compared and the context, differences may become more or less salient, echoes clearly with the findings of this research. Her use of the following example also relates to these findings:

> *(...) in the context of athletics, health care, social service support, and so on, wheelchair-bound people are different from others, but they are not different in many other respects. Traditional treatment of the disabled entailed exclusion and segregation because the differences between the disabled and the able-bodied were conceptualised as extending to all or most capacities.* (Young, 1990: 171)

Young considers that traditional politics has excluded or devalued people by suggesting that there are such things as essential differences. 'Difference' is therefore, best viewed as the result of social processes, as a *social construction.* According to Davis (1999) it is precisely this notion of essential difference that has been perpetuated by the highly criticised Medical Model of Disability. For those who are involved in the construction of welfare policy there has been a convenient tradition of assuming that disabled people are 'different'. This has had two results: firstly, the development of a number of often disempowering apparatuses of welfare for disabled people, based upon assumptions about their 'special needs' and their dependency. Secondly, it further supports the notion of 'bodily perfection', in which disabled people are viewed as the imperfect 'other' and the non-disabled community refuse to accept their own, perhaps less visible, bodily imperfections or vulnerabilities.

As Davis (1999) has commented, this attachment to the Medical Model and associated notions of ab/normality has been heavily criticised by the disability movement. Further, campaigns by organisations of disabled people based upon the notion that all people are vulnerable and interdependent to some extent during their lifetimes, strike at the very heart of widely held beliefs about 'difference'. According to Delanty (2000) this new emphasis upon personhood "*whereby the self is contextualised, contingent and decentred*" (p.69) is the result of human rights discourses impacting upon notions of citizenship. There is then, a risk of lapsing into a 'false consciousness' when considering identity and culture amongst disabled people. Everyone has an identity, and everyone has the right to have that identity respected by others. Further, it would be inaccurate to state that the imagery of 'identity', 'difference' and what Fraser (1995b) terms 'recognition', do not play a part in the disability movement's campaigns. There may be, however, misconceptions about the true nature of disability identity politics. The findings of this research suggest that whilst disabled people are keen to achieve recognition and respect, they are not seeking to be recognised as having essentially *different* identities from those of non-disabled people, or as being a part of a *different* culture, but rather, as equal *persons*.

Indeed, the evidence from this research suggests that most disabled people see themselves as having been 'labelled' as disabled, and that, therefore, their identity has been forced upon them. The disabled identity can thus be a negative social construct at times, and one that disempowers those who are forced to accept this label. The extent to which this 'label' has negative implications was clearly demonstrated by respondents who referred to the difficult transition and subsequent identity crisis that had occurred when they became disabled, or to their observations of this experience on the part of others.

It would seem clear that two key emotions are felt during this transition from a non-disabled identity to a disabled identity: firstly, a deep depression about the change in body capabilities further exacerbated by preconceived ideas, constructed whilst non-disabled, about the negative identity of disabled people. Secondly, anger is felt at the injustices experienced by disabled people and the subsequent development of a 'political identity' as a disabled person that may bear no relation to the person's sense of genuine personal identity.

Revaluing disabled people as possessing non-stigmatised identities has, therefore, been key to the limited number of identity-based campaigns by the disability movement. Evidence from this research suggests, however, that disabled people perceive there to be risks associated with such campaigns, for at times the political identity of disabled people that is key to a cohesive vision of the disability movement appears to be purposefully maintained in order to disguise the genuine lack of unity within the movement. Maintaining a unified political identity in this way then becomes too reductive of the complexities of social identities (Fawcett, 2000). Feminist approaches to disability have highlighted the fact that whilst power does appear to exist throughout the network of social relations, it does not circulate equally:

> (...) *challenges can be seen to be emerging in relation to the 'universalism' of disabled people's movements, based on the social model of disability, by calls for the inclusion of issues related to gender, 'race', impairment, ethnicity and age.* (Fawcett, 2000: 4)

Thus, disability is best viewed as a contested concept and issues of unity surrounding the homogeneity of the disability movement need to be considered carefully.

The great strength in Young's work, therefore, is in the way that she acknowledges that differences can sometimes be essentialised. At the same time, however, the manner in which she then goes on to utilise her understanding of difference to develop a model of democracy and citizenship is somewhat more problematic. Indeed, at times, it is hard to see how her own thoughts on difference connect with her theorising on democracy. This issue has already been discussed at some length in chapter 3, but whilst it is not the intention here to repeat the critique of Young's theorising that appears there, it is important to consider how the evidence from this research relates uneasily to some important aspects of her work.

The first way in which the evidence from this research does not appear to correspond with Young's analysis, is in relation to the idea that the self-organisation of group members in order that they achieve collective empowerment is both possible and desirable. As has previously been discussed in this chapter, both the views of the respondents and the arguments put forward by Bourdieu question Young's views in this regard. The findings of this research suggest that disabled people are far from being a *practical group* and many disabled individuals have profound concerns over the effects that a the transition towards such a group may have in relation to the abdicating of individual powers. This is a particularly thorny issue for disabled people in the light of the obvious divisions between disabled people and the lack of a unifying 'disability identity'.

The second way in which evidence from this research challenges Young's work is in relation to her reliance upon the idea that the only collectivities that should be given specific representation are what she defines as 'social groups' which are culturally determined. Whilst she acknowledges the existence of collectivities that are based on other factors such as interest groups, she nevertheless prioritises cultural issues over any other. As has already been discussed in relation to Kymlicka's work on cultural citizenship, the evidence from this research suggests that there are potential problems with Young's approach at this point. Firstly, disabled people along with many other disadvantaged groups within society still face major structural inequalities and for disabled people at least, these issues form the major focus of their campaigns. Further, as the previous discussion here and in chapter 6 has indicated, the 'culture of disability' is not a uniting factor amongst disabled people. According to Young's theory therefore, disabled people as a collective would not be considered to be a 'social group' and would not be allowed specific representation. It is hard to see, therefore, how Young's notion of democracy is likely to improve the position of groups who are concerned more with redistribution than recognition.

Further, as the previous discussion demonstrates, the issue of how to define a culture remains, and it is unclear, for example, whether Young would give representation rights to 'defensive cultures' which do not exist historically but have developed in the face of prejudice. Would Young give disabled people specific representation rights according to a 'culture of disability' that is based not upon an essential cultural difference between disabled and non-disabled people, but upon a process of defensive engagement in an unjust society? Since only limited numbers of disabled people regard themselves as being a part of a 'culture of disability', and many disabled people reject the idea or are ambivalent about it, giving such culturally based representational rights would have implications for any individuals who may appear to be members of that collective but who do not share the cultural identity. For any groups, such as disabled people, where their identities are clearly *embodied*, giving such a group representational rights on the basis of a purportedly shared culture runs the risk of locking all members of the group into an alleged shared identity which bears no relation to their own true sense of identity. That is to say, if you are *obviously a disabled person*, then clearly you must also be a part of that 'other' culture. The risks associated with such separatism were considered by several respondents in this research to be matters of grave concern.

Given this apparent disjuncture between some important aspects of both Young and Kymlicka's theories and the findings of this research, it must be concluded that in relation to disability at least, the pluralist accounts of citizenship do not appear to be entirely satisfactory. Of course, it must be stated that some of these problems have been acknowledged within even more recent pluralist accounts by authors such as Stevenson (1997a/b). Stevenson, for example writes about the need for a multi-layered notion of citizenship in which 'cultural citizenship' is viewed as a model in which a diversity of rights, both structural and 'identity' based can be guaranteed. Whilst this may at first seems a more convincing approach, the intractable problem of the continuing focus upon 'culture' and the idea that social groups can be defined by their need for cultural recognition remains in relation to disability.

It is at this point that I think it is interesting to return to the work of Berlin, and to propose that whilst undeniably a liberal, elements of his thinking may form the basis of a more convincing pluralist approach. Where Berlin differs from pluralist thinkers such as Kymlicka and Young is in the way that his particular *brand* of pluralism is not about seeking recognition for disadvantaged groups on the basis of respect for different cultures *per se*, although he would consider this to be entirely necessary under certain circumstances and for particular groups, but rather is about ensuring that all individuals are regarded as 'fully human'. In this respect, Berlin's work is clearly an important part of the human rights debate. Whilst some critics have pointed out that Berlin's adherence to the principle of a 'minimal moral horizon' common to all human societies and cultures, is an essentially universalistic concept, and therefore somewhat stands in tension to his anti-monistic theorising, I think that this aspect of his work is of considerable importance and merits re-consideration. In particular, the importance of Berlin's thinking is clear when it is compared with the writings of both Habermas and Mouffe, both of whom have provided some important alternatives to both the liberal and pluralist accounts of citizenship.

Beyond the pluralist account

Both the reflexive and post-structuralist accounts of citizenship may well provide some way out of this apparent disjuncture between pluralist accounts of citizenship and the true nature of the 'struggle' engaged upon by the disability movement. Shafir (1998) highlights the way in which the journey from modernity to late/post-modernity has resulted in an increasingly complex set of frameworks within which the individual constructs their citizenship identity. Further, it is easy to see how global citizenship and the notion of human rights can coexist uneasily and sometimes in out-and-out conflict with national or more community based notions of citizenship. It is in the light of these changes that Habermas developed his reflexive account of citizenship, and Mouffe her more post-structuralist account. Whilst both authors are firmly opposed to the liberal approach to citizenship, nevertheless, some interesting links can be seen between their work and that of Berlin.

Berlin's (1958) notion of a 'minimal moral horizon' is clearly echoed by Habermas when he proposes a form of citizenship as a 'minimal shared identity' in which consensus is reached between members of society by striving for a 'reflexive position'. Such a 'reflexive position' Habermas describes as being the critical appropriation of competing positions. Whilst essentially 'macro' in approach, the strength of Habermas' thinking in this regard is in his lack of focus upon the politics of difference as the 'end goal' of citizenship and instead upon processes of reflexive engagement which involve individuals and groups from a variety of different positions striving for shared interests. There are two problems with this approach however: the first relates to the fact that Habermas appears to have over-looked the importance of power when considering the ability of individuals to reflexively engage. Differentials of power, often flowing from differential control of resources of one type or another, still affect the degree of autonomy individuals have as actors. As the findings of this research show, disabled people still experience profound problems in what Habermas would term the 'pre-discursive' space in terms of lack of resources within or access to, the public sphere. These problems have clear implications in terms of limiting the ability of disabled people to actively participate in this process of reflexive engagement.

The second problem is clearly articulated by Mouffe (1992, 1993) in her consideration of the fragmentary effects of multiple identities upon the public sphere. Whilst Berlin's notion of a 'minimal shared horizon' is also clearly echoed in terms of the end goal of Mouffe's 'radical democracy', the strength of Mouffe's thinking is in her understanding of the polity as a 'societas' of individuals with shared interests, but with very different ideas about the meanings and definitions of these shared interests. Mouffe's ideas about the 'multiple self' is also key here for she also proposes that the multiple subject positions individuals inhabit will further complicate the processes within a radical societas as members of particular groups are likely to have very different ideas about the meanings and definitions of their shared interests. In the light of this complexity, achieving a 'minimal shared horizon' is likely to be increasingly difficult but all the more necessary if society is not to become dangerously fragmented. The considerable worth of Mouffe's thinking on this point is clear when compared to the findings of this research, for the fragmented nature of the disability movement is something that was clearly articulated by several respondents.

Divisions between disabled people on the grounds of impairment became apparent during the research, the major issue being the reluctance on the part of some people with physical impairments to associate themselves with people with a learning disability or a mental health problem. Although this is usually explained with regard to limits to the professional knowledge of the organisation

I suggest that in fact this division highlights two important points. Firstly, it suggests that if we consider 'disability' from within a framework of 'stigmatisation', then if people with a learning disability or a mental health problem are more cruelly or differently stigmatised by society than people who have a physical impairment, then it is understandable that physically disabled people who already feel their own identities to be stigmatised, would not wish to take on the stigma of others, through association. Secondly, it demonstrates how pervasive certain images of people with a learning disability or a mental health problem can be, if even amongst disabled people there is a degree of prejudice. Subsuming this diversity under one heading 'the 'disability identity'' and using this as something to rally around is, therefore, unlikely to be successful within the disability movement.

Clearly then, the pluralist notion of citizenship is brought into further question since, in the light of such complexity, identity politics and the 'politics of difference' are unlikely to achieve consensus. In the light of this, the idea that all individuals should be striving for a 'minimal shared horizon' becomes even more appealing, if even more difficult to achieve. That the nature of citizenship is changing in the light of this progressive fragmentation of the public sphere is something that Ellison (1997, 2000) has clearly identified and his theorising, it seems to me, represents a very interesting new development in this field. Ellison's approach seeks to combine a more convincing reflexive/post-structural account of contemporary citizenship with an understanding of current forms of protest and social movements. In doing this, he proposes that citizenship is now best understood as a process of defensive and/or proactive engagement in the context of a society characterised by increasingly complex social and political identities:

> *The argument here is that rapid change transforms the nature of citizen participation and 'encourages' engagement, willing or not, in the pursuit, or defence, or particular interests and/or social rights. In short, both the capacity to engage, and the differential nature of engagement itself, are rapidly becoming the most significant features of a citizenship conceived as a series of fractured 'contiguous belongings' (...)* (Ellison, 2000: para. 1.1)

Ellison's (2000) definition of *defensive engagement* is particularly useful when considering the position of disabled people because he defines it as being the activity of "*those lacking access to relevant power networks who find themselves engaged in efforts – perhaps to maintain a status quo, or to develop new arrangements – simply to preserve existing interests and entitlements.*" (para. 1.4) In other words, if the context in which a group engages is one in which power is concentrated in the hand of the 'opponent', then the group may only be able to engage defensively. In terms of understanding citizenship this is a useful model because it explains why some disempowered groups such as disabled people may appear to be more concerned with protecting and enhancing existing rights than with claiming 'new' rights. Thus, 'defensive engagement' is a useful way of explaining the findings of this research which suggest that many disabled people are more concerned about achieving *real* equal treatment in spheres where they are already 'officially' equal (for example in relation to equal opportunities legislation in employment), than they are about claiming 'new' rights on the basis of 'identity politics'.

Whilst providing a useful way of *understanding* the functioning of movements such as the disability movement, the really interesting aspect of Ellison's (2000) approach, however, is that he questions the extent to which, ultimately, '*defensive forms of engagement*' which are '*likely to be organised around social divisions already shaped by existing discourses*' enable true *agency* (para. 7.3). In defending particular sets of interests, he argues, a group may utilise identities such as the 'disability identity' as a way of appealing to a supposedly pre-existing sense of solidarity. Quite apart from the problems associated with whether or not such identities are true representations of solidarities, Ellison states that this approach does not give the same scope for agency that more pro-active engagement might provide. A more genuinely pro-active approach could move beyond existing discourses such as disabled/non-disabled and allow instead for the challenging of '*established assumptions about social divisions*' (Ellison, 2000: para. 7.3). New and differently conceived solidarities might then emerge which by the very nature of their formation will be inherently unstable.

Having stated that Ellison considers proactive engagement to enable agency more than defensive engagement that is not to say that he is overtly proposing that proactive engagement is the *preferable* form of engagement. Indeed, he states clearly that it is the hallmark of contemporary citizenship that individuals are able to engage defensively ***and/or*** proactively and the two forms of engagement are not mutually exclusive:

> *(...) individual citizens can simultaneously inhabit class, gender and/or ethnic solidarities for defensive purposes in particular areas of the public sphere, while rejecting the logic of these belongings when engaging proactively elsewhere.* (Ellison, 2000: para. 7.3)

I think that it might, in fact, be necessary to go one step further than Ellison and suggest that proactive engagement *is* likely to bring about the best long term results for disadvantaged groups since it is about *transforming* rather than working *within* existing social relations and in so doing is more likely to be able to tackle the assumptions that may be underpinning social exclusion. Further, my argument here is that the very act of defensive engagement only becomes necessary in the absence of previously successful proactive engagement. In other words, defensive engagement becomes necessary when disadvantaged groups have been excluded from decision-making processes and have thus been unable to influence the development of structures or policies that impact upon them. The hallmark of contemporary citizenship then becomes the ability to engage *proactively* and without the need to engage *defensively*. Whilst this idea may be slightly at odds with Ellison's theorising, nevertheless it remains true to his understanding of citizenship as a *process*. This aspect of his work is, I suggest, the most important.

Whilst the types of issues that may form the bases of this proactive engagement will be considered in the final section of this chapter, it is important to note that although Ellison's approach clearly represents an important new development in terms of our understanding of *citizenship*, by defining citizenship as a *process of* *engagement,* it is also a vital new development in terms of social movement theorising. As has already been discussed at some length in chapter 4, some important issues remain as yet unresolved within the social movement theorising.

Implications for social movement theorising

As has been discussed in chapter 5, the current debates in the field of social movement theorising focus upon the key differences that exist between what I have termed the First and Second Phase theorising and between the American and European traditions. Amongst British theorists in this area there has been a tendency to favour the Second Phase European approaches of authors such as Touraine, Habermas and Melucci and to embrace their ideas about ‘new’ social movements. Indeed, so popular has this approach been, that it has been used enthusiastically by some key figures within Disability Studies who claim that the disability movement is a ‘new’ social movement (see Oliver, 1997).

The findings of this research however, do not support the idea that the disability movement is a ‘new’ social movement. Whilst it is not my intention here to revisit my discussion of the second phase European theories at this point, it is important to highlight the fact that according to this tradition, ‘new’ social movements can be defined as acting within a broadly defined socio-cultural sphere and as having largely moved beyond a focus upon structural issues. For the disability movement to be a ‘new’ social movement, therefore, then the type of citizenship underlying the disability movement would *clearly* reflect the pluralist account of citizenship. As the previous discussion has demonstrated, it is not easy to locate the type of citizenship underlying disability campaigns in any one of the modern/contemporary models of citizenship, but it is especially difficult to analyse the goals of the movement in terms of the ‘politics of difference’ of the pluralist account.

By way of demonstrating this point, whilst in no way completely disregarding all of Touraine’s contributions to social movement theorising, his focus upon identity and culture as the basis of social movement activity is brought into question by the findings of this research. As the previous discussion has shown, the disability movement is not, on the whole, concerned with defending the cultural parts of private life as are, he suggests, other contemporary social movements. Further, the disability movement does not appear to be about redefining culture and lifestyle, the "*grammar of forms of life*" as Habermas (1981: 33) suggests, or about seeking a "*space for difference*" as Melucci (1985: 810) believes. In the light of the problems associated with the essentialising of difference and the rejection by many disabled people of the idea of a positive 'disability identity', such theories must be questioned.

Further, Melucci argues that contemporary social movements are positioned outside the established boundaries of political systems and are characterised by 'alternative' behaviour such as deviance and 'cultural experimentation'. Again, very little evidence emerged during this research to support the idea that there is a 'culture of disability' being widely celebrated by disabled people or that disabled people wish to be seen as 'deviant' from the 'norm'. Indeed, quite on the contrary, most respondents in this research questioned the notion that disabled people are 'different' from non-disabled people in any *essential* way. Further, several respondents, as discussed in chapter 6, highlighted what they considered to be the importance of establishing a firm place for disabled people in the established boundaries of political systems and of ensuring that the views of such individuals are taken seriously.

In the light of the findings of this research therefore, and according to current social movement theorising, the disability movement's status as a 'new' social movement must be placed in some doubt. Indeed when writers such as Oliver (1997) state enthusiastically that the disability movement is a 'new' social movement there is a sense in which he is attempting to theoretically hammer the 'square peg' that is the disability movement into the 'round hole' of existing theorising. I propose that the findings of this research indicate that the disability movement is unlikely to ever correspond to the existing theories of 'new' social movements and that a more productive approach may be to start by considering how an understanding of the disability movement might lead to the development of a more convincing theory of contemporary social movements.

Whilst it is not possible within the confines of this thesis to develop such an alternative approach, it is nevertheless interesting to consider where the point of departure might be for this new theorising. One question raised by the findings of this research is the extent to which it is either necessary or desirable to completely reject the first-phase theories of social movements. Blumer's ([1951] 1995) understandings of social movements, for example, seem very useful in the light of the disability movement. The movement would appear to reflect Blumer's definition of a 'general social movement' to the extent that the disability movement does appear to be moving in a groping fashion only slowly towards its goals, and to be structurally disorganised with no clear leadership or locational focus for its struggle. It is also interesting to note that Blumer's definition of a 'specific social movement' is also of use when analysing the disability movement, for it is the obvious lack of a 'we-consciousness' or shared identity amongst disabled people that marks out the movement as *not* being a 'specific movement'.

Further, according to Blumer, during the transition from general to specific social movement, ideology plays an important role for it must carry respectability and prestige and answer the genuine wishes and hopes of the members of the movement. That such a widely agreed upon 'populist' ideology is absent within the disability movement is evident from disagreements over issues such as the extent to which non-disabled people should be excluded from participating in the disability movement or disability research, or the nature of the relationship between illness and disability. It must be concluded from this that the disability movement is a long way from becoming a specific social movement. To define the disability movement in this way as a 'general social movement' in its early stages of development clearly corresponds with the comments made by respondents about the 'embryonic' nature of the movement.

The problem with Blumer's approach, however, as has been discussed in chapter 4, is that he somewhat assumed the natural 'career path' of social movements from general to specific. Whilst at times Tilly's approach to social movement theorising may be too programmatic, nevertheless, his critique of this aspect of the collective behaviour model of authors such as Blumer is instructive. Tilly's (1993) much more fluid definition of social movement activity sees them as: *"dragons living continuously somewhere in the social underground, but emerging recurrently from their labyrinths to stomp around roaring."* (p.6). In this way he does not give social movements the progressive life histories implied by the collective behaviour approach. Instead, he proposes that social movements are best understood as varying in nature according to the effects of four main factors: the nature of the claims being made by the movement; the prevailing political opportunity structure; the shared understandings of the participants, and the social structure from which members are drawn (1993: 19). This is an appealing approach because in terms of this research it explains how factors such as the continuing focus of many disabled people upon structural issues and the lack of a shared identity amongst disabled people, shape the nature of the disability movement. This approach also avoids the old/new distinction that may not, as has already been discussed, be entirely justified or productive.

Tilly's approach therefore avoids the underlying *implication* within Blumer's work: that the ultimate goal of a social movement *should be* to become homogenous. According to Tilly's schema it would therefore, be entirely possible for a movement to be comprised of both separatist and non-separatist factions, factions based upon differing ideological beliefs and factions based upon the addition of further factors of inequality. Such divisions, according to Tilly's schema, do not necessarily bring into doubt the existence of a movement, but do alter it's structure. Thus, to understand the disability movement in the light of Tilly's theorising, it is vital to *acknowledge* divisions within the movement, for example between the separatist and non-separatist factions, for such divisions will affect the nature of the movement.

Tarrow furthers Tilly's theorising by adding into the equation the idea that social movements must also be understood according to the level at which they are able to sustain collective action. Tarrow appears to share Tilly's definition of social movements as 'dragons' which emerge only sporadically to struggle against particular foes and particular threats. He adds to Tilly's definition, however, the idea that movements have inherent problems in relation to "*co-ordinating unorganised, autonomous and dispersed populations into common and sustained action.*" (Tarrow, 1994: 9) As the evidence from this research demonstrates the disability movement does indeed experience these collective action problems. Tarrow's analysis is therefore of considerable use in this regard. His work on 'mobilizing structures' can also be profitably employed when considering movements such as the disability movement. Although many key activists and writers in this field see organisations such as the British Council of Disabled People (BCODP) as a 'mobilizing structure', the evidence from this research demonstrates that not all disabled people agree on the importance of the BCODP to their lives or to the disability movement as a whole. It can be argued, therefore, that the very absence of such 'mobilizing structures' within the 'embryonic disability movement' accounts for the latter's problems in relation to activating and sustaining collective action.

A problem does arise in relation to both of these approaches however, for if a social movement is significantly divided in terms of its constituent groups, and has mobilizing difficulties, then how is it possible to state categorically that it is a social movement as opposed to a political coalition or a loosely structured protest event? It is the argument here that Della Porta and Diani (1999) provide the most convincing answer to this question:

> *The aspect which enables us to discriminate is the present of a vision of the world and a collective identity which permit participants in various protest events to place their action in a wider perspective. In order to be able to speak of social movements it is necessary that single episodes are perceived as components of a longer-lasting action, rather than discrete events; and that those who are engaged feel linked by ties of solidarity*

> *and of ideal communion with protagonists of other analogous mobilizations."* (p.19)

This is a useful quote because it explains how despite the apparently heterogenous nature of the disability movement, it can still be categorised as a social movement: Firstly, whilst the evidence from this research suggests that it is important to treat with caution the idea that a collective identity based upon a *positive 'disability identity'* exists within the disability movement, this is not necessarily the type of collective identity implied by Della Porta and Diani. It is the argument here that according to this approach the existence of such a collective identity may amount simply to the acknowledgement by constituent members that they have been labelled as being the *same*, in some way. In the case of this research the collective identity is therefore, the experience of the label of 'disability'. More importantly, despite the heterogeneity within the disability movement it is still possible to see that constituent members share an overall vision of the world as 'disabling'. This may be one of the only views behind which all respondents in this research would unite, but it is of fundamental importance to the disability movement. Finally, the evidence from this research also suggests that whilst total agreement does not exist amongst the various factions of the movement, an overall solidarity does exist. This solidarity was demonstrated by the reluctant way in which certain respondents criticised leading organisations, such as the BCODP. Such respondents clearly felt sufficient affinity with, and perhaps even 'loyalty' to, this organisation to be reluctant to criticise the organisation to any great extent.

However, despite the appeal of these aspects of previous models of social movements, in particular of their explanations for both 'how' and 'when' social movements can be seen to exist and mobilize, these theories do not provide adequate explanation for 'why' social movements come into being in the first place. In the light of this weakness in the older approaches, I propose that any new theory of social movements, whilst building upon some aspects of older traditions, would need to focus upon this 'why' aspect of movements. As has already been discussed, in the light of this research, the second phase European theorists' focus upon culture and identity as the being at the heart of the campaigns of 'new' social movements does not explain the activities and aims of all contemporary social movements and so this aspect of the approach is unlikely to provide the best starting point for this new theorising.

That having been stated, there are some strands of thinking within the second phase European approach that may prove to be more fruitful. When both Habermas (1981) and Melucci (1993) write that the important role of social movements is to prevent the system from closing in upon itself and in Melucci's (1993) view to expose the "*shadowy zones of invisible power*" (p.190), it is possible to see how these ideas link with the theory of engagement proposed by Ellison (2000) for they are both calling for a more radical sense of democracy.

Although Melucci is probably the chief proponent of this approach to social movement theorizing, what is often termed the Reactive/Defensive Model can also be seen in the work of Foweraker (1995). Foweraker (1995) echoes much of the work of Melucci when he states that 'new' social movements are the result of major changes in society, changes in particular to the boundary conditions of the social system. Reflecting Melucci's (1993) theorizing on the "*shadowy zones of invisible power*" (p.190), Foweraker draws upon the work of Foucault (1979) when he comments that 'new' social movements challenge the 'microphysics of power'. Thus, the role of these movements becomes one of reaction to negative aspects of these changes in the social system and to the 'microphysics of power', in defence of the position of the group. As the previous discussion and Bourdieu's work has demonstrated, care must be taken when using the term 'group', nevertheless, Foweraker's overall conclusion, that 'old' or 'new', in the end, the central focus of all social movements is *citizenship*, is an important contribution to this debate.

Here again, the link between Foweraker's work and Ellison's notion of 'engagement' is also clear for they both consider understanding 'citizenship' to be at the heart of understanding contemporary social movements. Ellison's work is of central importance because it highlights the need for greater understanding of not only the process of engagement, but also the kind of rights that are in need of defence or are being proactively sought. In other words, what Ellison proposes is that understanding the true nature of the contested citizenship is key to understanding social movement themselves.

The future for citizenship theorising?

As has already been considered earlier in this chapter, one of the departure points for understanding the true nature of contested citizenship may be Ellison's understanding of the difference between the goals of those engaging *defensively* or *proactively*. As has also been discussed, the work of Berlin on the 'minimal moral horizon' and Habermas on the 'minimal shared identity' combined with Mouffe's understandings of 'radical democracy' and the nature of the 'societas' are also theoretically important. There may be other areas of theorising that need to be considered along side of these however, and it is the argument here that such areas include: *human rights discourses; theories of personhood; and theories of embodiment.*

In chapter five, new trends in Medical Sociology were discussed which stress the need for a more *embodied* understanding of disability (Bendelow and Williams, 1995, Hughes and Paterson, 1997). Thus there are calls for a more highly developed theory of impairment and for Disability Studies to actively engage with the sociology of the body. Such research has been concerned with the ways in which both lay and professional attitudes towards disabled people can radically constrain the competence of disabled individuals. Whilst these new ideas are being increasingly embraced by Medical Sociology, Disability Studies appears to have been reluctant to consider such issues. This reluctance on the part of Disability Studies may be due to concerns about the possible weakening of the Social Model of Disability that might result from proper engagement with issues of embodiment. It is the argument here, however, that the costs in terms of questioning the Social Model of Disability may be outweighed by the benefits that can be gained by placing disability firmly at the centre of contemporary theorising on the embodied self.

As has already been discussed in chapter 3, Turner has developed a sociology of the body which places theorising about the *embodied* nature of human life at the heart of many of the central sociological debates. Whilst it is not possible within the limits of this thesis to consider in any great depth the implications of all of Turner's theorising here, it is important to note how his concerns with the ethical implications of medical interventions into people's lives is of considerable value to debates surrounding the eradication of congenital disabilities via genetic screening and other new techniques. His ideas about the cultural formation of the body also have implications for understanding the effects of powerful images such as the 'body-beautiful' on both the lives of disabled people and perceptions of disability amongst non-disabled people. At this point in Turner's theorising, the links between his ideas and those of Goffman (1968) on stigmatised bodies and Foucault (1979) on 'abnormal' bodies and stigma is clear. As has already been discussed, Goffman's work, in particular, remains central to understanding both the attitudes of non-disabled people towards disabled people and the divisions that exist between disabled people and which account, at least in part, for the fragmented nature of the disability movement. Further, the work of Foucault (1979) on the manner in which the body has become increasingly governed by the state and is firmly connected to systems of domination and oppression has clearly influenced Turner. Understanding the ways in which the body is both governed and oppressed is of great value when considering the lives of disabled people. Where Turner departs from both Goffman and Foucault, however, is in his rejection of the earlier theorists' views of the body as being almost *entirely* socially constructed.

According to Turner, the central problem with the view of the body as entirely socially constructed is that it ignores the materiality of embodiment. In this respect there are clear links between Turner's theorising on the body and Jenkins' (1998) notion of the 'materiality of identity'. Thus, for Turner ([1996] 2000):

> *There is a phenomenology of the life-world as a lived experience, about which cultural relativism and structuralism have no interest or purchase*. (p.492)

Again, the links between Turner's work and current moves within Medical Sociology in terms of developing a more embodied notion of disability are clear and the frequent use of his work within current Medical Sociology reflects this. The strong point of his approach is that it appears to provide a way of closing the divide between impairment and disability. This is important because despite arguments by authors such as Oliver (1997) in favour of the development of a separate model of impairment that together with the social model of disability may produce a *social theory of disability,* it is the argument here that *closing, not redefining* this divide is essential. It is no longer possible to ignore or bracket off into a separate 'category' the experiences of such things as pain and the effects that such sensual experiences have upon the 'self' and identity. For Turner, there should be equal focus upon this 'materiality of embodiment' as upon the historical controls that have been placed, for example, upon disabled bodies by non-disabled medical professionals. It is understandable given the level of importance Turner gives to the materiality of embodiment that some proponents of the Social Model find this approach threatening. Turner's views should not be seen in this way, however, for his ideas do not threaten the central tenet of the Social Model, that society 'disables' individuals with impairments. Rather, his ideas are of considerable importance in dealing with the real threat to the Social Model, which is that many disabled people who are not 'able-disabled' or who experience illness or pain, have felt that their experiences fall 'outside' the Social Model. If the Social Model of Disability is to be truly inclusive of the experiences of all disabled people then it must engage with issues of embodiment or it will risk losing veracity.

Having established his Sociology of the Body, Turner then turns his attention to the implications of this embodied understanding of personhood to discourses of citizenship and human rights. He proposes that: "*given frailty and precariousness, human beings need a universalistic legal framework in which to seek protection.*" (Turner, [1996] 2000: 496). In other words, Turner is proposing a theory of personhood as inherently fragile and a corresponding theory of human rights that rests upon the awareness of every individual of their own vulnerability. Thus:

> *Human beings will want their rights to be recognised because they see in the plight of others their own (possible) misery.* (Turner, 1993b: 506)

Clearly there is some way to go before the majority of people become so 'enlightened', but it is an appealing ideal.

There is, as yet, however, an unresolved problem in Turner's work and this is whether or not such a notion of human rights removes the need for citizenship rights? Turner (1993b) suggests that human rights debates are beginning to replace citizenship debates and that achieving proper human rights for all would mark the end of the need for citizenship. I am uneasy about his thinking in this regard, however, for he appears to be avoiding the problem of *governance*. Even if a universally agreed set of non-culturally specific human rights could be drawn up, and this is itself likely to be a utopian aim, individuals would still remain the 'citizens' of a given state. The apparatuses of that state would remain central to the lives of individuals and be the main context within which individuals seek support against risk. Under such circumstances the idea of human rights as existing beyond the boundaries of the state is problematic.

By way of tackling this problem, this thesis argues for a new understanding of citizenship as ***a** process of proactive engagement, in a radical democracy, for the achievement of human rights for all citizens on the basis of a universal acceptance of vulnerability.* Rather than rejecting Turner's theory of human rights, therefore, I suggest that the way to overcome this problem of governance is to position human rights at the heart of citizenship, with citizenship acting as an 'umbrella' for Human Rights rather than the other way around. In this way, human rights can be viewed as representing what Berlin termed the 'minimal shared horizon' and citizenship becomes a process akin to Mouffe's notion of radical democracy or Ellison's proactive engagement in which the goal is to guarantee that this 'shared horizon' is experienced by all.

Such a notion of citizenship as a *process* also avoids overly emphasising rights as opposed to responsibilities, for if the nature of the 'minimal shared horizon' is an understanding of personhood as vulnerable and contingent, then each individual in claiming their right to be protected from the effects of potential vulnerabilities is also defending the rights of others to receive support in the light of their *actual* vulnerability. Such a notion of citizenship is one that avoids marking out certain groups as 'other' and in so doing makes it clear that we are all vulnerable in terms of disability, poverty or other forms of social exclusion. Such a concept of citizenship also removes the need to make a distinction between structural and identity based rights, for since cultural identity may be an important part of an individual's sense of personhood, then they must also be protected from forces which might attack this aspect of their person. Dominant groups must acknowledge their own cultural specificity and that their own cultural identities are potentially precarious and need to be defended, in so doing, as argued above, they guarantee that those whose cultures may *actually* be vulnerable, receive protection in this regard.

Conclusion

This research has demonstrated that by placing disability at the heart of citizenship debates, valuable insights can be made into both the strengths and the weaknesses of a number of modern/contemporary theories of citizenship. The argument in this chapter and throughout the thesis has also been that analyses of contemporary social movements such as the disability movement must go hand in hand with the development of new theories of citizenship, for it is clear that if citizenship is to be seen as a process of engagement, then social movement activity is likely to be a major part of that engagement. Finally, it has also been the contention in this research that whilst competency, personhood, embodiment and human rights are becoming important areas of debate within Medical Sociology, Disability Studies must not avoid such issues for it seems likely that they will be key to the citizenship debates of the future. As has been demonstrated in this chapter and throughout the thesis, it is vital that disability be placed at the heart of these debates.

Chapter 8

Conclusion

Theoretical Issues

The aim of this research has been to reconsider the appropriateness of existing theories of citizenship and social movements in the light of the structure and aims of the disability movement. It has been contended within this thesis that a consideration of the true nature of the 'struggle' faced by disabled people serves to illuminate useful links between citizenship theorizing and current approaches to social movements and in so doing provides the basis for the development of a new model of citizenship. Central to the argument put forward in the preceding chapters have been the important links between the work of Berlin, Habermas, and Mouffe; to the value of Ellison's ideas about 'proactive and defensive engagement'; and to Turner's 'sociology of the body'.

The conclusion to this research, however, whilst having clear theoretical antecedents, nevertheless remains original in that it proposes a new understanding of citizenship as a process of proactive engagement, in a radical democracy, for the achievement of human rights for all citizens on the basis of a universal acceptance of vulnerability. In proposing that an understanding of personhood as fragile and contingent should be the basis of human rights, which in turn should be located within the umbrella of citizenship and form the basis of the 'minimal shared horizon', the argument put forward in this thesis thus stands in some contrast to existing theories.

In proposing a new model of citizenship, however, whilst making some suggestions at a fairly abstract level, this thesis does not profess to have provided an account of how such a model could be 'operationalised'. In leaving the theorising at this abstract level, therefore, there is always the risk that the model can be criticised on the basis that it is as utopian as previous models. In the confines of this thesis, however, it has not been possible to extend the theorising beyond the abstract. Clearly, however, it is important for the validity of the argument put forward here, that the model be 'operationalised'. Future research is needed, therefore, to support the theorising in this thesis and there are a number of likely avenues that such research might take. The importance of education and political institutions in fostering this model of citizenship as something that is empowering for every individual, is something that particularly interests this author. The scope of this model in terms of challenging a range of powerful discourses based around 'the body' also means that it could be usefully taken up by those involved in emancipatory politics, for example, by activists and academics in the field of 'race' and gender. Future research in these areas might consider how the idea of universal vulnerability can be used to challenge, and move beyond, discourses surrounding black/white and male/female.

It is crucial, however, that any future research which uses this model, as well as harnessing its potential for challenging existing power imbalances, also acknowledges that such imbalances of power are likely to have an adverse effect on the ability of disempowered groups to do precisely this, to oppose powerful discourses. Whilst theorising thus may seem like a contradiction in terms, nevertheless, failing to acknowledge that the development of any new model of citizenship must take place within existing frameworks of power/powerlessness would bring into considerable doubt any proposed methods for making the model work in the real world. In the future, therefore, as well as research into the 'operationalising' of the model, more abstract theorising will also need to continue in order to understand the effects that power imbalances may have upon the development of this idea of citizenship.

Methodological Issues

As has been discussed in chapter 2, it has also been a central concern of this research to inject the voices of disabled people into the citizenship/social movement debates and to provide a platform for their opinions. For this reason a qualitative research paradigm was employed that sought to maximise the inclusion of the voices of the respondents in the text, whilst minimising the over interpretation of their views by the author. At a meta-theoretical level, it has been contended in this thesis that the abductive approach to research is the best way of ensuring that theories generated during the research are both clearly linked to the data and accessible to the social actors in question.

An effort to remain reflexive in relation to my position as a non-disabled researcher has also been key to the methodology of this research. Whilst it has been contended in this thesis that non-disabled people can do research in the field of disability providing that they remain reflexive in this way, nevertheless, some issues remain surrounding the relationship of researcher/respondents during research carried out as part of a PhD. During this research, in the light of the fact that the sole responsibility for the collection of the data and the authorship of the thesis lies with the PhD student, the problem of how to make the research methodology more collaborative, proved to be intractable. As discussed in chapter 2, 'the equality proviso' as defined by Humphrey (2000), did not function to any great extent within this research and this author must remain uneasy surrounding this issue. As proposed in chapter 2, it is hoped that some flexibility will be allowed into the PhD process of the future, to allow for such uneasy asymmetries in power to be minimised.

As things stand, however, subject to the additional funding that would have been required, it might have been better to have carried out this research collaboratively with research respondents and to have produced jointly authored material from the findings. The author may then have been able to negotiate the use of these findings as the basis for an individual PhD. Such funding was not readily available, however, and so a fairly pragmatic decision was made that the need for the research to be carried out outweighed concerns surrounding some imperfections of methodology. This author hopes that readers will accept the basis for this decision.

Bibliography

Abberley, P. (1993) 'Disabled people and normality' in Swain, J., et al (Ed.s) *Disabling barriers – enabling environments.* London, Sage in association with the Open University.

Abberley, P. (1997) 'The limits of classical social theory in the analysis and transformation of disablement – (can this really be the end; to be stuck inside of Mobile with the Memphis blues again?)' in Barton, L. and Oliver, M. (Ed.s) *Disability studies: past, present and future.* Leeds, The Disability Press.

Ablon, J. (1981) 'Stigmatised health conditions', *Social Science and Medicine,* 15B, 5-9.

Albrecht, G. (1992) *The disability business: rehabilitation in America.* London, Sage.

Alvesson, M. and Sköldberg, K. (2000) *Reflexive methodology. New vistas for qualitative research.* London, Sage.

Arendt, H. (1958) *The human condition.* Chicago, The University of Chicago Press.

Audit Commission (The) (2002) *Special educational needs. A mainstream issue.* London, The Audit Commission.

Baker, T. L. (1999) *Doing social research.* London, McGrawHill College.

Barbalet, J. M. (1988) *Citizenship.* Milton Keynes, Open University Press.

Barber, B. (1984) *Strong democracy: participatory politics for a new age.* Berkeley, CA, University of California Press.

Barnes, C. (1992a) 'Qualitative research: valuable or irrelevant?' *Disability, Handicap and Society,* 7, (2), 115-124.

Barnes, C. (1992b) for the British Council of Organisations of Disabled People, *Disability and employment.* Viewed on web at:

Barnes, C. (1992c) for the British Council of Organisations of Disabled People, *Disabling imagery and the media: an exploration of the principles for media representations of disabled people.* Halifax, Ryeburn Publishing. Viewed on the web at:

Barnes, C. (1996) 'Disability and the myth of the independent researcher', *Disability and Society,* 11, (1), 107-110.

Barnes, C. (1997) Introduction to article by Rae, A. 'Bolton data for inclusion: survivors from the special school system', Bolton, Bolton Institute. Viewed on web at:

Barnes, C. (1999) 'Disability studies: new or not so new directions?', *Disability and Society,* 14, (4), 577-580.

Barnes, C., et al (1999) *Exploring disability. A sociological introduction.* Cambridge, Polity Press.

Begum, N. (1992) *Something to be proud of: the lives of Asian disabled people and carers in Waltham Forest.* Waltham Forest, The Race Relations Unit of Waltham Forest.

Begum, N. (1994) 'Mirror, mirror on the wall' in Begum, N., et al, *Reflections: the views of black disabled people on their lives and community care.* London, CCETSW.

Bendelow, G. and Williams, S. (1995) 'Transcending the dualisms: towards a sociology of pain', *Sociology of Health and Illness,* 17, 139-165.

Berg, B. L. (1989) *Qualitative research methods for the social sciences.* London, Allyn and Bacon.

Berlin, I. (1958) *Two concepts of liberty. An inaugural lecture delivered before the University of Oxford on 31st October 1958.* Oxford, The Clarendon Press.

Blaikie, N. (1993) *Approaches to social enquiry.* Cambridge, Polity Press.

Blair, A. (Tony) (1995) *The rights we enjoy reflect the duties we owe.* Spectator Lecture, Queen Elizabeth Conference Centre, Labour Party Press Release, 22 March. London, Labour Party.

Blair, A. (Tony) (1996*) New Britain: my vision of a young country.* London, Fourth Estate.

Blumer, H. [1951] (1995) 'Social movements' in Lyman, S. M. (Ed.) *Social movements. Critiques, concepts and case-studies.* Basingstoke, MacMillan.

Booth, T. and Booth, W. (1994) *Parenting under pressure: mothers and fathers with learning difficulties.* Buckingham, Open University Press.

Booth, T. and Booth, W. (1998) 'Risk, resilience and competence: parents with learning difficulties and their children' in Jenkins, R. (Ed.) *Questions of competence. Culture, classification and intellectual disability.* Cambridge, Cambridge University Press.

Bourdieu, P. (1987) 'What makes a social class? On the theoretical and practical existence of groups', *Berkeley Journal of Sociology,* 32, 1-18.

Bourdieu, P. and Wacquant, L. J. D. (1992) *An invitation to reflexive sociology.* Chicago, University of Chicago Press.

Branfield, F. (1998) "What are you doing here? 'Non-disabled' people and the disability movement: a response to Robert F. Drake", *Disability and Society,* 13, (1), 143-144.

Branfield, F. (1999) 'The disability movement: a movement of disabled people – a response to Paul S. Duckett', *Disability and Society,* 14, (3), 399-403.

Burchardt, T. (2000) (JRF Findings) *Enduring economic exclusion: disabled people, income and wealth.* Viewed on the web at:

Burchell, D. (1995) 'The attributes of citizens: virtue, manners and the activity of citizenship', *Economy and Society,* 24, (4), 540-58.

Bury, M. (1996) 'Disability and the myth of the independent researcher: a reply', *Disability and Society,* 11, (1), 111-113.

Bury, M. (1997) *Health and illness in a changing society.* London, Routledge.

Butler, J. (1993) *Bodies that matter: on the discursive limits of sex,* London: Routledge.

Butler, J. (1995) 'Contingent foundations: feminism and the question of postmodernism' in Nicholson, L. (ed.) *Feminist contentions: a philosophical exchange.* London: Routledge.

Byrne, D. (1999) *Social exclusion,* Buckingham, Open University Press.

Calhoun, C. (1994) 'Social theory and the politics of identity' in Calhoun, C. (Ed.) *Social theory and the politics of identity.* Oxford, Blackwell.

Caminada, K. and Goudswaard, K. (2000) 'International trends in income inequality and social policy". Paper given at the Year 2000 International Research Conference on Social Security, Helsinki.

Campbell, J. (2002) 'Diversity: the disability agenda – we've only just begun", *Disability and Society,* 17, (4), 471- 478.

Catterall, M. and Maclaren, P. (1997) 'Focus group data and qualitative analysis programs: coding the moving picture as well as the snapshots", *Sociological research online,* 2, (1). Viewed on the web at:

Clarke, P. (1996) *Deep citizenship.* London, Pluto Press.

Cohen, J. L. (1985) 'Strategy or identity: new theoretical paradigms and contemporary social movements', *Social Research,* 52, (4), 663-716.

Corbett, J. (1994) 'A proud label: exploring the relationship between disability politics and gay pride', *Disability and Society,* 9, (3), 343-357.

Corker, M. (1998) *Deaf and disabled, or deafness disabled?* Buckingham, Open University Press.

Corker, M. (1999) "Differences, conflations and foundations: the limits to 'accurate' theoretical representations of disabled people's experience?", *Disability and Society,* 14, (5), 627-642.

Coser, L. A. (1971) *Masters of sociological thought. Ideas in historical and social context.* New York, Harcourt Brace Jovanovich.

Cox, O. (1970) *Caste, class and race.* New York, Monthly Preview Books.

Daone, E. and Scott, R. (2003) *Ready, willing and disabled – executive summery and recommendations for employers.* Viewed on the web at:

Davis, K. (1999) 'The disability movement: putting the power back in empowerment' in Barnes, M. and Warren, L. (Ed.s) *Paths to empowerment.* Bristol, The Policy Press.

Dean, H., et al (1999) *Poverty, riches and social citizenship.* Basingstoke, MacMillan.

Delanty, G. (2000) *Citizenship in a global age. Society, culture, politics.* Buckingham, Open University Press.

Della Porta, D. and Diani, M. (1999) *Social movements. An introduction.* Oxford, Blackwell.

Douglas, M. (1966) *Purity and danger.* Harmondsworth, Penguin.

DPTAC (1989) '*Public transport and the missing six millions: what can be learned?*' London, DPTAC.

Duckett, P. S. (1998) "What are you doing here? 'Non-disabled' people and the disability movement: a response to Fran Branfield", *Disability and Society,* 13, (4), 625-628.

Duncan Smith, I. (2002) *Defeating the Five Giants.* Speech given at Toynbee Hall on Iain Duncan Smith's first anniversary as Party Leader 13/09/02. Viewed on the web at:

Dwyer, P. (2000) *Welfare rights and responsibilities. Contesting social citizenship.* Bristol, The Policy Press.

Ellison, N. (1997) 'Towards a new social politics: citizenship and reflexivity in later modernity", *Sociology,* 31, (4), 697-717.

Ellison, N. (2000) 'Proactive and defensive engagement: social citizenship in a changing public sphere", *Sociological Research Online,* 5, (3). Viewed on web at:

Erevelles, N. (1996) 'Disability and the dialectics of difference", *Disability and Society,* 11, (4), 519-537.

Eyerman, R. and Jamison, A. (1991) *Social movements. A cognitive approach.* Cambridge, Polity Press.

Faulks, K. (2000) *Citizenship.* London, Routledge.

Fawcett, B. (2000) *Feminist perspectives on disability.* Harlow, Essex, Pearson Education Ltd.

Fierlbeck, K. (1998) *Globalizing democracy.* Manchester, Manchester University Press.

Fine, M. and Asch, A. (1988) *Women with disabilities: essays in psychology, culture, and politics* Philadelphia, Temple University Press.

Finkelstein, V. (1980) *Attitudes and disabled people.* New York, World Rehabilitation Fund.

Finkelstein, V. (1996) "Outside, 'inside out'", *Coalition,* April.

Foucault, M. (1970) *The order of things.* London, Tavistock Publications.

Foucault, M. (1979) *Discipline and punish.* Harmonsdworth, Peregrine.

Foucault, M. (1980a) *A history of sexuality.* New York, Vintage.

Foucault, M. (1980b) *Power/knowledge: selected interviews and other writings, 1972-1977.* New York, Pantheon.

Foweraker, J. (1995) *Theorizing social movements.* London, Pluto.

Fraser, N. (1989) *Unruly practices.* Cambridge, Polity.

Fraser, N. (1995) 'False antithesis: a response to Seyla Benhabib and Judith Butler' in Nicholson, L. (Ed.) *Feminist contentions: a philosophical exchange.* London, Routledge.

Fraser, N. (1995) "From redistribution to recognition? Dilemmas of justice in a 'post-socialist' age", *New Left Review,* 212, 68-93.

Fraser, N. (1997) *Justice interruptus: critical reflections on the "postsocialist" condition.* New York, Routledge.

Galipeau, C. (1994) *Isaiah Berlin's liberalism.* Oxford, Clarendon Press.

Gibbs, A. (1997) 'Focus groups' *Social Research Update,* 19. Viewed on the web at:

Giddens, A. (1982) 'Class division, class conflict and citizenship rights' in Giddens, A. *Profiles and critiques and social theory.* London, MacMillan.

Giddens, A. (1984) *The constitution of society.* Cambridge, Polity Press.

Giddens, A. (1993) *Sociology.* 2nd edition. Cambridge, Polity.

Gilson, S. F., et al (1997) 'Ethnographic research in disability identity: self-determination and community", *Journal of Vocational Rehabilitation,* 9, 7-17.

Gilson, S. F. and Depoy, E. (2000) 'Multiculturalism and disability: a critical perspective", *Disability and Society,* 15, (2), 207-218.

Glaser, B. G. and Strauss, A. L. (1968) *The discovery of grounded theory.* London, Weidenfeld & Nicolson.

Glendinning, C. (1986) *A single door: social work with the families of disabled children.* London, Allen and Unwin.

Goffman, E. (1968) *Stigma: notes on the management of spoiled identity.* Harmondsworth, Penguin.

Goodey, C. F. (1995) 'Mental retardation: social section – section I' in Berrios, G. and Porter, R. (Ed.s) *A history of clinical psychiatry: the origins and history of psychiatric disorders.* London, Athlone Press.

Goss, J. D. and Leinbach, T. R. (1996) 'Focus groups as alternative research practice: experience with transmigrants in Indonesia", *Area,* 28, (2), 115-123.

Gray, J. (1995) *Berlin.* London, Fontana.

Guigni, M. (1999) 'Introduction. How social movements matter: past research, present problems, future developments' in Giugni, M., et al (Ed.s) *How social movements matter.* Minneapolis, University of Minnesota Press.

Gussow, Z. and Tracey, G. (1968) 'Status, ideology and adaption to stigmatised illness", *Human Organisation,* 27, 873-84.

Habermas, J. (1981) 'New social movements', *Telos,* 49, 33-37.

Habermas, J. (1984) *The theory of communicative action. Volume 1. Reason and the rationalization of society.* Trans. T. McCarthy, Boston, Beacon Press.

Habermas, J. (1987) *The theory of communicative action.* Cambridge, Polity Press.

Habermas, J. (1992) 'Citizenship and national identity: some reflections on the future of Europe", *Praxis International,* 12, 1-19.

Habermas, J. (1996) *Between facts and norms: contributions to a discourse theory of law and democracy.* Cambridge, Polity.

Habermas, J., et al (1998) *The inclusion of the other: studies in political theory.* Cambridge, MA, MIT Press.

Hall, S., et al (1988) 'New Times', *Marxism Today,* October.

Harraway, D. (1991) *Simians, cyborgs and women: the reinvention of nature?* London, Free Association Books.

Harris, J., et al (1997) *Wheelchair housing and the estimation of need.* Preston, University of Central Lancashire.

Hayek, F. (1944) *The road to serfdom.* London, Routledge.

Hearn, K. (1988) 'Oi! What about us?' in Cant, B. and Hemmings, S. (Ed.s) *Radical records: thirty years of lesbian and gay history.* London, Routledge.

Heenan, D. 'It won't change the world but it turned my life around: participants' views on the personal advisor scheme in the New Deal for disabled people', *Disability and Society,* 17, (4), 383-401.

Heywood, A. (1994) *Political ideas and concepts.* London, MacMillan

Hobbes, T. (ed.) (1973) *Leviathan.* London, Dent.

Hudson, R. (Bob) (2000) 'Adult care' in Hill, M. (Ed.) *Local authority social services: an introduction.* Oxford, Blackwell.

Hughes, B. and Paterson, K. (1997) 'The social model of disability and the disappearing body: towards a sociology of impairment", *Disability and Society,* 12, (3) pp.325-40.

Humphrey, J. C. (2000) 'Researching disability politics, or, some problems with the social model in practice', *Disability and Society,* 15, (1), 63-85.

Hunt, P. (1966) *Stigma: the experience of disability.* London, Geoffrey Chapman.

Hurd, D. (1988) 'Citizenship in Tory democracy', *New Statesman and Society,* April, 29.

Imrie, R. (1996) *Disability and the city: international perspectives.* London, Paul Chapman Publishing.

Imrie, R. and Kumar, M. (1998) 'Focusing on disability and access in the built environment', *Disability and Society,* 13, (3), 357-374.

Isin, E. F. and Wood, P. K. (1999) *Citizenship and identity.* London, Sage.

Jenkins, R. (1996) *Social identity.* London, Routledge.

Jenkins, R. (1998) 'Culture, classification and (in)competence' in Jenkins, R. (Ed.) *Questions of competence. Culture, classification and intellectual disability.* Cambridge, Cambridge University Press.

Jones, A. and Longstone, L. (1990) *A survey of job centre vacancies.* Employment Services, Sheffield, Department of Employment.

Jordan, B. (1996) *A theory of poverty and social exclusion.* Cambridge, Polity.

Kallianes, V. and Rubenfield, P. (1997) 'Disabled women and reproductive rights', *Disability and Society,* 12, (2), 203-221.

Karpf, A. (1988) *Doctoring the media.* London, Routledge.

Kenny, M. (2000) 'Isaiah Berlin's contribution to modern political theory', (Review Article), *Political Studies,* 48, (5), 1026-1039.

Kitchen, R. (1998) "'Out of place', 'knowing one's place': space, power and the exclusion of disabled people", *Disability and Society,* 13, (3), 343-356.

Kitchen, R. and Law, R. (2001) 'The socio-spacial construction of (in)accessible public toilets', *Urban Studies,* 38, (2), 287-298.

Kvale, S. (1996) *Interviews: an introduction to qualitative research interviewing.* Thousand Oaks, CA, Sage.

Kymlicka, W. (1991) *Liberalism, community, and culture.* Oxford, Clarendon.

Kymlicka, W. and Norman, W. (1994) 'Return of the citizen: a survey of recent work on citizenship theory', *Ethics,* 104, 352-381.

Kymlicka, W. [1995] (1998) 'Multicultural citizenship' in Shafir, G. (Ed.) *The citizenship debates. A reader.* London, University of Minnesota Press.

Lipton, P. (1993) *Inference to the best explanation.* London, Routledge.

Lister, R. (1997a) *Citizenship: feminist perspectives.* Basingstoke, MacMillan.

Lister, R. (1997b) 'Citizenship: towards a feminist synthesis', *Feminist Review,* 57, 28-48.

Lloyd, M. (1992) 'Does she boil eggs? Towards a feminist model of disability', *Disability, Handicap and Society,* 7, (3), 207-221.

Lloyd, M., et al (1996) 'Whose project is it anyway? Sharing and shaping the research and development agenda', *Disability and Society,* 11, (3), 301-315.

Locke, J. (ed.) (1965) *Two treatises of government.* New York, New American Library.

MacFarlane, A. (1994) 'On becoming an older disabled woman', *Disability and Society,* 9, (2), 255-256.

MacLennan, R (Bob). (2000) quoted in Liberal Democrat Press Release (12/12/02) *Equality Act Long Overdue.* Viewed on the web at:

Macleod, A. M. (1998) 'Instrumental rationality and the instrumental doctrine'. Paper given at the Twentieth World Congress of Philosophy, Boston, Massachusetts. Viewed on the web at:

Mann, M. (1987) 'Ruling class strategies and citizenship', *Sociology,* 21, (3), 339-354.

Marks, D. (2001) "Disability and cultural citizenship: exclusion, 'integration' and resistance" in Stevenson, N. (Ed.) *Culture and citizenship.* London, Sage.

Marshall, T. H. [1963] (1998) 'Citizenship and social class' in Shafir, G. (Ed.) *The citizenship debates. A reader.* London, University of Minnesota Press.

Marshall, T. H. (1972) 'Value problems of welfare capitalism', *Journal of Social Policy,* 1, (1), 15-32.

Marshall, T. H. (1981) 'Reflections of power' in *The right to welfare and other essays.* London, Heinemann.

Martell, L. (1994) *Ecology and society. An introduction.* Cambridge, Polity Press.

May, T. (2001) *Social research. Issues, methods and process.* 3rd Edition, Buckingham, Open University Press.

McAfee, N. (2000) *Habermas, Kristeva and citizenship.* New York, Cornell University Press.

McCormack, M. (1992) *Special children, special needs: families talk about living with mental handicap.* Wellingborough, Thornson.

Mead, L. M. (1997) 'Citizenship and social policy: T.H.Marshall and poverty', *Social Philosophy and Policy Foundation,* 14, (2), 197-230.

Meehan, J. (1995) (Ed.) *Feminists read Habermas: gendering the subject of discourse.* New York, Routledge.

Meier, C. (1990) *The Greek discovery of politics.* Cambridge, Harvard University Press.

Melucci, A. (1985) 'The symbolic challenge of contemporary movements', *Social Research,* 52, (4), 789-816.

Melucci, A. (1989) 'Movements as messages' in Keane, J. and Mier, P. (Ed.s) *Nomads of the present. Social movements and the individual needs in contemporary society.* London, Hutchinson Radius.

Melucci, A. (1993) 'Paradoxes of post-industrial democracy: everyday life and social movements', *Berkeley Journal of Sociology,* 38, 185-192.

Melucci, A. (1994) "A strange kind of newness: what's 'new' in new social movements?" in Larana, E., et al (Ed.s) *New social movements. From ideology to identity.* Philadelphia, Temple University Press.

Melucci, A. (1996) *Challenging codes. Collective action in the information age.* Cambridge, Cambridge University Press.

Merleau-Ponty, M. (1962) *Phenomenology of perception.* Trans. C. Smith, London, Routledge.

Michels, R. (1959) *Political parties.* New York, Dover.

Miles, R. (1982) *Racism and migrant labour.* London, Routledge.

Miles, R. (1993) *Racism after 'Race Relations'.* London, Routledge.

Modood, T. (1992) *Not easy being British: colour, culture and citizenship.* London, R.T.Trentham.

Modood, T. (1997) *Ethnic minorities in Britain: diversity and disadvantage.* London, Policy Studies Institute.

Morris, A. (1993) 'Centuries of Black protest – its significance for America and the world' in Hill, H. and Jones, J. E. Jr (Ed.s) *Race in America – the struggle for equality.* Madison, University of Wisconsin Press.

Morris, J. (1989) *Able lives: women's experience of paralysis.* London, Women's Press.

Morris, J. (1991) *Pride against prejudice.* London, Women's Press.

Morris, J. (1996) (Ed.) *Encounters with strangers: feminism and disability.* London, Women's Press.

Mouffe, C. (1992) 'Democratic politics and the question of identity' in Mouffe, C. (Ed.) *Dimensions of radical democracy: pluralism, citizenship, community.* London, Verso.

Mouffe, C. (1993) *The return of the political.* London, Verso.

Murray, C. (1990) *The emerging British underclass.* London, IEA.

Murray, C. (1994) *Underclass: the crisis deepens.* London, IEA.

Nozick, R. (1974) *Anarchy, state and utopia.* Oxford, Blackwell.

Oakeshott, M. (1975) *On human conduct.* Oxford, Oxford University Press.

Oberschall, A. (1973) *Social conflict and social movements.* Englewood Cliffs, New Jersey, Prentice Hall.

Offe, C. (1984) *Contradictions of the welfare state.* London, Hutchinson.

Oldfield, M. (1990) *Citizenship and community: civic republicanism and the modern world.* London, Routledge.

Oliver, D. and Heater, D. (1994) *The foundations of citizenship.* London, Harvester Wheatsheaf.

Oliver, M. and Zarb, G. [1989] (1997) 'The politics of disability: a new approach' in Barton, L. and Oliver, M. (Ed.s) *Disability studies: past, present and future.* Leeds, The Disability Press.

Oliver, M. (1990) *The politics of disablement.* Basingstoke, Macmillan.

Oliver, M. (1992) 'Changing the social relations of production?', *Disability, Handicap and Society,* 7, (2), 101-114.

Oliver, M. (1995) *Defining impairment and disability: issues at stake.* Unpublished paper.

Oliver, M. (1996) 'A sociology of disability or a disablist sociology?' in Barton, L. (Ed.) *Disability and society: emerging issues and insights.* London, Longman.

Oliver, M. (1997) 'The disability movement is a new social movement!', *Community Development Journal,* 32, (3), 244-251.

Pakulski, J. (1997) 'Cultural citizenship', *Citizenship Studies,* 1, (1), 73-86.

Parker, G. (1993) *With this body: caring and disability in marriage.* Buckingham, Open University Press.

Parsons, T. (1951) *The social system.* New York, Free Press.

Parsons, T et al (1961) *Theories of society.* Vol.1. New York, The Free Press of Glencoe.

Parsons, T. (1969) *Politics and social structure.* New York, Free Press.

Pateman, C. (1988) *The Sexual contract.* Cambridge, Polity Press.

Patterson, S. (1963) *Dark strangers.* Harmondsworth, Penguin.

Peirce, C. S. (1867/1960) *Collected papers of Charles Sanders Peirce.* Cambridge, Harvard University Press.

Peters, S. (1996) 'The politics of disability identity' in Barton, L. (Ed.) *Disability and society: emerging issues and insights.* London, Longman.

Pinder, R. (1997) 'A reply to Tom Shakespeare and Nicholas Watson', *Disability and Society,* 12, (2), 301-305.

Priestley, M. (1995) "Commonality and difference in the movement: an 'Association of Blind Asians' in Leeds", *Disability and Society,* 10, (2), 157-169.

Priestley, M. (1999) *Disability politics and community care.* London, Jessica Kingsley Publishers.

Prioetto, R. (1995) 'New social movements: issues for sociology', *Social Science Information,* 34, (3), 355-388.

Putnam, R. (1993) *Making democracy work: civic traditions in modern Italy.* Princeton, NJ, Princeton University Press.

Rawls, J. (1971) *A theory of justice.* Cambridge, Cambridge University Press.

Rawls, J. [1985] (1998) 'Justice as fairness in the liberal polity' in Shafir, G. (Ed.) *The citizenship debates. A reader.* London, University of Minnesota Press.

Rawls, J. (1993) *Political liberalism.* New York, Columbia University Press.

Rawls, J. (1996) 'Priority of the rights and ideas of the good' in *Political Liberalism.* New York, Columbia University Press.

Reed, G. F. (1980) 'Berlin and the division of liberty', *Political Theory,* 8, (3), 365-380.

Rex, J. and Tomlinson, S. (1979) *Colonial immigrants in a British city: a class analysis.* London, Routledge and Kegan Paul.

Rickell, A. (2003) 'Our disability is political' *The Guardian* 1st October. Viewed on the web at: <http:www.guardian.co.uk/comment/story/o,3604,1053066,00.html> Date: 08/02/04

Roche, M. (1987) 'Citizenship, social theory, and social change', *Theory and Society,* 16, 363-399.

Roche, M. (1992) *Rethinking citizenship: welfare, ideology and change in modern society.* Cambridge, Polity Press.

Roche, M. (1995) 'Citizenship and modernity', (Review Article), *British Journal of Sociology,* 46, (4), 715-733.

Roche, M. (2000) *Rethinking social citizenship: national, transnational and European dimensions* draft paper presented at "The Foundations of modern Citizenship Debates" ESRC Research Seminar programme on 'Citizenship and its Futures' University College of Northampton.

Ross, K. (1997) *Disability and broadcasting: a view from the margins.* Cheltenham, Cheltenham and Gloucester College of Higher Education.

Roulstone, A. (2000) 'Disability, dependency and the New Deal for disabled people', *Disability and Society,* 15, (3), 427-443.

Rousseau, J.-J. (ed.) (1913) *The social contract and discourses.* Trans. G.D.H. Cole, London, Dart.

Scambler, G. and Hopkins, A. (1986) 'Being epileptic and coming to terms with stigma', *Sociology of Health and Illness,* 8, 26-43.

Shafir, G. (1998) (Ed.) 'Introduction: the evolving tradition of citizenship' in *The citizenship debates. A reader.* London, University of Minnesota Press.

Shakespeare, T. (1992) 'A response to Liz Crow', *Coalition,* September.

Shakespeare, T. (1993) 'Disabled people's self-organisation: a new social movement?', *Disability, Handicap and Society,* 8, (3), 249-64.

Shakespeare, T. (1994) 'Cultural representation of disabled people: dustbins for disavowal?', *Disability and Society,* 9, (3), 283-299.

Shakespeare, T. (1996) 'Rules of engagement: doing disability research', *Disability and Society,* 11, (1), 115-121.

Shakespeare, T. and Watson, N. (1997) 'Defending the social model', *Disability and Society,* 12, (2), 293-300.

Shakespeare, T. (1998) 'Choices and rights: eugenics, genetics and disability equality', *Disability and Society,* 13, (5), 665-681.

Sharma, A. and Love, D. (1991) *A change in approach: a report on the experience of deaf people from black and ethnic minority communities.* London, Royal Association in Aid of Deaf People.

Silver, M. (2002) 'Reflections on determining competency', *Bioethics,* 16, (5), 455-468.

Smelser, N. J. (1963) *Theory of collective behavior.* New York, Free Press.

Smyth, M. and Robus, N. (1989) *OPCS surveys of disability in Great Britain: report 5 – the financial circumstances of disabled children living in private households.* London, HMSO.

Soysal, Y. N. (1994) *Limits of citizenship: migrant and postnational membership in Europe.* Chicago, University of Chicago.

Stevenson, N. (1997a) 'Globalisation, national cultures and cultural citizenship', *The Sociological Quarterly,* 38, (1), 41-66.

Stevenson, N. (1997b) 'Global media and technological change: social justice, recognition and the meaningfulness of everyday life', *Citizenship Studies,* 1, (3), 365-388.

Strauss, A. L. and Glaser, B. (1975) *Chronic illness and the quality of life.* St Louis, Mo, C.V. Mosby and Co.

Stryker, S., et al (2000) 'Introduction. Social psychology and social movements: cloudy past and bright future' in Stryker, S., et al (Ed.s) *Self, identity, and social movements.* Minneapolis, University of Minnesota Press.

Stuart, O. (1992) 'Race and disability: just a double oppression?', *Disability and Society,* 7, (2), 177-188.

Stuart, O. (1993) 'Double oppression: an appropriate starting point?' in Swain, J., et al (Ed.s) *Disabling barriers, enabling environments.* Buckingham, Open University Press.

Stuart, O. (1994) 'Journey from the margin: black disabled people and the antiracist debate' in Begum, N., et al (Ed.s) *Reflections: the views of black disabled people on their lives and community care.* London, CCETSW.

Swain, J. and French, S. (2000) 'Towards an affirmation model of disability', *Disability and Society,* 15, (4), 569-582.

Tansey, S. D. (1995) *Politics. The basics.* London, Routledge.

Tarrow, S. (1989) *Democracy and disorder. Protest and politics in Italy, 1965-1975.* Oxford, Oxford University Press.

Tarrow, S. (1994) *Power in movement. Social movements, collective action and politics.* Cambridge, Cambridge University Press.

Thatcher, M. [1988] (1989) speech to the Church of Scotland, in Raban, J. *God, man and Mrs Thatcher.* London, Chatto and Windus, May.

Thomas, A. (1997) *Exam performance in special schools.* Bristol, Bristol Centre for Studies on Inclusive Education.

Tilly, C. (1978) *From mobilization to revolution.* Reading, MA, Addison-Wesley.

Tilly, C. (1993) 'Social movements as historically specific clusters of political performances', *Berkeley Journal of Sociology,* 38, 1-30.

Tilly, C. (1999) 'Conclusion. From interactions to outcomes in social movements' in Giugni, M., et al (Ed.s) *How social movements matter.* Minneapolis, University of Minnesota Press.

Touraine, A. (1985) 'An introduction to the study of social movements', *Social Research,* 52, (4), 749-787.

Touraine, A. (1987a) 'Social movements: participation and protest', *Scandinavian Political Studies,* 10, (3), 207-222.

Touraine, A. (1987b) *The workers' movement.* Cambridge, Cambridge University Press.

Turner, B. S. (1984) *The body and society. Explorations in social theory.* Oxford, Blackwell.

Turner, B. S. (1986) *Equality.* London, Tavistock.

Turner, B. S. (1992) *Regulating bodies: essays in medical sociology.* London, Routledge.

Turner, B. S. (1993a) 'Outline of a theory of human rights' in Turner, B. S. (Ed.) *Citizenship and social theory.* London, Sage.

Turner, B. S. (1993b) 'Outline of a theory of human rights', *Sociology,* 27, (3), 489-512.

Turner, T. (1994) 'Bodies and anti-bodies: flesh and fetish in contemporary social theory' in Csordas, T. (Ed.) *Embodiment and experience: the existential ground of culture and self.* Cambridge, Cambridge University Press.

Turner, B. S. [1996] (2000) 'An outline of a general sociology of the body' in Turner, B. S. (Ed.) *The Blackwell companion to social theory.* 2nd Edition. Oxford, Blackwell.

UPIAS (1976) *Fundamental principles of disability.* London, UPIAS.

Vernon, A. (1999) 'The dialectics of multiple identities and the disabled people's movement', *Disability and Society,* 14, (3), 385-398.

Warnock report (1978) '*Report of the committee of enquiry into the education of handicapped children and young people.* London, HMSO.

Warren, L. (1999) 'Conclusion: empowerment: the path to partnership?' in Barnes, M. and Warren, L. (Ed.s) *Paths to empowerment.* Bristol, The Policy Press.

Williams, F. (1996) 'Postmodernism, feminism and the question of difference' in Parton, N. (Ed.) *Social theory, social change and social work.* London, Routledge.

Williams, M. and May, T. (1996) *Introduction to the philosophy of social research.* London, UCL Press.

Williams, R. (1980) *Problems in materialism and culture.* London, New Left Books.

Williams, R. (1981) *Culture.* Glasgow, Fontana.

Wolfensberger, W. (1989) 'Human service policies: the rhetoric versus the reality' in Barton, L. (Ed.) *Disability and dependence.* Lewes, Falmer Press.

Wood, R. (1991) 'Care of disabled people' in Dalley, G. (Ed.) *Disability and social policy.* London, Policy Studies Institute.

Young, I. M. (1990) *Justice and the politics of difference.* Princeton, N.J., Princeton University Press.

Young, I. M. [1989] (1998) 'Polity and group difference: a critique of the ideal of universal citizenship' in Shafir, G. (Ed.) (1998) *The citizenship debates. A reader.* London, University of Minnesota Press.

Zarb, G. (1992) 'On the road to Damascus: first steps towards changing the relations of disability research production', *Disability, Handicap and Society,* 7, (2), 125-138.

Zarb, G. and Oliver, M. (1993) *Ageing with a disability: what do they expect after all these years?* London, University of Greenwich.

Appendix Contents

Page:

Angharad E. Beckett, University of Sheffield,

Tel:
Email:

Dear All at

I am writing to you to ask for your help. My name is Angharad Beckett and I am a researcher at the Department of Sociological Studies, University of Sheffield. At the moment I am doing some research into the role of the Disability Movement and issues of citizenship and social exclusion. As part of this research I am hoping to meet a number of organisations run *by* disabled people, *for* disabled people and your organisation has come to my attention as being organised in this way.

I am aware that you are probably extremely busy and may feel that you have not got time to be involved in this project. However, all that I would ask is for one group discussion with a number of your members on some of the key issues in the research. The timescale for the project is fairly flexible, so your involvement would be at your convenience, and I would, of course, travel to you.

Some of you may have had some bad experiences of research in the past and I so want to assure you that my project will be as empowering as possible for those involved. For this reason I have involved disabled people from the beginning of the research and will provide feedback throughout the project. I am also following the British Sociological Association's guide for ethical practice in research.

I would be extremely grateful for your involvement and am open to any suggestions of ways that I might be of assistance to you in your work. Should you have any questions that you would like answered before you even consider becoming involved in the research, please do not hesitate to contact me.

Finally, what I would like to say to all your members is that I truly believe that my research will provide a platform for the voices of disabled people and I feel sure that you have a lot of very interesting views that I would really like to be able to include in the research. I look forward to hearing from you and very much hope that I will be able to meet you all at some point.

Yours sincerely,

Angharad Beckett.

Outline of Questions for Discussion Group

Your group has been asked to be a part of this research because it is either a member of the British Council of Disabled People (BCODP), and is therefore run *by* and *for* disabled people, or is a similar organisation that is not affiliated to the BCODP. I am most grateful for your interest in this project.

This piece of research will be abiding by the British Sociological Association's "Code of Ethical Practice in Research". In addition, the research aims to be participatory as far as is possible within the constraints of a piece of work which will ultimately form the basis for a PhD, and which, therefore, must in the end have single authorship. In practical terms I envisage that this process will involve the development and maintenance of a dialogue between all respondents and myself. Feedback will be welcomed throughout the research.

The questions listed below are only meant as a guide, to indicate the interests of the research. You may wish to answer some of the more straightforward questions in section A before we meet and to send me your responses to this section at your convenience.

Section A

1. Who is ....*for?* Who can become a member of your organisation?

2. a. Are there any types of people who would not be welcome within your organisation?

Yes/No

b. If the answer to the previous questions is "Yes", then who are these people and why are they not welcome within your organisation?

3. Are there any non-disabled people who are members/workers within your organisation?

Yes/No

4. a. If the answer to the previous question is "Yes", then what is their role in your organisation?

b. Are there any limits to their role within the organisation?

5. Why is it so important that you run your own organisation?

6. How do you recruit new members to your organisation?

7. If I was a disabled person who had heard about your organisation and was interested in joining, what would you say about yourselves that might persuade me to join?

8. What do you personally gain from being a part of this organisation?

9. Have you in the past been, or are you currently, a part of any similar organisations? If "Yes" could you indicate the nature and/or names of these other organisations?

Section B

1. What would you say was the central function/s of .... for example, group support/campaigning etc?

2. What would you say were the central hopes/aims of your organisation?

3. Has your organisations been involved in any campaigning, for example, for rights for disabled people? If "yes", could you give me any examples?

4.a. Would you say that campaigning is a significant part of the function of your organisation?

b. If the answer to the previous question is "no" – what reasons do you have for working in alternative ways?

5. What do you regard as the major achievements of your organisation?

6. Are there any obstacles in your way preventing you from achieving your organisation's goals or aspirations? What are the major obstacles?

Section C

1.a. Do you maintain any links with other organisations working within the field of disability, or with any other organisation?

b. If you do maintain links with other organisations would you please specify which organisations and why they were selected?

2. Is it important that the organisations you are linked to are also run in a similar way to your organisation? If so, why?

3. How would you describe these links, for example, formal/friendship?

4. What would you say were the value of these links?

Section D

1. Is it realistic to talk about the "Disability Movement" in the same way that people talk about the "Women's Movement" for example?

2. If you do believe that there is a Disability Movement, do you consider yourselves to be a part of it?

3. If you do consider yourself to be a part of the Disability Movement, what is it like to be a part of it?

4. Are there any groups, organisations or people (not specific individuals) who you do not regard as being part of the Disability Movement, and if so, why not?

Section E

1.a. During your own lifetimes what, if any, improvements have occurred in the lives of disabled people?

b. Could any of these changes be further improved?

c. In your opinion, what role, if any, has the Disability Movement had in causing these changes?

2.a. Are there any further improvements that could be made to the life experiences of disabled people?

b. Why do you think that these improvements are not already happening?

c. What could we do to make these things happen?

3.a. Is there anything that you do not like that is happening currently in the lives of disabled people?

b. Why do you think these things are happening?

c. How could we stop these things from happening?

4.a. Have you any fears for the future in relation to the lives of disabled people?

b. Are there any perceived potential changes or risks that would affect the lives of disabled people?

c. Are there any unacceptable situations that do not currently occur and which we must make sure never happen?

Section F

1. Are any of the following words or phrases important to you if so, why? What words have been omitted that *are* important?

Social Exclusion	**Sense of Community**
Respect	**Citizenship**
Rights and Responsibilities	**Empowerment**
Choice	**Control**
Independence	**Quality of ....?**

2. In terms of language how do you prefer to identify yourselves, for example, "disabled people" or "people with disabilities"?

3. Is language important to you, and if so, why?

4. Is there such a thing as a "disability identity"?

5. If there is a "disability identity", what kind of image exists of the "disabled people" and what is it like to experience this identity?

6. Is there such a thing as a "culture of disabled people"? Do you find this a realistic concept?

7. Is it helpful/useful to talk about a "disability culture"? If so, why? If not, why not?

Finally...

Are these the *important* questions? Bearing in mind the overall theme of this research, do you think that there are any more pertinent questions that I could have asked?

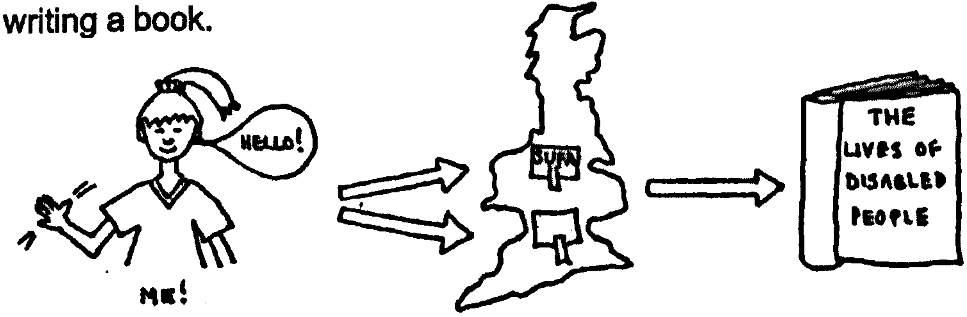
Have you any feedback on the questions? This is a rather formalised list and is only meant as a guide.

I am most grateful for your time and help! I look forward to meeting you all.

Department of Sociological Studies,
Sheffield, S10 2TU. Tel:
Email:

Dear All at

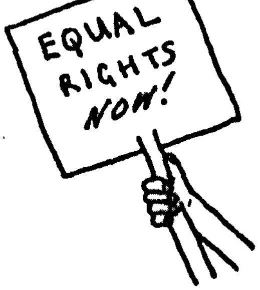
"Hello!" My name is Angharad Beckett and I work at the University of Sheffield. At the moment I am doing a project about the lives of disabled people. After I have found out lots of information I will be writing a book.



As part of my research I would like to visit lots of groups that are run *by* disabled people. I would really like to talk to some of the members of your group because I have heard about you and think that what you are doing is really exciting.

My research is all about asking disabled people their opinions about things like:

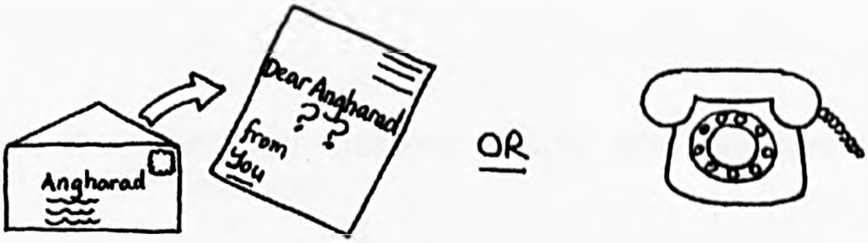
"being full citizens"
"rights for disabled people"
"links with other organisations"



If you would be interested in being involved in my project, I would like to have one, group discussion with some of the members of your group. It would be like having a chat between your group and me, but I would record all of your views so that I can write them up into my book. This would be a good chance for people to "have their say"! But, if anyone felt that they did not want me to use their name, that would be okay too.

When I have finished my project I hope that lots of students will read my book and that it will help them to understand about the lives of disabled people.

If you decide that you are interested in helping me with my project, then you can ask me as many questions about it as you want to.



I really hope that I will get to meet you all, I feel sure that you have a lot of views and opinions and hope that you will share them with me.

With Best Wishes,

Angharad Beckett.

Questions for the members of Speaking Up For Action (SUFA)

With all these questions there is no right or wrong answer. I am just interested to hear all of your views. You do not need to answer all the questions and you do not need to write your answers down. If it is okay with you all I will tape-record your answers.

1. Who is SUFA *for?* Who can become a member of your group?

2. How do you find new members for your group?

3. If I was a person with a learning disability and I had heard about SUFA, what would you tell me about yourselves that would make me want to join your group?

4. Is there any kind of person who would not be welcome in your group?

5. Are there any non-disabled people who are members of SUFA, or who help out?

6. What do the non-disabled people who are a part of SUFA do for the group? Is there anything that they are not allowed to do?

7. Why is it important that you run your own group?

8. What is SUFA all about? Why do you have this group?

9. What kind of things do you do as members of SUFA?

10. As a group does SUFA have any hopes or dreams that you are aiming for?

11. Have you ever stood up for the rights of disabled people? Could you give me some examples?

12. Do you think that it is important that SUFA should stand up for the rights of people with a learning disability?

13. If you had to choose one thing, what is the best part about being a member of SUFA?

14. Have you ever met anyone from any other groups of disabled people? Which groups were they from and do you keep in touch with them?

15. Thinking back over your life, has anything happened that has made your life better?

16. Is there anything in your life today that you would like to change?

17. Is there anything that is happening in your life that makes you unhappy?

18. If there are things that make you unhappy, why do you think that they happen?

19. Do you think that any of these words, written below, are important? Why are they important?

Respect

Rights

Responsibility

Choice

Being a citizen

20. Which words do you prefer, people with a ***learning disability*** or people with a ***learning difficulty***?

21. Are there any names that people in society may call people with a learning disability that you do not like? Why do you dislike these names?

Thank you for helping me with my project!

Deafmail Posting

A request for help with research – your views appreciated...

I am currently doing some PhD research into the role of the Disability Movement and the issue of Citizenship and the major part of my fieldwork has involved travelling around the country holding group discussions with a number of groups run *by* disabled people, *for* disabled people. Although I have met people with a number of different impairments, I have not as yet been able to gain the views of any members of the Deaf community and I would very much like to include your opinions in my work.

You may not feel that it is appropriate for someone who is researching the *disability movement* to contact Deaf people. For this reason, I would be most interested to hear your views about whether Deaf people are *disabled*?

Any views that you send to me will be handled according to your instructions. If you would be willing for me to quote you I will do so accurately and without re-interpretation. Please let me know whether you are happy to be quoted. If you do not specify whether or not I can quote you, I will assume that I can.

I would value your opinions on whichever of the questions below interest *you.* I am not asking you to answer them all. If you have any questions about the research that you would like me to answer before you even consider offering your views on the questions, please do not hesitate to contact me. I hope to hear from you!

The questions:

Are Deaf people *disabled*?

Are Deaf people a part of a disability movement? If "no", could you tell me why this is so? If "yes", do you personally feel a part of a disability movement?

Do you feel a part of a Deaf community? If "yes", how is this different from your experiences within the hearing community?

Is there a Deaf identity and/or a Deaf culture that is different from those of hearing people?

Have any important improvements been made in the lives of Deaf people in your lifetimes? What do you feel has brought these changes about?

Are there any improvements that need to be made in the lives of Deaf people and how could these be brought about?

Do you have any concerns for the future in relation to the lives of Deaf people? What could we do to stop these things happening?

How do you see the new developments in technology effecting Deaf people? For example, advances in knowledge surrounding genetics?

Angharad Beckett, Department of Sociological Studies, University of Sheffield,

Email:

SUFA REPORT

In the following report, the names of respondents have been removed in order to maintain their anonymity.

Notes from meeting at Speaking Up For Action (SUFA) on 14th December 2000.

The members of SUFA kindly agreed to discuss some questions with Angharad Beckett, from the University of Sheffield, to help with her research. These are the notes from that discussion.

People Present:

(M = SUFA Member)
M1
M2
M3
M4
M5
M6
M7
M8
Support Worker (SW)
Angharad Beckett

All the members of SUFA introduced themselves and said "Hello!" to Angharad.

About SUFA...

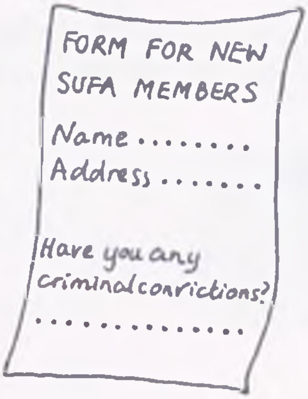
Angharad asked who SUFA is *for*?

M7 said that: "The Speaking Up For Action group is for people with learning difficulties to say what they want in their lives and they can speak up and to be independent." M7 also said that SUFA is for adults with a learning disability.

M7 said that SUFA does not have any members who have NOT got a learning disability. Non-disabled people, like SW can be the worker with the group, or be a volunteer with the group like Angharad but they would not be allowed to take control.

M3 said that everyone is involved in the decision making of the group and this gives everyone responsibility.

Everybody felt that there were some people that SUFA might not want to join the group. These were people such as paedophiles, fraudsters and murderers. It was explained to Angharad that police checks are done when a new member wishes to join the group.



FORM FOR NEW SUFA MEMBERS

Name........

Address.......

Have you any criminal convictions?

....

Angharad asked what SUFA is all about and why other people with a learning disability might like to join?

M7 said that SUFA members "come to speak up for *ourselves*, and others might want to come to speak up for *themselves*."

M3 said that SUFA was about having <u>choices</u> and being treated with <u>respect.</u>

M2 said that SUFA was about stopping people from getting bullied and lots of people said that they had been bullied, attacked or treated unkindly. Everyone agreed that SUFA is about standing up against these things.

Everyone said that SUFA was about getting control over your own life, having responsibilities, and being independent.

M7 also said that SUFA was about making services better for people with a learning disability, and this is why SUFA have been going to the Joint Planning Group Meetings and the Joint Investment Plan Meetings.

Finally M7 I also told Angharad about the SUFA newsletter, SPEAKING UP, and he said that new members might like to help with the newsletter, or even put something into it.

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Angharad asked everyone what they, personally, thought was the best part of being a member of SUFA?

M6 : felt that he had met some nice people at SUFA and that the really good thing about the group was that everyone sticks together.

M7 said that being a member of SUFA had given him the chance to say want he wanted to say. He also enjoyed travelling down to London, to a meeting with the Downs Syndrome Association which had been held at the House of Commons and meeting two famous people there - Dr Who, as played by Peter Davidson and Damian Hill. M7 also said that he had enjoyed the nights out at the Banker's Draft.

M6 : said that had really enjoyed going to the Barnsley College to learn about being a committee. M2 said that he had had a good time there too.

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Angharad asked how SUFA finds new members to join the group?

M7 said that the SUFA group had organised several conferences and had invited lots of people. He also told Angharad about visiting Gateway to run some workshops and about visiting daycentres to tell people about SUFA.

? Angharad asked whether people from SUFA had ever met any other groups of disabled people?

M3 and M7 said that SUFA had met Stevenage People First and that they had shown SUFA a video about what they were doing in their group.

M7 said that SUFA had also met the Speak Up group from Rotherham, and the Down To Earth group from Manchester.

M3 said that SUFA had met Our Vision Our Future, a group from Chesterfield.

SW commented that there had been groups from all over the country at the conference at Swanwick that SUFA had attended.

M7 said that some of the groups that SUFA has met have got a constitution and a committee and everyone agreed that this was something that SUFA was going to do in 2001.

M7 also said that not all groups for people with a learning disability are run *by* people with a learning disability. He said that the problem with the Downs Syndrome Association is that it does not give people with Downs Syndrome the chance to speak – and that it is, after all, only people with Downs Syndrome who can know what it is like to have Downs Syndrome.

Angharad asked whether anyone had ever stood up for the rights of disabled people, either as part of the SUFA group, or as an individual?

M3 told Angharad about a time when he had been in a pub in the city centre and had heard someone being rude to someone he knew. M3 told the security people and the man who was being rude was asked to leave. Everyone thought that this was a really excellent and brave thing to have done.

SW said that in the future SUFA hoped to be able to reach out to people with more severe learning disabilities, to make sure that their voice is being heard.

About ourselves…

Angharad asked whether the members of SUFA have any hopes or dreams for the future?

People said that they had lots of hopes and dreams for the future. Here is the list of the things that people said:

M4 said that he would like his own flat and to share it with a friend. He also said he would like to go to visit Australia one day.

M6 said that he would like to have his own house and to share it with some of his friends. He also said that he would like to get married one day, to the right girl! M6 also dreams about winning the lottery.

M2 said that he would also like to win the lottery and to be collected in a limousine from outside his house. He would also like to get married one day.

M7 said that he would like to live by himself in his own house and to be an actor.

Angharad asked everyone whether anything had happened in their own lifetimes that had made them happier?

M3 said: "Having my baby girl! It was exciting."

M5 said that she liked it when she became an Aunt to three little boys and M3 said that he liked being an Uncle.

M4 told Angharad that his life was better now that he speaks up for himself and that SUFA has helped him to do this.

M6 said that his life had changed for the better now that he stands up for himself and does his own thing.

M7 said that his life had become much better and changed a great deal since God came into his life.

? Angharad asked everyone whether there was anything in their lives that made them unhappy, or that they would like to change?

M8 said that he would like to see his friends and family more, because he does not see them very often. He said that to change this he needs to make more arrangements to go to see people.

M8 also said that he would like some of the people he lives with to be more understanding.

M2 said that he would like his neighbours to stop being noisy late at night and that this makes him unhappy. He said that his neighbours do not listen to him when he asks them to be quieter at night-time.

M6 said that he would like girls to be much nicer to him.

M7 said that he is trying to change his life by losing weight and being healthier, and that God is helping him to do this.

M4 said that he would like his sister to let him go out more with his friends at night-time. He said that he knows that his sister cares about him, but he needs to tell her that he *is* going to go out. He said that he could also ask her whether his friends could visit him at home.

M5 said that she is bullied when she is at Crown Hill and that this makes her very unhappy. She would like this to stop.

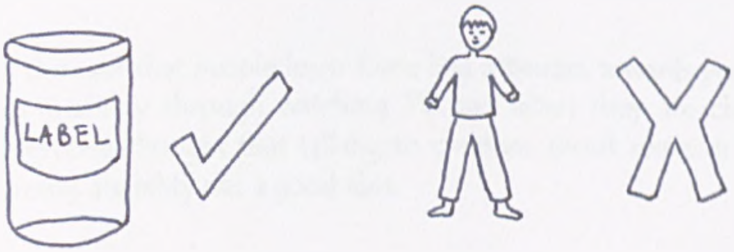
Angharad asked everyone about the different names that people call people with a learning disability and she asked everyone why they thought that people used unkind names?

The SUFA group said that they would like to Speak Up against the use of the words in this list because they are disrespectful and hurtful:

Spastic
Four-eyes
"From the Funny Farm"
Mental
Nutter

M7 said that he thought that some non-disabled people were frightened of people with a learning disability and that this was why they used disrespectful names. M2 said that he thought that the people who call people with a learning disability cruel names were just "thick"!

M2 said that in the end any label can be a bad thing: "We just don't want to be labelled like jars!"



Angharad asked everyone what they thought could be done to change the way that people treat people with a learning disability?

M8 said that he thought that anyone who is nasty to someone with a learning disability has got a problem themselves and that they need to sort it out. He said that being aggressive back to someone who is nasty to you is not a good idea because they might become more aggressive towards you. Talking to people is the best way of sorting out problems.

M6 said that he thought that people needed to be reminded that he is a *person* with feelings.

M7 said that he thought that people needed to see him as an adult. He also said that he thought that having a rally in the city centre would be a good way of making people aware of the bad attitudes that some people have towards people with a learning disability.

Everyone thought that people learn these bad attitudes towards people with a learning disability through watching TV and when they are children at school. Everyone thought that talking to children about respecting people with a learning disability was a good idea.

Finally! Angharad had made a list of some words that she thought might be important to the members of SUFA and she asked them for their comments on each word. This is what people said:

RESPECT – everyone thought that this was a very important word and that people had mentioned it many times during the meeting!

RIGHTS – everyone thought that this was a very important word.

RESPONSIBILITY – M7 said that the members of SUFA were responsible for claiming their own rights. He also said that everybody is responsible for looking after their parents and families.

M3 said that it was important to have responsibility for, and to be responsible about, your own money. M3 also said that everyone was responsible for themselves.

M2 said that everybody is responsible for looking after their own homes.

CHOICES – M2 said that he wanted choices about what he wants to do. He said that having choices was a part of being independent. He likes being able to choose when he goes out and when he comes back home.

M8 said that having choices about having relationships was important.

Michael and M7 said that you need information and advice to be able to make real choices.

BEING A CITIZEN – M6 said that this is important because it means being a part of the community. He also said that being a citizen is about having responsibilities, like being a part of a neighbourhood watch scheme.

Paul said that being an equal citizen means that everyone has their say in the community and no-one is left out.

This was the end of the meeting. Angharad said a "BIG THANKYOU!!" to everyone at SUFA for their help with her research.