NOT QUITE HUMAN: AN EXPLORATION OF POWER RESISTANCE AND DISABILITY

VOLUME 1

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To Marcus

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ABSTRACT

This thesis, as the title indicates, is concerned with notions of power; how it operates, who and/or what it serves, and how we might resist, subvert or challenge it. It is equally concerned with issues surrounding disability. I start by looking at Goffman's stigmatization theory and role theory in general and then move on to theories of oppression. I take issue with these traditional accounts as I argue that they cannot adequately explain disabled people's economic and social position within our society. However, by utilizing Foucault's re-conceptualization of power I highlight the constructed nature of The Disabled and argue that we are produced through the discourse of disability and power relations. By examining Foucault's notion of counter discourse, in relation to the experience of disability, I suggest that resistance is always open to the dangers of neutralization and reinterpretation. I then go on to critically assess Foucault's later body of work and suggest that whilst this does have some major drawbacks it could have great benefits for disabled people in terms of strategies of resistance that are enacted on an individual and immediate level. Foucault's work, whilst offering many insights into the workings of power is, however, not without its limitations. These are principally concerned with the concepts of agency and autonomy. It is for this reason that I return to the work of Goffman in an attempt to ground Foucault's work in a more micro sociological approach. Indeed I argue that there are many similarities between Goffman's notion of the subject and that of Foucault's which have generally been overlooked by sociologists. I conclude that for disabled people to resist normalization it is important to supplement Foucault's work with that of Goffman.

Throughout the text I have drawn upon the experiences of people who have become disabled and who I interviewed at the start of this project. Equally, I have not hesitated to draw upon my own experiences as a resource in this thesis.

CHAPTER ONE

INTRODUCTION

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There is no better starting point for a consideration of disability than the speech of Richard, Duke of Gloucester, at the very beginning of Shakespeare's *Richard III*:

> But I, that am not shaped for sportive tricks,
> Nor made to court an amorous looking-glass;
> I, that am rudely stamp'd, and want love's majesty
> To strut before a wanton ambling nymph;
> I, that am curtail'd of this fair proportion,
> Cheated of feature by dissembling nature,
> Deform'd, unfinish'd, sent before my time
> Into this breathing world, scarce half made up,
> And that so lamely and unfashionable
> That dogs bark at me as I halt by them;
> Why, I, in this weak piping time of peace,
> Have no delight to pass away the time,
> Unless to see my shadow in the sun
> And descant on mine own deformity:
> And therefore, since I cannot prove a lover,
> To entertain these fair well-spoken days,
> I am determined to prove a villain,
> And hate the idle pleasures of these days.
> (Richard III. Act I. Scene I. Ist soliloquy. in Losey 1927)

Here we have clearly stated a Renaissance view of disability that has persisted up to the present day: that the body is a mirror of the soul. The hunchback Richard is driven by self-disgust and envy of those more perfectly formed to become "false and treacherous". In Renaissance psychology, deformity is both the cause and expression of villainy. Disability is a metaphor for 'otherness'.

Clearly this notion of disability as otherness exists today. An individual with a disability is commonly seen as being someone who either cannot, or is limited in their ability to, engage in 'normal' everyday activities. The underlying assumption behind this view rests on the unquestioned belief that disabled people are impaired individuals, separate and different from the rest of society.

The prevailing view of disability is that it is a personal tragedy which requires medical attention. This is common knowledge. That becoming disabled is an individual tragic event, which destroys the life of the 'afflicted', is unquestioned. People 'suffer' from a disability. It is these taken-for-granted assumptions regarding disability which inform our disablist ideology.

We do not have to look far to see negative representations of disabled people. Popular culture, be it films, television, novels, magazines, theatre or charity advertising, is rife with examples of 'brave', 'courageous' disabled people who have 'overcome tragedy, despite all odds'. Alternatively popular culture portrays disability as the bodily expression of a flawed character. In other words impairment becomes, as we saw in the Shakespearean excerpt quoted above, a metaphor and a symbol for a socially unacceptable person. The basic assumption is that disability is seen as a tragic event that befalls a few unlucky individuals. The disabled body becomes the focus of attention, and it is seen as a flawed able body. Thus the accepted idea is to 'treat' the impairment (or the flawed body), to place the disabled person under the medical gaze. This has, of course, its own consequences.

The medical approach to disability produces its own definitions of disability which, by their very nature, are partial and limited.

Underpinning most of these definitions is the assumption that disability is a problem, and that these problems have to be measured in such a way as to define, not just the needs of disabled people, but also to define The Disabled.

Definitions of disability are of great importance. Oliver (1990) argues that if disability is understood to be an individual tragic occurrence, then, not only might disabled people come to perceive themselves as victims of this tragedy, but also we will be treated in all our day-to-day encounters, as pitiable objects in need of compassion.

Furthermore, this has serious ramifications for social policy implementation. Oliver (1990) goes on to say:

> it logically follows that if disability is defined as social oppression then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Such a view will be translated into social policies geared towards alleviating oppression rather than compensating individuals. (Oliver 1990:2/3)

The personal tragedy view of disability is the hegemonic currency of disability *par excellence*.

Historically the definition of disability has been important as a justification and explanation of unemployment and poverty (Stone 1985). Disabled people were the 'deserving poor', as opposed to the 'undeserving poor' who were seen as idlers and layabouts. In other words, the classification and identification of disabled people provided a legitimate social status for us. (Oliver 1990) However, as will be made clear in the following work, this original division between those unable to work and those unwilling to work, has been greatly elaborated upon. Throughout the last century classification, segregation and categorization has intensified, with the result that an ever-increasing range of definitions and measurements of disability is now firmly embedded within society. These new definitions rely upon expert medical knowledge of the disabled subject, and we can trace the medicalization of disability through this disciplinary knowledge.

The growing awareness amongst disabled people that definitions play an important part in our oppression is reflected in our rejection of disablist language and thus disablist definitions. "The Spastic Society" recently changed its name to "Scope", reflecting the unhappiness of people with cerebral palsy with the negative term 'spastic'. Equally, words such as 'cripple', 'moron', and 'mongol' are rejected as definitions of disability. This is a slow process and the recent ridiculing of 'politically correct' language does little to foster any positive changes in definitions of disability.

With the medicalization of disability a correlative field of disability professionals emerged. They, in accompaniment with the Welfare State, needed further definitions of disability and this resulted in a number of surveys, the most recent being "The Prevalence of Disability Amongst Adults" (Martin, Meltzer and Elliot 1988). This survey has its roots in work which was started in the 1960's. The Office of Population Censuses and Surveys (OPCS) carried out the first national survey of disability in

Britain (Harris 1971) and the views and definitions it employed remain substantially unchallenged, and still in official use today.

However, this is not to say that definitions articulated in these works have been without criticism from disability groups and theorists. Oliver (1990) systematically outlines the problems with official definitions of disability. These are outlined below.

These definitions rely heavily upon the medical model of disability, and they classify disability in the same manner as illness is defined. In so doing:

> ...it conserves the notion of impairment as abnormality in function, disability as not being able to perform an activity considered normal for a human being and handicap as the inability to perform a normal social role. (Oliver 1990:4)

Underlying these definitions is the uncritical belief that normalcy is an unproblematic, ahistorical and acultural given. Thus the medical model of disability is reinforced as the 'problem' of disability lies with the impaired individual and not with the environment, or the definition.

A further criticism of official definitions of disability is that they completely fail to take into account the lived experiences of disabled people. Disabled people become docile bodies on which professional disability experts can exercise power. We become:

> ...passive objects of intervention, treatment and rehabilitation. This has not just trapped professionals within the medical approach but has had oppressive consequences for disabled people. (Oliver 1990:5)

Davis (1986) argues that denying disabled people a voice in this way means that the solutions to our problems also become oppressive. In other words, we are defined by the able-bodied and treated by the able-bodied. The treatment here refers to all aspects of disability, from social policy to corrective medicine.

In brief then, disability is understood to be a medical and individual problem. The solution is also couched in terms of the medical and individual model. Both definitions of, and services for, disabled people are constructed for us by the able-bodied.

Whilst this medical model of disability has received much criticism (Oliver 1981; Brisenden 1986; British Psychological Society 1989; Abberley 1991) it still remains the dominant way in which disability is defined and understood. However whilst acknowledging this I have decided not to engage with the vast body of literature on this topic. The reasons for this are twofold. Firstly the majority of texts produced under the rubric of disability theory more than adequately cover this area (see, for example, Lonsdale 1990; Morris 1991; Oliver 1990; Swain, Finkelstein, French and Oliver 1993; UPIAS 1976; Wood 1981; Hunt 1960), and I do not want to simply reproduce their arguments here. Secondly, my concern in this work is principally that of investigating how power produces the subject. The disabled subject is produced through discourse and the medical model is obviously of crucial importance in the construction of the disabled subject. However, by rejecting a simple historical analysis of the medical model of disability in favour of a genealogical approach I hope to highlight the constructed nature, the disparate influences and random fashion out of which the medical model was born.

By failing to acknowledge that disability is culturally and historically bound, the prevailing ideology, the common understanding of disability, that is the medical model, is profoundly disablist. Certain characteristics are seen to be inevitable and natural consequences of being disabled. These include poverty, depression, loneliness and a non-sexed identity. Furthermore, this ideology understands disabled people's behaviour in terms of individual psychological problems. As Jenny Morris points out:

> Susan Hannaford's research (1985) on institutional establishments for physically disabled people found, for example, that a wish to leave the institution was categorized as troublesome and inappropriate, and explained either in terms of a feature of the disability, such as 'multiple sclerocis euphoria' or in terms of a failure to accept the disability.
> (Morris 1993 in Swain, Finkelstein, French and Oliver 1993:86)

Other research such as that carried out by Miller and Gywnne (1972) reinforces the notion that psychological problems are part and parcel of being disabled. Indeed Miller and Gywnne's research is an apposite example of the ideology of disablism, which uncritically adopts and reinforces the medicalization and individualization of disabled people. This study which Morris (1993) suggests must be "one of the most oppressive peices of work ever published" (Morris 1993:86) not only describes us as "the incurables" and "the cripples" but, moreover, the whole premise upon which it is based is extremely tyranical and insulting:

> ...the problems of providing residential care for the physically handicapped and chronic sick are in many ways intractable and will remain so until and unless there is a pronounced change in the values of society, *which may make the parasitism of some of its members more acceptable to all.* (Miller and Gwynne 1972:15 italics added)

Furthermore this research has not been relegated to the wastebin, where it deservedly belongs. Far from it. Miller and Gwynne's (1972) study is oft cited and recommended by many social workers and social policy researchers. Indeed Morris (1991) recounts the time in 1990 when she listened to many researchers into disability issues regurgetating Miller and Gywnne's views. (Morris 1991:130)

In addition if, as it has been argued (Finkelstein 1993), criticisms of the medical model have resulted in changes, it by no means follows, as Finkelstein (1993) goes on to point out, that these have been changes for the good of disabled people.

Indeed the shift from the confines of the medical health care to those of community care and social welfare has merely increased those areas of our lives that 'experts' can pronounce upon. In other words the medical model of disability has merely cast its net a little further. As Finkelstein remarks:

> The shift towards community based services is transferring the duty to other professionals without, however, changing the basic approach to intervening in the lives of disabled people. (Finkelstein 1993:15)

In response to these official definitions of disability, disability theorists such as Oliver (1990; 1986), Finkelstein (1980; 1993), Barnes (1993) and Zola (1981), amongst others, have been arguing for a 'social theory' account of disability.

This account claims that disabled people are not disabled by their impairment, but rather the problem lies with our physical and social environment. Unlike the medical model of disability, the social theory model places disability firmly within the political arena. In accordance with this the following re-definition of disability and impairment has been produced by the Union of Physically Impaired Against Segregation (UPIAS):

> *impairment* lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.
> disability the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS 1976:3/4)

Whilst the social model of disability is a vast improvement upon the prevailing medical model, it is not without its own limitations and shortcomings. Chief amongst these is the denial, once again, of disabled people's lived experiences. The medical model focuses its attention on the impairment and denies the socially constructed aspects of disability; the social model focuses on the socially constructed nature of disability and denies the impairment. These arguments will be developed further in this work. It is enough to say here that the social model is the one that has been adopted by the disabilities movement and that the medical model remains the prevailing framework in which disability is understood in our society today.

In this thesis: "Not Quite Human: An exploration of Power, Resistance and Disability", I have set out to examine the ways in which disabled people become disabled subjects. By examining power relations and resistance I hope to suggest a viable account in which to not only theorise the disabled condition, but to suggest an emancipatory politics of disability.

Throughout this text I have used the term "disabled people". Although "people with disabilities" is generally preferred as it places the person before the disability, signifying that the disability is not necessarily the key, defining aspect of a person's identity, I have chosen to use "disabled people" precisely because this reflects the object created by a disablist society. In addition, I have used the term "disabled" because it is used widely by my informants. I am, however, aware of the problems surrounding terminology. By using a category, in this case "disabled", I am at risk of consolidating the very category I am attempting to deconstruct."The disabled" are not a homogenous group. There are not set limits as to who belongs or who does not belong to this group: "disability is not a static category but one that expands and contracts to include 'normal' people as well." (Davis 1995:XV)

Disability makes non-disabled people curious. Questions concerning the nature of the disability, how long one has had it, how one copes with it, abound. And disabled people have to answer these questions. Issues of 'race', gender and class normally do not induce such questions. Women do not have to say how long they have been female, black people do not have to explain how they cope with their blackness, poor people do not have to account for their lack of money. But for disabled people these types of questions are common-place, and they demand a response. As Davis (1995) comments:

> the disabled body must be explained, or at least tolerate the inquisitive gaze (or the averted glance) of the questioner. (Davis 1995:XVI)

Studies on 'race' and feminism tend to be controlled by people from ethnic minorities and by women respectively. There is a call within disability studies that those doing the research should be disabled. Only disabled people can understand the experience of disability. Whilst on one level this existential argument is valid, it is problematic for an emancipatory politics. We must accept that various subject positions can be shared by others in different but related circumstances.

When reading a text, unless the author makes it explicit, a disability remains hidden. People reading this do not know if I am disabled or not. So in one sense it is irrelevant, but again, on a political level it is important to know that I speak, in this work, as a disabled person. It is for this reason that I use the pronoun "us" for the most part, as "them" removes me from the disabled experience. Yet I am also very aware of perpetuating the distinction between "us" and "them". Furthermore, by using the pronoun "us" I am in danger of suggesting that disabled people form an undifferentiated group, who share similar experiences and impairments. However, I do not think there is a viable alternative and, as in this work I draw upon my own experiences of being a recently sight-impaired person I think the pronoun "us" is the most appropriate.

The first chapter, following this introduction, is concerned with the methodology employed in this work. Although it is traditional to begin a thesis with a relevant literature review, I decided against this approach, preferring instead to incorporate my interpretations of other works into this text as appropriate. Whilst there has been a recent expansion in sociological writings on disability, there seems to be a general consensus among them as to the approach taken. As I take issue with many of these authors I felt it was more appropriate to this work to locate such texts within my overall argument. I open with this chapter as it introduces the people I interviewed and from whom I quote throughout the rest of the text. At the end of this chapter there is a short precis of each interview; the transcripts, in their entirety, are in Appendix 1.

Chapter Three, "The Disabled Role", starts with an evaluation of Goffman's work *Stigma* (1963b). In this Goffman produces an account of disability which is persuasive and, from my own subjective point of view as a disabled person, easily identifiable with.

However, this is not to say that Goffman's work is unproblematic. Stigmatization theory suffers from two major deficiencies: ontological and historical. At no time in his work does Goffman address the question of why certain beliefs and values have a meaning for people in a certain place or time, nor is he concerned with why a certain morality is adopted in a specific era. The substance of a moral order remains unquestioned; it is the maintenance in terms of how members of a group achieve order in their daily lives that is examined. In other words Goffman is more interested in the necessary preconditions that must exist for meaning to be produced rather than social objects or meanings which are produced.

Nevertheless, Goffman's stigmatization theory remains a viable account of a society which is dependent upon notions of deviance, otherness and normalization. It is precisely because of this that I return to Goffman's work later in this thesis.

The next section of Chapter Three is an exposition of 'the disabled role'. Drawing extensively upon both my own experiences of being disabled and upon my interviews with disabled people I outline the expectations and limitations that others (the able-bodied) place on us.

Role accounts, however, are not exhausted by symbolic interactionism and stigmatization theory. Other role theories derive from the functionalist school of thought, and it is with these that the next two sections of Chapter Three are concerned. By using the work of Parsons (1958), King (1962), Seligman (1975) and Thomas (1970), I am able to illustrate how disabled people learn the role that is expected of them. This generally first happens in a hospital situation where people learn helplessness, dependency and insecurity. Obviously the hospital setting is not the only institution through which disabled people learn their role. Many aspects of culture reinforce negative stereotyping of disability and it is with this in mind that section 3 looks at how the disabled role is reinforced through literature.

There are, however, serious limitations to using the concept of role as a theoretical tool in an analysis of power, resistance and disability. The insurmountable problem faced when we attempt to use notions of role theory to inform a theory of disability and a politics of resistance is that whilst they can prove to be useful for an analysis of stereotypes, they remain theoretically undeveloped in terms of emancipatory politics. Thus Chapter Four turns to other theories which concentrate more on an analysis of oppression.

Chapter Four is concerned with theories of oppression, with particular reference to how they have been applied to gender, 'race' and class. I divide this chapter into four sections under the following headings: biological accounts, cultural accounts, psychoanalytical accounts and class accounts with the aim of evaluating what they might have to offer disability researchers.

I take issue with each of these accounts in so far as they can be applied to an emancipatory politics of disability. Whilst on one level we cannot deny that disabled people's oppression is compounded by other factors such as gender, race and class, our oppression cannot be understood simply in terms of such concepts. There is a fundamental difference between disabled people's subordination and other oppressed groups. For example, as a woman I am a member of a subjugated group. However, I do not wish to become a man and nor is it a viable option for the majority of women. Similarly black people, with, perhaps, the exception of Michel Jackson, have never advocated cosmetic surgery in the hope of overcoming their subordination. Yet as a visually impaired person I feel, and most of my respondents feel the same way, that if an operation existed to make us non-disabled then we would happily undergo such treatment. In other words, for women, for black people, for homosexual people, their oppression is not physically embodied within them. Gender, sexuality, the colour of ones skin and our attitudes towards them are clearly seen to be social constructs. Disability is inherently negative, particularly when it is accompanied by pain, fatigue and frustration. As Liz Crow writes:

> There is nothing inherently unpleasant or difficult about the other groups' embodiment: sexuality, sex and skin colour are neutral facts. This does not mean our campaigns against Disability are any less vital than those against heterosexism, sexism or racism. However, we do need to recognise that for other groups, when 'The Struggle' is over they will simply be allowed to 'be'; for many Disabled people, the

> personal struggle of impairment will remain. (Crow 1992:6)

The conceptualization of 'race', class and gender has clear ramifications for all people. Our understanding of these constructs shapes, not only the lives of women, poor people and black people, but all our lives. Equally our conceptualization of disability has implications for all people, not just those categorised as The Disabled. Disability is part of an historically constructed discourse that is peculiar to itself. It is for this reason that theories of oppression which do not explicitly recognise disability are unsatisfactory. Chapters Five, Six and Seven examine the concept of disability as a function of the concept of normalcy. For, as Davis (1995) comments: "Normalcy and disability are part of the same system". (Davis 1995:2) The purpose of Chapter Five is to understand and theorise the discourse of disability and to highlight the set of social, historical, economic and cultural processes that regulate and control the very way in which we think about and think through our bodies.

Following this chapter I have explored an alternative Foucauldian position. Drawing upon Foucault's later works and interviews with him I argue that an aesthetics of the self can be utilized as a tactic that enables us to resist at the individual level. I am not suggesting that this has implications for political action on a group level. Indeed, a politics of the disabled self is not at issue here. Rather this work has implications purely on an individual level of resistance. And it is on this level that many disabled people, both historically and at the present time, "do" their disability.

Chapter Seven returns to Goffman's stigmatization theory, comparing and contrasting it to the work of Foucault and ultimately working towards some kind of engagement between the two thinkers.

Foucault does not systematically outline an account of disability. However, as he documents the rise of our disciplinary society, and with the identification of two modes of objectification through which power and knowledge create the subject, we see how his work informs a study on disability. For the first mode he identifies is the discourse of enquiry which becomes the social sciences which create the subject of which they speak. In the second mode of objectification subjects are created by 'dividing practices' which are informed by the human sciences. These practices result in subjects being defined, and at times confined, according to their perceived differences from others. Thus it is we have the sane and the mad, the criminal and the law-abiding, the sick and the healthy, the able and the non-able. By classifying subjects, according to knowledge, in this way individuals become divided, not only from others, but within themselves.

Whilst Foucault grounds his work in an historical, socio-economical and cultural context, Goffman sites his analysis in analogy. His dramaturgical approach is perhaps, the most problematic aspect of his work. The notion that all the world is a stage has its limitations, for, as Goffman himself points out, nothing real or of consequence happens to contrived, rehearsed and staged characters. This is obviously not true of everyday life where each action has its real and lasting consequence.

Furthermore, players at 'make believe' take off their make-up, hang up their costumes and return home to their 'real' lives. Again this is patently untrue of the everyday. The selves that we invest in, the selves that we produce in the everyday are not cast aside but become part of a long-term identity - that of whom we 'truly' are. To paraphrase Mead (1934): the objective self of social interaction is the foundation of the subjective, 'inner' self.

For Foucault the self is seen as a discursive practice, which constructs an identity. For him the self is always located in discourse, that is it is always located in history, in society.

If we look briefly at the way in which Foucault treats sexuality, for example, then we can see the practical implications of his theory.

The traditional Anglo-Saxon way of thinking about will and desire, about the body, is in terms of evolution and survival of the species. Will and desire are seen as 'pre-programmed', natural and biological. Foucault does not go along with this doxa. In *The History of Sexuality* (1978) he analyses sexuality and overturns the notion of sexual instincts and the myth of their repression:

> We believe in the full constancy of instinctual life and imagine it continues to exert its force indiscriminately in the present as it did in the past. But a knowledge of history easily disintegrates this unity, depicts its wavering course. We believe, in any event, that the body obeys the exclusive laws of physiology and that it escapes the influence of history. But this too is false. The body is moulded by a great many distinct regimes. (Foucault, 1978:56)

According to this model even our most basic instincts - our sexual instincts - are not so 'natural' after all. If we agree with Foucault we have to give the cultural superstructure priority over the supposed biological base, and thus we can no longer perceive sexuality as the product of some innate self. Indeed, as has been said, Foucault clearly sees sexuality as a product of a discourse. A discourse that has been produced through the relation of power to sex. In *Discipline and Punish* Foucault wrote:

> We must cease once and for all to describe the effects of power in negative terms: it 'excludes', it 'represses', it 'censors', it 'abstracts', it 'masks', it 'conceals'. In fact power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and the knowledge that may be gained of him belong to this production.
> (Foucault, 1977:49)

If we wish to consider a history, be it madness, prisons, sexuality, disability or indeed the notion of self we need to do more than merely listing, in isolation, certain events or happenings. We need rather to locate it alongside other institutional, epistemological, socio-economic and cultural developments. The notion of bodies cannot be easily separated from the notion of self. And equally, as Foucault clearly demonstrates, cannot be isolated from, or transcendental to, cultural impositions.

There are problems, however, for those who use the Foucauldian approach. Rather than connecting truth to objects outside of language as the positivists do, or connecting truth to the consciousness of individual knowers as phenomenologists do, this approach sees subjects and objects as 'object-effects' of institutionalised social process. Instead of being prior to language the existence of subjects and objects are inseparable from language use. Because truth is embedded in the intercourse of everyday life, truth is not seen to be static but rather, in accordance to the situation, in a state of flux.

For Foucault questions relating to how we know and what kinds of knowledge become institutionalised in established practices are of great interest, because knowledge and the constitution of available identities are connected to the operation of power in society. Definitions are part of constitutive practices, and thus they do more than just 'label' people. They constitute identities and in so doing participate in the maintenance of relations of dominance.

By discussing the problems connected with learning to manage one's own identity as disabled, symbolic interactionists treat disability as if it were a real condition. Foucault, and those who share his view, would not agree. However, to inform a disabled person that their impairment is not a real condition but one that has resulted from discursive practices is hardly the answer. To suggest that empowering disabled people is contributing to the constitution of disability seems unproblematic. Yet from the 'lived experience' of disabled people, minority pressure groups can change things so that the everyday life of disabled people is made easier; for example, access to buildings, auditory signals at cross roads, installation of hearing loops. It cannot though, be forgotten that to gain a voice, as far as disability goes, is to gain a disabled voice and thus that voice participates in, maintains and reinforces the discursive practices that constitute disability.

In the chapters that follow I will attempt to trace some of the ways in which a disabled identity is constituted in our society at the present time. The investigations try to describe the conditions which site disability within a network of power and under a normalising gaze. Yet at the same time I do not want to lose sight of the experience of becoming disabled. In other words I want to use both Foucault and Goffman in an attempt to make sense of becoming disabled in modern society.

My approach differs from those that look at disability solely from the viewpoint of disabled people. Whilst I conducted interviews with people who have disabilities, I do not intend these interviews to be anything other than some people with disabilities talking about their experiences. I do not wish to continue in the practice of dehumanizing disabled people by allowing a small sample to speak for all. Yet at the same time I believe that hearing disabled speakers, other than myself, is valid as I equally do not wish to, nor am I qualified to, speak for all disabled people.

The implications of this work for an emancipatory politics of disability are consequential. We must be aware of the Foucauldian notion of subjects being constructed through discourse, and of how normalization sets up the criteria in which everyone is placed. In other words the self is constituted as a subject of discipline and normalization. Goffman's view of the self as a performance put on for the benefit of others also lets us see how subjects become stigmatised and thus how stigma becomes part of the body. Both Goffman and Foucault let us see how the oppression associated with power cannot be located within a single socio-political apparatus; they make it clear that power is dispersed in complex networks of social control. Therefore freedom is no longer linked to something whole and universal.

There can be no complete or total synthesis between Goffman and Foucault's work. However, I believe that both thinkers are extremely useful in terms of explaining the way in which disabled people not only perceive themselves, but, more significantly, how we might find the resources to resist.

CHAPTER TWO

METHODOLOGY

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Abstract: This chapter opens with an account of the concerns I had regarding interviewing disabled people, and explains my choice of the narritive method of data collection. This leads to a discussion of the experience of the interviews, which in turn leads to a section which explores the theoretical base of this thesis. The final section of this chapter provides the reader with a brief profile of each of the people I interviewed.

INTRODUCTION

There are numerous ways in which interviews can be structured and carried out. However, as Ann Oakley has made clear, the conventional social scientific paradigm on interviewing relies heavily upon objectivity, value freedom, distance and interviewer control (Oakley 1981). This is an essentially 'masculinist' perspective on interviewing, derived from a masculinist model of social science and, maintains Oakley, particularly inappropriate where women or feminists are interviewing other women. For Oakley it was both 'politically' and morally necessary to enter into a responsive and intimate relationship with the women she interviewed (Oakley 1981:41).

In studying disabled people's experience's I have become aware of a tension between subject and method. For, as Oakley says in regard to women, the very act of conducting surveys on women's oppression is in itself experienced as 'a contradiction in terms'. I felt the tensions most acutely at the moment of data collection itself when I, as a feminist, and as a disabled person, confront other disabled people. The possibility of manipulation and misrepresentation, latent in all social research, appears as soon as the interviewer role is adopted.

It is for this reason that I thought it necessary to employ the narrative method of data collection. By asking people to tell their own stories the integrity of the social actor's own experience is recorded and preserved. Obviously I did not want the subject's entire life story, but only that which related to one aspect of their life: their disability.

During the summer term of 1991 I interviewed sixteen people about their relatively recent disabilities. Unlike the more precisely formulated interview schedule I used an 'interview guide'. This guide introduced themes and issues on which individuals were encouraged to reflect at length. The order and the emphasis changed according to the subject's personal priorities and to what I knew of their background. For example, the physical form the disability took and how recently it had occurred. The areas covered included biographical information, experience of disability (for example chronology, extent of impairment, limitations imposed by disability), reflections on bodily changes since the onset of the disability, interpersonal relationships - both with significant and less significant others - and other aspects which affected the subjects' views of themselves. (see Appendix 2:3)

Ten of the interviews took place in the subject's own home, and four were carried out in a day centre. The choice of setting was the subjects. The remaining two interviews were conducted at a residential centre where I and the two interviewees were staying in order to train with our new guide dogs. In both these instances I was also interviewed by my interviewees at a different time, for different reasons. David interviewed me for an article he was compiling for a talking newspaper, and Colin interviewed me for his local consumer group magazine.

Subjects were selected on the grounds that they had all recently experienced a physical injury which had left them in some way physically disabled. I made contact with these people by first sending letters to various organizations and institutions such as Social Services and The Young Disabled Unit at the District Hospital. The letters stated the aims of my research and explained the nature of the interviews. I asked anyone willing to be interviewed to contact me, thus leaving it completely up to the individuals to decide if they wanted to take part in my research. (Appendix 2:1) A covering letter was also sent asking for the letters to be handed to anyone with a recent disability. (Appendix 2:2) Thus the selection was random and not carefully balanced on lines of gender, age, class or any other criteria. The interviews are not intended to be some kind of representative cross-section of disability, but rather they should be considered as the voices of some disabled individuals talking about their concerns and experiences. They are not speaking for all people with disabilities but rather for themselves.

During these interviews I asked if the respondents were willing to have a 'follow-up' interview. These were conducted six months later and the aim was to cover any areas that had arisen in some of the first interviews but were not covered by all respondents.

Interviewing disabled people about their experiences differs from other research settings in several ways. Firstly, although I have attempted to protect the respondents' identity (by changing their names and certain information) it can never fully be safeguarded due to the personal and unique nature of the data. Thus respondents can easily be identified, in this thesis, both by themselves and by others. Secondly, as Brannen (1988) makes clear, "identification carries with it the associated risk of sanctions and stigma." (Brannen 1988:552) Thirdly, the personal and often traumatic nature of the topic means that for many of the respondents 'telling their stories' is both stressful and potentially emotional. This is true for both the respondents and for myself as interviewer. I was fully aware that I did not want to, nor have the right to, make interviewees confront aspects of their 'changed circumstances' which they themselves were either reluctant to speak of, or had not yet considered. Thus I felt that I had certain responsibilities towards the respondents. These centred around the notion of protection, protection both towards the confidences that were shared with me, and towards emotions that were expressed. Furthermore, the emotional demands placed on the interviewee were, at times, shared by the interviewer. By this I mean that in general the topics under discussion, or the life story of the respondent were so similar to my own worries and concerns regarding my own disability that I found it very stressful as they talked at length about themselves.

Power is ever present in the interview situation. And it is exercised by both the respondent and the researcher. Expressing extremely personal feelings immediately places the interviewee in a vulnerable position. Finch (1983) maintains that women are "easy interview targets", and notes that women interviewed by other women are particularly susceptible to this. I felt that it was important not to exploit my respondents in this way, and thus I conducted the interviews with this in mind.

The respondents were aware of the nature of my research before they contacted me. Thus, the first very open question that I asked each respondent was "Tell me your story". This was deliberately vague so that they were free to interpret it as they wished and in a manner with which they were comfortable. This is reflected in the interviews, with some respondents talking at length, recounting their life stories and others, such as Brad, simply saying:

> I had an accident in '74 in Australia. I was at university so I finished off the degree I was doing and started working, I've been working for the same organization...I had three months or so in the hospital, which was a bit short, most people have about six months or more, but I wanted to get out as soon as I could. I wanted to return to university or else I would have missed a year. (Brad:167)

1. EXPERIENCE OF INTERVIEWS.

In discussing the methodology of her project "Becoming a Mother", Oakley (1981) lists three principal reasons as to why she rejects the text book code of ethics laid down for interviewing subjects. First, it is not reasonable to adopt a purely exploitative attitude to interviewees as sources of data. Second, Oakley regarded sociological research as an essential way of giving the subjective situation of women greater visibility, not only in sociology, but also in society. And thirdly, the notion that 'rapport' be established between interviewer and interviewee has always been maintained, but to follow the masculinist lines and to establish rapport is contradictory.

As Oakley puts it:

> 'Rapport', a commonly used but ill-defined term, does not mean in this context what the dictionary says it does ('a sympathetic relationship', O.E.D.) but the acceptance by the interviewee of the interviewer's research goals and the interviewee's active search to help the interviewer in providing the relevant information. The person who is interviewed has a passive role in adapting to the definition of the situation offered by the person doing the interviewing. The person doing the interviewing must actively and continually construct the 'respondent' (a telling name) as passive. (Oakley 1981:35)

Feminists such as Oakley (1981), Graham (1983) and Finch (1984) argue that the traditional survey interview not only precludes disclosure but this form of interviewing objectifies female experience and mutes women's self-expression. Moreover, Oakley and Finch argue that women interviewers and interviewees share the same subordinated structural position in a patriarchal society. As a consequence the researcher and the researched have a shared identification as women and thus a genuine rapport is established in the interview situation.

These three reasons appositely fit my own beliefs regarding the interviewing of disabled people. There has been much research carried out by the social sciences whereby disabled people are dehumanized and their personhood negated. I wanted to avoid this exploitative aspect of so much masculinist research, and to affirm disabled people's position and situation in society.

This having been said, however, I am also aware of the criticisms that writers such as Oakley and Finch have received. Wise (1987) claims that Oakley uses the notion of woman's shared structural position as a "magical devise for the instant dissolution of inequalities" (Wise 1987:66). That is to say that

> ...success in interviewing depends more on a complex interrelation between the relative structural positions of interviewer and interviewee and the interviewer's skill and personal style, than it does on a simple identity of gender.(Lee 1993:109)

These criticisms by Wise (1987; see also Smart 1984; Warren 1987) clearly had to be borne in mind when conducting the interviews.

Many of the people interviewed asked me questions. As the standardized interview, with its asymmetrical distribution of disclosure rights, would have it I should refrain from answering and fob the interviewees off with remarks such as: "My job at the moment is to get opinions, not to have them." (Selltize et al 1965:576 in Oakley 1981:35) As a women with a visual impairment what sort of rapport would be established if I said this when asked, by another newly registered blind women: "Do you think it will take me long to have the confidence to go out on my own?"?

Most of the questions asked are lost. They were either asked before the tape recorder was switched on, or after it had been turned off. However they generally fell in to three categories: First, questions for practical information such as 'How do you get hold of a speaking blood monitor machine?' or 'Do you know where I can get a list of bed and breakfast places in Scotland that have wheelchair access?' Second, questions relating to the research such as, 'What practical purpose do you think it will serve?' or 'Will it become a book?' And third, personal questions such as 'How long have you been blind?' or 'Are you married?'

I answered all the questions asked of me as honestly as I could. Personal questions I answered instinctively. I did not find self-disclosure in these circumstances difficult as I felt that I was intruding on these people and asking them all sorts of personal, and sometimes painful questions. It seemed only right to me that I should be prepared to be equally honest. It was in this area that I think I mostly communicated my feelings of commonality with other disabled people. I tried to ensure that the people I interviewed knew something about me. Karlie, my guide dog, was present during all the interviews and I felt that it was important to say how long I had had her, how long I had been registered blind, how long I had lived in the area and what I was doing here. Taking the dog with me was, in all instances, a good way of 'breaking the ice'. In a nation of dog lovers a guide dog provides a convenient focus of attention whilst initial contact is established.

In answering requests for information I shared what knowledge I had and if I did not know the answer myself, as was often the case, I pointed the person in the right direction to obtain the information. On more than one occasion I got in touch with the interviewee after I had interviewed them, and after I had found out some piece of information for them that they had requested.

I was however both an 'insider' and an 'outsider'. As a sight impaired person I was disabled and an insider. This came across in numerous instances throughout the interviews. In many cases I was told for example: "you must know what I mean"; "you'll understand this"; and "I'm sure this must have happened to you", all of which reinforce the notion that we have a lot in common, that I was an insider and would therefore understand what it was they were talking about. In addition to this, some of the interviewees drew upon what they knew about me to clarify or articulate their own feelings. For example:

> Well I suppose you know what I mean - what with you having a guide dog...that's like...like having a wheelchair, a signal of being different. Do people notice the dog and not you? (Brad:169)

Here the man is not only acknowledging that we both have disabilities but he is also recognising that we share similar problems. In other words the interviewee is constructing a common identity for us both as disabled.

For others though, I was an outsider, as I knew little of their disabilities and of the limitations that were imposed by them. This resulted in some of the interviewees being able to play the role of 'expert' vis-a-vis me as interviewer. In some instances I was able to ask genuinely naive questions which redresses the balance or inequality in the interviewer/interviewee relationship. This meant that in recounting their experiences and thoughts on being disabled the interviewee did not have to say "Well you've been through it, you know how it is" but could feel that as a disabled person I could empathise with their experiences and yet at the same time not know of them. I was an 'outsider/insider'.

In-depth interviews allow for power to shift from interviewer to interviewee in a manner that more structured interviews do not. In-depth interviews give considerable opportunity for the respondents to control the information they decide to give. Thus, to a large extent they can control the form and content of the data. This was particularly evident when I asked about the interviewees' sense of their masculinity or femininity. Again I was deliberately vague in asking these questions. This was a conscious decision on my part, enabling the respondent to disclose what they felt comfortable with. Thus when asked "Do you feel less of a man?" Paul responds by saying:

> Well, I think women can still look attractive, made-up nicely, hair done nicely, dressed nicely in a wheelchair. I don't think there's any reason whatsoever why a woman shouldn't look as feminine as a woman should look. (Paul:187)

Paul does not address the question of his own masculinity and the effect, if any, his impairment has upon it. Whereas the same question posed to Steven gets a very different response:

> Well with sex I try to get round it really. I mean there is other things apart from sex, apart from the old bonk, there are a lot of other things you can do in bed as well. So I just try to get around it that way. The worst thing is that the women when you do it she gets more peeved because she can't really please you - that's the worse thing about it on the women's side. But if you explain the fact that you know it's in the mind really as well as I get pleasure out of pleasing her and er you are working that way really. That's the best way to do it. But it doesn't really worry me that you are not more of a man or anything like that because in a relationship sleeping is a minimal part of it really it is like ten per cent and ninety per cent of the time you spend together. (Steven:247/8)

Whereas a similar question to Debbie gets this answer:

> It's bound to change isn't it. I mean I think it's because women are brought up to certain standards where they are told: you are the carer, you do the washing, you look after the children, and when you end up in a wheelchair all that goes out of the window, and you've no self-esteem or anything. (Debbie:43)

This exemplifies the way the 'in-depth' interview redresses the power relationship inherent in the interviewing situation.

I felt that the long interview was more beneficial, not just to my own research, but also to the respondents. Whilst participation in this form of qualitative research would seem to have its drawbacks, for example, it can be time consuming, privacy endangering and intellectually demanding, it also has its merits. I was aware before I started any of the interviews that asking personal questions of a potentially traumatic nature could prove very tiring and stressful to the respondent. However, I need not have worried. On nearly every occasion the interviewee proved to be more energetic and tenacious than I was. In attempting to understand this aspect of the 'in-depth interview' Cannell and Axelrod (1956) and Caplow (1956) comment that the qualitative interview gives the respondent the opportunity to engage in an unusual form of sociality. As conversation analysts (see Atkinson & Heritage 1984; Sacks, Schegloff & Jefferson 1974; Nofsinger 1991) have demonstrated, the usual form a conversation takes involves participants 'taking turns' to speak. In the 'in-depth interview' situation interviewers forsake their 'turn' and eagerly listen and encourage the respondents to speak (Stebbins 1972). This has numerous advantages for the interviewee, for instance, they become the centre of another person's attention (Ablon 1977); it gives them the opportunity to state a case which might otherwise remain unheard (Leznoff and Wesley 1956); it gives them the chance to scrutinise themselves without fear of self-indulgence (Merton and Kendall 1946); and, a feature that many interviewees commented upon, it allowed them to experience a kind of catharsis (Lee 1993).

Not every person interviewed wanted to know the same amount of details about me. Indeed some did not want to know anything. At first this surprised me, but I think the reason for this lack of interest in the person who was asking them these questions was perhaps due to their understanding of what the interviewer/interviewee relationship should be. I think that the scientific paradigm governed some interviews and self-disclosure on my part was deemed as inappropriate. Thus it was that in every interview the rules were negotiated, and identities imputed.

The point of this is that the interviewees were not passive subjects but were active in the interviewing process. They decided on how much information to give me, and they had the right to 'draw back' when or if they wanted. The interviews were an interactional process with the interviewees deciding how much personal involvement there should be.

2. THE THEORETICAL BASE.

Once the interviews had been conducted and the transcripts completed I was able to identify certain recurring concerns within the texts. It was immediately apparent that a dominant theme running throughout the interviews was the way in which the interviewees reported on her/his invisibility in social situations. We hear from David, for example, that social invisability is an every day occurance for him:

> Once I went down into club, I went to bar for a pint, and my father-in-law comes round and he says: "Oh I'm just going down to other end of bar." So I says: "O.K." One of me mates come across and I were talking to him, next minute father-in-law comes across and he says:

> "Who are you talking to?" And I were talking to my mate and he had just left and not even said he were leaving and I were talking away to him. Talk about embarrassing! You just don't know where to put your face because people must have been watching me, thinking you know, well who's he talking to? You know if the people come up to you and say like - Oh just a minute I'm going to see so and so - but they don't. They just walk away *as if you are not there.* (David:3)

This comment from Debbie is also typical:

> And the thing I found was if me and my husband go out people talk to him, over the top of me, *as if I am not there.* (Debbie:40)

Equally apparent and related to this was the interviewees obsession with the gaze of the other. Sarah sums up many of the interviewees feelings when she says:

> Well, I've been watching people when I go into town to see what their faces are like when I look at them. I mean a lot of them smile at me, a lot of others just look down at you and just don't bother, I don't know what people think, maybe embarrassment. I mean that a lot of people think that because you are in a wheelchair then your head's gone as well. But it's not. I mean I have got that from a lot of people...(Sarah:97)

Throughout the transcripts there are continuous attempts to define one's identity in terms of some image of the normal. Another typical comment, from people who use wheelchairs but who can walk short distances, is this one from Rachel:

> And I like to be stood up, I like...I just feel I look better when I'm stood up, even though my leg looks a bit bent. I feel better in myself walking. So...I suppose it's all part of my image. (Rachel:195)

This is to say that stigmatization, normalization and role distance are implicit in the ways in which the disabled people I interviewed tell their stories.

I felt that the interviewees, without exception, felt that they were defined by others as 'abnormal'. My initial response to this was to look at Goffman's stigmatization thesis. For stigma theory explains, or justifies the exclusion of stigmatized persons from normal social interaction. Thus the next chapter of this thesis opens with a critique of Goffman's 1963 book, *Stigma: Notes on the Management of Spoiled Identity*.

However, as becomes clear in the following chapter, stigmatization theory and role theory in general, do not adequately explain all aspects of the experience of becoming disabled. Furthermore notions of resisting the prescribed disabled role are undeveloped and do not provide a theoretical base from which change may grow.

In the previous chapter I have outlined the development of this thesis, but I want to emphasis here that both Goffman and Foucault were suggested to me by the data. As stated above, normalization and the gaze of the other were central concerns of all the interviewees, and, I should add, of myself as a disabled woman with a very visible signifier of difference - my guide dog. Thus I thought it would be useful to consider the work of Michel Foucault in relation to notions of normalization, power and resistance.

I have placed the methodology section of this thesis after the introductory chapter as the interviews with disabled people structured the form that this work has taken. Throughout the text I quote from the disabled people interviewed and thus I thought it necessary to write brief summaries of each interview before commencing with the main body of the thesis, in order to introduce these people to the reader. A full transcript of each interview can be found in appendix 1. The page numbers after each quote from a respondent refer to this appendix.

In the final part of this chapter I am going to paint a brief picture of each of the respondents. In each case the name of the person and of their friends and family has been changed, as too have certain pieces of information.

3. THE RESPONDENTS

3.1. DAVID

I interviewed David at 'The Guide Dogs For The Blind' teaching centre where he was training with Blue, his fourth guide dog. David lost his sight in 1978 following an explosion at the chemical works where he was employed. He is in his early forties, and as he says:

> Before my accident, really, I were just a working chap, married, two children, third on the way, and it were just like a routine...you know, running about, going to work every morning, getting up and paying bills...(David:6)

David was forced into taking early retirement, which, he says means, that now he is sight impaired, he has had the opportunity to develop interests, such as working for the talking newspapers, making tape recordings and promoting Guide Dogs, which he would not have had otherwise. David says he is "totally different from before", that he now has far more confidence and freedom. This, he says, is because if things do go wrong he, and more importantly others, blame his lack of sight, rather than see it as a personal failure. But he also feels that he has lost a lot of freedom; freedom to browse in shops, freedom to go where he wants, when he wants.

David's accident and resulting sight impairment has, he says, put a lot of strain on his marriage and family in general. They have had to work hard but he says "we've cracked it now".

David and I spent a month training at the residential guide dog centre. This meant that by the time I interviewed him we had spent a lot of time together, and had passed a lot of this time discussing our worries and concerns about our sight impairments, as well as sharing many jokes regarding "The Sighted". We became friends and are still in contact with each other. Obviously this familiarity influenced the interview situation.

3.2. COLIN

I also interviewed Colin when we were both residents at 'The Guide Dog For The Blind' centre, and both of us were training with our first guide dogs.

Colin, 39, was registered blind four years ago as a result of diabetic retinopathy. His initial reaction was anger and bitterness and, as he says:

> I smashed up the house a couple of times. You know you take it out on people who don't deserve to have it taken out on them. (Colin:27)

This turned, he says, to fear, and a complete disillusionment with the 'helping professions'. He felt very isolated and unable to discuss his impairment with friends or family. Eventually he attempted suicide, but "didn't make a very good job of it", and from there on decided to "get on with life". He finds that it is the small repetitive problems he encounters daily, such as making a cup of tea, which frustrate him more than the major problems associated with his lack of sight. This is compounded by the general public's total lack of understanding which often gives him the impression that he is not only blind but invisible as well.

Colin now belongs to a consumer group for the visually impaired and this forms the focus of much of his social life. Although he and his wife, Rita, still keep in contact with their old friends he finds it easier and less embarrassing being with other sight impaired people. But, he says:

> ...it's a catch 22 situation. Because on the one hand it is good to talk with people with the same disability and share ideas and tips and problems, but on the other you put twenty people with a disability together in the same room it becomes us against the rest of the world. Whether you are blind, deaf, dumb or crippled you have to live in the world. (Colin:31)

Colin believes that we need to educate "the so-called normals" into understanding that disabled people have rights too. Colin says that his relationship with Rita has changed. Before his sight impairment their's was an equal relationship, with both of them employed, sharing the housework and bringing up the children. Now this has all altered. He feels that he has accepted that for some things to be done properly you need sight, but he still gets very angry and frustrated. He feels that he is the same person as when he could see but that other people obviously do not think this is so.

As with David, Colin and I were in each other's company for one month and thus our relationship was far more familiar than with all the other interviewees.

3.3. DEBBIE

I interviewed Debbie at a day centre for physically disabled people. Debbie is thirty-five and has severe arthritis and uses a wheelchair. She was house bound for three years, before she got a wheelchair and this left her with agrophobia which she is now learning to manage.

Debbie thinks that by being in a wheelchair - as she has been for the past two years, people tend to treat her "as if I were ga-ga".

> ...the thing I found is if me and my husband go out people talk to him, over the top of me, as if I'm not there...And I say to them: 'I am down here, you can talk to me, you don't have to talk over me, about me, as if I'm not here'. (Debbie:40)

Debbie admits that she is quite bitter about her disability. She feels that it has greatly affected her relationship with her family and her husband and that it has changed both her and him:

> Before he used to be a very placid day to day sort of person, and now he is a worrier. You can see that things get on top of him quicker than they did before. (Debbie:42/3)

Debbie says that she is extremely frustrated by the fact that she cannot do things that everyone else takes for granted. At the time of the interview Debbie told me she was undergoing counselling for self-mutilation which she felt was caused by frustration. Debbie dreads the future as already all her independence has gone. She says that she is frightened of being left by her family, but at the same time she feels that she is pushing them further from her.

Debbie started going to the day centre as part of her therapy for managing agoraphobia. She says being with other people "who are worse off than me" makes her think she shouldn't be moaning, so "it gives you a better outlook coming here". She sees her disability as "like fighting yourself all the time".

As Debbie puts it the last two years have been particularly hard: "we've had a lot of contributory things that have happened as well as my disability. These include her fifteen-year-old daughter being raped by Debbie's brother; her son taking drugs and hitting her and her husband throwing him out of their home. Her daughter's rape

> brought back the fact that I was raped at her age and although I was trying to console her it was upsetting me as well. (Debbie:51)

Because she can do very little Debbie says that her children tend to go to their father rather than her now. She fears constantly that she is driving her family away and that she is a burden, a nuisance. She says that she is so wrapped up in her own fears that she has no time for her family's problems and she feels very guilty about this. The day centre makes Debbie concentrate on the things she can do, not on those she can not.

Debbie's husband gave up work two years ago, on their doctor's advice, to become her full-time carer. However, they are still fighting for attendance allowance. The Department of Social Security have told them that if they do not get attendance allowance then he will have to return to work. This is "worrying me to death". Being disabled, Debbie says is very expensive, and the money spent on her "makes you feel selfish".

Whilst I felt emotionally drained at the end of this interview Debbie said, once the tape recorder was switched off and the interview 'officially' over, how she had enjoyed talking to me, and how much easier it was to talk to strangers than family. Six months after this interview Debbie was in a psychiatric hospital following another suicide attempt.

3.4. EDDY

I interviewed Eddy at the day centre for physically disabled people. In 1988 Eddy was told he had multiple sclerosis. At the time he was training to be a methodist preacher and felt "it was all wrong because I had gone there to be the help, there was no way that someone else could come and help". However he completed his two year training without the M.S. symptoms returning and worked as a minister for seven months "before the M.S. cropped up again. And it cropped up quite badly." He could neither walk nor see, and then he went into remission for a further two years.

> I think the second attack was worse looking back. Both physically and to handle emotionally.(Eddy:60)

At this point Eddy wondered "if this was the end". Although Eddy says the church was supportive he was retired at the age of thirty-five: "thirty years too early for me." He says he was not angry, just very disappointed. He never asked "Why me?" because the question "Why not me?" seemed just as pertinent. Eddy says that since coming to the day centre it all makes much more sense:

> As a station minister I wouldn't have had time to even visit places like this, or the younger disabled unit at the hospital, but now I can. And so it makes sense. I come here as a minister or what I think a minister is. (Eddy:61)

Eddy's wife has always been, and continues to be, supportive, never asking "awkward questions of the doctors or me." His children too have accepted his illness. Eddy says that if you are disabled it is important that you can talk about it and his disability has brought him and his wife closer. His anger and frustration, he says, is directed at himself when he cannot do simple things. He does not feel "ordinary". He says he does not feel any different but that others obviously see him as being different.

Although Eddy was again in remission at the time of his first interview, he had spent a lot of time previously using a wheelchair. He states:

> Once you have legs which are no use for walking and you've got to use a wheelchair it is something that you have got to come to terms with. But out and about it is other people who have the problem. (Eddy:64)

He feels that it is other people's embarrassment that makes them ignore him and talk to the person he is with. They are embarrassed because he is different, and he finds this "strange".

Eddy traces his M.S. back to a childhood bout of measles, which, although he thinks the doctors might not agree with him, helps him make sense of it all. However the major factor for Eddy is that as a minister in a wheelchair he can empathise far more readily with other wheelchair users, and would "be used by God in a special way". By not being healed by God Eddy feels normal because:

> a lot of people He didn't heal, He healed some, the ones we get to hear about. But there must have been thousands and thousands of others who He didn't heal. So not to be healed made me one of the crowd as it were, not special. (Eddy:66)

Eddy would not change anything in his life and would never go back to being "a normal minister". He says he has to "learn to use what he has got". Eddy now feels that "M.S. is part of me and that my life continues."

During this interview I felt very much an outsider. Not only did I know very little about M.S. but I do not share Eddy's religious beliefs, which are obviously central to him and his experience of being disabled.

3.5. LINDA

Linda contacted me after receiving my letter via her social worker. I interviewed her in her home. Linda has multiple sclerosis and has used a wheelchair for the past twenty years.

Linda still finds it upsetting that people "look at me sideways", and when she first used a wheelchair she feels even her friends were worried, and needed reassurance from her husband "that it was not my brain that was gone". Four years ago Linda's husband died, which was a big shock to her, but she:

> picked up the pieces again...it's like going round the Grand National course I tell everybody...another hurdle, I'll jump it. I might fall next time round at Beecher's but I'll have a go. I'll go on as long as I can. I see my life as a challenge. (Linda:86)

Linda's philosophy is that you have to fight M.S. or it will take over. Linda believes that the best way to do this is by knowing your limitations and knowing when to rest. She finds it very hard to ask people for help, and curtails many of her activities because of this. Much of Linda's time is spent actively working for a charity, which she finds very rewarding.

Since the death of her husband Linda has lost much of her freedom as she is reliant on help getting to bed and getting up in the morning. Although Linda says she is not bitter she feels "as if someone had taken part of my life away", but as there is no one she can blame she feels she just has to accept her disability:

> You can't blame your body because you are your body and you can't blame yourself. (Linda:94)

Nowadays Linda's life is run to a schedule, otherwise she says it would "be all of a jumble". She doesn't look to the future and has always found it best "to take one day at a time". Linda hates having to rely on others, and finds it particularly hard that she has to employ a cleaner in her house.

If she had known that she was going to develop M.S. Linda says she would never have married:

> I wouldn't have burdened anybody with it. Definitely. It is a burden. It is a heavy sack on your back, and it is there every day. (Linda:94)

But she did marry and she says: "I couldn't have had it any better".

A short time after this interview she had a severe relapse and after a short spell in hospital Linda died.

3.6. SARAH

I interviewed Sarah at the day centre for people with physical disabilities. Sarah has muscular dystrophy which first showed symptoms when she was twelve but then disappeared. At nineteen it returned and for the past two years Sarah has used a wheelchair. Recently, however she is beginning to walk a few steps with a walking frame and callipers. The doctors, she thinks, have been good "from a medical point of view" but she feels they have given her no encouragement in her attempt to walk: "it's all come from me". She finds that when she is in her wheelchair people tend to think " your heads gone as well". She puts this down to embarrassment. Her parents never mention her disability.

Sarah enjoys going to the day centre because she finds it much easier being with other disabled people:

> I mean they know what I'm going through in here. Not only that but in here people know what other people can and cannot do. (Sarah:98)

Sarah feels that non disabled people assume she cannot do anything. She is learning to drive and thinks this is "brilliant". Sarah's main ambition is "to get back on my feet, to get walking again. To get back to normal". She hates the way people look at her in her wheelchair as if she were a "wierdo".

Being disabled makes Sarah feel very isolated, and she spends a lot of her time alone. "If I could walk again, well, I'd have my freedom". Even so Sarah says she does go dancing in her wheelchair and says: "it's like the wheelchair becomes part of you."

Sarah gets angry with the lack of access for wheelchair users in towns. She says that non disabled people "just don't think about us", and she feels that there are many practical things that would make her life much easier. She is thoroughly disillusioned with the social services who are always promising help but it never materialises.

Sarah says she spends a lot of time being depressed, especially when she is on her own, but feels she is not bitter. Once the doctors had explained to Sarah that she had muscular dystrophy she found it much easier to talk about her disability as she had a name for it. Sarah wants:

> People just to treat us as normal, as normal people...if people just accepted us the way we are. I mean we are not from another planet or anything. I mean sometimes you would think we were. (Sarah:104)

I tried to contact Sarah for a second interview but she no longer attended the day centre and no one knew what had become of her.

3.7. HILARY

Hilary was interviewed at the day centre for physically disabled people. I interviewed Hilary twice, with a nine month gap in between.

Hilary is forty-seven and has M.S. Twenty years ago she spent time in hospital because she was loosing her sight and had problems walking. However she recovered from this and had no idea that she had M.S. Twelve years later she had a second attack and was told she had M.S. Again she went into remission but nine years ago she had "a hell of a relapse". Now she feels that she has accepted it:

> I've come to terms with it. There are some days better than others, some minutes better than others...until you come to terms with what you have wrong with you, you are fighting a loosing battle.
> (Hilary: 108)

Hilary says that the worst thing about M.S. is that you have no control over it: "it can just go hay wire when it feels like it". She says she doesn't love M.S. or hate it: "it is just part of me. I am just a M.S. person."

Although Hilary is in pain she tries to see this as positive, because if she had no feelings that would be worse. Her parents never discuss her disability with her, and she has a pact with her husband that she will only ask him to do something if she really cannot do it herself. Hilary says that the wheelchair frightens her:

> I hate going in it. I'd rather crawl than get in it. Because I know, because I have a progressive disease that I am going to finish up getting in it. Eventually. (Hilary:111)

Hilary is a great believer, as she says, in "use it or loose it", and she spends much time exercising. In addition to her wheelchair Hilary has an electric scooter which she much prefers using because she feels in control on the scooter. She thinks this is because she doesn't want to be classified by other people as disabled. Hilary says she is not frightened of the future but if her M.S. "ever got that bad I wouldn't want to go on". She says that her only real fear is if it affects her brain. Hilary feels that her disability has not changed her relationship with her husband in any way, he "occasionally washes up for me now". She firmly believes that any anger and frustration she may have due to her disability should be expressed: "it is only harmful to bottle things up".

Hilary likes to be with other disabled people because they can understand what she is going through, but at the same time she likes being with non-disabled people: "I like a cross-section because it is a cross-section world." Hilary feels she has been lucky in life, that:

> life's been good to me, apart from my health. That is the only thing that has let me down. We can't really say that that is too bad can we? If we only have one thing go wrong, health. Mind you that is a very important thing isn't it? (Hilary:122)

Hilary's two interviews are the longest two I have. I asked her very few questions and she was happy to talk at length about herself and her disability. When I arranged the second interview with her, she told me that she was looking forward to it as it gave her the opportunity to talk about herself a lot.

3.8. ALEX

Alex is a thirty-one year old post-graduate student. He contacted me after hearing "on the grapevine" the nature of my research. I interviewed him in his office.

After trying his hand at many jobs Alex came to university. It was at the end of his first year that, Alex, then twenty-six, had a stroke. This caused paralysis of the left-hand side of his body, and sight impairment. He decided, against medical advice, that:

> nothing was going to induce me to get better faster than having to force myself, to look after myself...I just wanted to get straight back.
> (Alex:142)

Now, five years on, Alex has not regained the use of his left arm and his sight is still poor. He has problems balancing and "drags" his left leg when he walks. Alex had always been fit, he loved sport, and he boxed when he was in the Navy. The stroke was an enormous shock to him:

> I always expected to smash myself up on a motor bike but I'd never expected my body to let me down...I'm sure I thought I was invincible before I had the stroke. (Alex:151)

Alex says that he doesn't get frustrated, he can do most things, but some take him so long, for example cooking, that he rarely does it even though he always enjoyed cooking before he became disabled. But he says most things: "you can just overcome with ingenuity."

Alex believes the stroke has changed him: "I think I became a lot more selfish. Yeah, straight away much more selfish. I got to look after myself and all that sort of business." He says that he hates failure and so will not attempt to do things if he thinks he might be unable to do them: "I restrict my activities to those which I am sure of success in."

Alex thinks that since becoming disabled he has lost self confidence: "about how employable I am for a start." He continues:

> It seems to me that a bloke who is now over thirty and recently disabled, bad eye sight, can't drive, he hasn't got much chance of getting a job. (Alex: 147)

His lack of physical prowess makes Alex feel "nervous" in certain social situations. His lack of balance and sight impairment, for example, can make him feel "intimidated". But he feels this is his own fault as he tries so hard to look "normal", to not look disabled. This, he says is because people treat you differently if they see you as disabled.

Alex says he has become less tolerant, especially towards other disabled people. He feels that he can get on with his life so why can't they. But "any whimpering gets on my nerves". If he sees a wheelchair user now Alex says he is far more likely to think "How's that poor sod going to get down there without a ramp", rather than feeling sorry for them: "the sympathy I got never did me any good."

I got the feeling from talking with Alex that he was not used to discussing his disability and feelings about being disabled with another person.

3.9. FRANK

Frank contacted me after having received my letter via the Young Disabled Unit at the local hospital. I interviewed him in his apartment. Frank is a student, he is twenty-five and had a car accident when he was twenty-one. He is now paralysed from the waist down. After the accident and a spell in hospital Frank returned to his parents' house but found it suffocating as they were too protective of him. Frank, at first, viewed his wheelchair as a prison, and felt that he had lost his freedom and independence. His old friends, he feels, never got over the embarrassment of seeing him in a wheelchair, and he has lost contact with most of them.

The changing point for Frank was when he started attending a day centre, initially for therapy, but he met:

> other people in wheelchairs that...well even some of the therapists were in wheelchairs and seemed quite happy. They had cars and could flit around and go away for weekends and some people were talking about going to India and people had travelled and it...and well I got quite interested in reading about disability. (Frank:160)

This made Frank aware that people in wheelchairs don't necessarily have to be helpless. He also liked being able to talk about disability with other disabled people without embarrassment or pity being expressed. But at the same time he also felt uncomfortable at the day centre: "it's like a club where everyone is patting each other on the back". He also did not like feeling good about being less disabled than some of the others. He finds "normals'" embarrassment of him "offensive": "in a wheelchair people impose a whole set of values on to me which I don't like."

Frank says that he is a completely different person since becoming disabled. He talks of the death of the person he was before the accident, but also feels " a certain element of rebirth" as he is more "aware" and "optimistic" than before. He has accepted his disability and feels that this has made him accept himself.

Frank says that because his choices have been narrowed he now has more direction. He is now at University and finds that the main problems he encounters are to do with lack of access. Socially, he says it has been "great", "because people have never known me before, people have always known me as being in a wheelchair."

Frank participates in sport, although before the accident he thought disabled people who undertook various sports "were trying to prove something". Because he uses a wheelchair Frank maintains that he is far more socially adept than before. This is because "the onus is on me to make people accept me and make people feel comfortable with me." It took Frank sometime to learn this skill and he says the people he met at the day centre really helped him in this.

Frank was totally uninterested in my research or my disability. He seemed at ease, even accustomed to 'telling his story' and we conducted the interview more or less as soon as I arrived and I left immediately afterwards.

3.10. BRAD

Brad contacted me via the disabilities officer at the university where he was studying. I interviewed him in his room. Brad had a car accident when he was eighteen which left him paralysed from the waist down. This happened at the beginning of the summer vacation and he resumed his course the following October without missing any of it. He says: "it was convenient that way". Brad says the main problems associated with using a wheelchair are that other people do not know what is appropriate help, and that "they don't understand". But he says he had not appreciated the ramifications of using a wheelchair at first and it "was all a bit of a muddle". But he adds that as he had "direction", "a goal" he did not need any form of rehabilitation. He feels that, initially at least, his family suffered more than him: "it was a bit like a suicide or death in the family". He says he is used to other people staring at him in his wheelchair, that at first this upset him but now he doesn't worry about it. He tries to avoid people who patronise him, and also tries to avoid "over helpful people":

> All you can do is to try to understand what they are saying, what their feelings are, and just be kind to them. (Brad:169/70)

But he admits "it can get too much" and he resents being treated as an invalid.

Brad says he knew from the first that he wasn't going to walk again but that he kept hoping for a medical breakthrough. He says it takes time to understand all the implications of having to use a wheelchair. Brad is unsure of whether he has been changed by his disability. He feels he might be more independent but as he was so young when it happened he had "growing up to do anyway". He tries not to let his disability stop him from doing anything he wants to do and he has tried scuba diving and parachuting. "But I don't have a burning ambition to prove anything."

Brad maintains that "you have got to drive" if you are disabled. "You can't wait until you are given public transport for a wheelchair."

As for his social life Brad does not think that it has been affected by his disability. "The real pain is physical. The logistics of getting around the place." Yet Brad finds forming relations with women more problematic:

> You've got to find someone who will accept the disability plus you have to find the right person for yourself. I think on adding up the numbers the odds are against you. (Brad:174)

I found Brad quite a difficult person to interview as he obviously did not find self-disclosure particularly easy. He asked me no personal questions at all. The tape recorder basically recorded all of our encounter. Brad is Australian and returned home a short time after this interview.

3.11. <u>PAUL</u>

Paul contacted me after receiving my letter via his social worker. He has M.S. and uses a wheelchair. Five years ago Paul gave up work "to lead the life of Riley!" Paul uses a wheelchair in the house, but once outside he has his "electric buggy". "I get on that and I'm gone". Paul spends a lot of time with a friend who also has M.S. and uses a buggy.

He says their paths would never have crossed in normal circumstances as he was a sales director and his friend a lorry driver. But "that doesn't mean anything once you are disabled."

Initially Paul says he was very bitter and angry, but his wife told him that he couldn't carry on like that and told him he had to "pull himself together". From that moment onwards it has been a lot easier for Paul. He feels he is less selfish than he used to be, and far more considerate of his wife's needs. The only thing Paul says he is completely intolerant of is when people come up to him and tell him all their medical problems.

Paul is an active member of the local Access group, and he feels they are "chipping away, like water on a stone", but because making buildings wheelchair accessible generally costs money "it is not a process where everybody welcomes you with open arms." Paul and his friend attend a day centre once a week where they try to give advice to less experienced disabled people: "From political problems, financial problems, health problems and things like that."

Paul feels that there are certain aspects of being disabled that you must accept and then you can get on with your life.

Paul says he feels:

> useless a lot of the time, because you aren't able to do anything, not able to earn your own keep...which has always been very important to me. It is very important for a man to be able to maintain his own standard of living and his wife's. You see Rosemary goes out to work five days a week, she leaves here at ten past eight, and she gets back about five. She runs an office, but I feel beholden to her to a certain

> degree which I don't like doing because she never had to do that sort of thing. (Paul:187)

But generally Paul feels he has come to terms with his disability. He does not try to make any sort of sense out of his life, it is more a case of "que sera sera, what ever will be will be". On the other hand he does, he says, get envious of able-bodied people "particularly on the golf course." And:

> occasionally...when I can't get to sleep I play a superb round of golf in my mind, but that's all you know. I don't try and go back. I think all you would achieve is a sense of misery for yourself. (Paul:191)

Paul was very interested in my life as a disabled person, my experiences and my research. After the tape recorder was switched off and the 'official' interview over, Paul asked me as many questions as I had asked him.

3.12. RACHEL

The disabilities officer at the university passed my letter on to Rachel. I interviewed her in her college room. Rachel broke her back in a car accident less than a year ago. Rachel uses a wheelchair but is optimistic that she will improve with time and be able to walk again. At the time of interviewing her she could walk a few steps with a walking frame and callipers. She says after her accident and ten months in hospital: "I just carried on really." She feels that she should have been offered counselling:

> I don't know if I felt I needed it, but I know I did. Looking back and what I've gone through since I came back here. All the problems of being aware of yourself and that sort of thing. You need to go through it as soon as you can, as soon as you are able to because otherwise it

> just weighs you down. I think there should be some sort of...like your physio, you start off slowly and then you build up to all the issues which are very personal and perhaps you wouldn't have talked about before. But you need to get it all over with and discussed. (Rachel:194)

Rachel prefers to walk if she can because then people treat her "normally". She says she feels better in herself walking. Most of her friends, she says, have been great, neither over-helpful nor pitying. She finds that with people who did not know her before she had the accident it is a little more difficult, because:

> they don't know that I laugh half the time about the things I can and cannot do [...] and that it is not as bad and depressing as they might think. (Rachel:196)

For Rachel the main difficulty is that her disability stops spontaneity, and also means that she has to be organized. "...having to be organized is killing me." She always wanted to be a teacher but now is unsure if she can do this. Rachel doesn't think that she is bitter and says she is glad it happened to her rather than to someone else because at least she knows that she can cope with it.

Rachel feels her disability has made her shyer and her self-esteem is low. She feels she never looks attractive. But she says she is not unhappy, her life is different: "but is no less enjoyable." Rachel feels she must be nice to people even if they are irritating her because:

> if I need them to help me it's really awkward if you have just shouted at them, or snapped at them or something. (Rachel:202)

Rachel believes that if she had not "had the accident in the car I would have had it somewhere else." Rachel is not a member of any groups of disabled people, which, she says, is wrong, but she doesn't like the way the able-bodied stare when there is a group of wheelchair users out together.

Rachel seemed quite comfortable talking about herself and we spent a lot of time, once the tape recorder was switched off, discussing interaction between the able-bodied and disabled people.

After completing her degree Rachel studied for a P.G.C.E. and is now teaching.

3.13. BETH

At the time of the first interview Beth was a third year undergraduate, about to sit her finals. Nine months later, when I met her again Beth was trying to decide if she wanted to pursue an academic career, or find work, hopefully with disabled people, a field in which she had already worked on a voluntary basis.

Beth was involved in a car accident five years ago which left her unable to walk. She uses a wheelchair. After the accident Beth was led to believe: "it would be a long process but something would happen. You know, that I would get out of bed and start walking again." Beth spent over a year in hospital, as there were "complications" and she now has "a little movement". She found that the doctors:

> Weren't very approachable at all. You know very medically orientated, they were here to see to your medical needs and your physical needs,

> but not necessarily your psychological needs. (Beth:210)

Once Beth realised that her "situation was going to be reasonably permanent" she says she came to terms with it "by shutting it out really and getting on with life." Beth says that she mainly uses her wheelchair but:

> psychologically it feels better standing up. It's easier to talk to people, say if I go to a pub, I like to walk in, because you look a bit more 'normal' - in inverted commas - if you are in a standing position. (Beth:211)

Beth feels that there is a lot of stigma attached to being in a wheelchair, but is optimistic that this is breaking down. She tries to "present a more positive image". She says she tries to convince herself that it is only curiosity that makes people stare at her and not embarrassment. She says most encounters with able-bodied people are not "natural", that she has to "make the effort more. It's more my side to make people comfortable", and this is a conscious effort on her part.

Although most of the friends Beth had before the accident "were initially supportive" now they "are not on the scene" so much. Her mother and step-father have been very supportive, even though Beth says that as her step-father was driving "there were some guilt hang-ups". Beth admits that at times she does feel resentment towards him, even though she realises that it was not his fault. But Beth says that her mother and her have become much closer:

> It's been over all very positive, what's come out of it. So we haven't regretted it really...too much. (Beth:214)

However nine months later Beth feels that it would be nice not to have to be "on the wagon and the voice box" but just to try and live a "normal life". But she says she feels pressured by her mother who has become very involved with disability rights.

> We are always talking about disability. I live disability and I would sometimes like just to forget it and she doesn't always appreciate that. (Beth:227)

Beth thinks it is "inevitable" that sexual relationships have been affected by her disability. She says: "I've had a few boyfriends but not as many as I would have had if it had not been for my accident." Two of the three boyfriends that Beth has had have also been disabled. Beth says that her goals and ambitions have changed, but not necessarily in a negative way:

> My goals are probably set higher now I've been exposed to a lot of opportunities which I wouldn't have been exposed to before. For example I've got involved in a lot of voluntary work and because of my experiences as a disabled person I've been invited to join various committees. (Beth:216)

She feels her disability has made her a much stronger person, more committed and confident, and she also feels that she is old for her age, with little in common with other twenty-one year olds. She says she spends a lot of time with other disabled people and although she doesn't feel disabled it is easy being with other disabled people as they can appreciate the difficulties.

At university Beth feels she's "been a bit of a burden" as her department is upstairs and there is no lift so that all seminars have had to be rescheduled to the ground floor. Beth says:

> In myself I don't feel like a disabled person but it is always brought home to me by situations and other people. (Beth:220)

Beth misses spontaneity and feels being in a wheelchair is "pretty naff really". But she also says it does have some advantages:

> I won't meet the guys who mess people around because you know they are not attracted to someone with a physical disability. (Beth:221)

Beth thinks that maybe "I am making a career out of disability" but does not see this as wrong as it is of great interest to her.

Whilst Beth thinks that people's attitudes can be oppressive she does not feel oppressed by her disability. Access, she says, is a real problem, but she thinks "it's a real drag having to fly the flag for disability all the time."

Beth is very involved in sporting events for disabled people and says that when she is participating, and being with other disabled people she forgets her disability. But with the able-bodied it is more difficult.

Beth told me that she had been interviewed on several occasions by other researchers which she resented. However as I was also disabled she thought that my research might be of value. She felt angry at the way disabled people were the focus of much research but the recipients of no funding, grants or practical help. Although I didn't necessarily agree with all that Beth said, I was seen by her very much as an insider and we talked freely and extensively on both occasions.

3.14. STEVEN

Eighteen months ago Steven "was driving down the M1 and er...I fell asleep at the wheel [...] just a split second and that was it." The accident left Steven paralysed from the waist down. Steven's parents both died when he was young and he has "this sort of attitude anyway in life that if something happens you've got to crack on with it."

Steven was offered no counselling but says that being in a spinal injuries unit you see:

> a lot more people who were worse than me, with neck injuries and that and you think 'bloody hell, at least I have the use of my arms' [...] and you think 'well, I haven't got so much to worry about. (Steven:241)

Steven says he tries not to let his disability "hold me back". He says he just tries to get on with his life.

Steven says he has "a good bunch of mates" who have helped him a lot. At first he says it was awkward, but once one of his friends asked for his ski boots and "broke the ice" he says it "was back to normal really".

Steven does not like to consider questions such as what the public image of disability is. He says he just tries to be as normal as possible. He really does not like the way that some disabled people who were in the spinal injuries unit are "just hangers on, two years on, and still going twice a week."

Steven had been living with his girl friend for four years when he had the car accident.

After this they parted ways: "She just found it really stressful". He says that it is best to be on your own "until you get organized."

Steven realises that many people are awkward when they see that he is in a wheelchair, and he finds that he has to put other people at ease and make them realise that he is the same person as he was before he had the accident. He thinks it is understandable in some ways as he says he was exactly the same before his own accident:

> I was exactly the same with wheelchairs, I mean before the crash, a lot of my friends were as well, 'bloody hell the lad's in a wheelchair!' I don't know why the reason is. I mean I was exactly the same. (Steven:243)

Steven says that lack of access for wheelchair users does not make him feel disabled, but his body does. He says that he has had to learn to be very organised since his disability, and that a daily routine is now essential for him. He feels he is fortunate as he has not had to give up his job, in fact he carried on working, using a mobile phone even whilst he was in hospital. He thinks it is very important to keep busy and not feel sorry for himself.

For Steven his disability is "just a fact of life":

> It's there and you have just got to cope with what you have got. It's happened and that's it. Can't see the point of doting on it really. (Steven:249)

Steven says that whilst his accident means that he has lost spontaneity, it has also given him a more relaxed attitude towards life.

Steven does not like associating with other disabled people as he thinks that other people will not treat them as normal. As he says:

> I just try to get on and keep away from it because I think that if you hang around people in wheelchairs people think 'Oh here comes a clan of them together'. I try to keep away from what the others were like you know. A lot of them used to go to the pub together, four wheelchairs in a pub together all the time and I just try to keep my distance from the whole situation really, just try to get back with the people I used to mix with before. (Steven:252)

3.15. CHRIS

Chris had an accident on his bicycle. He has no memory of what happened, but it left him unable to walk without sticks and with little use in his left arm. He was in a coma for three months and he spent over a year in hospital. He maintains that without the love, support and "bullying" from his parents he would still be unable to walk at all and might well have died.

Chris says that he has not kept in touch with all his old friends: "Some friends, yeah, but a few friends just dropped off. They don't want any more contact with me." He thinks this is because they thought he was different "and they couldn't handle it". He also feels that people now use him:

> I'm a good touch and always got dope or something like that round so they'd come round and see me, drink my beer and stuff like that. (Chris:259)

Chris feels he puts up with this because "I need company, I can't get out."

Chris says that people can react badly to him

> Tourists are really pigs, you know, they just bump into you, treat you as if you are not there, you know, that I find really annoying. I swear more now than I ever did: 'Hey fucking watch it, I'm here!' You know, that sort of thing. Usually gets people's attention, they'll give you a dirty look, but so what, at least I'm able to walk and not get pushed over. (Chris:260)

Chris feels that he hasn't changed, but now people are always stopping him "just because I walk with sticks they think they can intrude on me."

Chris says that the doctors told his father that he would not live, or if he did he would be a vegetable, "so it's quite an amazing recovery I've made." He says he is not bitter about his accident, "I rarely think about it actually. It's something that happened."

His main regrets are lack of mobility, spontaneity and lack of money. He also misses going on holiday. After his accident Chris' parents' church paid for him to visit Lourdes.

Chris says that since he has become disabled he spends a lot of time day-dreaming:

> I day-dream a lot about how I would like my life to be, you know, things like that, you know, things I could be doing, people I could be with, you know, I think that it is because I am disabled that I have the day-dream now. I used to dream a lot before but I day-dream more and more now...sometimes it's with me walking properly. (Chris:268)

After his accident Chris says that he hated his body but that now he is beginning to love it again. He says he notices:

> ...improvements all the time. You've got to really because it keeps you living. Keeps you enjoying life and you think this is really good. You've got to give yourself little goals. (Chris:269)

I found this interview with Chris very difficult. When I arrived at his house I declined his offer of a beer. He was angry saying that he had got them in especially for me. Throughout the interview he would suddenly shout and get angry and it was difficult to leave the house after the interview. I felt quite intimidated by him. I did not arrange a second interview.

3.16 KAY

Kay contacted me after receiving my letter via her social worker. Kay has diabetic retinopathy and is registered blind. At the time of the first interview Kay had a little residual sight, but nine months later she had lost this and was also using a kidney dialysis machine.

When her sight first deteriorated Kay was devastated:

> Basically it just shattered me. Completely. You know I had a good job, I enjoyed my job, I drove the car. I just didn't expect...kidney failure I expected to happen [...] My eyes were always good and I never thought anything at all would happen to them. No pain or anything. It just happened. I woke up and I couldn't see. (Kay:271/2)

Kay gave up work, sold her house and bought a bungalow near to where her parents live. Her parents have been supportive, but she finds her friends still expect her to be able to do everything that she could when she was sighted, "except drive the car". Kay feels that she is not the same person that she was before her sight impairment:

> I'm more rattier and I get mad easily and I'm jealous of people who can see. Definitely jealous. [...]I cry more now and I get sort of frustrated. (Kay:275)

Kay was registered as blind and felt that as she had some sight this was wrong. She was frightened that she was going to become "black blind" but would get no help or sympathy as she was already registered as blind.

Kay says that she hates herself now. She has no confidence and hates not being able to do things such as applying make-up and doing her hair.

Kay thinks that her relationship with her boyfriend, Richard, has changed. She feels that she is more dependent upon him, but she also says that she uses her lack of sight as an excuse to get her own way:

> I do play on it. He said 'Don't forget to tell her when she comes that you play on it'. I said 'I do not'. But I do.(Kay:281)

Kay says that she no longer has to "prove herself" as she can say "I can't see". Kay hates being classed as disabled, she hates using her white stick, and she hates the way people talk down to her. She avoids contact with other blind people as she finds the idea of mixing with The Disabled very depressing. She says:

> I don't want people that are blind near me, you know what I mean. I'm sure they all wear purple hats and orange trousers - I suppose that's actually trendy! But you know what I mean - the crimpoline look! (Kay:298)

Kay says that she has not come to terms with her, now, total blindness. She asked her doctor if they could perform eye transplants:

> He said: 'When we can do brain transplants, yes'. So I took that, well, it's not around the corner...when they can do brain transplants...so I took it, well, I don't know how to take it, I'd like to think, yes, one day they will be able to do brain transplants. I've got to have some sort of hope because I can't...I can't say 'Oh I'm blind and that's it for the rest of my life'.(Kay:298)

I found both interviews with Kay emotionally draining. Although Kay asked me very few personal questions, she was very keen to do a follow-up interview, and seemed very happy to talk at length about herself. I believe that I found the interviews tiring as her medical history is very similar to my own, and I shared some of her feelings. We did not however discuss my situation or any notion of commonality.

CHAPTER THREE

THE DISABLED ROLE

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Abstract: This chapter is divided into five sections. After the introduction I critically assess Goffman's stigmatization thesis. In the second section I examine disability as role performance, what this role comprises off, how we learn this role, and in section three I look at how this role is reinforced through cultural artifacts, in this instance, literature. The forth section reviews the limitations of role theory and the final section is the concluding remarks.

INTRODUCTION

In this chapter I am going to discuss and evaluate role theory as a basis for an analysis of disability, power and resistance.

Within sociological literature the concept of role is often undefined, used inconsistently or defined inadequately. Too often status, position and role are not differentiated or consistently treated as separate analytical concepts:

> The basis of roles such as norms or standards of expected behaviour for occupants of given social positions are often confused with, on the one hand, general (and often abstract) cultural ideals and, on the other, actual everyday conduct, and sometimes, somewhat oddly, both at the same time. (Edwards 1983:390)

In addition to these conceptual difficulties, role theory is generally recognised as occupying central positions within two different sociological perspectives. The first systematic use of the concept was in 1934 by G.H. Mead, a forerunner of symbolic interactionism. In this usage roles are depicted as the outcome of a process of interaction that is tentative and creative. The second approach derives from social anthropology, in particular the work of Linton (1936), and was subsequently incorporated into functionalism. In this model role taking is no longer seen as the characteristic form of interaction. Rather, roles are viewed as essentially prescribed and static expectations of behaviour. In other words, roles are seen as prescriptions inherent in particular positions.

This chapter is divided into five sections. The first looks at Goffman's stigmatization thesis. Although a general critique of role theory does not necessarily include an evaluation of this work, Goffman has made important contributions to role analysis. Moreover, *Stigma* which although written as long ago as 1963, is still, perhaps, one of the most significant works to systematically outline a theory of difference. For Goffman the social order is always precarious because it is disrupted by embarrassment, withdrawal and the breakdown of communication. And it is with these issues that *Stigma* (1963b) is principally concerned. Following on from this section I will examine notions of disability as role performance and document how this role is learnt. These two sections are informed by the more functionalist approach to role theory. I will then address the wider social aspects of learning the disabled script. It is hoped that by examining this role some of the problems and difficulties that arise when we attempt to resist this role will be highlighted. Fourthly I will consider some of the objections and shortcomings of role theory, before drawing some concluding remarks.

I. GOFFMAN'S STIGMATIZATION THESIS.

The best known interactionist account of disablement can be traced to the work of Erving Goffman and his concept of stigma. Goffman produces an account of the disabled personality which is moulded by a series of stigmatizing encounters. A basic tenet of interactionism rests on the assumption that once it is recognised that a person possesses a stigma then a set of expectations, norms and behaviour follow:

> By definition, of course, we believe the person with the stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma theory, an ideology to explain his inferiority, and account for the danger he represents, sometimes rationalising an animosity based on other differences, such as those of social class. We use specific stigma terms such as cripple, bastard, moron, in our daily discourse as a source of metaphor and imagery, typically without giving thought to the original meaning. We tend to impute a wide range of imperfections on the basis of the original one, and at the same time to impute some desirable but undesired attributes, often of a supernatural cast, such as sixth sense or understanding... Further we may perceive his defensive response to his situation as a direct expression of his defect, and then see both defect and response as just retribution for something he or his parents or his tribe did, and hence a justification of the way we treat him. (Goffman 1963b:15/6).

In *Stigma* (1963b), Goffman is specifically concerned with the issue of mixed contacts. That is to say, the moments when stigmatized and normal are in the same 'social situation', that is in one another's immediate physical presence, whether in a conversation-like encounter, or in the mere co-presence of an unfocused gathering.

Mixed encounters, between the visibly stigmatized and normals can foster, Goffman suggests, unease and awkwardness. The stigmatized may cower or face mixed contacts with hostile bravado or alternatively, alternate between the two.

It is not only the stigmatized who make the interaction unsmooth. The normals feel the stigmatized to be too aggressive, or too shame-faced "and in either case too ready to read unintended meanings in to our [the normals] actions." (Goffman 1963b:29) Each encounter between a socially abnormal and a normal is precarious. According to Goffman, whether ordinary people react by rejection, by over hearty acceptance or simply by embarrassment, their main concern is with such an individuals deviance, not with the entire, whole personality.

In this account of disability, Goffman uses extensive quotations from autobiographies and interviews with stigmatized individuals to argue that stigma is closely related to stereotype and that both are associated with the unconscious expectations and norms which act as unseen arbiters in all social encounters.

Central to Goffman's account are the two concepts of "virtual" social identity and "actual" social identity. On each encounter with a stranger we anticipate the category to which the person seemingly belongs and the attributes we assume them to possess. In other words we anticipate a stranger's social identity based on our expectations from first appearances. We then "lean on these anticipations...transforming them into normative expectations, into righteously presented demands." (Goffman 1963b:12)

Generally it is only when the person fails to live up to the assumptions and expectations that we have of them that we are made aware of these demands in the first place. Goffman terms these demands, demands made "in effect" and the character that we impute to the individual - a characterization "in effect"; in other words a virtual social identity; those that one could be proved to possess, the actual social identity. When a discrepancy arises between actual social identity and virtual social identity a stigma can occur.

> While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the categories of persons available for him to be, and of a less desirable kind... He is thus reduced in our minds from a whole and usual person, to a tainted, discounted one. Such an attribute is a stigma. (Goffman 1963b:12)

It is then, maintains Goffman, this difference between actual and virtual identity which is important. "It constitutes...a social relationship between attribute and stereotype." (Goffman 1963b:4). In his comprehensive study on Goffman, Burns (1992) suggests that Goffman, at this point, is merely repeating what he has made perfectly clear earlier - namely that society at large imposes a differential grading system on individuals and by introducing the notion that stigma arise at the point of discrepancy between virtual and actual identity, Goffman is not only repeating the notion of grading inherent in the categorisation system that he started with, but he is also confusing the point that he wishes to make later. That is the distinction between "the discredited" (individuals whose stigmatising characteristics are either visibly evident or known about beforehand), and "the discreditable" (where the stigma is not self evident and the person is under threat of discovery).

The "categorisation system" that Goffman draws for us, enables us to grade, place and sort persons we meet according to the characteristic expectations we have for persons met in society. As *Stigma* (1963b) unfolds it becomes apparent that it is not merely a neutral categorisation system at work, but the system is for grading people and this can hardly be called neutral.

For some members of society to be stigmatised, to be members of a minority group such as, to cite the examples Goffman gives, "Mennonites, gypsies, shameless scoundrels and orthodox Jews", (Goffman 1963b:34) is to be so strongly bonded with other group members that their identity is strengthened and the effects of stigma are not as negative as for the majority of stigmatised individuals.

Most stigmatised individuals become aware of their stigma whilst at the same time becoming aware of the 'normal' attitude towards their stigma. Indeed they share with the normals their beliefs and attitudes about normality. Thus people born with a stigma can become socialised into their disadvantageous situation "even while they are learning and incorporating the standards against which they fall short". (Goffman 1963b:46)

For others born with a stigma Goffman suggests an alternative "moral career": the fact that they have a stigma can be hidden from them. Only at a certain time, which will depend on differing factors such as nature of stigma, social class and so forth, will the individual be rudely woken to the fact of her stigma. This often occurs when the child starts school, and Goffman suggests that for the individual who is sent to an institution for "his own", having to admit that this group is not what she thought her own was can be shocking. Even if the individual gets through school with some illusions left it is highly improbable that they will survive dating and job hunting with any delusions as to the view that the public at large take of them.

The third pattern of moral career Goffman identifies as those people who become stigmatised later in life. The majority who fall into this group are informed of who they are going to have to be by the medical profession. These stigmatised individuals already know about the normal and the stigmatised well before they must see themselves as deficient. One of the interviewees, Steven, comments:

> Some people are just dead shy, I know a lot of lads who'll say hello but don't want to sit and talk with you. So I have to go and talk to them. I was exactly the same with wheelchairs, I mean before the crash, a lot of my friends were as well, 'bloody hell the lad's in a wheelchair!' I don't know why the reason is. I mean I was exactly the same. I mean I used to go and see this farmer who had had a horse riding accident and I was always on a nerve when I used to go and see him because he was sat in a wheelchair. It always used to put me on a bit of a nerve you know. (Steven:243)

The fourth pattern is illustrated by those who learn one way of being in an alien community and then who must adopt a second way which is felt by the surrounding community to be a more real and valid way.

The phase during which the individual learns that she possesses a stigma often is a time when that individual develops new relationships with others with that stigma. Given the ambivalent nature that exists between the individual and her stigmatised category it is not surprising that Goffman writes: "... oscillations may occur in his support of, identification with, and anticipation among his own." (Goffman 1963b:51)

Nevertheless, the sympathetic others whom Goffman terms "The Own", are important in establishing social contacts and membership of groups for the stigmatised wherein they may feel less awkward and sure that they will be accepted. This is, of course in contrast to how they feel in mixed contacts, where they can never be sure of how they will be received.

These meetings of people sharing the same stigma can, in Goffman's eyes, certainly have their disadvantages. He describes the stigmatic amongst his own using:

> his disadvantage as a basis for organising life, but he must resign himself to a half world to do so. Hence he may develop to its fullest his sad tale accounting for his possession of the stigma. (Goffman 1963b:32)

He continues:

> Then there are the huddled-together self help clubs formed by the divorced, the aged, the obese, the physically handicapped, the illeostemied, the colostomied... (Goffman 1963b:34)

Hardly positive images of such groups. But as Goffman points out, the very nature of such groups is bound to be restrictive. The very reason that these people "huddle-together" is precisely because normal encounters for them are difficult, if not impossible. As Debbie says in respect of going to a day centre: "...you know there is a difference between 'them out there' and 'us in here'" (Debbie:46)

Further, these organised groups can put the stigmatised individual under additional pressure. Just how far should we identify with our own when socialisation tells us that to be identified as 'one of them' generally means non-acceptance by normals. "In brief he can neither embrace his group nor let it go." (Goffman 1963b:32) And it is this attitude that is reflected in much of the writing, drama, talking and humour that is produced by people with stigmas, who have come into the public eye. In summarising Goffman's attitude on this point Burns (1992) aptly quotes the following passage from Primo Levi:

> I cannot understand, I cannot tolerate the fact that a man should be judged not for what he is but because of the group to which he happens to belong. (quoted in Burns 1992:223 from Primo Levi 1988:143)

Or as Frank says when he is trying to explain his ambiguous feelings about mixing with ;his own':

> [The day centre is a] sort of club where everyone is patting each other on the back. I suppose you get an element of 'Oh I'm lucky to be less disabled than that person down there', which I wasn't too keen on [...] but it was also a lot of help because it opened up possibilities, it made me realise that I could talk about my disability and find out about disability without embarrassment and without having other people impose their stereotypes on me, and without this feeling of pity that you get from a lot of people. (Frank:161)

There is another group of people besides those sharing the same stigma with whom stigmatics form understandings. These Goffman labels "The Wise". That is to say "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatised individual and sympathetic with it." (Goffman 1963b:41) The Wise may be relatives, or they may work with the stigmatised, either in the medical profession, social services or in other ways such as, to quote Goffman: "Gentile employees in delicatessens... straight bartenders in homosexual bars, and the maids of Mayfair prostitutes." (Goffman 1963b:42)

The problems faced by the stigmatised spread out in waves of diminishing intensity, thus the relatives of the stigmatic acquire a degree of stigma of their own. This "courtesy stigma" provides a model of "normalisation" states Goffman, which allows normals to see how people with stigmas can be treated as if they did not have one.

The Wise can, however, make both the normals and the stigmatics feel uncomfortable. She confronts the "stigmaphobic response of the normals" with "too much morality" (Goffman 1963b:44) and their easy-going, offhand way of handling the stigma can lead to misunderstandings.

The relationship a person with a stigma has with their group is crucial:

> If he turns to his group, he is loyal and authentic if he turns away, he is craven and a fool. Here, surely, [states Goffman,] is a clear illustration of a basic sociological theme: the nature of an individual, as he himself and we impute it to him, is generated by the nature of his group affiliations. (Goffman 1963b:137/8)

It is these group affiliations which, for the stigmatic are the crux of the problem. To exemplify this Goffman looks at the case of the militant stigmatic. She wants to be accepted as normal but the very stand she must take to fight for this draws attention to the difference. In addition, by highlighting the situation of her own she may actually help to consolidate a public image of their differences as a real thing and thus of her fellow group members as constituting a real category. Equally if it is not affiliation the individual wants but separation, then it is likely that she will have to adopt the language and style of those who do not support her views. The militant stigmatic feels disdain for a society which rejects her, but which can be understood only in the language of that society:

> In short, unless there is some alien culture on which to fall back, the more he separates himself structurally from the normals, the more like them he may become culturally. (Goffman 1963b:139)

This, as Burns (1992) says is very convincing but it is assuming that all members of modern society "share the same uniform, homogeneous, self-consistent cultural values and beliefs." (Burns 1992:223) Burns explains Goffman's oversight in terms of his preoccupation with "macrosociology" in that he tends to treat social structures and cultural systems as "given" and therefore factors whose influence cannot be gauged.

The stigmatized individual then, is asked to look at herself from her own group, but Goffman considers the view point of a second class, namely the normals and the wider society that they constitute. The language used from the previously discussed viewpoint was political, now the rhetoric is psychiatric "the imagery of mental hygiene." (Goffman 1963b:140) The stigmatic is urged to make "a good adjustment" which covers several points. They are to see themselves - in all respects bar one or some - as full human beings, without letting their stigma get in the way. However, on the other hand, they should never look as if they were denying their stigma. They should always be cheerful, happy, and not self-pitying or bitter, for after all normals have their problems too. Normals, who, after all mean no harm, should be helped. Skills that people with stigmas have developed through their dealings with normals should be used to help the normals in mixed social situations. The overriding qualities that stigmatized people must develop, in dealing with mixed social situations are tact and diplomacy. Normals "don't know better. They should therefore be tactfully helped to act nicely." (Goffman 1963b:141) It is up to the stigmatized person to, as Goffman puts it "break the ice" if there is tension and awkwardness in a mixed social situation. This can be done in various ways, amongst which Goffman suggests the stigmatic can show that for them the failing is a matter of no concern, even levity, or by attempting to discuss the stigma in a serious manner thereby not making it a taboo subject. Frank explains how he had to learn these skills:

> Well, it was something that going to the day centre taught me, you know, talking with other disabled people. Sort of like an exchange of information on how to put people at their ease with jokes and things like that. It's in a sense very artificial. The day centre is a little bit like a learning social skills school. I mean, if people feel frightened about me being in a wheelchair they can also sort of walk away or ignore it whereas I'm in a wheelchair, I can't. Physically I'd find it harder to walk away! So I have to tackle the problem head on. (Frank:166)

In addition the tactful stigmatic can, on meeting new acquaintances, allow them time to compose their response. When normals encroach upon the privacy of a person with a stigma, usually by showing unsolicited interest, offering sympathy and help, then that person should respond with politeness, tact and as if these infringements were appreciated. Equally normals like to believe that the stigmatic is at ease with her failing because this belief makes it easier for them to be at ease with her.

> In brief, the stigmatized individual is advised to accept himself as a normal person because of what others can gain in this way, and hence likely he himself, during face-to-face interaction. (Goffman 1963b:145)

But at all times the stigmatized individual should be aware of the boundary between normal and stigmatized and not attempt to cross it: "acceptance is conditional." (Goffman 1963b:146) On no account should the stigmatic test the limits of the acceptance shown them, or assume that they can make additional demands upon it. "...tolerance, of course, is usually part of a bargain." (Goffman 1963b:146)

A good adjustment therefore, means that normals are sheltered from any of the pain and unfairness of having a stigma; it means that normals never have to face their own intolerance and their own lack of tact; and it means that normals and stigmatised do not generally become intimate, thus leaving the normals' identity beliefs unquestioned and secure. As Robert Scott, in his study *The Making of Blind Men* (1969), points out:

> In fact, the blind person who deliberately thrusts himself into the everyday life of the community is soon treated as a nuisance, and the blindness worker who persues too seriously the avowed goal of reintergration soon wears out his welcome in the community. (Scott 1969:92)

A stigmatised person is expected to act so as to give the impression that her failing is no problem to her and that it has made her no different from normals; at the same time she must help normals sustain this belief about her. She can only really do this if she keeps her distance from normals. In Goffman's words:

> ...he is advised to reciprocate naturally with an acceptance of himself and us, an acceptance of him that we have not quite extended him in the first place. (Goffman 1963b:147)

In other words what Goffman labels a "phantom acceptance" provides the foundations for a "phantom normalcy". The final irony of this, for Goffman, is that for a stigmatized individual to lead as normal a life as possible it would appear that the best course of action is to embrace this phantom acceptance, acting as if she had achieved full acceptance, but being sure not to push her luck, not to cross the boundary dividing normal and stigmatized. It is, of course, this tolerance, this 'being nice' to able-bodied people, that is the essence of the liberal approach to difference.

Who are the stigmatics that Goffman has so sensitively produced in his essay? Well, they seem to just about include everyone: the blind, the deaf, the crippled, the maimed, deformed, disfigured, diseased, prostitutes, homosexuals, mentally ill people, alcoholics and criminals. They also include Blacks, Jews, 'ethnics', people from the lower classes, the aged, ex-mental patients, ex-convicts and on to people with colostomies, mastectomies, and the illiterate, and diabetic. The list seems endless.

Goffman's purpose is not just to catalogue those who are stigmatised. For as he says at the end of his essay:

> The role of normal and the role of stigmatised are parts of the same complex, cuts from the same standard cloth. (Goffman 1963b:155)

Whenever there are identity norms the process of stigma management is taking place. Goffman argues that whether the differences are of the type that would traditionally categorise the individual as stigmatic or whether they are of a trifling nature, the same features are involved. Secondly the stigmatic and the normal share the same standard psychological make-up which makes them equally equipped to play both roles. And thirdly it would seem that there are definite similarities in regard to certain beliefs regarding identity. The notion of shameful differences rests on this assumption, that is to say that people whilst maybe having abnormal feelings and beliefs share the same normal concerns and carry out the same normal behaviour to conceal these abnormalities from others.

In *Stigma* (1963b) Goffman shows how an individual can play both the role of a stigmatic and a normal:

> Stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatised and the normal, as a pervasive two-role social process in which every individual participates in both roles, at least in some connections and in some phases of life. (Goffman 1963b:163)

Goffman does not deny that some individuals with certain attributes are typecast and play the stigmatised role in most of their social situations. This he says makes "it natural to refer to him... as a stigmatised person whose life situation places him in opposition to normals." (Goffman 1963b:164) But this only refers to the frequency of her playing a certain role.

This account of disability is not then, just an account of the disabled. It is an account of a discriminatory system of which, as Goffman makes quite clear, we are all a part, and which we all operate. This is to say that the account of society which Goffman draws for us in *Stigma* (1963b) is dependent upon notions of deviance and otherness. It is, in the final analysis, only because of our ingrained notions of normalization, of our expectations and anticipations of what a person should be that we are able to identify and discriminate against those who "are not as they should be". This concept of normalization will be returned to again and again in the following chapters. Indeed in

Chapter Five I shall be considering Michel Foucault's concept of power and normalization. For Foucault disciplinary power is an insidious, subtle form of power which operates on all deviants and transgressors internally. The upshot of this concept of power is that the ranks of the 'normal' are consolidated against all others.

In the next section of this chapter I want to examine the concept of disability as role performance, to explore what a disabled role is and how it is learnt, and to consider modes by which resistance may be experienced.

2. DISABILITY AS ROLE PERFORMANCE

In our society there is a clearly defined role for disabled people to perform. We are all familiar with role playing, yet what separates a disabled role from the majority of roles is the apparent lack of power in this role. The roles traditionally played by oppressed groups induce feelings of powerlessness in the players. Without power there is no hope, no means to change the status quo, things are accepted as being the way they are. For women and blacks, and indeed other oppressed groups things are changing as a result of members of these groups coming together, joining forces and denying the conditioned role, denying powerlessness. However, for disabled people there is little about our situation which seems positive. Whilst acknowledging that disabled right's activists have, in the past few years gained a voice, the majority of disabled people remain unpoliticised and fragmented. There are a number of reasons why this is so. Principally, as I have outlined in the introductory chapter, the prevailing view of disability as a medical and individual problem does little to unite disabled people. By examining the role expected of disabled people I hope to find new ways of resisting this role.

2:I THE ROLE.

Newly disabled people soon learn that one of the demands that able-bodied people make of us is to behave as 'normally' i.e. as much like an able-bodied person, as possible. Thus it is that we see people who are perfectly mobile in their wheelchairs, painfully struggling to walk another step, refusing to "give up" and sit down. This point was made clearly by a number of people I interviewed who found that, although they thought of their callipers and crutches as ugly, they preferred to enter a pub, a night club or whatever, standing, rather than being in their wheelchairs. In their cases not only did this mean that they had to exert a considerable amount of effort, but they were also putting themselves at risk from falling as none of them was very stable and the slightest knock could effect their balance. Yet they felt that this was worthwhile, firstly because normals would mistake them for normals with broken legs or other such temporary impairments, and thus treat them as normal. Moreover, striving to walk, striving to overcome the disability is assumed to be what a disabled person wants and what is best for us.

For other disabled people who have a less noticeable impairment, energy is put into hiding the disability altogether. As one man says:

> I make a great effort not to show that I am disabled. I try to walk without a limp...I want to be treated as a normal person...I keep it [the

> disability] hidden very well. (Alex:149)

People with facial disfigurements go through hours of surgical operations to 'improve' their handicap, so they will look more like non-disfigured, normal people. Indeed, one of my own consultants suggested that I have "cosmetic treatment" as the cateract covering one pupil "ruins your looks". Furthermore it is not an uncommon experience for disabled people to be offered "corrective surgery", when in fact what is being offered has no value in terms of the impairment, but which would be of value in terms of being more socially acceptable. A case in point being the cosmetic surgery on offer to people with downs syndrome, or more specifically their parents.

Able-bodied people are uncomfortable with a body that is physically different from their own. They do not seem to be able to imagine that disabled people might be able to accept themselves the way they are. Allan Sutherland (1981) suggests that this reverence for normality has more to do with the needs of able-bodied people than the needs of disabled people:

> Many able-bodied people have a great need to be reassured that there is nothing wrong with their bodies. They find it very difficult to conceive that we might attach more importance to our personal comfort, or to having adequate mobility, than to trying to look like them. (Sutherland 1981:75)

But for many disabled people the demand from able-bodied people to be as normal as possible, to strive for this, is part and parcel of being disabled. It becomes integral to the role prescribed to disabled people.

It is not, however, just the physical aspect of a disability which disabled people are expected to mask from normals. The role of disabled person demands that able-bodied people are reassured and their irrationalities and anxieties which surround disability are calmed by the disabled people themselves. Rachel tells us:

> When we go out...sometimes they go somewhere where it is a bit awkward and I say: 'Well, I don't feel like it'. I never say I can't go because of the ...steps or whatever. (Rachel:195)

Equally Beth comments:

> Before my accident the interaction would be natural, whereas now I feel I have to make the effort more. It's more on my side to make people feel comfortable. (Beth:212)

Disabled people become experts at putting other people at their ease, even if this means they denigrate themselves in the process:

> [I have to] be more assertive and joke a lot more and make fun of my situation. I use words like "crip" and that sort of thing, which is not terribly attractive but somehow it breaks the ice a little bit. (Beth:219)

People with disabilities all seem to have experience of the over-helpful able-bodied person. Blind people are marched across roads they do not want to cross, wheelchair users are pushed up kerbs that they are quite capable of mounting on their own, and they are always expected to be grateful.

> During the first year that I was registered blind I was endlessly thanking people. When I am carrying the stick people presume that I am helpless and thus in need of their help. The fact that I may not require any help is of no importance. If, as in the instance on the train, when I turned down my fellow passengers help and went to the buffet unaided, people are offended. Sometimes it is easier to accept the help, and fall into the

> role of the defenceless, grateful, blind girl.(Branfield 1988)

It is assumed that disabled people are in need of help from normals. Able-bodied people who 'help' disabled people would be horrified to think that they are, in effect, denying personhood to that individual. They like to help and 'the poor little cripple' or 'the helpless blind girl' are perfect recipients of their bounteousness. Perceiving disabled people as dependent, unfortunate, and in need makes the majority of able-bodied people feel worthwhile. It is reassuring to be normal, to be better off than they, to be able to help.

The demand from normals, that disabled people should be grateful at all times for help and assistance, even if unneeded and unasked for, constructs a double bind for disabled people. Firstly, it is difficult when someone so obviously thinks they are doing you a favour, to refuse that help. It can be stressful and awkward to take control of the situation and make it known that no help is required without offending and upsetting the able-bodied person. Secondly, what is particularly difficult for a disabled person is not just refusing the help, but to refuse it in such a way as not to reinforce stereotypes of disabled people. The problem is that when disabled people challenge the stereotype of themselves what so often occurs is that able-bodied people become uncomfortable because they are being asked to change previously unquestioned assumptions. This in turn can lead to the able-bodied finding a new framework in which to interpret what is happening. Thus disabled people who reject offers of unwanted help are accused of being bitter, of having not accepted their disability, of being resentful. Equally unwanted is the patronising praise that is given as an explanation for the disabled person's deviance from the stereotype: 'She's so proud...' 'She clings to her independence...' 'She has to prove she can do it...'

Of course, I am not suggesting that the able-bodied consciously interpret our actions and behaviour in such a way as to neutralise resistance and strengthen negative stereotypes. On the contrary, the able-bodied are responding to a moral imperative, to obey rules and unquestionably accept norms.

It is understandable then, that in many instances it is easier to say nothing, to accept the help and not to challenge the stereotype.

This is not to say that all offers of help and assistance are unwanted. It is though, to acknowledge that when a disabled person is aided by a normal they should then not expect gratitude, but rather should question why it was their help was required in the first place. If there was a pelican crossing would the blind person have needed help crossing the road? If the building had ramps would the wheelchair user have needed help up the steps? Help is sometimes required, but it should be given as a matter of respect for the needs of another individual, who would equally respect another's needs, and not be used to bolster a negative stereotype of disabled people.

It is not only the issue of accepting unneeded help which reinforces the stereotype, the role of disabled person.

Disabled people are approachable. They can be talked to, asked personal questions and told about their own disability endlessly. It is rare for a normal to be intruded upon in this way.

> ...I am eminently approachable. Complete strangers come and talk at me: I hear how the man at number 32, just down the road from Martha's sister is blind. ("Really - how interesting"). I hear how the next-door-neighbour's father-in-law has recently had a cataract removed. ("Really - how fascinating"). I hear how a woman nearly lost her sight, due to shingles, when she was seven. ("Really - how awful"). I hear that I am brave, I'm courageous, I'm admired: a whole catalogue of stories and judgments from people who believe that in return for offering a little sympathy or help, can intrude on me in a way they wouldn't dream of doing when my stick is folded in my bag. (Branfield 1988)

Faced with this daily, many disabled people once again are not sure how to react. If they smile politely and let themselves listen to these strangers some people feel angry, others adopt the expected passive role, whilst others reject these overtures. But in their rejection once again they end up reinforcing their dependent role. Once again able-bodied people adjust reality to their expectations, make excuses for the 'rude' disabled person and strengthen their image of The Disabled.

Performing the disabled role means that disabled people are expected to accept discrimination against them, they will not draw attention to it, nor will they cause embarrassment or create a fuss. Indeed, not questioning their oppression is part of the expected role for disabled people. It is tacitly understood that disabled people will not make demands upon the able-bodied, but will quietly and passively accept what help is offered and be grateful.

It is not just that disabled people traditionally will not protest when they cannot enter their own university college, civic centre, town hall, museum or cinema, doctors' surgery, church - the list is endless. This assumption, this expectation from the able-bodied world means that even the most basic communication between able-bodied and non able-bodied can reinforce the learned helplessness of disabled people. For example, the responsibility for any difficulty in communication always lies with the disabled person. The blind person who does not understand when someone is nodding at her, the deaf person who will not go to a badly lit pub because she cannot see her companion's lips, the person with a speech defect who does not want to go to a noisy pub because others can not hear her so well, these instances and many more, are seen to be the responsibility of the disabled person. Moreover disabled people are made to feel that they are the ones at fault.

Disability is always seen as a personal problem, the individual with the disability is always responsible and never society, societal attitudes and prejudices. Disabled people are perceived as Disabled. This negates any other aspect of that person. Thus any anxieties, troubles or problems, for example, are assumed to be related to the disability, and cannot be problems in their own right. Rachel says that she has to remind herself that if she gets depressed it is not necessarily because she uses a wheelchair:

> Because I am in a wheelchair I think 'Oh well, it must be the wheelchair that is making me depressed'. When in actual fact I have all this work to do, and I have no money, I've got a huge overdraft, and all the things that used to make me fed up before. (Rachel:201)

If a person is disabled they are first and foremost a disabled person. We seldom hear of an actor who just happens to be deaf, but we know of the deaf actor. David was well aware of the fact that the amount of publicity he received for winning the gardening competition was because he was a blind gardener, and not because of the astonishing flowers he produced.

If a person has one disability able-bodied people commonly assume that they also have other impairments. If you are blind it is assumed that you are also deaf, dumb and stupid. If you are lucky people speak slowly, in raised voices. If you are less fortunate people ignore you altogether and address the able-bodied person you might be with. Most disabled people have experience of this 'Does he take sugar?' syndrome, and yet when able-bodied people get to know a disabled person, to see beyond the wheelchair, the white stick, the crutches and so forth, they do not acknowledge that they have been wrong in their assumptions about The Disabled, but rather they insist that they never think of their friend as being disabled.

This insistence from some able-bodied people that a disabled person is not disabled is akin to denying a person her identity. It is the same as saying 'he played like a white man'; 'She spoke with the authority of a man'. It is to deny what might well be a key aspect of a person's identity. Furthermore it is generally intended as a compliment. When a disabled person is told by her friends that they never think of her as disabled it allows them to continue with the belief that impaired people are not like normal people and that the one disabled person they know is somehow different. Thus the able-bodied definitions of disability remain unquestioned and their assumptions remain intact.

These established assumptions held by the able-bodied about non able-bodied people can mean that when an adult unexpectedly joins the ranks of The Disabled, it is very difficult for them to accept that they have become 'abnormal'. David remembers his first encounter with a blind person, before he too lost his sight:

> I mean the first time I ever came across a blind person was on a bus. And I must admit I've been the same as sighted people treat me now. Because he come and nearly sat on my knee and I just hunched up, pushing myself further back, not even saying a word to him. (David:24)

Many newly disabled people retain the stereotype of The Disabled. They cannot accept that they are now perceived by normals as disabled and they do not see themselves in this light. They try to be as normal as possible, and avoid the company of other disabled people, never seeing beyond the stereotype. Conversely, for others the fact that they are adults when they become disabled means that they already have developed a strong sense of individuality and thus find it easier to play the part expected of them.

For it does not seem to matter if the disabled role is internalised or embraced, so long as it is played. For in practice it appears that very few disabled people fully embrace this role and stereotype completely. For as Sutherland (1981:83) points out: "It's difficult to suppress entirely one's awareness of one's own abilities and individuality." It is, of course, more difficult to internalise a role that is full of contradictions. The disabled role demands that disabled people are

> ...stubbornly brave and independent, walking the tightrope over Niagara Falls on crutches, and being too proud to accept any help whatsoever, even that to which one is legally entitled. (Sutherland 1981:83)

But to do this and be a poor, pathetic, helpless cripple at the same time is impossible and unrealistic.

What is more realistic is that with the constant conflicting demands from the able-bodied world disabled people become confused. Disabled people often feel confused about who they are, how they should act, what they should do. And it is this confusion that expresses itself in the fact that disabled people traditionally have felt incapable of making their objections to the demands and criticisms of the able-bodied world known. Thus it is that disabled people appear to accept the stereotype that is placed upon us, appear to be passive and dependent. Which is, after all what is expected of us.

Living up to expectation, playing the role, accepting the behavioural prescriptions associated with being impaired can mean that the newly disabled person gains social approval. If social stereotypes are fulfilled able-bodied people are more willing to accept the abnormal person because they are less threatening: "conformity to expectations arouses no disruption of status and power hierarchies". (Breakwell 1986:121) Thus it is that resistance to this role is seldom seen as a positive, viable option.

2.2 LEARNING THE ROLE.

When a person becomes unexpectedly disabled it usually involves a period of hospitalization. This results in the person being exposed to a characteristic set of expectations. Parsons (1958) outlines four requirements of the 'sick role'. First that the sick person is exempt from the performance of certain of their normal social obligations. Second, the sick person is also exempt from a certain type of responsibility for their state. That is to say that they are not expected to get better by will alone, but that they must be cured by having something done to them. Third, to be sick is to be denied full legitimacy. Hence being sick is defined as socially undesirable and should be remedied as soon as possible. Finally, the fourth aspect of the sick role outlined by Parsons is that to be sick is to be, in all but the mildest cases, 'in need of help'. This in turn leads to certain obligations, especially that of cooperating with the doctor and/or therapist in the business of getting well.

In addition to this sick role there is also a set of expectations peculiar to the subculture of a hospital. King (1962) documents five sets of expectations to which the patient is exposed. The first is that of dependency, of compliance by the patients to hospital rules and regulations, to daily routines and decisions that are made for them by doctors and nurses. The second, in line with dependence, is that the patients are expected not to fulfil their normal role responsibilities. Thirdly, there is a de-emphasis on external power and prestige. Fourthly, suffering and pain are par for the course and it is expected that they be borne with as much grace as possible. And finally it is assumed that patients should want to get well and do all they can to aid this process. Any sign that the patient is not doing all they can to help themselves is quickly picked up by doctors and nurses and is a sign that patients are not fulfilling their obligations.

To these expectations Thomas (1970) adds the point that there must also be tolerance for prognostic uncertainty. This period, existing between the time when something is acknowledged to be wrong medically and the time when there is relative certainty concerning the prognosis for the individual can last, for disabled people, for weeks, months, even years. It is a time of great uncertainty and for the disabled person and those close to her, a time lacking in any authoritative opinion as to what levels of performance can be realistically set.

The role of patient is often a temporary state, but for a disabled person most of the elements of the sick role are elaborated upon or made enduring.

It is clear then that autonomy is denied, dependency is fostered, and uncertainty and confusion can result from hospitalization. For many people our first experience of being disabled takes place within these institutions and it is here that we first learn what is expected of us as one of The Disabled.

Hospitals ensure that helplessness is learned. The phenomenon of learned helplessness was first documented by Seligman (1975). It describes what occurs when people are denied the right to make decisions, when everything is done for them, until they become incapable of making decisions, incapable of doing things for themselves. Not only do they feel redundant to society but also to themselves. As Colin says:

> If you have lost enough sight, you can't even go and shop for clothes. I have to have someone with me and ask them: "Do you think this will suit me?" Where as before I used to love going out to buy nice clothes. And presents for somebody else. I know for a fact I don't do as much decision making as I used to. I mean before if my wife and I went out shopping, for furniture or whatever, it was a decision made by both of us. If you can't see what a carpet looks like you may as well not bother. Those decisions are taken off you. And it's the same with wall paper, colour of paint. Even going for clothes, you

> might know what you want in your mind's eye, but how many shades of blue are there? Shop assistants are actually useless at describing the stuff they are selling. All your choices are cut away. (Colin:36)

It is not just in the matter of shopping, but in all spheres of life. When decision making is taken from you, when that choice has gone, you soon forget the knack of making decisions, making choices and planning goal-directed action. You become dependent and helpless.

The helplessness and dependency that is first learnt in the hospital can only too readily be encouraged when the person returns home. Family and friends can create a 'protective capsule' around the 'patient'. Frank recalls his parents' reaction to his impairment:

> My parents reacted very badly. I mean they, er...sort of like started to do everything for me, especially my mother, she tends to be quite neurotic and protective anyway, so that just like made it even worse...I spent about a year with my parents in my parents' house, getting more and more depressed and more and more angry and I felt completely ineffectual...having to spend hours and hours explaining to my mum and dad that I would be O.K. (Frank:158)

In Frank's case he had, as we have seen others do, fallen in to the role of reassuring normals. Reassuring them that he could cope, that he could manage, that he could handle what was happening to him. In order for him to gain any independence he had to struggle against the well-meaning over-protectiveness of his parents.

For other families the disability can become practically a taboo subject.

> I don't think my mother has accepted it yet...I don't think my brother, who is younger than me will accept that I can't walk. And I don't know why. He has never said as much but it's just a sort of feeling between brothers that I feel that he doesn't accept it you know. Sometimes he'll go to any lengths not to mention it, and I say to him: "Jeff it's not a dirty word you know." "I don't want to talk about it". And this kind of thing. (Paul: 185/6)

It is as if by not talking about the disability it is unacknowledged and thus it is not real. But it is a reality for the person with the impairment and a lot of people with disabilities find this non-acceptance of their impairment akin to non-acceptance of them.

However the majority of newly disabled people found most members of their families to be supportive. After the initial shock most partners/parents seem actively to encourage disabled people to have as much independence as possible, to do as much for themselves as they can and not to view themselves as helpless and dependent. This story is typical:

> I were fortunate with wife, I mean she didn't sit there, well she did for the first week or two, change all my bandages and things like that, but I mean after a bit she didn't sit there and molly coddle me and say like: "Oh love just sit there and I'll make you a cup of tea", and things like that. I mean I used to get up and make my cup of tea and her one and she would say nought. (David: 13)

It is only in a few instances then that we can talk of family blatantly encouraging learned helplessness as a viable role for a disabled person to play.

But it is not the blatant instances of discrimination that alone teach disabled people their role. It is the subtler ways in which self confidence and self value are eroded that need to be examined. Loosing one's job; having one's driving licence revoked; being unable to carry out home repairs and decorating; not having access to your children's school - these real examples alter how a person feels about herself and bolster the stereotypical role of The Disabled.

There are many aspects of culture from which we are all made aware of role expectation. These include advertising, film, music, popular magazines, art, news broadcasting and literature. In the next section of this chapter I will concentrate upon the portrayal of disabled people in literature.

3. REINFORCING THE ROLE: DISABILITY IN LITERATURE

Throughout fiction villains are given disabilities to emphasise their separateness from normal human values. The disability is used to provoke fear, loathing or disgust, and disability and evil are inseparable, each feeding the other, as in Richard III. Blind Pugh in *Treasure Island* is all the more sinister for his blindness, tapping his way through the fog at the opening of the book, whilst Long John Silver with his wooden leg is quite literally less than human. In *Peter Pan* the figure of Captain Hook is made more menacing by the metal hook which replaces his missing hand; the recent film version emphasises the metaphor by changing the title to *Hook*. Captain Ahab with his wooden leg is obsessed by revenge in his search for the white whale, *Moby Dick*.

In popular fiction it is an easy short cut for the writer to underline a character's wickedness by making him 'different' in some obvious way, either by race - the 'impassive oriental' - or through disability, the dark glasses of the blind, the leather glove of the maimed, the wheelchair. All of these become sinister in a James Bond-type movie, as do the over- or under-sized, the fat man or the dwarf. In *The Old Curiosity Shop* Charles Dickens makes quite sure that the reader has no sympathy for Quilp in his attentions to Little Nell by making him "dwarfish".

The reverse of this use of disability in popular fiction is sentimentality, and the writer uses the disability in an easy appeal for sympathy. Dickens illustrates both sides of this coin: where Quilp arouses our loathing, we are meant to feel pity for Bob Cratchit's son Tiny Tim, who is lame. A disability may be exploited for its pathos. The girl in the wheelchair finally takes a few steps towards her mentor. In the film version the music soars; faith and will-power are triumphant. In fictions of this sort, the disabled person tends to be a child or young woman, tugging all the more on the reader's heart strings.

A male character might be used in the appeal for sympathy if he fits into the myth of Beauty and the Beast. There are a number of stories of disfigured heroes. Cyrano de Bergerac, whose disability is the length of his nose, thinks himself ugly and unlovable; the truth of his love is recognised by the reader but it is too late before it is realised by his love, Roxanne. Other variations of this story are found in *The Hunchback Of Notre Dame*, *The Phantom of the Opera* and *The Elephant Man*. The disabled lover is acceptable in fiction, as long as the reader feels sorry for him; as long, that is, as his love remains frustrated.

In the examples we have looked at so far, the presentation of disability has been totally exploitative. The writer seeks to arouse disgust and fear, or easy pity. Sometimes a disability is used as a device for - at least authorial - retribution, as at the end of *Jane Eyre* when Rochester is blinded. Shakespeare has Gloucester blinded in *King Lear*; here it carries a metaphorical meaning, for it is only after he has lost his sight that Gloucester begins to see clearly in a moral sense.

Disability is a metaphor, too, in the lameness of Rickie, the hero of E.M.Forster's first novel *The Longest Journey*. "Rickie was slightly deformed, and so the shoes were not the same size, and one of them had a thick heel to help towards an even walk." His lameness emphasises the contrast with "the perfect form of Gerald, his athletic walk, the poise of his shoulders". It is also a correlative for Rickie's - and E.M.Forster's - unacknowledged homosexuality.

One of the characters best known for his disability in twentieth century fiction is Clifford Chatterley. He is used entirely by Lawrence to serve the needs of the plot. Wounded in Flanders, he is "shipped over to England, more or less in bits". After two years he "could return to life again, with the lower half of his body, from the hips down, paralysed forever." A little later he writes of Chatterley "crippled for ever, knowing he could never have any children." Lawrence insists heavily upon his impotence, for this is necessary to his story of Constance Chatterley and Mellors the gamekeeper. His exploration of Clifford's situation is perfunctory, to say the least:

> He had so very nearly lost his life, that what remained was wonderfully precious to him. It was obvious in the anxious brightness of his eyes, how proud he was, after the great shock, of being alive, but he had been so much hurt that something inside him had perished, some of his

> feelings had gone. There was a blank of insentience.(Lawrence 1960:2)

This is all that Lawrence has to say, apart from occasional reinforcing remarks:

> But Clifford was really extremely shy and self conscious now he was lamed. He hated seeing anyone except just the personal servants. For he had to sit in a wheelchair or a sort of bath chair...But his very quiet, hesitating voice, and his eyes, at the same time bold and frightened, assured and uncertain, revealed his nature. His manner was often offensively supercilious, and then again modest and self-effacing, almost tremulous. (Lawrence1960:16)

He was afraid of the miners, "he could not bear to have them look at him now he was lame." (Lawrence 1960:16)

His paraplegia, besides being an essential plot device, is also used as a symbol of the lack of vitality in the English ruling classes of the day. After that, Lawrence's interest shifts entirely to Constance and her sexual frustration, and its release in her affair with Mellors.

This from the twentieth century writer who has the reputation of exploring character and relationships with more depth and subtlety than any other. So where are the great novels and works of art that portray the experience of disability from the inside? It is part of experience, and in art we expect all human life to be there. We must conclude, sadly, that they do not as yet exist. Milton wrote about his blindness, directly in a sonnet and indirectly in *Samson Agonistes*. But there is a great disproportion between disability in life and in literature.

In recent years there has been some recognition of this, and there are more plays, films and novels which try to present a truthful picture of disabilities. This is a review from The Guardian's radio column:

> Sunday's World Service had a new play by Ken Blakeson, Lost For Words, about a once glamorous M.P. now suffering from motor neurone disease. As you would expect from Blakeson, it was well researched and written with clarity and understanding. The invalid talked through a computerised voice, and the contrast between this mechanical device and his own mutilated accents was skilfully managed by two actors, Nigel Anthony and Kerry Shale, in Gorden House's effective production. Suffering, contrary to the old adage, seldom ennobles - and the strains that the illness put both on the sufferer and his wife were treated sympathetically in the plot. The kind of well crafted play with a strong social theme that used to be a pillar of the Radio 4 schedules...

There are many plays and films in this category, decent, well-researched and well-written. There is John Mortimer's portrait of his blind father in *Voyage Around My Father*. A blind girl is the main character in *Crystal* and Elizabeth Quinn won an award for her portrayal of a deaf women in *Children of a Lesser God*.

It contributes to understanding and could provide useful role models if people with disabilities are presented in plays, books, and films not just in terms of their disability, but as real human beings. But are such well-researched, well-crafted plays also exploitative in their own way? Ken Blakeson's *Lost For Words* would seem to be inspired by the very popular story of Stephen Hawking, the physicist with motor neurone disease, just as Tom Kapinski's *Duet For One*, about a pianist with multiple sclerosis would seem to be inspired by the story of Jacqueline du Pre. There is exploitation in this: the radiophonic delight, for example, in the computerized voice of the 'once glamorous M.P.' contrasting with 'his own mutilated accents', to say nothing of the obvious use of real people whose lives have been altered by disabilities.

The same question arises in the film treatment of Christy Brown's *My Left Foot*, where the part of the young man with cerebral palsy is played by Daniel Day Lewis, an abled actor of remarkable looks and box office attraction. It is reminiscent of Laurence Olivier 'blacking up' for the part of Othello. Is it better to have the 'truth' portrayed by a lie, or not show it at all? Why cannot the truth be truthfully portrayed?

Disability has been exploited by literature, whether high- middle- or low-brow. It has been used as a sort of short hand to indicate character, often appealing to the prejudices of the reader. It has been used for its frisson and melodrama, and for sentimentality. It has been used as metaphor or narrative device. Rarely has it been written about in a way that illuminates human experience, and we must be careful that the new openness to it as a subject, whilst preferable to much of the stereotyping of the past, does not become another form of exploitation.

It is clear then that literature provides people, both abled and disabled, with a set of expectations associated with the disabled role. It reinforces patterns of behaviour learnt through social interaction and does nothing to challenge the oppressive role disabled people are required to act out.

This is just a brief look at the way that disability is articulated through culture. It is by no means exhaustive and I have not taken literature as an example because it has more importance than other aspects of culture, but rather it is an illustration of the way that attitudes towards disability and the disabled role are reinforced through seemingly neutral cultural artifacts.

Up until very recently no one has questioned the role that disabled people are expected to play. It is assumed to be an individual tragic occurrence. As a disabled person you find yourself in a position of need, of having less, of being dependent, and you are in this position solely because you have an impairment. Until a disabled person's oppression is viewed in terms of social relationships which are open to negotiation, our position will remain unchanged.

In the fourth section of this chapter I am going to look at the limitations of using the concept of role as a theoretical tool in an analysis of power, resistance and disability.

4. LIMITATIONS OF ROLE THEORY

Critical literature on the concept of role dates back to at least the 1950's, with writers such as Coutu (1951), Neiman and Hughes (1951) and Turner (1956) recognising that attempts to utilise role theory to explain the relationship between the individual and society were beset with theoretical and moral difficulties. Dahrendorf (1968) comments:

> ...by reconstructing man as *homo sociologicus* ... [the bearer of socially determined roles]...sociology creates for itself once again the moral and philosophical problem of how the artificial man of its theoretical

> analysis relates to the real man of our everyday experience. (Dahrendorf 1968:25, in Edwards 1983:386)

And it is this relationship between "artificial man" and "real man" that highlights the limitations of using role theory as a basis for a theory of disability.

By using the concept of the 'disabled role' we are in danger of fostering the impression that disabled people *are* their disabled role. It would be nonsensical to describe and understand the able-bodied in terms of their able-bodied role. The able-bodied are seen as a heterogeneous group who perform all manner of roles, whereas disabled people, in this schemata, are firmly constituted within one negative stereotype which is implicit to the disabled role.

It is when 'role' dissolves into 'stereotype' that we must be mindful of falling into a trap that could result in these roles becoming reified. As Connell (1987) comments in regard to 'sex roles':

> Most sex role theory is not constructed around problems raised by field observation, but as analysis of a normative standard case. (Connell 1987:51)

This concept of a "normative standard case" is important when considering the suitability and applicability of role theory to disability. As we have already seen in this chapter, the standard case is stereotypically an abstract notion of disability signifying a helpless, dependent, and pathetic individual. 'Standard' refers then, to the assumptions others (non-disabled people) make of how we live; and it is normative in two ways. Firstly it refers to the prevailing notions of how we are expected to live and thus it defines actual role expectations. Secondly, it is generally regarded as the proper way to live by theorists as well as society at large. The problem is, however, that what is *normative* is not necessarily *standard* (Connell 1987). From my own experiences and from my interviews with disabled people this is more than apparent.

Beth hardly fits into the normative standard model of a helpless, dependant and inferior disabled person. She is not sure:

> whether to go back to further study or to go out for a job. Social policy is one option I have been invited, if you like, or encouraged to come back here and do a M.Phil/D.Phil in social policy but there are other options. I am considering a M.Sc in Health Education and Health Promotion and also a M.SW. (Beth:223)

Equally Eddy does not fit into the normative standard disabled role. Eddy had to take early retirement, "thirty years too early" from his post as a Methodist minister, when he developed M.S. He was, he says, very disappointed, but:

> ...since coming here, to the day centre, it has made more sense. As a station minister I wouldn't have had time to even visit places like this or the younger disabled unit at the hospital, but now I can. And so it makes sense. I come here as a minister. (Eddy:61)

Colin talks of the assumptions that even his old friends make about him:

> We used to go to dances quite a lot, but they seem to think that because you can't see you can't enjoy yourself dancing. Which is a bit strange. I still love dancing and go regularly. (Colin:30)

Whilst reading the interviews with disabled people it soon becomes evident that the prevailing negative view of The Disabled is not how disabled people actually see themselves. We are all only too aware of what this view is, what the able-bodied expect of us, but we do not generally live our lives to fit these dictates. Once it is acknowledged that what is normative is not necessarily what is standard, or what is common, new areas are opened up for debate:

> It becomes possible to see what is 'normative' not as a definition of normality but as a definition of what the holders of social power wish to have accepted. This raises questions about whose interests are embodied in the 'norms'; how far the daily life of other people represents resistance to those interests; and what potentially normative principles might emerge from currently non-normative but widespread practices. (Connell 1987:52)

The concept of deviancy is logically required by proponents of role theory. Without this concept those instances of behaviour which are not accommodated for within role theory remain unaccountable. However, once the concept of deviancy is introduced we can understand the non-normative, non-standard case. In reference to the disabled role, disabled people who do not fit the normative standard case are labelled as 'non-accepting', 'bitter', 'maladjusted' or that they are having difficulties in 'coming to terms' with their disability. All manner of euphemisms are called upon, when in reality it is deviancy from the expected norm that is being cited.

The consequences of using role theory and its corollary, deviancy, is that any resistance to the normative standard role is eliminated. That is to say that resistance and social struggles for change, and to reform normative social practices are rendered impotent.

If we assume, as role theory seems to, that a person performs certain roles in order to fulfil expectations and norms, and that these roles gain cohesion through positive sanctioning, then the question we must ask is why does the interactant, that is to say the person holding the counter-position, give positive or negative endorsement to that role? This cannot be answered by simply saying that the second party is fulfilling *their* role expectations, for if this were the case then role theory would fall into a downward spiral of infinite regress. The only option left open, to avoid this reductionism, is that individual agency and free will must account for the way in which we apply negative and positive sanctioning:

> It quickly comes down to a question of individual will and agency, revolving around choices to apply sanctions. The social dimension of role theory thus ironically dissolves into voluntarism, into a general assumption that people choose to maintain existing customs. (Connell 1983:50)

Thus it is that Connell (1983) is able to write that role theory is "internally incoherent and incapable of providing a genuinely social analysis of social process." (Connell 1983:192) In other words, role theory cannot explain the relationship between personal agency and social structure. Role theory manages to side-step this issue by simply conflating structure into agency.

A major deficiency of role theory as an analytical tool for discussing the experience of being disabled is that it describes attitudes rather than the realities that these attitudes uphold and perpetuate. The economic, domestic, cultural and political power that is exercised over disabled people can never be adequately explored in a role framework that relies on a rigid dichotomous distinction between abled and disabled.

A theory that explains the disabled role in terms of complete social absorption "suggests a society in which there is a perfect fit between the individual and role demands, and this, to say the least, is a dream of social theory, not reality." (Brittan 1989:22)

Furthermore, according to role theory, and in particular the liberal account of it, we are all equally oppressed as we are all locked within its normative framework. And it is this normative framework which results in role theory having no adequate analysis of power. Disabled people are defined by biological differences and thus the difference is viewed as inevitable and unproblematic. In other words, role theory eliminates the element of power from able/disabled interaction.

However there are other interpretations of role theory. In *Stigma* (1963b) Goffman stresses the notion that we all classify and grade the people we interact with. This happens without us even being aware that we are doing this. This grading and classifying of others determines how we act towards them, and how we expect them to act towards us. The idea of a grading system is not unique to contemporary society, but what is novel is that this grading system has been ingested, absorbed and assimilated into the normalization process of the modern nation state. As Foucault puts it:

> Modern society...from the nineteenth century up to our own day has been characterised on the one hand by a legislation, a discourse, an organisation based on public right, whose principle of articulation is the social body and the delegative status of each citizen; and, on the other

> hand, by a closely linked grid of disciplinary coercions whose purpose is in fact to assure the cohesion of the same social body. (Foucault 1980:106)

In other words, normalization is a form of power. I will be exploring this notion later in this thesis as it is a central theme to this work. For the present however, it is enough to note that *Stigma* (1963b) differs from Goffman's earlier essays in that no longer is he focused on the neutral rules governing social interaction. In *Stigma* (1963b) Goffman is interested in how this grading system, which is applied by society, operates and functions on individuals through interaction. And it is here that we see that Goffman does indeed have a theory of power. This will be examined in Chapter Seven.

5. CONCLUDING REMARKS

One of the most attractive aspects of role theory is that it provides a model to describe how individuals fit into social relations. As we have seen in this chapter, role theory can account for the insertion of disabled people into society, and it explains how a disabled person learns the appropriate set of expectations demanded of the role, thus enabling us to act accordingly. This, as I have shown, happens through interaction with the able-bodied, and is strengthened through various social agencies and cultural phenomena.

In addition role theory is attractive as it appears to offer guide lines for change. If we understand disabled people's oppression as being the result of role expectations and norms that define us as inferior and 'not quite human', then the obvious solution is to change these expectations. Disabled rights activists have, in recent years, begun challenging the negative social stereotyping which is, at present, part and parcel of being disabled.

Yet, as we have seen, role theory is not without its limitations.

One of the central dangers implicit in role theory is that we become the role that is expected of us. Thus the normative standard role of The Disabled becomes reified through our understanding of what this role requires. However it is apparent that this, in actuality, does not happen. We all adopt certain roles at certain times, but it is the instances of resistance in the daily lifes of real people that is of more import than the instances where we 'toe the line'. Role theory does not adequately address resistance.

Role theory can be a useful tool in an analysis of stereotypes of disabled people. It allows us to question the disabled role in terms of social constructs and cultural ideals, as well as allowing us to investigate media and other cultural portrayals of disabled people. However, role theory, in the final analysis, fails to provide an account of opposition, counteraction or resistance to the prevailing view of The Disabled.

It is for this reason that in the following chapter I am going to look at various accounts of oppression and their relation to women, black people and class, with the hope that we might learn from the experiences of other oppressed groups.

CHAPTER FOUR

THEORIES OF OPPRESSION: GENDER, ‘RACE’ AND CLASS

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Abstract: *This chapter considers the relevance of existing theories of oppression to a discussion of disabled people's subjugation. I briefly examine four accounts of oppression: biological, cultural, psychoanalytical and class. Whilst some of these approaches obviously have compounded the position of disabled people in modern Western society, none are wholly satisfactory as explanations for our unequal situation within this society. Our social and economic location cannot be adequately explained by simply reducing it to an effect of one of these approaches. The fifth section in this chapter summarises the arguments and suggests that we need to find alternative, non-deterministic and non-universalizing ways to comprehend our oppression.*

INTRODUCTION

Since 1948 parallels have been drawn between the experience of disabled people and that of other oppressed groups: "the physically disabled person is in a position not unlike the Negro, the Jew and other under-privileged racial and religious minorities" (Barker 1948:31). Abberley (1987) cites numerous cases in the literature of disability where researchers comment on the similarities between disabled/normal interactions and those encountered in the study of race relations. However, it would appear that comment is all they do, for as Abberley remarks: "the sociological literature of disability has carried such ideas no further." (Abberley 1987:6)

To argue that a theory of oppression would be a useful tool in attempting to analyze the position of disabled people is not to claim that all oppressed peoples experience of that oppression is the same. There are qualitatively different forms of oppression. It should also be remembered that more that half of the disabled people in Britain today carry the additional burden of racial and/or sexual oppression (Campling 1981).

To say that a certain group is oppressed is to argue that this group is at a disadvantage compared to the rest of society; it is also to argue that there is nothing natural or inevitable about this disadvantage; and it is to argue that the disadvantages are dialectically related to an ideology which perpetuates the position of inferiority. In addition to claim oppression for a certain group must, it would seem logical to argue, involve identifying who benefits from the situation which allows the oppression to exist in the first place. Yet the meaning of oppression has shifted in recent years. A traditional approach to a theory of oppression would posit at its centre the exercise of tyranny by a ruling group over an oppressed group. With the emergence of the new left social movements of the 1960's and '70's oppression took on a different meaning. As Iris Young comments:

> ...the tyranny of a ruling group over another [...] must certainly be called oppressive. But oppression also refers to systemic constraints on groups that are not necessarily the result of the intentions of a tyrant, oppression in this sense is structural, rather than the result of a few people's choices or policies. Its causes are embedded in unquestioned norms, habits, and symbols, in the assumptions underlying institutional rules and the collective consequences of following these rules. (Young 1990:41)

This is to say that for a group to be oppressed it is not necessary for there to be a correlative oppressing group. This idea will be further explored in Chapter Five, when we consider the work of Michel Foucault and in particular his understanding of power.

Following the arguments laid down by Brittan and Maynard (1984) in their analysis of sexism, racism and oppression, the ensuing work briefly examines some of the commonly used arguments surrounding these issues and looks at their validity and application to a study of disability. By using similar categorizations as Brittan and Maynard (1984), namely: 1. biological accounts; 2. cultural accounts; 3. psychological accounts, and 4. class accounts, I hope to be able to assess what disability researchers can learn from other theories of oppression and thereby place disability on the agenda for inclusion in any debate on inequality and oppression. Furthermore, it is hoped that by considering oppression, light will be thrown upon possible modes of resistance.

I. BIOLOGICAL ACCOUNTS

Underlying biological essentialism is the basic notion that biological differences are construed as being the grounds on which unequal treatment is justified. Until relatively recently biological essentialism has been used to explain the naturalness of social and gender differences, and hence the inevitability of inequality. But what exactly does 'naturalness' or 'nature' mean? Lynda Birke (1986) suggests that these terms can have a variety of meanings. She takes the statement 'gender differences are natural', and examines the use of the word 'natural'. Firstly it can mean every woman 'naturally' wants to be a mother; there is an innate, inherent maternal instinct. A second meaning is that of being closer to, and therefore more readily influenced by, nature. This implies that anything that is closer to nature is at once more removed from cultural modifications. Thirdly, statistical normalacy is implicated. That is to say that the thing most commonly done is the more natural. This leads into the fourth meaning which has normative connotations; that is that what people most commonly do is what people ought to do. (Birke 1986:13/14)

When any statement is made about the naturalness of a specific feature of human nature, there are then at once different meanings which can be imputed to it, and it is never clear which one is intended. Undoubtedly, the one thing that we can be sure about though, is that whenever something is deemed 'natural' then it is expected to remain unchanged. To change something that is natural to humans is to go against innate, in-built human nature.

The consequences of biological essentialism then, are that there are clearly defined boundaries that do not allow for changes in social arrangements.

Disabled people, old people, blacks, women, poor people, indeed all out-groups, have at one time or another shared similar conceptualizations. That is to say the popular notion that disability, poverty, blackness of skin, the female gender all entail a biological inferiority:

> Therefore the disabled person is often considered to be less intelligent, less able to make the right decisions, less 'realistic', less logical and less able to determine his own life than a non disabled person. (Safilios-Rothschild 1981:5)

If we consider biological essentialist claims about women's sexuality we can illustrate how these universalising, determinist theories have dangerous political implications for women's lives, and hence we become aware of the danger implicit in biologically essentialist claims on all oppressed groups.

Women are passive, men are active. Sex is something that happens to women. Women are receptive, men are perpetrators and aggressors. These views of sexuality have a long tradition within Western culture, and are more often than not, attributed to underlying biological differences between the sexes.

For example, the notion that a male sexual urge must find some outlet otherwise it becomes repressed and can thus be the cause of all manner of social ills, (see Reich 1975) relies heavily upon the assumption that sexuality is innate, an essence of self, an 'unknown force to be reckoned with'.

That this innate sexual drive is different for men and women allows for and excuses such things as pornography and rape.

Basically then, the notion of an innate sexual drive, which differs radically in women and men, has been used to legitimate male power over women. But it must not be forgotten however, that this notion can be used to divide women. Disabled women are all too frequently portrayed, and presumed to have no sexual urges, drives, or indeed sexuality. Rachel, in explaining why she prefers to walk, even though this is painful for her, says: "I think being in a wheelchair sort of makes you look asexual, it takes away your sexuality" (Rachel:200). Black women on the contrary, have been portrayed as having an innate sexual drive which is quite unquenchable. This has been used in the past to justify white men's sexual abuse of black women (see hooks 1981). Equally studies have shown that the very construction of women's bodies as frail and "corporally ineffective" (Cockburn 1991) is the result of prevailing power interests rather than due to any innate notions of women's 'natural' physical inferiority.[1] It is clear then that notions of power do not enter the biological essentialist arena, that is to say that questions of power are either ignored or seen as unproblematic.

Feminists have exposed the cultural and historical specificity of the body, thus demonstrating that it can hardly be dismissed as a fixed given as proponents of biological essentialism would have it. Furthermore, biological explanations for disability cannot incorporate those instances in which the disability is contingent, accidental, or due to an 'act of God'.

Whilst not denying that biology has its relevance to the understanding of human behaviour, Brittan and Maynard (1984) object to this position which sees biological difference as being responsible for hierarchy and inequality. They suggest an alternative perspective which

> would see oppression as the social construction of the body as an object. (Brittan and Maynard 1984:12)

Both 'race' and gender can be seen to be social constructions of the body as an object. Geneticists have shown that 'race' does not exist in that the differences in a population are often greater than the differences between populations (Bodmer and Cavalli-Sforza 1976, in Brittan and Maynard 1984). Yet this does not stop 'race' being discussed, researched, accepted and experienced as a reality. Similarly, feminists have clearly demonstrated that gender is an acquired characteristic. But as a 'lived experience' both 'race' and gender are mediated through the body. In other words the body becomes the object of coercion, for there are strong forces at work without which the constructions would not hold.

Similarly, disabled people have been categorized, labelled and defined in such a way as to create an out-group called The Disabled. This term both depersonalises people with disabilities and points to the disability as being the key aspect of identity for the individual with the impairment. Moreover, the term evokes a well-established set of assumptions and stereotypes:

> The Disabled are generally understood to be a small, clearly defined section of society, quite distinct from the public at large - poor, dependent creatures, immediately recognisable as physically different from normal people. (Sutherland 1981:13)

A person who is treated and classified as a disabled object comes to define her own body as 'disablized'. When a person defines herself in terms of her physical difference from others she has been forced to join the ranks of The Disabled.

As we have seen in the first chapter of this work, the medical model of disability relies primarily upon a biological essentialist model of bodily difference. The medicalization of disability is so ingrained within our culture that it becomes very difficult for disabled people to question this prevailing view. Physical and functional well-being are prioritised over civil rights issues and 'needs' as expressed by disabled people. In Chapter Five I shall be examining how the medicalization of disability occurred historically as part of a far wider social process of discipline and surveillance. However, the relevance of the medical model of disability to understanding our oppression cannot be disregarded.

Indeed it can be argued that it is the medical model of disability which lies at the core of all our oppression. For whatever gender, class or 'race' we are, we are all categorised, labelled and defined within the terms and constraints of the medical model of disability.

Furthermore, it is generally assumed that the distinction made between the able-bodied and The Disabled is natural and unproblematic. Yet as we have already briefly illustrated in respect to gender acquisition, many oppositions between normal and deviant operate as a system of control. In the next section of this chapter I shall be exploring the problems encountered when we start to label, categorise and segregate.

So far, in this section I have looked at biological theories that, in the final analysis, describe disability as bodily damage. I now want to turn to biological accounts of disability that give precedence to genetics.

An underlying assumption of proponents of biological reductionism is that by studying animal behaviour we can learn what is 'natural' behaviour for human animals. All behaviour can be reduced to certain traits. Thus racism can be understood to be an expression of in-group/out-group hostility, and so presumably can instances of disablism.

If we look at the way in which animals treat disabled members of their pack or herd we find that aging, impaired and/or sick animals are often left to die, or, alternatively, are killed by younger, fitter animals. The disabled animal is a liability, a burden to its fellow group members and thus for the group to survive, to remain strong, the abnormal animal must die.

Are we to take this as a blue print for how to cope with disabled people in our society? Or does it excuse the way in which disabled people are treated, by providing a sociobiological explanation: the trait is there, it is natural, inevitable and unavoidable.

To extrapolate some trait which appears to be universal in the animal domain, to human societies is obviously problematic. Cultural, historical and social specificity are overlooked, in favour of reducing human behaviour to some basic animal behavioural traits. The danger of biological essentialism is that it serves to legitimate existing inequalities by naturalising them. By giving credence to the notion that oppressive social arrangements are dictated by our biology removes all possible hope for change, and leaves no space for resistance.

2. CULTURAL ACCOUNTS

This section is divided into two sub-sections: 2.1 The Socialization Argument, and 2.2 Culture and Discourse.

2.1 THE SOCIALIZATION ARGUMENT.

The term 'socialization' refers to the process by which individuals learn to conform to social norms, and whereby the transmission of 'culture' between generations is made possible. In other words, socialization is the internalization of social norms. If we accept this argument, then it becomes evident that oppressive practices can be acquired and maintained through this process of socialization. Much of early feminism saw socialization as the process by which women were ascribed specific 'feminine' personalities and acquired a gendered identity. Similarly, racism can be explained in terms of certain societal values which are learnt and reproduced through the process of socialization.

This argument certainly appears to have validity for the position of disabled people. We have only to look at such things as the annual "Children In Need" campaign to realise what values are widely perpetuated and associated with disability. As one year's event got under way a letter in "The Guardian" spoke for many disabled people:

> Imagine a society where 10 per cent of the population cannot use the same schools, cinemas, houses and public transport as everyone else. Imagine a society where 10 per cent of the population are almost all thought to be incapable of the same work as everyone else and have to

> live around or below the poverty line. Imagine a society where 10 per cent of the population have to rely on other people bathing in baked beans or wearing gorilla costumes for the money to provide basic services and have as charity what others have as right. Imagine a society where 10 per cent of the population are not allowed to speak for themselves but are beholden to princes and chat show hosts to tell society who they are, what they feel and what they need. Imagine a society where all pride in yourself, your dignity and freedom is reduced to a bear with a bandage and eye patch. Today you won't need to imagine it any more. It's Children in Need day. (The Guardian 22.11.91.)

If people with disabilities are kept hidden, not integrated with 'normals' through education, work and leisure, and who are only seen by the general non-disabled public as helpless, dependent and 'in need' then the socialization argument would seem to hold sway in that non-disabled people are socialized into seeing disabled people in a certain way. Equally, disabled people are socialized into their disabled roles, they learn their scripts and thus perceive themselves as less than full members of society. Disability, from this point of view becomes a matter of learning the appropriate expectations linked to the disabled role.

Cross-cultural studies on gender acquisition have clearly shown that in different cultures gender can be construed in different ways. The anthropologist, Margaret Mead demonstrated as long ago as 1935, that in societies other than our own, widely different attributes were assigned to, and expected of, males and females. There were cultures, for example, where men were expected to be, and were, peace-loving, whilst women were expected to be, and were, war-like. (Mead 1935; Leacock 1981).

Equally in different cultures disability does not always signify an inferior, helpless, dependent position. Perhaps the best known, and most well-documented case being that of Martha's Vineyard.

Martha's Vineyard is an island off the coast of New England which, for over two hundred years had a high incidence of hereditary deafness. To compensate for this condition the residents, both deaf and hearing alike, used sign language. This language, like English, was not officially taught, but rather was assimilated and learnt at a young age by all the islanders.

To be deaf on Martha's Vineyard was not to be handicapped:

> Unlike individuals similarly handicapped on the mainland, deaf Vineyarders were included in all of the community's work and play situations. They were free to marry either hearing or deaf persons. According to tax records, they generally earned an average or above average income...and they were active in church affairs...the social attitude was fully accepting of deaf individuals. (Groce 1985:50)

As there were no communication barriers between deaf and hearing people, the deaf people were not excluded from any aspect of community life, and deafness did not have the same negative connotations that it has in society in general. Indeed to be deaf had little more significance than the colour of someone's eyes. As one islander remembers:

> Well, not quite so much - but as if, ah, somebody was lame and somebody had trouble with his wrist. (Groce 1985:51)

Or, as Groce goes on to say:

> The community's attitude can be judged also from the fact that until I asked a direct question on the subject, most of my informers had never even considered anything unusual about the manner in which their deaf townsmen were integrated into the society. (Groce 1985:51)

The 'bilingualism' of Martha's Vineyard effectively meant that being deaf in this community was not a disability. Thus it can be argued that it is the social arrangements and practices which, through linguistic shortcomings, disables deaf people.

Constructing disability is an active process. Groce, (1985) in her study of Martha's Vineyard is the one who creates deafness as a topic. For the islander's deafness is taken for granted, it is seen as natural. It is only when the values of a hearing world impinge that deafness is constructed. "The very idea of defining deafness may itself, therefore, be seen as a social construction." (Gregory & Hartley 1991:1)

Cross-cultural studies on disability remain few and far between. However one thing is clear; that is that what is a disability in one culture is not necessarily a disability in another. Gwaltney's (1970) study of blindness in a Mexican village, for example, found that blindness was regarded as being "the consequence of omnipotent, divine intervention." (Gweltney 1970:v) This belief elicited an accommodative cultural response. Blind people were provided with child guides, social accolades were given to those who were deferential to blind people, social opprobrium to those who were not. Blind people were fully integrated into the community and this was ensured through an elaborate system of informal social mechanisms. Further, as Oliver (1990) points out, no attempts were made through their own medical, technological or social systems to try and cure blindness. Rather than being seen as a pitiful, tragic figure the blind villagers of Gweltney's study were seen and treated as part of a community problem which was the result of the harsh life they all lived (Oliver 1990).

Disability has always existed in different cultures, at different times. However, what is a disability in one culture is not always constituted as such in another.

> For example, carrot-coloured hair is a physical feature and a handicap in certain social situations but a person with this characteristic is not included in this class. Nor is the symptom itself the only criterion, for though the person afflicted with infantile paralysis may limp as a result of the disease and be deemed to be handicapped, yet the person with an ill fitting shoe or a boil on his foot may be excluded. When one introduces the concepts of other cultures than our own then confusion is multiplied. Even assuming the existence of such a class in other societies, its content varies. The disfiguring scar in Dallas becomes a honorific mark in Dahoney. (Hanks & Hanks 1980:11, in Oliver 1990)

In principle then, it would appear that if one were to accept the socialization argument, all we need to do to have a well-integrated, non-disabling society is to change patterns of socialization vis-a-vis disability. This point is very cleverly illustrated by Finkelstein (1981). In his article "To Deny Or Not To Deny Disability" (1981) he suggests that it is society that disables disabled people:

> The cause then, of disability is the social relationships which take no or little account of people who have physical impairments. (Finkelstein 1981)

To test this hypothesis Finkelstein asks the reader to imagine an 'upside-down' world where the abled become the disabled and the disabled the abled. In this world over a thousand wheelchair users come together to form their own self-contained community. Non wheelchair users seldom visit and the wheelchair users run all aspects of their lives.

> In fact, for the village, being in a wheelchair is like everybody else in their world of people that she or he meets in daily life. They see wheelchair users on the television and hear them on the radio. Able-bodied people, however, are only rarely seen and little understood. (Finkelstein 1981:35)

The environment is altered to meet the needs of the wheelchair users. So, doors become a regulatory five foot, and ceilings too are lowered. After some time a few able-bodied people "through no fault of their own" come to live in the village. Soon they all have bruises on their foreheads as a result of continuously hitting their heads on the low door frames, and back ache from bending down all the time. They are sent to see a whole array of professionals about these problems, all of whom are in wheelchairs. These doctors, psychiatrists, social workers and so forth, report that the able-bodied people suffer a "loss or reduction of functional ability" which results in a handicap. The handicap causes further problems which makes them disabled in this society.

It does not stop here. Special aids are designed for them: helmets and braces (to keep them at the same height as wheelchair users), and wheelchair users are unwilling to employ these able-bodied disabled people. New professions spring up to try and understand the problems of this group and to care for them. Charities form to collect money for them, and upturned helmets become the symbol of this stigmatized group. It gradually dawns on the able-bodied disabled group that none of the wheelchair users ever ask them for their opinions of their problems, they are never addressed. And they begin to wonder if society might not be responsible for some of their problems. They begin to fight for social change, but, of course, many of the wheelchair users think that they have not accepted their disabilities and carry chips on their shoulders. Nevertheless they form a union to fight segregation and they:

> ...even argued that perhaps, just perhaps, their disabilities could be overcome (and disappear!) with changes in society. (Finkelstein 1981:36)

However, it would be too naive simply to say that racism, sexism and disablism are merely the result of the reproduction of certain societal values. If this were the case sexism, racism and other forms of oppression would not be an issue. Socialization would ensure that they are generationally transmitted. Out-groups are not simply oppressed because they are different, or because socialization underlines this difference. Oppression implies power and whilst power has a cultural dimension, it is a dimension which is not the same as claiming power to be exclusively cultural.

2.2 CULTURE AND DISCOURSE

Disablism, like racism and sexism, does not exist outside of the institutional structures through which it is expressed. And these structures are, by their very nature, cultural. To suggest anything other is to imply that disablism is inevitable.

As has been shown, cross-cultural studies clearly illustrate how disability is understood differently in different societies. The ideas and attitudes that an individual holds regarding her health and disability, are obviously important. But they are not formed in a cultural vacuum. It is the ways in which ideas and attitudes are framed by society, the ways in which they are organized, the ways in which they become subordinate to a particular discourse which is of relevance here.

By looking at different societies it would appear that disability is socially constructed and culturally bound. In this respect then, disability has no objective reality. This does not however, negate the fact that disability does remain a social reality. Yet, it is important to remember that whilst we valorize disabled people's lived experiences, it should not be forgotten that these experiences are produced within a framework. That is to say that they are produced within a discourse that mediates the truth, the reality of that experience. In other words, it is the discourse that offers particular ideas and constructs of the situation, as well as defining the nature, source and solution of any given 'problem'. To understand disabled people's oppression, therefore, it is necessary to explore the general framework, the discourse, in which disability is traditionally understood.

As has been said, the ideas and attitudes that an individual holds regarding her disability, are organized within a particular discourse. This discourse is not neutral, rather it is evocative of a historically specific set of received ideas and codes of intervention (Armstrong 1987).

Now a particular form of humanist philosophy pervades the discourse of disability. And as such it provides both an ontological and epistemological framework in which to understand the world (Atkin 1991).

Humanist values are deeply ingrained in the twentieth century mode of discourse. Whilst there are many different accounts of humanism (see Soper 1986) it is with post-enlightenment thought that our main concern lies. Central to the humanist philosophy is the notion that human beings share core, essential, innate properties. These properties include 'consciousness', 'reason', 'compassion', 'responsibility', and 'choice'. It is these features that define humans as separate and different from all other creatures. Humanist thought sites people at the centre of the universe. It is a philosophy of action whereby people make their own history, as a result of their own will. It perpetuates, writes Rojek et al:

> ...the idea that human beings mould and fashion the world themselves in accordance with their fixed and definite self-appointed ends. (Rojek et al 1988:114)

That is to say that human action is perceived to be ahistorical and asocial. This leads to the notion that we all basically have the same problems, worries, and concerns.

Humanist philosophy has had considerable impact on many professions. If we consider the influence it has had on social workers, a group most Western disabled people have had some contact with, we see that:

> ...the occupational self-image of social workers volunteers a strong philosophy of expert caring and responsible intervention to alleviate distress. (Rojek et al 1988:114)

In other words social workers regard themselves as helpers, carers and enablers.

Traditional social work relies heavily upon certain key concepts: 'acceptance', 'trust', 'abled', 'disabled', 'normality', 'abnormality'; categories and properties which all people are assumed to fit and/or adopt. This approach, which derives from humanist philosophy, has been criticised for ignoring the socio-historical context of the client and her situation. Clients are seldom listened to, and, as in the earlier example provided by Finkelstein, (1981) social workers frame both the problem and the solution in their own terms.

It has been made clear by Foucault and other commentators that this, which informs the discourse of disability, is highly paradoxical.

On the one hand we have a group of professionals whose self-professed aim is to provide care, help and solutions to the problems of life. And yet in doing so they set into motion a whole array of mechanisms which ultimately reduce individual freedom. For example, to receive "Disability Living Allowance", a person has to be examined and seen to fulfil certain statutory requirements. Forms detailing the person's physical abilities have to be completed and signed by a social worker or other suitably qualified carer; the disabled person's status is evaluated, their defects analyzed, their functioning monitored. In other words patterns of surveillance and control, mechanisms of power are put into practice as a result of this form of humanism. The individual becomes, in Foucault's terms, "a docile body" which reflects a particular "political anatomy" (1977) that can be subjected, transformed and improved. In short, the aim is to normalise the individual and expose deviance and antagonism.

In accordance with humanism, meaning becomes fixed and definite, truth becomes knowable, and the conscious subject becomes the centre for resources. In this discourse the relationship between the individual and society is one of "functional harmony" (Atkin 1991:39). Any imbalance in this harmony is perceived to be a sign that the individual is 'unwell', and must therefore receive treatment in order to regain harmony. In other words:

> ...individuals become distributed, categorised and manipulated around a given norm. (Atkin 1991:40)

Problems are produced and solutions imposed.

Donzelot (1979) suggests that a new domain of consideration is opened up to discourse. This realm is neither private nor public: it is the social. A domain where the balance of power lies with the social worker, the psychiatrist, the juvenile court, and so forth. Thus we can see that providing welfare for disabled people involves monitoring and regulating family and individual life. This results in the creation of a regulated social sphere which lies between state institutions and the self-regulating civil society. It is within this social sphere that normalising technologies operate. And it is these normalising technologies that create deviance, that create the categories abled and disabled, and which entail management on an individual level.

This is not to claim that all state care is necessarily negative. On the contrary, the positive effects cannot be overlooked. Guaranteeing individual rights, relieving suffering, expanding people's horizons and so on, are all genuine benefits. But they have a price and that is the paradox. Power, as Foucault makes abundantly clear, is not solely negative. The nature of power is dualistic. It is both negative and positive, constraining and enabling, repressive and liberating.

We cannot argue that disabled people are not oppressed, but, as in the case of women and ethnic groups, it is the doxa, the prevailing 'truth' of a given time that organises, produces and maintains deviance. From this point of view it can be claimed that it is indeed culture that perpetuates oppression. A culture in which all deviance, all behaviour defined as 'abnormal', 'inadequate' or 'unhealthy', is identified, measured, and regulated in order to rehabilitate it and render it harmless. Foucault has clearly demonstrated how order and control, through 'care' and discipline, is perpetuated through cultural institutions, such as medicine, psychology, education and public assistance. However it is important to remember that both the socialization and discourse perspectives have been critised for their neglect of hard structural relationships. That is to say they ignore the reality of oppressive practices (Eisenstein 1979, Brittan and Maynard 1984). These arguments, along with a consideration of resistance, will be examined in more detail in the following chapter.

3. PSYCHOLOGICAL ACCOUNTS

The influence of psychoanalysis on our understanding of the human mind can be felt in all aspects of everyday culture. From Hollywood movies depicting the psyche of a serial killer, to debates surrounding censorship and childhood development, the figure of Freud looms large. It is therefore, no surprise that theories employed to understand personal responses to disability make the unquestioned assumption that the onset of disability not only brings about physical changes, but emotional ones as well. In other words it is assumed that before a person can become psychologically whole again they must 'come to terms' with their altered physical state.

Central to the normative assumptions in this model of adjustment lies the concept of loss. Loss, not just of the ability to see, hear, walk, or of whatever functional capacity has been impaired, but loss of independence, spontaneity, employment, sexuality, social status. In short, loss of normalacy.

In learning to cope with the problem of adjusting to the onset of disability, relevant professionals, such as social workers, therapists and counsellors have drawn upon already existing psychological theories to explain these difficulties.

Grief theory has been adapted to produce a theory, a schemata, through which disabled people are supposed to pass, before we can accept our disability and become psychologically entire once more. Grief theory, of which Kubler-Ross's (1969) work is perhaps the most influential, indicates that people go through five, generally progressive, emotional stages: denial, anger, bargaining, depression and finally acceptance. Kubler-Ross's analysis has been applied to experiences of dying and bereavement, as well as to disability. If we do not go through these stages we cannot hope to become well-adjusted disabled people.

In an article entitled "Learning to Survive and Cope With Human Loss", Raymond Berger (1988) looks at human responses to traumatic loss and disability. His aim is to identify "common reactions and coping strategies and [he] suggests several principles for effective intervention." This paper appeared in *Social Work Today*, a respected journal for social workers.

By using the psychological model of loss, Berger (1988) is able to clump together the following groups of people:

- burn victims and victims of other traumatic injuries
- the physically disabled and deformed (sic)
- natural and man-made disaster victims
- survivors of the Hiroshima and Nagasaki bombings
- concentration camp survivors
- the severely and terminally ill
- families which experienced the death of a child (Berger 1988:14)

For all these 'victims' Berger (1988), following on from Kubler-Ross, (1969) suggests that the first stage of the grief process which must be gone through, is denial. This, he maintains, is a universal response to all loss. And even whilst disabled people say they did not experience this stage, this is taken as further evidence of denial.

> Occasionally a newly disabled person does not seem to be particularly depressed, and this should be a matter of concern. In almost all instances something inappropriate is taking place. A person should be depressed because something significant has happened, and not to respond as such is denial. (Siller 1969:292)

As Lenny (1993) points out:

> ...this classic psychological response of denial places disabled people in a catch 22 situation; to deny that adjustment to their disability is a problem for them shows just how great their adjustment problem really is. (Lenny 1993:234)

Berger (1988) however, sees no such problem with denial. He insists on its universal character, saying that this initial reaction serves as a "psychological blister" to cushion the initial impact of the loss, until the individual is able to "gradually integrate the reality of the situation." (Berger 1988:15)

Berger (1988) continues to advise social workers for disabled people that denial of the loss should be encouraged as it is the 'normal' reaction to loss. Denial, he states, should be seen as a "helpful friend", and these feelings should be welcomed as "the first steps in a long process towards integration and acceptance". (Berger 1988:14)

Social workers should also be aware, writes Berger (1988), that 'clients' who appear to manage well at the time of the initial loss, might well 'fall apart' at a later date. Thus all behaviour and subsequent actions can be understood in terms of "delayed traumatic stress syndrome".

Berger (1988) next outlines three modes of counselling which can help 'loss victims' adjust. First there is religious counselling, for those individuals who feel "God did this to me because I am a bad person". (Berger 1988:15) Second is some form of assertiveness training. The aim of this is to improve the client's self-esteem. The general rule is "start acting like a person who feels good about yourself, and you will begin to feel good about yourself." (Berger 1988:16) The third form of counselling is what Berger refers to as the need to "bear witness". This sharing of experiences Berger explains as "the struggle to give meaning to their pain by sharing it with others, in the hope that their experience will not have been in vain." (Berger 1988:16)

I have drawn extensively on this report by Berger (1988) as it embodies much of what is at fault in these fixed stage psychological theories, which continue to have a significant impact upon professional interventions. Their very existence has, however, been questioned by some researchers (Silver and Wortman 1980), and other studies have shown that these fixed stages, through which we must pass, do not accord with our own experiences. Indeed, Trieschman (1980) maintains that theories of loss and adjustment are oppressive as they rely all too readily upon the personal tragedy theory of disability, which defines a disabled person as a victim. Additionally, work undertaken by Campling (1981), Sutherland (1981), and Oliver et al (1989) amongst others, demonstrates clearly that the experience of loss is certainly not central to all disabled people's experience of the onset of impairment. Furthermore, as Lenny (1993) makes clear:

> The denial mechanism is tautological and explains nothing and everything at the same time. (Lenny 1993:235)

There are other, more general criticisms of stage theories. Germain and Gitterman (1980) argue that any theory which encourages the notion of one developmental path also implicitly encourages the labelling of any deviation from it, as abnormal.

In short then, loss models locate the problem of adjustment firmly within the individual. This is reinforced through 'helping professionals' who again deny any social or political role in the oppression of disabled people. The problem of adjustment is defined as an individual, tragic problem, whose 'victims' must come to terms with their loss in order to be psychologically whole.

If we return to the three forms of counselling that Berger (1988) advocated for 'loss victims' we can see the tragic, personal theory of disability, upon which they are based, highlighted.

Religious counselling is based upon a false premise. Berger (1988) maintains that a high level of guilt often accompanies a loss. This is not in accord with my own experiences, both as a disabled person, a researcher and through discussions with other disabled people.

The assertiveness training advocated by Berger (1988) totally negates the fact that self-esteem amongst newly disabled people reflects societal attitudes towards us, which will not be easily overcome by 'positive thinking' alone. Low self-esteem amongst disabled people is not simply a psychological problem. Rather it is the epiphenomena of a culture and ideology which is based upon imposed norms of the body beautiful.

The psychological model of loss and adjustment to the onset of disability has further oppressive functions for disabled people. We have already briefly looked at cultural images of disabled people and it soon becomes obvious that this psychological model informs much of the cultural stereotypes of the maladjusted disabled figure.

In a discussion concerning the cultural constructed images of disabled people Paul Longmore (1985) writes:

> The most prevalent image in film and especially in television during the past several decades has been the maladjusted disabled person. These stories involve characters with physical or sensory, rather than mental, handicaps. The plots follow a consistent pattern: the disabled central characters are bitter and self-pitying, because, however long they have been disabled, they have never adjusted to their handicaps, and have never accepted themselves as they are. Consequently, they treat non disabled family and friends angrily and manipulatively. At first, the non disabled characters, feeling sorry for them, coddle them, but eventually they realise that in order to help the disabled individuals adjust and cope they must "get tough". The stories climax in a confrontation scene in which a non disabled character gives the disabled individual an emotional "slap in the face" and tells him or her to stop feeling sorry for themselves. Accepting the rebuke, the disabled characters quit complaining and become well-adjusted adults. (Longmore 1985:34)

Portraying disabled people in this way strengthens the idea that disability is a problem of psychological self-acceptance, or emotional adjustment. Thus it is an individual problem rather than an issue of social prejudice and inequality.

Professionals who work with disabled people are clearly influenced by cultural images and ideological constructions of disability as a personal, tragic and medical concern. Stage theories and notions of psychological adjustment are the focus for much professional intervention which reinforce the oppressive model of disability.

Psychological approaches to disability then, fail to account for people's lived experience of disability. The experience of disability cannot be understood solely in terms of internal psychological or interpersonal processes. The dominant psychological understanding of the experience of disability reinforces the oppressive nature of the individual, tragic, medical model of disability and leaves no room for resistance.

4. CLASS ACCOUNTS

Traditionally the concept of class and stratification have been used to analyze inequality, disadvantage and subordination. The major theorist of class oppression is, of course, Karl Marx.

Following Brittan and Maynard's (1984) discussion of "the class problem", there are two key questions which, when considering the relationship between out-groups and class, need to be examined.

Firstly, can women and out-groups fit into pre-existing hierarchical or class structures? And secondly, can the development of the capitalist productive system adequately explain women's, black people's, disabled people's and all out-groups' particular position within these structures? In other words can out-group oppression be subsumed within working class oppression?

In the work of Westergaard and Resler (1975) the question of both women's and black *people's oppression* are marginalised when they argue that they are part of working class oppression. That is to say that they suggest that gender and 'race' are both experienced as an accentuation of the inequalities and oppression that working class people (white able-bodied men) experience.

Now disabled people who experience inequality and disadvantage in education, health care and prevention, housing, transport and employment, amongst other things, (Barnes 1991) can be classified as a particularly disadvantaged sector of the working class. However, as in the case of 'race' and gender this marginalization effectively dissolves or subsumes disabled people's oppression within a generalised working class oppression. It claims, in effect, a universal, acultural, ahistorical nature to oppression. Furthermore, this approach renders gender, 'race' and disability unproblematic:

> ...because neither 'race' nor gender are regarded as independent contributors to an oppressed state, both women and out-groups can, from this perspective be incorporated into a hierarchical system already defined in *a priori* terms. (Brittan & Maynard 1984:35)

An alternative strategy to the position of out-groups in relation to class concentrates upon occupation as the unit of analysis for class. This, for feminists in particular, has been highly problematic. Does the woman automatically join the class dictated to her by her husband's occupation? What happens if her occupation places her in a higher class? (see Delphy 1981). As Delphy argues women are assigned a class according to the men they marry and not in terms of occupation. In addition domestic work, carried out in the home, is not considered, by most social theorists, to be an occupation.

Likewise, the question of 'race' has been subsumed under the rubric of the white stratification system. Historically it was believed that the 'race' question would be resolved when blacks had, to all intents and purposes, 'melted' or merged in with the indigenous population. The culture and specific experiences of ethnic groups would disappear as these people were absorbed into the white class system.

In a similar way disabled people are marginalised when it is assumed, for example, that employment legislation and notions of independent living will guarantee that disabled people will blend in to society, or dissolve into the 'normal' population. Whilst for some disabled people this may well be all that is needed, for others their impairment cannot so easily disappear. As a sight impaired tutor it is important to me that my students, for example, sit in the same seats each week, give their essays to me on tape, and identify themselves to me if we meet outside of the tutorial. No matter how many adjustments are made to the social and physical environment I shall always be handicapped by my physical impairment. This is not to say that the social model of disability is of no relevance; on the contrary I believe it to be of crucial importance in overcoming many problems faced by people with disabilities. For me, however, not recognising people, not being able to interpret non-verbal forms of communication and having to tolerate people's enthusiasm for my guide dog are real problems that I cannot envisage will be easily overcome by social manipulation. Steven, who uses a wheelchair says:

> I do not feel disabled you know but O.K. you can't get into places and stuff like that but...certain things like I have to wear a sheath now because you have no control over your bladder and you have to do your own bowels on the toilet, that is one of the worse things of the whole

> thing because you have to put the sheath on and if that comes off then you just piss yourself really. That is the worse thing. That is the thing *that pisses me* off the most...like in a meeting when the sheath comes off... (Steven:243/6)

For Steven it is not the social barriers that surround disability which concern him. Rather it is his body, his somatic experience which he feels disables him. (see also French 1993:17-25 & 44-45)

This highlights the problematic nature of classification and categorization and their inevitable denial of individual experience.

What value then has this second sociological approach when we consider disabled people's oppression?

In order to address this let us consider one aspect of disabled people's oppression, namely employment and income.

Obviously disability, unemployment and poverty are closely linked. In our society employment not only means economic independence, but it also gives meaning to people's lives. Our job is one of the crucial ways in which we identify ourselves:

> Apart from income, work provides a sense of identity and self-esteem, opportunities for social contacts outside the family home, skill development and creativity, as well as a sense of time, obligation and control. (Barnes 1991:62)

There has been much research carried out which looks at the psychological effects of long term unemployment, all of which is relevant to unemployed disabled people. Paul, for example, recounts how he felt when he lost his job due to his impairment:

> As I say, I was sales director there, I had a very good job, good money, I had a good car etc. etc. It well, it just made you feel a little bit more useless for want of a better word. I felt useless a lot of the time, because you weren't able to do anything, not able to earn your own keep and that sort of thing, which had always been very very important to me. It is very important for a man to be able to maintain his own standard of living and his wife's. (Paul: 187)

However people with disabilities come up against a number of barriers which effectively deny them meaningful employment, which non-disabled people do not experience.

It is difficult to assess accurately the number of unemployed disabled people, for the current unemployment figures include only people available for and 'actively seeking' work. Inevitably, given the present disablist climate, there are a lot of people who would work but who have given up looking for meaningful employment as it appears to be such a hopeless task. For example, a recent OPCS survey reported that 85 per cent of the men, and 65 per cent of the women who were not actually seeking employment, and who defined themselves as 'unable to work' had previously attempted to find meaningful employment but had given up. (Martin, White & Meltzer 1989:69 in Barnes 1991:64; see also Morris 1989; Oliver et al 1988).

A recent report produced by the R.N.I.B. states that:

> ...4 in 5 blind people of working age are unemployed, and that two thirds left work after the onset of their visual impairment. (R.N.I.B. 1991:246)

Only ten per cent of sight-impaired people not working were 'registered as unemployed and looking for work' with their local job centre. Yet when asked for the R.N.I.B. survey if they would like to work, fifty-nine per cent of partially sighted people between the ages of sixteen to fifty-nine and thirty-nine per cent of blind people expressed a desire to work (R.N.I.B. 1991).

The Department of Employment suggests, in its document entitled "Employment and Training For People With Disabilities" (1990) that:

> It is clear that the chances of someone with a disability being unemployed are significantly higher than someone without a disability. The 1989 EC Labour Force survey puts the rates at 20.5 per cent and 5.4 per cent respectively. (Department of Employment 1990:13)

Discrimination, both direct and indirect, focused on disabled people is not only experienced when looking for work. Once in employment disabled people in full-time occupation earn less than full-time employees in the general population. On average disabled men in full-time employment earn almost a quarter less per week than their able-bodied counterparts (Barnes 1991:67). This discrepancy cannot be accounted for by differences in hours worked (Martin & White 1988 table 3.1). Abberley (1992) suggests that the OPCS surveys provide evidence of a decrease in earnings for severely disabled men, but not for women. He continues by looking at the work of Smith

(1974) in regard to similar earning patterns amongst ethnic minorities. Smith explains that white and black women's earnings are very similar, not because of racial equality, but because of

> the enormous disparity between men and women in this respect left little scope for racial disadvantage to have a further additive effect. (Quoted in Abberley 1992:147)

In other words whilst this might indicate that disabled women fare better than disabled men in terms of pay, women generally are treated unequally in the British labour market (Lonsdale 1986).

Not only do disabled people earn less, but the majority of people with disabilities have expenditures which non-disabled people do not have to meet. The OPCS survey divided these additional expenditures into three groups. Firstly, lump sum expenditure on special items such as a chair lift, home conversions, special furniture, electric wheelchair etc, etc.; secondly, regular expenditure on special items such as costs associated with regular hospital visits, private domestic help, readers, transport, etc. etc.; and thirdly, regular expenditure on items required by most people but on which disabled people need to spend more. This would include such things as special dietary requirements, clothing, heating and so forth.

As a result of these expenditures, combined with low levels of income:

> Altogether eight per cent of disabled householders thought they were getting into financial difficulties, but there were significant differences between household types, with thirty-six per cent of the albeit small group of single parents, twenty-three per cent of single childless

> householders, but only three per cent of pensioners reporting difficulties. (Abberley 1992:149/50)

It cannot be denied that disabled people are seriously disadvantaged in this instance.

Classical Marxism then, marginalises unemployed people in two ways. Firstly by privileging the labour/capital distinction it renders unemployed people peripheral. And secondly because economic determinism is prioritised women's, disabled people's and black people's oppression becomes an ideological effect. 'Race', disability and gender cannot be treated as secondary to class relations. There are many feminist critics of orthodox Marxism, (see Sargent 1981) and the notion that the overthrowing of a capitalist mode of production will result in the 'ideology' of women's oppressed status being abolished is well documented as well as being problematised. For disabled people, as well as women, the capitalist mode of production may well have heightened and compounded their economic disadvantage (Oliver 1990; Barnes 1992; Finkelstein 1980) but it cannot be claimed that the abolition of capitalism will result in economic equality for disabled people. The nature of disabled people's oppression, like racism and sexism, is deep-rooted and complex, and cannot simply be reduced to an effect of ideology.

5. CONCLUDING REMARKS

So far then, we have looked at theories of oppression and in each instance found them problematic. To define a category of people in terms of their biological functioning is to compound oppression rather than subvert it. This has been clearly illustrated by feminist theories which seek to reappropriate women's bodies from patriarchal forms of control, and thus escape the negative values associated with female biology. This has led to essentialist claims about women's 'innate' caring and nurturing functions, which many women do not relate to, and find extremely questionable. The return to biology as the basis for a specific feminine sexuality or meaning seems to defeat the feminist premise that biology is not destiny. For disabled people biology may be an important aspect of identity, but it is not determinate of it. Theories of disability that repeatedly focus on the impaired body do not address the social oppression of disabled people and overlook issues of power, history and politics.

As we have seen, different socialization patterns have operated to construct disability differently in different cultures. According to cultural theory then, disablism can simply be subverted by adopting different practices towards disabled people, women and ethnic groups via different child-rearing practices.

This is problematic, for to assert that sexism, racism and disablism can be explained by the presence or absence of certain values in a particular society implies that out-groups are out-groups simply as a result of a lack of understanding of one group's way of life:

> Jews did not go to concentration camps because the Nazis did not interpret Jewish culture correctly. (Brittan & Maynard 1984:19)

As has been stated, oppression does not exist outside of the institutional structures through which it is expressed, and thus by definition it is cultural. Humanist philosophy underlies our understanding and construction of disability. Yet this approach has at its heart, a paradox. As Foucault points out, disciplines based upon humanist philosophy do not provide care and help without employing mechanisms which ultimately reduce individual freedom.

Cultural determinism is problematic then, in that a disablist, sexist or racist culture does not exist independently of the institutional structures through which it is expressed. (Brittan & Maynard 1984).

Inevitably, given our therapeutic culture, psychological explanations of the experience of the onset of disability exist. The prevailing view is that disabled people need to pass through several psychological stages before we can unproblematically accept our altered selves. This view is premised upon the individual, tragic, medical account of disability and is therefore oppressive. It is reproduced and strengthened via many cultural institutions. It negates any notion which attempts to locate the experience of disability within a wider social context. In other words it fails to consider the wider social forces which structure the experience of disability.

Any explanation of the experience of disability which makes judgements about individual disabled people's adjustment to their disability, and any explanations which imposes its own meaning on situations and reinforces the tragic, medical, model of disability repudiates the material components of the experience of disability and is therefore highly unsatisfactory.

Marxist theory looks at power in terms of relations of production and economic control, and the exercise of that control through the dominant ideology. Whilst this obviously has relevance in respect to disabled people's oppression, it cannot explain that oppression. An economic perspective is of great importance in a capitalist society, yet this approach lacks a critique of the constitution of the subject, as well as having shortcomings in terms of feminist analysis, or in terms of explaining black people's and disabled people's oppression.

What therefore needs to be explored is an approach to oppression which is not determinist, which does not rely exclusively on one explanation, and one that takes in to consideration oppressed people's lived experience.

It is with this in mind that I now turn to the work of Michel Foucault, and in particular contemporary feminist readings of his ideas.

1. Atkin (1993) argues that women's exclusion from manual work is not the consequence of any innate specificities of the female body, but rather it is the outcome of the categorization of women's bodies as physically frail. Atkin suggests that the exclusion of women from manual labour was due in part to the production of discourses, specifically those of class and gender, which led to the formation of the middle classes during the eighteenth century, which informs our understanding of women's bodies today.

CHAPTER FIVE

FOUCAULT: POWER, KNOWLEDGE AND THE BODY

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FOUCAULT: POWER, KNOWLEDGE AND THE BODY

Abstract: *This chapter is divided into three sections. First I outline Foucault's ideas regarding power, resistance and the body. In the second section I critically assess the relevance of his work, and in particular his notion of docile bodies, productive power and resistance, to disability researchers. I argue that it is only through a Foucauldian perspective that we can understand how particular kinds of subjects are produced as effects of discursive and power relations. The notion of resistance is explored and its fluid, ever-shifting and precarious nature exposed. Foucault's insight that power is productive is examined in relation to the prevailing discourse of disability and his assertion that technologies of power are neutral (in the sense that power is a mode hypothetically available for multiple users), is examined from the perspective of the victims of power. The final section: 'concluding remarks', suggests that whilst Foucault is invaluable to our understanding of the received notions of The Disabled, it might be useful to explore his later works to see if here Foucault can provide us with a more rounded version of the self.*

INTRODUCTION

In this chapter I am going to outline Michel Foucault's position on power, knowledge and the body. I will then examine the implications of this for a theory of disability and resistance. I want to argue that Foucault demonstrates how our's is a disciplinary society, and that it is mechanisms and technologies of discipline which construct the subject. Central to Foucault is the idea that wheresoever power is exercised the possibility of resistance is always present. In the second section of this chapter I will examine the nature of this resistance and consider if Foucault can show us a valid means of resisting normalizing power.

The first section of this chapter is an exposition of Foucault's argument, and in particular those aspects of his work which have resonance for disability researchers. It is not until the second section of this chapter that I articulate the implications that his thought has for us. It is in this second section that I draw heavily upon my empirical data to bring to light both the contributions Foucault can offer disability theorists and the shortcomings and problems associated with his work. I have deliberately separated these two sections as I feel it is important to have a clear understanding of Foucault's position before assessing the implications and validity of his thought in respect of disability research. Whilst I acknowledge that this means that the first section of this chapter is principally concerned with theory, I believe that only after this has been detailed can we attempt to ground his analysis in accordance with our lived experiences as disabled people.

1. FOUCAULT'S ARGUMENT

Power in the West is traditionally perceived to be repressive, juridical and prohibitive. Power, it has been believed can be seized, acquired or shared. In this scheme power filters down from above in a negative fashion. Unlike Marx and other social and political theorists[1], Foucault did not see power as something possessed by one class who strove to maintain it whilst another class struggled to win it. Power, for Foucault has no essence, it is not unitary. Quite the opposite in fact.

Power, Foucault maintains, is everywhere. There are as many forms of power as there are social relationships, between groups and between individuals. Obviously some groups of people, for example, children, prisoners, the 'mad', and disabled people, might not have as much opportunity to exercise power as other groups, but even so *they can and* do exercise power over other individuals.

It is not within the scope of this work to examine the reason as to why power in the West has been conceived of in this repressive, juridical manner. However, for the sake of clarity I will very briefly outline Foucault's genealogy of power.

If we return to the Middle Ages we can witness the ascent of the monarchy. This happened against the backdrop of bitter struggles between feudal power agencies. For the monarch to succeed it had to be able to quash these struggles, maintain peace and put an end to violence. In other words:

> It made itself acceptable by allocating itself a juridical and negative function. (Foucault 1980: 121)

Power soon came to be represented by the sovereign, Law and prohibition. And, inevitably, as soon as this came about the sovereign exceeded its limits.

This is the legacy of power we have inherited. It still forms a bedrock to much political theory,

> Such theories still continue today to busy themselves with the problem of sovereignty,

Foucault continues:

> What we need, however, is a political philosophy that isn't erected around the problem of sovereignty, nor therefore around the problems of law and prohibition. We need to cut off the kings head: in political theory that has still to be done. (Foucault 1980:121

When theories of disability and disadvantage are looked at and questions or problems posed in terms of 'The State' then power is still being conceived of as a repressive, prohibitive, sovereign, law. Foucault does not want to undermine the importance of the State, but he stresses the fact that power relations extend far beyond the confines of the State. Firstly the State, however omnipotent and monolithic its apparatus, cannot fill all possible relations of power. And secondly it is already existing power relations that enable the State to function.

State power can be conceived of as a kind of 'meta power' that, however can only operate in relation to other power relations that:

> supply the necessary basis for the great negative forms of power. (Foucault 1980:122)

This conception of power negates the Marxist opposition between State and Revolution. Foucault's formulation of the State consisting in the "codification of a whole number of power relations which render its functioning possible", (Foucault 1980:122) sees revolution or resistance as having the same power relations as the State, but a different codification of them. Hence there are as many different kinds of revolution as there are power relations. Or, to put it another way - there are as many points of resistance as there are subversive recodifications of power relations. It is also possible to have revolutions that do not disturb the power relations that enable the State to function. (Foucault 1980:123)

> Are there no great radical ruptures, massive binary divisions, then? Occasionally, yes. But more often one is dealing with mobile and transitory points of resistance, producing cleavages in a society that shift about, fracturing unities and effecting regroupings, furrowing across individuals themselves, cutting them up and remoulding them, marking off irreducible regions in them, in their bodies and minds. (Foucault 1976:96)

So, what needs to be examined is how can a Foucauldian model of power and resistance inform the question of disability and dissent?

Now, the body plays a central role in Foucault's theory. But by placing the disabled body at the centre of disabled people's oppression we have fallen into biological determinism and essentialism. And, as we have seen in the previous chapter this is a problematic and unsatisfactory account of disability. However, certain feminists such as Lois McNay (1992, 1994) have shown how Foucault's work can be interpreted to demonstrate a way of placing the body at the centre of women's oppression that does not fall into biological determinism or essentialism. This is obviously of the utmost importance for the position of the disabled body.

In the next section I will look at Foucault's notion of the body and its implication for a theory of disability.

1:1. THE DISCIPLINED BODY

Foucault in *Discipline and Punish* (1977) produces an image of a disciplinary society, an account of the contemporary world, which, whilst detailing the birth of the prison, is also concerned with the development of the disciplined body. Foucault clearly illustrates how a coercive, corporal, solitary, secret model of the power to punish replaced the representative, scenic, signifying, public, collective model. However this did not happen in isolation. Foucault stresses that it is only by turning to developments in the rest of society that we can begin to understand this shift. It is these developments that can also help us to understand the prevailing view held of disability today.

Throughout the Classical age we find a concern with the disciplining, the ordering, the organizing, the separating, the compartmentalising of bodies. Bodies have to be disciplined, they have to be organized, they have to be managed in such a way as to make them suitable for labour power. A work force that is suitable has to be created, bodies have to be turned into labour power. This, Foucault maintains, can only be done through knowledge - the knowledge of the body. It is this knowledge that makes it possible to subjugate bodies in to docile, useful roles. This knowledge is not linked to class. Foucault is not talking in the Marxist sense, of one class using its power to direct another class to behave, or fulfil this or that function. The disciplinary knowledge that Foucault documents in *Discipline and Punish* (1977) is, in fact, a knowledge that permeates society. It is a knowledge which stretches across all institutions in society, from the prison to the hospital, from the school to the barracks. It is here for all society and thus a simple class analysis is hardly adequate.

Historical materialism can, claims Oliver (1990), Finkelstein (1990) and Finkelstein (1980) add to our understanding of the history of disabled people in that it can tell us what happened to people with disabilities with the onset of the industrial revolution. The basic story is that once industry left the home and moved into the factory disabled people, no longer able to physically 'fit' the machinery, suffered economic deprivation through exclusion from the production process:

> The speed of factory work, the enforced discipline, the time-keeping and production norms - all these were a highly unfavourable change from the slower, more self-determined and flexible methods of work into which many handicapped people had been integrated. (Ryan & Thomas 1980:101 in Oliver 1990:27)

Whilst Foucault would not disagree with this account per se, his work can be seen as both a continuation of, and yet a departure from, the Western Marxist tradition. If we look at Foucault's detailed account of the formation of the disciplined body, of the docile body, we see the construction of a new truth of bodies.

The history of the disabled body cannot be divorced from the history of the abled body. As McNay (1992) argues, bodies are inscribed by many formations: gender, class, race, commodity fetishism. At different times different formations may be prominent, and as such the polarity abled/disabled may not always be foremost. As disabled feminists have illustrated conceptions of the disabled body transcend and call into question the notion of a homogeneous category of women's body (see, for example, Morris, 1991; Davis, 1987; Fisher and Galler, 1988). The institutional mechanisms and technologies which act upon the abled body are not necessarily separate and different from those that act upon the disabled body. This is not to deny the different ways in which the abled and disabled body are constructed but rather to acknowledge that both abled and disabled bodies are worked upon in culturally and historically specific ways. Thus, an analysis of the disabled body needs to show not only the disciplinary techniques particular to this body, but, moreover, how it is entwined within the history of the able body, and hence, how both are connected to changes within the social domain.

Perceptions of bodies were changing throughout society, it was not just the disabled body that was being affected. The disabled body changed as a result of the changes that were taking place in the rest of society. Thus it is not adequate to look at the history of disabled people in isolation from the rest of society.

By contrasting the management of discipline in two different periods of time, namely pre-revolutionary and post-revolutionary France, Foucault is able to define two distinct penal styles and thereby highlight how punishment changed from being "an art of unbearable sensation ... [to being] an economy of suspended rights". (Foucault 1977:11) The initial contrast that Foucault makes is between the treatment afforded to Damiens, the regicide who had attempted to kill Louis XV, and with a time-table of a young persons prison some eighty years later. The first is a fearful description of Damiens execution. The punishment was visited upon the body. It was a physical, mutilating torture:

> ...the flesh shall be torn from his breasts, arms, thighs and calves with red-hot pincers, his right hand, holding the knife with which he committed the said patricide, burnt with sulphur, and, on those places where the flesh shall be torn away, poured molten lead, boiling oil, burning resin, wax and sulphur melted together and then his body drawn and quartered by four horses and his limbs and body consumed by fire, reduced to ashes and his ashes thrown to the winds... (Foucault *1977:3)*

This was by no means a gratuitous assault upon the body. This was a carefully calculated, measured and modulated system of punishment.

Peculiar to this system of punishment was the fact that this treatment was spectacularly public. It was performed on stages, before large audiences. There was no sense of punishment being carried out quietly, in dungeons, underground cells or secret police head-quarters. Furthermore during these days of the ancien regime, the sovereign was regarded as being semi-divine. Hence these attacks on the body were in the nature of being the sovereign's revenge. Crimes that were committed were regarded as crimes committed against the king. All crime was treason, and therefore the king had to take his revenge. The public executioner and the officials present at an execution were the king's representatives, and as such exercised the king's power.

It is clear then, that the suplice is a symbolic punishment, a show put on by the king, for the people. Its aim is to display to all, the sovereigns power and right to power and hence instil, in the people, conformity.

This system of punishment is contrasted with the rules drawn up by Leon Faucher, "for the house of young prisoners in Paris". (Foucault 1977:6) This time table, written less than one hundred years later details the movements of the offender throughout one day. For example:

> Art.18. Rising. At the first drum-roll, the prisoner must rise and dress in silence, as the supervisor opens the cell doors. At the second drum-roll they must be dressed and make their beds. At the third, they must line up and proceed to the chapel for morning prayer. There is a five minute interval between each drum-roll.

And:

> Art.20. Work. At a quarter to six in the summer, a quarter to seven in winter the prisoners go down into the courtyard where they must wash their hands and faces, and receive their first ration of bread. Immediately afterwards they form into work teams and go off to work, which must begin at six in the summer and seven in the winter. (Foucault 1977:6)

The type of crime and the criminal in each instance is different, yet the two stand as representatives of two distinct penal styles. Foucault extracts the premises which inform each style and thereby demonstrates that to merely regard one as barbarous, inhuman, perversive, and the other as progressive and humanitarian is not a valid understanding of the change in penal styles.

Now this concern with time-tables was not restricted to the prison. The time-table becomes a critical mechanism of control in many aspects of life. A detailed time-table which controls time, space, and movement. This was seen for example in the army, which had previously been a motley collection of men, now becomes transformed in to a well oiled, disciplined machine. The idea was to "be rid of the peasant" and to gain a man with "the air of a soldier". (Foucault 1977:135) The late eighteenth century saw the soldier as something that could be constructed:

> ...out of a formless clay, an inapt body...posture is gradually corrected...recruits became accustomed to holding their heads high and erect, to standing upright, without bending the back, to sticking out the belly, throwing out the chest and throwing back the shoulders...likewise, they will be taught never to fix their eyes on the ground, but to look straight at those they pass...to remain motionless until the order is given without moving the head, the hands or the feet...lastly to march with a bold step, with knee and ham taut, on the points of the feet, which should face outwards. (Foucault 1977:135/6)

Barracks were constructed to enclose the army, to create "a protected place of disciplinary monotony". (Foucault 1977:141)

We see it too in secondary schools, where the monastic model was gradually imposed and where the boarding school appeared as the most efficient educational regime. Education was seen as a "learning machine" for "supervising, hierarchizing, rewarding". (Foucault 1977:147) No longer were classrooms scenes of undifferentiated masses; now pupils were classified, separated, and assigned different spaces. There were correct ways to sit, to walk, to speak, to hold ones pen etc. As Foucault showed in the case of the army, here too in education, the body was being disciplined, coerced, manipulated.

The division of time, space and movement was seen very clearly in the factories which appeared at the end of the eighteenth century. For the first time people were told where their position was, how to stand, what their body was to do. Clearly this affected all people, not just people with disabilities.

The hospital also reflected this new concern. Rochefort, a naval hospital, was both an experimental hospital and a model. In order to deal with the large number of goods, sailors, diseases, and epidemics that circulated in this port, the hospital had to act as a filter, a mechanism that partitions, separates, compartmentalises. The medical supervision of diseases and contagions is inseparable from a whole array of other controls. These include:

> The military control over deserters, fiscal control over commodities, administrative control over remedies, rations, disappearances, cures, deaths, simulations. (Foucault 1977:144)

Obviously this demanded the rigorous distribution and partitioning of space. At first it was the medicines which were kept under lock and key and their use supervised. But gradually the disciplinary techniques took hold of the patients, recording their number, which regiments they belonged to. Then came the assignation of specific beds in specific wards, the patients movements were curtailed, and later still, came the isolation of contagious people.

> Gradually, an administrative and political space was articulated upon a therapeutic space; it tended to individualize bodies, diseases, symptoms, lives and deaths; it constitutes a real table of juxtaposed and carefully distinct singularities. Out of discipline a medically useful space was born. (Foucault 1977:144)

The medical model of disability, which, in the West has had the most influence over our thinking and practice towards disability and illness, was born out of this disciplinary technique. A technique which relies upon social practices which categorize, compartmentalize, hieracize. The medical model of disability is a mechanism by which disciplinary techniques create the disabled subject.[2]

During the Classical age then, the body is discovered as an object and target of power. As we have seen it can be trained, coerced, manipulated. Yet, equally we have seen that this was not the first time that the body had been the object of commands, of rules, of power. On the contrary, the body in all societies

> was in the grip of very strict powers, which imposed on it constraints, prohibitions or obligations. (Foucault 1977:136)

However what we see happening for the first time is the inception of a system of discipline that acts upon the body:

> The human body was entering a machinery of power that explores it, breaks it down and rearranges it. A 'political anatomy', which was also a mechanism of power, was being born. (Foucault 1977:138)

There are a number of points that differentiate these disciplinary techniques from earlier power mechanisms. Firstly there was the scope of the control. The active body was worked upon in an infinitesimal number of ways. Movements, gestures, attitudes were coerced and manipulated at the individual level. Secondly there was the object of the control. This was no longer at the level of signification or language, now the object of the control was that of economy, of efficiency of movement. Third is modality. This implies a constant mechanism of power, a technique of supervising the action as opposed to the result. It operates by a careful partitioning of time, space and movement.

These new methods which, as Foucault makes clear:

> ...made possible the meticulous control of the operations of the body, which

> assured the constant subjection of its forces and imposed upon them a relation of docility-utility, might be called disciplines. (Foucault 1977:137)

The growth of these disciplinary methods was not a sudden, swift change, but rather

> ...a multiplicity of often minor processes, of different origin and scattered location, which overlap, repeat, or imitate one another, distinguish themselves from one another according to their domain of application, converge and gradually produce the blueprint of a general method. (Foucault 1977:138)

Foucault assembles his theory of the growth of a disciplinary society, from what at first appears to be merely the juxtaposition of a series and set of details. However, it is from this detail, this catalogue of minor particulars concerning time, space, hierarchy, evaluation, observation, normalization that Foucault persuades his reader that not only is "discipline a political anatomy of detail," (Foucault 1977:139) but that it is only through

> a meticulous observation of detail, and at the same time a political awareness of these small things, for the control and use of men, emerge through the classical age bearing with them a whole set of techniques, a whole corpus of methods and knowledge, descriptions, plans and data. And from such trifles, no doubt, the man of modern humanism was born. (Foucault 1977:141)

Disciplinary practices were used then, not only to punish but also to reform. The purpose of such practices was to produce a new, useful individual, one who is subjected to discipline and whose capacities could be utilized as labour power. Whilst these disciplinary techniques were aimed at the soul, they operated upon the body. The goal was to instil self control within that body and thereby in the soul as well. These practices both objectify the individual - knowledge is produced of that individual upon which power can direct its operations - and subjectifies the individual - in that they have the necessary in built controls over the body and the self. As Foucault puts it:

> Thus discipline produces subjected and practised bodies, 'docile' bodies. Discipline increases the forces of the body (in economic terms of utility) and diminishes these same forces (in political terms of obedience). In short, it dissociates power from the body; on the one hand, it turns it into an 'aptitude', a 'capacity', which it seeks to increase; on the other hand, it reverses the course of the energy, the power that might result from it, and turns it in to a relation of strict subjection. (Foucault 1977:138)

1:2. THE RISE OF THE CALCULABLE INDIVIDUAL

It is clear then that Foucault does not see power as necessarily a destructive and negative force. Power produces. And power relations produce the individual:

> In fact, it is already one of the prime effects of power that certain bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals. The individual, that is, vis-a-vis of power; it is I believe, one of its prime effects. The individual is an effect of power, and at the same time, or precisely to the extent to which it is that effect, it is the element of its articulation. The individual which power has constituted is at the same time its vehicle. (Foucault 1980:98)

Thus it is the strategies and techniques of power relations which produce the human body and turn it in to a given social subject. To further exemplify this Foucault documents the manner in which the production of the subject takes place in the prison. Here the prisoner is forced to internalise the rules and regulations and to act accordingly for she can never be certain if she is being watched. She must therefore assume that she is always under surveillance and it must become second nature to act accordingly. As Burkitt puts it:

> A different individual is being produced here according to the dictates of power and knowledge. (Burkitt 1991:94)

Rather than being triumphant, excessive or omnipotent this power is suspicious, modest and calculating. It operates through hierarchical observation and normalising judgement. Disciplinary power relies on a continuous form of surveillance to become an integrated system, a multiple, automatic, anonymous power, which, whilst it rests on individuals it functions as a network, a piece of machinery.

"In discipline," writes Foucault, "Punishment is only one element of a double system: gratification-punishment." (Foucault 1977:180) All behaviour can be judged in terms of good and bad works. Moreover a penal accountancy "constantly brought up to date, makes it possible to obtain the punitive balance-sheet of each individual." (Foucault 1977:180) This balance-sheet can be contrasted and compared to other balance-sheets and thus the disciplinary apparatuses hierarchies the 'good' and the 'bad' subjects in relation to one another:

> Through this micro-economy of a perpetual penalty operates a differentiation that is not one of acts, but of individuals themselves, of their nature, their potentialities, their level or their value. By assessing acts with precision, discipline judges individuals 'in truth'; the penalty that it implements is integrated in to the cycle of knowledge of individuals. (Foucault 1977:181)

It is by way of this knowledge of individuals that discipline exercises a normalising judgement.

The consequences of a normalizing judgement are complex.

> It proceeds from an initial premise of formal equality among individuals. This leads to an initial homogeneity from which the norm of conformity is drawn. But once the apparatus is put in motion, there is a finer and finer differentiation and individuation, which objectively separates and ranks individuals. (Dreyfus and Rabinow 1982:158)

The single technique which combines surveillance and normalizing judgement is that of examination. In the disciplinary mechanisms we find that in all cases the examination is highly ritualised: "For in this slender technique are to be found a whole domain of knowledge, a whole type of power." (Foucault 1977:185)

The hospitals of the eighteenth century witnessed the demise of the irregular, rapid inspection and saw in its place the rise of the highly ritualized, routinized observation that placed the patient under constant surveillance, and endless examination. This happened as a result of the knowledge the physician sought, and the method he employed in order to get that knowledge. Gradually the nature of a hospital shifted, from being more or less a poor house, to accommodating the physicians rounds and examinations in his quest for a particular knowledge. The hospital, as a mechanism of discipline became the physical counterpart of medical discipline.

Equally in educational institutions and in the army the examination was being established as a mechanism of power/knowledge. So, for example Foucault writes:

> The examination did not simply mark the end of an apprenticeship; it was one of its permanent factors; it was woven in to it through a constantly repeated ritual of power. (Foucault 1977:186)

The examination enabled the teacher to transmit his knowledge to the students but it also served to give the teacher knowledge of his students which was not shared with them. Just as Foucault demonstrated how, in the case of the hospital, the examination allowed for the "epistemological 'thaw' of medicine", (Foucault 1977:187) here too in the school he shows how the examination allowed for a pedagogy that functions as a science. In the army the development of a vast tactical knowledge was influenced by the examination.

The examination set in to being a mechanism that combined a specific type of knowledge to a certain form of the exercise of power. This has important implications for our present understanding and perception of disability.

"The examination", writes Foucault, "transformed the economy of visibility into the exercise of power." (Foucault 1977:187) Disciplinary power is, as we have already noted, not the ostentatious, brilliant display of sovereign power, but rather now it has become invisible. That is to say that where once those upon whom power was directed remained in the shadows, now they become visible. It is the disciplinary power that holds subjects in its gaze; in a compulsory visibility. The examination is the technique by which power is able to imprison subjects in a mechanism of objectification.

> In this space of domination, disciplinary power manifests its potency, essentially, by arranging objects. The examination, is, as it were, the ceremony of this objectification. (Foucault 1977:187)

A second consequence of the interplay between disciplinary techniques and a normalizing gaze is the introduction, by the examination, of individuality in to the field of documentation.

The accumulation of documents, the seriation, the organization of comparative fields made it possible to classify, to categorize, to determine averages, and to fix norms. The individual becomes describable, an analyzable, calculable object. Consequently the individual becomes knowable in her individuality. At the same time the constitution of a comparable system made possible the measurement of overall phenomena, so that individual distribution in a given population could be assessed.

A society in which individuals become 'cases' is constructed. These cases become both objects for knowledge and sites for the exercise of power. Individuals are judged, measured, and compared with others in their individuality. They are trained, corrected, classified, normalized and/or excluded. For the first time writing serves a new technique of power. No longer a procedure of heroicization, writing now functions as a procedure of objectification and subjection. Previously, in the days of the ancien regime individuality was marked by rituals, written accounts, ceremonies, by extravagance and ostentation - the more power and privilege one possessed the more one was marked with individuality. This was what Foucault calls "an ascending individualization". In contrast, the disciplinary regime has "descending individualization":

> ...as power becomes more anonymous and more functional, those on whom it is exercised tend to be more strongly individualized; it is exercised by surveillance rather than ceremonies, by observation rather than commemorative accounts, by comparative measures that have the 'norm' as reference rather than genealogies giving ancestors as points of reference; by 'gaps' rather than by deeds. (Foucault 1977:193)

In a disciplinary system a child is more individualised than an adult, a patient more than a healthy person, a mad person more than a sane person, a disabled person more than an able bodied person. Individualizing mechanisms are focused on the child, the patient, on a mad person and on a disabled person rather than on the 'normal' healthy adult. It is this historical reversal of the procedures of individualization which is, according to Foucault, responsible for the origin of the sciences, analyses or practices which employ the root 'psycho-'.

> The moment that saw the transition from historico-ritual mechanisms for the formation of individuality to the scientifico-disciplinary mechanisms, when the normal took over from the ancestral and measurement from status, thus substituting for the individuality of the memorable man that of the calculable man, that moment when the sciences of man became possible is the moment when a new technology of power and a new political anatomy of the body were implemented. (Foucault 1977:193)

It was pointed out earlier that Foucault would not deny that the onset of the Industrial Revolution resulted in economic and social deprivation for certain groups in society. It is clear, however, that the inception of our disciplinary society, and not just the Industrial Revolution had far reaching ramifications for all members of society, including disabled people.

The birth of the social sciences signalled a new mode of objectification through which power and knowledge create the subject. It is these social sciences which produce realities and thus the subjects of which they speak.

In *Discipline and Punish*, (1977) as in *The History of Sexuality, Vol 1* (1979) Foucault examines the ways that different regimes of domination are legitimised through the arbitrary and violent constructions of the body.

As soon as a person is registered as blind, for example, information is gathered concerning this individual. The disabled person becomes a 'case' not only for doctors and the medical profession, but also for social workers, counsellors and voluntary organizations.

The gradual disciplining of European societies, since the eighteenth century, has not resulted in the members of these societies becoming increasingly obedient, but rather what has happened is that there has been an ever growing expansion in the invigilating process of adjustment. A process which has become more and more rational and economic. It is this process which has set the agenda for our perception of disability today.

Having concentrated so far upon how a Foucaultian perspective might account for our present understanding of disability, I now want to focus on some of the difficulties within such an outlook.

2. REFLECTIONS ON THE VALUE OF FOUCAULT'S ARGUMENT FOR DISABILITY THEORISTS.

2:1. DOCILE BODIES.

Certain feminists, such as Lois McNay (1992), Judith Butler (1990), Caroline Ramazanoglu (1993), have criticised Foucault for his notion of docile bodies, for, as they rightly say, women do not meekly adopt their passive and socially prescribed feminine roles. Thus, for many individuals, be they women, black people or homosexual people, the reduction of individuality to docile bodies is not only an inadequate account of individuality, but also negates the changes and freedoms that some oppressed groups have fought for and gained in modern society.

Equally it does not necessarily follow that disabled people experience their lives as 'docile bodies'. If this were true then there would be no room for resistance, no call for change, and disabled people would simply accept their inferior, subjugated position.

Beth clearly does not experience herself as a docile, passive body on which power is exercised:

> ...there is a lot of stigma attached to being in a wheelchair. I still feel that - you know - there's this automatic assumption that you have some intellectual impairment, but I think this is gradually breaking down, and I deliberately try and present a more positive image. I have a sporty wheelchair, it's red and black, so it's completely different to the National Health chairs, I try and wear colourful modern clothes and that sort of thing. So hopefully it dispels that kind of myth. (Beth:211/2)

She continues:

> I've tended to preempt people and over compensate for the embarrassment. You know I try to be more out going and assertive and speak first and that sort of thing - try to make people easy. (Beth:212)

And when she first returned to college as a wheelchair user she says:

> I had to sell myself if you know what I mean, to make myself look...em what's the word...well acceptable I guess. (Beth:213)

Equally Hilary hardly experiences her life as a passive, docile body over which she has no control:

> You've got to work at you. I mean you have to move your hands and I did exercises just moving the fingers and wiggling them around and that type of thing. Bending the arm and wiggling the toes up and down for the muscle, things like that. Swimming is the best thing you can do for it as well, if you can get in once or twice a week. Just keep going as long as you possibly can and everything. (Hilary:112)

Nor is Alex fulfilling the passive, prescribed role as one of The Disabled when he comments:

> It seemed to me that the thing to do was to continue in my studies and prove that I am still quite capable despite the fact that, you know, I've got a range of disabilities. I still wouldn't put it on my C.V.. that I've had a stroke, cos there's a lot of people who just wouldn't give you an interview. But if I get into a situation where I can be interviewed then I can make it quite clear. (Alex:148)

And Brad does not sound like someone upon whom power is exercised, leaving him with no sense of freedom of action:

> I like it to not stop me doing things, you know. I don't really want to go

> climbing Mount Everest but I do active sports like I have always and would have normally done. I've tried scuba diving and parachuting that sort of thing. So I like to do what's possible but I don't have any burning ambition to prove anything. If I want to do something I try to find a way to do it. There are things that you can't do, it is a limitation, but if there is an opportunity and you want to do it then you try and you sort of work around it. (Brad:171)

Indeed the interviews are full of examples of the ways in which disabled people resist the normalising powers which, according to Foucault would have us all acting solely as docile and inert bodies.

Foucault's conception of the body as a passive entity upon which power stamps its own image is clearly problematic. It results in a one-dimensional account of identity. In disability theory the recent emphasis has been on the discovery, revaluation and valorization of disabled people's own experiences. The disability movement is increasingly becoming more politicised and calls are being made for disability to be present on all civil rights agendas. For example, Disabled People's Direct Action Network (DAN) campaigns ceaselessly for our equality.

This would appear to run contrary to Foucault's notion of docile bodies.

And yet, to hear the interviewee's voices simply as acts of resistance to social practices is open to question.

It can be argued that disabled people, like Beth, who attempt to be as 'normal' as possible are in fact 'docile bodies'. They are often only too aware of the system of values they are reacting to and, it can be maintained, perpetuating. When Steven says:

> I try to distance myself away from it [his disability] as much as I can...if there is a disabled programme on television I won't watch it. I mean I make a conscious effort not to watch it. Just because I want to keep myself as normal as I can, (Steven:254)

and equally when he says:

> I try not to know other people in wheelchairs...I think if you hang around people in wheelchairs people think 'Oh here comes a clan of them together!' I try to keep away from what the others were like [in the spinal injuries unit] you know. A lot of them used to go to the pub together all the time and I just try to keep my distance from the whole situation really. (Steven:252)

Steven is reproducing 'voluntarily', through self-normalization and self-surveillance the disablist practices of our culture.

Steven is by no means alone in this. Many of the interviewees expressed similar views:

> I don't like self-help groups or things like that. I don't want to go where other people are blind. I don't want to be classed as a blind person, and everyone sat round with their dogs and their white sticks in a semi-circle talking about their experiences. [...] And I thought it would be all doom and gloom to talk to one of these groups. (Kay:284)

In Foucault's model then, Steven and many disabled people who reject other disabled people and who attempt to subvert dominant cultural norms are acting as docile bodies. But this overlooks the experiential reality of the situation. Social practices which train the body in docility and conformity to normative standards and cultural dictates are at the same time *experienced* in terms of power and control. (Bordo 1985, 1993)

By 'distancing' himself from other disabled people, and from "the whole situation" Steven feels less disabled, more empowered. Beth and Rachel's choice to have "sporty wheelchairs", and to wear "colourful modern clothes", makes them feel good about themselves; they are "dispelling the myth" - the stereotypical dowdy image of disabled people. Kay's insistence that blind people are "all old and wear crimpolene", and that she has nothing in common with "The Blind", I would argue, empowers her at an individual level. Indeed Rachel is fully aware of why she avoids the company of other wheelchair users:

> I don't like being in a big group of wheelchair users. [...] But it is just the fact that everybody stares at us, it is more of a focus for people's attention. (Rachel:208)

These instances then are experienced by the individuals as resistance to prevailing social practices. Whether they are interpreted by others as such is another matter.

Moreover when disabled people feel powerful, feel good about themselves, this does not necessarily indicate a true reflection of their position in society. As Bordo (1993) writes:

> ...the bodily experience of feeling powerful, or 'in control', far from being a necessarily accurate reflection of ones actual social position, is always suspect as itself the product of power relations whose shape may be very different. (Bordo 1993:192)

Bordo is concerned about the situation of women, but this point is extremely relevant for disability researchers.

It should also be remembered that docility itself, can be empowering. By this I mean that responding to cultural norms, in some instances, can lead to acts of resistance. So, for example, disabled people often learn to be competent at managing potentially difficult social situations. As Frank remarks:

> I suppose being in a wheelchair has made me a lot more socially adept because the onus is on me to fight people's preconceptions and people are frightened if somebody is different, whether they are blind or in a wheelchair or got any physical deformity. So I've had to, in a sense I've had to...I'm a much more confident person. The onus is on me to make people accept me and make people feel comfortable with me.
> (Frank:166)

For Frank then, the disablist social practices that make him appear as 'other', that construct him as 'less than human', at the same time empower him. Frank is reacting to disablist social practices and paradoxically gains strength from them in order to resist them. We can witness this process in other people's experiences. Beth, for example says:

> When I compare myself to other people of my age I think [...] I have become a lot more active now than if I hadn't had my accident [...] But, yes, I think I'm a much stronger person after my accident. I mean I have come into contact with a lot of people and situations that have boosted my confidence and I feel that I am a lot older for my age. (Beth:217)

Equally David says: "I think I am more confident than I used to be when I was sighted" (David:5), while Eddy says that for him, being in a wheelchair means that he is altogether better qualified to be a minister for other disabled people because an able-bodied person can never understand the frustrations of being disabled.

Foucault insists on the cultural and historical specificity of bodies. This insight provides disability theorists with the means to write the history of the disabled body, a history which documents the 'grip' of systematic power on the body. Yet he then goes on to emphasise the way in which bodies can resist this grip. Resistance can occur at any point where power is exercised, and as such reinforces the unstable nature of subjectivity and the precariousness of hegemony.

However, as I have already shown, resistance is not a simple, uncomplicated matter. The next section will examine how resistance can be rendered invalid.

2:2. THE NEUTRALIZATION OF RESISTANCE

At times power can call upon the resistant forces to serve its own ends. This becomes evident through establishing norms, by labelling and by highlighting difference. In other words Foucault's rhetoric of resistance can itself be utilized to serve normalization. We have looked briefly at the way in which disabled people's resistance can be neutralized by the prevailing doxa and I now want to examine this phenomenon in more detail.

Stephen Hawking might well appear to be an ideal role model for disabled people. Whilst a post-graduate researcher at Cambridge University Hawking developed the first signs of motor neuron disease. By 1985 Hawking, now Lucasian professor of mathematics, was a wheelchair user and spoke with the aid of a computer-driven voice synthesizer. For a profoundly disabled person to reach such lofty academic heights Hawking has clearly had to resist disablist social practices which deem so many disabled people worthless. He has had to fight for better provisions for disabled people at Cambridge University and if it were not for The Nuffield Foundation and support from an American trust, he would have been forced to abandon his career and to live in a nursing home.

In 1988 Hawking published *A Brief History of Time* - a lay persons guide to cosmology. It has had a remarkable success: with world wide sales exceeding 10 million; it has been translated into twenty-two languages; and it has featured on The Sunday Times best seller list for one hundred and eighty-six weeks, eighteen months of which was in first place. In the wake of this phenomenal success Hawking has become the focus of numerous newspaper and magazine articles and several television documentaries. But of the thousands who have bought a copy of *A Brief History of Time*, it is widely believed only a handful have gone beyond page seventeen. (The Sunday Times. 3.7.1992)

Other scientists claim this book, though well written and lucid, is not original. For example, Richard Feynman and Steven Weinburg, both respected physicists, have written on the cosmos with equal intelligibility but with considerably less success. The Observer makes the following point in regard to this:

> They, of course, lack the romance of a genius trapped in a wheelchair but still apparently able to turn mental cartwheels around the cosmos. (The Observer 12.1.92)

It is this 'romanticising' of disability which neutralises resistance. Hawking is no longer seen as a human being, he has been turned into "a caged mind" (The Observer 1992), that "explores the universe from his wheelchair" (Times 1992). Indeed Giles Smith in reviewing Errol Morris' film of *A Brief History of Time* writes:

> Philip Glass...spoke of the paradox of 'a man who didn't move, who goes on the greatest journey of all'. And in that one metaphor, sticky with sentiment, you saw what snagged the whole project: nearly everyone involved seemed to have thought they were making E.T. (Smith 1992)

And indeed Hawking has been turned into something other than human. There are numerous articles about him which are strewn with adjectives and phrases that attest to this. His "unearthly Speak and Spell voice", (the Spectator); "the extraordinary figure of Stephen Hawking sits in his wheelchair...his intellect has ranged from the edge of the cosmos to the start of time." (The Independent); "And the man who...believes his physics has dethroned God...sits crumpled like a broken doll in a wheelchair." (The Independent); "...this man exploring the heavens from his wheelchair" (The Times). And from The Observer we have, in an article entitled "Caged Mind that Roams The Universe" the following:

> Locked within the wasted limbs and wearily lolling head of Stephen Hawking lies a fundamental contradiction. His physical form maybe declining, yet his imagination seems to strengthen daily, launching him on journeys that soar further and further beyond the limits of our comprehension.
>
> Two cross-currents - one marking cerebral progress the other corporal degeneration - have coalesced in the withered frame of the world's most

> famous living scientist. (The Observer. 12.1.1992)

Equally the fact that Hawking was given two years to live, thirty years ago, is quoted extensively, again suggesting that there is something not quite human about him.

We see here then, ways in which a man has been rendered 'other'. His resistance to normalising powers has enabled him to achieve great acclaim and success, but in doing so, these same normalising powers have recreated him as a distinctively inhuman, marginalised, different species. His is the great mind, trapped within a broken body. But Hawking, it is inferred, needs no body as he exists on a cerebral plane, his mind "launching him on journeys that soar further and further *beyond the limits of our comprehension"*. He is different, he explores new frontiers where no one has gone before. Constructing Hawking as such, makes him a fascinating figure, a freak from the carnival show, and, most importantly, it makes him harmless. Harmless in the sense that he no longer challenges peoples perception of disability. He is so completely other that his resistance is unthreatening and neutralised. The normalising gaze which initially was resisted, is now restored. Hawking's difference is elaborated upon and ultimately is employed to serve normalization.

It is worth mentioning here, that the success of Stephen Hawking's book is not due solely to his 'freak' status. On the contrary it can be argued that the image of him, sitting in his wheelchair, which adorns the cover of this book, appeals to people in a way that most scientific texts (even those written for the lay person) do not. Science is widely perceived as a discipline with no human agency. Scientists are white-coated, empirical and objective. Hawking, paradoxically, puts the human element back into science.

Ultimately though, Hawking's subversion of prevailing 'truths' of disability, becomes incorporated into the main stream. The potency of his resistance is turned against him, and against all disabled people, and we are all constructed, under the normalising gaze, in the guise of E.T.

I would like to stress however, that Hawking no doubt experiences his success as personal empowerment. Equally I am not claiming that my reading of 'the Stephen Hawking phenomenon' is the only interpretation available to us. The point I am making here is that resistance is not a straight forward affair. Resistance can always be interpreted in such a way as to render it impotent, ineffectual and harmless. It is always possible to read acts of resistance in a way which supports and reaffirms the status quo.

I chose to look at the media's treatment of Stephen Hawking precisely because it is a very clear and apposite example of the neutralization of resistance. However, most people are seldom in such a bright spot-light. And yet, even so, the disabled people I interviewed give many examples of the ways in which their attempts to resist normalization are habitually neutralised. Many of the interviewees talk of the way people "talk down" to them, no matter what the disabled people say to them. As Sarah puts it:

> When people talk down to me I let them know. I talk back to them, not the way they are talking to me, but I'll talk back to them like I am letting them know that it is annoying me the way they are talking to me. I won't come out and say it directly but I let them know in my own way. I had to learn that. I mean they used to talk down at me on and on and the more they did it the more annoyed I got. I mean somebody else would say: "Oh, she talks down to us as well". I just find it worse for somebody in a wheelchair to be talked down to. Even when I was in hospital and the nurses came: "Hello Sarah, are you alright?" I'd think 'Oh go away!' And the next minute they are talking normally with somebody else. I mean if you can't talk to me normally don't talk to me at all. I mean my brothers and sisters talk to me normally...just normal like I was anybody else, they never talk down to me. (Sarah:105)

This experience of performing an everyday task is also typical:

> Now I find that I can hoover up and do a great job and then Rita comes in and does it again. The same with the washing-up. (Colin:35/6)

In a similar vein Debbie's resistance is neutralised. As a result of being 'house bound' for some years Debbie now has agoraphobia. Debbie and her husband have devised a "training programme" because:

> I felt so strongly that I wanted to help myself rather than having someone coming round and saying 'You've got to do this, this and this'. I wanted to do it gradually by myself. (Debbie:47)

Whilst Debbie is proud of the way she is learning to manage her agoraphobia, she goes on to say:

> Other people with disabilities tend to look and treat you as an equal but able-bodied people don't. Like I said, just because you are in a wheelchair they think you are mentally defective or something. And you are not. [...] They tend to treat you as if you are not there, you're invisible. Some people won't even look at you eye to eye contact, you know, they are sort of looking away all the time like they don't want to acknowledge you in a wheelchair [...] and another thing is that they

> tend to treat you like you're a five year old: 'Alright dear?' You know - that kind of thing. You know you talk to me as if...Oh God I'm a grown woman not a child. (Debbie:48)

So even whilst Debbie is trying to resist the cultural dictates that cast her as poor, helpless and dependent she is continually frustrated in her attempts and her resistance is robbed of any power.

A further way in which normals neutralize our resistance is by undermining our sense of our own normalacy. As we saw in the Stephen Hawking example, this is commonly achieved by focusing on and elaborating upon our difference. As disabled people our disabilities are not always foremost in our minds. Yet as Beth comments:

> When I am involved in sport and go down to Stoke Mandeville, I am involved with wheelchair tennis at a national level and hopefully soon on an international level, I feel quite happy. Disability isn't an issue, people I am involved with have spinal injuries, they have had an able-bodied life, you know, and a disabled life and they seem to be quite able. So, no, I don't necessarily always feel disabled or handicapped when I am there. But when I go out with my able-bodied friends I am very conscious of being disabled because it impacts on their lives. (Beth:230)

I have already noted the way in which normals intrude on our privacy as we go about our everyday business (see Chapter Three). The majority of the people I interviewed can cite instances of this personal invasion. Whilst the normals, no doubt, are acting out of a sense of charitable benevolence, for the disabled people it is often experienced as confirmation of our otherness. As Rachel explains:

> They always want to be pushing you or helping you or...it's not that I mind exactly, it's just that I don't need it. You don't go up to someone

> who is walking up the street and ask if they need help in going up a
> step. (Rachel:200)

One of the ways in which disabled people resist is by attempting to do what normals take for granted, what normals can take as their right. When we cannot even go down our local high street without having this resistance neutralised and rendered invalid we see how problematic and complex the issue of resistance really is.

Having outlined the arguments and counter arguments surrounding Foucault's notion of resistance I shall now examine his notion of productive power, and consider it's value for disability theorists.

2:3. PRODUCTIVE POWER AND THE PROBLEM OF VIOLENCE

Foucault's work differs from other revolutionary theories in many respects. He does not believe that oppression can be traced to an original well spring, such as the Marxist belief in capitalism as the cause of oppression, or the radical feminist argument that patriarchy is the origin of women's oppression. Rather Foucault's analysis of power is fundamentally opposed to overarching, universalising accounts.

There are three main features of power, which Foucault outlines. Firstly that power is not primarily repressive, quite the opposite in fact it is productive. Secondly, power is not possessed, rather it is exercised. And thirdly, power is not seen as filtering down from above, but on the contrary is analyzed as coming from the bottom up. (Sawicki 1991)

There are however, problems with Foucault's notion of power being primarily a productive and positive force.

As we have seen Foucault maintains that power constitutes the individual on whom, and through whom, it is exercised and operates. Yet, as Dews (1987) says:

> If the concept of power is to have any critical political import, there must be some principle force or entity which power 'crushes' or 'subdues', and whose release from this repression is considered desirable. (Dews 1987:162)

If this is not present, and power is conceived of in purely productive terms then, argues Dews, the analysis ceases to be one of power, and becomes simply that of examining the make-up and functioning of social systems.

Whilst Foucault asserts that:

> Power must be analyzed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organization. And not only do individuals circulate between it's threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation. (Foucault 1980:98)

his historical texts do not always depict power in this ubiquitous manner. As we have previously seen the very notion of "subjected and practised bodies, 'docile bodies'" (Foucault 1977:138) as produced through disciplinary methods, hardly suggests a heterogeneous, productive power. On the contrary Foucault in his historical analyses is portraying power as a

> centralised, monolithic force with an inexorable and repressive grip on its subjects. (McNay 1992:38)

This perspective, argue McNay (1992), and Dews (1987) has come about as a result of Foucault's unidirectional gaze. That is to say that Foucault's examination of power is one sided. In the prison it is the 'official' representation of power that Foucault centres on: it is the governor's, the architect's etc. viewpoint that we hear, those upon whom power is exercised are silenced. Thus it is, as Dews (1987) points out, no voice is given to other knowledges, such as a prison sub-culture, or inherited customs. We only hear those who instill institutional power, and do not listen to those "who lie a little beneath history" upon whom power acts. The result of this is that Foucault gives more credence to the efficacy of disciplining forms of control, than perhaps is appropriate.

Nevertheless, Foucault insists that the relationship between a productive power and resistance is strong. In an interview given in 1980 he states:

> ...as soon as there's a relation of power there's a possibility of resistance. We're never trapped by power: it's always possible to modify its hold, in determined conditions and following precise strategy. (Foucault 1980b:13)

Power can, maintains Foucault, only be exercised over 'free' subjects.

> It is a total structure of actions brought to bear upon possible actions; it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action. A set of actions upon other actions. (Foucault 1982:220)

Slavery is not then, in Foucault's definition of power, a relationship of power. The slave is not free; the action of the slave owner does not allow for possibilities of action. The relationship between slave and slave owner is one of force, of violence. In contrast to this a power relationship recognises that the one on whom power is exercised has at all times the freedom to act. Consequently when dealing with a power relationship all manner of responses, results and potentialities may be realized. This is not to say however that power relations exclude the use of violence:

> ...consensus and violence are the instruments or the results, [but] they do not constitute the principle or the basic nature of power. (Foucault 1982:220)

The exercise of power is a set of actions upon other actions. That is to say that power relations become evident when an individual or group want to influence the actions of another individual or group. As a consequence then, there is always room for resistance. Power is not to be conceived of as triumphing over resistance, for when this occurs power relations collapse in to force relations. The operation of power relations is patterned or structured but not forced.

This is not to argue that there are no dominant ideologies or social structures; an 'impersonal' view of power which claims that no one holds power does not mean that we all hold power equally. On the contrary, people and groups are positioned differently, at different times, in different locations, within power.

> No one may control the rules of the game. But not all players on the field are equal. (Bordo 1993:191)

Now the question that disability researchers need to address in order to evaluate Foucault's applicability in this area is whether or not such a conception of power is valid and useful when considering the position of disabled people today.

To conceive of power as neutral relies upon the suppression of violence. And yet violence is an instrument of power. MacCannel and Flower MacCannel (1993) identify three forms of violence which make power possible:

> 1. *Direct violence*: verbal abuse, physical brutality, rape, murder and so on, and threats thereof.
> 2. *Legal and/or bureaucratic violence*: formal filing of false accusations, arbitrary firings and evictions, insertion without due process of 'black marks' into a person's record, blacklisting and any other (ab)use of rules and regulations for the sole purpose of destroying an individuals capacity to support themselves and their dependants, maintain minimal standards of shelter and safety, protection from disease and so on.
> 3. *Administrative violence*: zealous and sadistic execution of office in such a way that it destroys the life chances and sometimes the lives of those who come in contact with the organisation. Locally thought of as 'progressive' or 'hard nosed', 'responsible' administration, it is not an abuse of the rules as in item 2 above. Rather, it is a heartless, soul-killing over-application of rules and regulations... (1993:213)

These types of violence are present in many existing forms of social arrangements. It is, claim MacCannel and Flower MacCannel (1993) violence, not the gaze, which carries power to the margins of society. Disabled people are only too familiar with these forms of violence. Direct violence can be conveyed in a look, in verbal abuse, and more recently with the rise of neo fascism in Europe, with physical attacks upon our bodies. In Germany, in the state of Lower Saxon alone, more than fifty physical attacks on disabled people were recorded in the year 1992-93. One such attack left

Bruno Kappi, a disabled person, dead. The British National Party's 'policy' document describes us as: "physical degenerates who are a burden on the state medical system." (RNC Feb.'94). One of the respondents described a violent encounter he had had with a normal prior to our interview:

> Yesterday morning I had a nasty experience. I was, sometimes on this electric machine of mine we ride on the footpath, and I was on the footpath and a youth, who is one of the town roughs, came diving out of the paper shop and ran into me. And I got a mouthful of abuse from him and I'm afraid I lost my temper with him and I said: 'You just come close enough my friend', because I always carry a walking stick on the car, on the machine, and I said: 'I'll give you a bloody good hiding'. But of course I've heard it all before and off he went sort of thing, but...er...the words he called me I'm not prepared to repeat - he called me a so and soing spastic you know, which hurt as you can well imagine. (Paul:177)

But it is not just fascist extremists who demonstrate direct violence towards us. It is evident in the way we are ignored whilst our able bodied friends are spoken to; in the looks we receive; in the assumptions that are made about us. As Colin puts it:

> The worst thing was friends, you know me and my wife would be walking down the street they would stop and chat for a while and then they would ask Rita "How's Col?" and I'm standing right there. The first couple of times it didn't really bug but after a while it got me highly annoyed. I mean I'm not Einstein but cos my eyes don't work doesn't mean to say that my brain doesn't. I think this attitude [...] people [...] never seem to realise how that actually does hurt. Lots of people seem to do it, in shops it's annoying. I think I'm invisible because they will serve the person who has come in after me. Specially if your eyes aren't really that...I mean mine aren't particularly horribly bad. So if you're standing there with something you want to purchase and they see you standing there, particularly if you have a white cane, somebody walks up behind you they will turn to them first. (Colin:29)

Coin continues by talking about the assumptions that the able-bodied make about him:

> The mere fact that you have a disability means that you have got all the time in the world, it doesn't really matter if you need serving, if you're in a hurry. (Colin:29)

Colin is by no means unique in his experience. The interviews contain many instances of direct violence that disabled people experience in our day-to-day contact with the able-bodied world.

Equally we have experience of legal and/or bureaucratic violence. I have already looked in the previous chapter at the discriminatory practices that are aimed at us in the job market and in our incomes. This is violence that reduces our life chances and renders us 'in need'.

We have only to look at Debbie's experiences to find evidence of administrative violence. Debbie has severe arthritis and on the advice of her doctor her husband gave up work to become a full time carer. That was two years ago and at the time of writing they are still battling to get attendance allowance. As Debbie puts it:

> ...but we are still having a lot of problems with that because em...trying to get through all the bureaucratic nonsense is ridiculous. That's difficult, that's another side of being disabled. Oh God! I mean trying to get attendance allowance and mobility is...well I've been fighting for it for ages now. (Debbie:55)

This has left Debbie feeling that she is a nuisance and a burden to her husband and children. In her words:

> It's getting on top of me it really is. It upsets me because it's like denying the fact that I am disabled. That makes me more depressed than anything else going on in my life. I keep saying to my husband:

> 'But they're saying there's nothing wrong with me. If there's nothing wrong with me why can't I get out of my wheelchair?' (Debbie:56)

Foucault's formulation of power ignores and negates the everyday experiences of those upon whom violence is exercised. The victims perspective is never articulated. From the viewpoint of the victim, localized power, in its myriad forms, is always backed up with the possibility of force and violence. According to MacCannel and Flower MacCannel (1993) Foucault's insightful notion of 'capillary' power operating throughout the body politic should be concomitant with a notion of 'capillary violence'.

> Power did not leave forceful threat and the actual use of violence behind as it moved to the margins. Wheresoever power is found, violence is sure to be. Wheresoever resistance to power is encountered, force will be applied. Threats, or actual application of direct, legal or administrative violence back up all power. (MacCannel & Flower MacCannel 1993:212)

Foucault's conception of power suggests that there is a historical decline in physical violence. Yet for disabled people, at least, this does not appear to be the case. In addition to the three types of violence that MacCannel and Flower MacCannel (1993) identify I would like to add a fourth category: that of medical violence. By this I mean the violence that many disabled people have done to them by the medical profession in the name of medical science. The 'treatment' that is designed to make us appear as 'normal' as we possibly can, is often extremely painful, both psychologically and physically, and the results can be negligible. Moreover, some of these treatments, which we are told will benefit us, are carried out purely for the interests of science, with little thought of the consequences they might have for the patient. A case which appositely illustrates both these aspects of medical violence is that of Philip Olds, a policeman who was shot and left paralysed from the waist down.

For six years, between 1980 and 1986, P.C.Olds was Britain's most famous disabled person. From the outset of his paralysis the press followed his story with all the ferocity of a pack of wolves. It had all the major ingredients for media attention: a police officer, armed only with his baton, shot down in the line of duty, whilst protecting others. He became a police hero, and was decorated by the Queen. Unlike other police officers who become disabled he was not pensioned off, but was given a desk job. By all accounts Philip Olds thrived on the attention he was receiving and counted the reporters as his friends. A documentary was made, produced by Desmond Wilcox, in which his wheelchair is portrayed as the enemy, as his prison and, as Olds says: "It [his wheelchair] was worse than death". The major theme of *The Visit* was Olds' struggle to walk again. The visit refers to his stay at Right State University, Ohio, where 'pioneering' work was being carried out by Dr. Jerry Petrofsky. Petrofsky was a bio-medical engineer and computer expert. In an experimental research programme he was using paralysed people as guinea pigs in an attempt to give movement to dead limbs and life to wasted muscle.

Olds' visit to America was paid for by The Daily Mail. This meant that Olds was under tremendous pressure to be a success, to walk again. Indeed he told The Daily Mail readers shortly before he left for America that he was going to come home walking: "I know I will bloody well walk again. I know I will do it." It was never explained to Olds just how young this experimental programme was, nor what to expect from it. Talking of their time in Ohio, several years later, his girl friend, Vanessa Perkins says:

> It was a research project and we thought it was going to be a bit further down the road than it actually was. And we thought walking with the electronics wouldn't be quite so crude. (Altered States BBC2 July 1992)

They both believed that Olds would be able to strap on the equipment and walk as before the shooting. This was painfully untrue. But Philip Olds struggle to walk had become a newspaper crusade. The Daily Mail made his first 'walk' headline news, and showed a picture of him, standing in police uniform, with a discarded wheelchair upturned in a ditch at his side. Words such as "courage" and "miracle" abounded. In reality Olds was strapped into heavy boots, callipers and electronic pads were attached to his legs. Wires seemed to be going in all directions. With the help of the research team and supporting himself on parallel bars, Olds was able to make a few painful and poignant steps. Whilst this was being heralded as a "breakthrough for people in wheelchairs" by the newspapers and media, Philip Olds was gradually realising that his disability was for life and that there was no miracle cure on offer. On the first of October 1986 Olds took a fatal overdose of painkillers and alcohol.

Philip Olds was the victim of the press and equally of medical research and science. He was thoughtlessly and cruelly used by both. The promise of walking that was held out to Olds, with little thought of any psychological harm, ultimately killed him. This admittedly was an extreme case, but many of the interviewees spoke of pointless operations they had undergone, and my own experience of the medical profession backs up this notion of violence done to us in the name of science. I underwent several extremely painful operations on my right eye, believing this would result in my sight being restored. After six such operations it was declared that they were successful, but I still have no sight in that eye. The operations were a 'success' in their terms, in terms of scientific research.

This is not to argue that all medical research into various disabilities is negative. Of course medical knowledge has benefited many disabled people. However it is important not to overlook the notion that medical technology and research is a disciplinary mechanism - an instrument of power.

A further consequence of the manipulation of Philip Olds by The Daily Mail and other media coverage and by the medical profession is less direct but equally violent. Portraying disability as an individual tragic event is harmful to other disabled people. By concentrating on individual cases like this, other, more urgent and liberating issues, such as demanding civil rights for disabled people, remain ignored.

In addition, the power of the medical model of disability is further consolidated by such media and medical treatment. A recurrent theme in the interviews is the respondents dream of a "medical breakthrough". Time and time again we here comments such as this from Sarah:

> My hope is to get back on my feet, to get walking again, to get back to normal. (Sarah:99)

And from Brad:

> It didn't really drive home, I don't think until I was home. You can't

> really understand because you think there will be a medical breakthrough in the next couple of years and it will be all sorted out. (Brad:170)

Rachel says:

> Medically it is better for me to walk and I always keep that in my mind. The more I walk and the more I do it then if there is ever a cure, which isn't completely impossible these days, if I haven't been walking I can't because my bones would just collapse if I stood up, so I've got to keep walking for that. (Rachel:195)

And another respondent comments:

> And I said: 'Is there any chance in the future...will they be able to do anything for retina people?' And he said: 'When we can do brain transplants, yes.' So I took that, well, it's not around the corner...when they can do brain transplants. So I took it...well. I don't know how to take that. I'd like to think that yes one day they will be able to do brain transplants. (Kay:298)

By focusing on individual cases and holding out the promise of medical break throughs the medical model of disability is further perpetuated and the oppression associated with this model remains solid and uncontested.

Seldom do any of the disabled people I interviewed talk of social equality being achieved other than in terms of cure for the medical problem.

Violence, be it direct, administrative, bureaucratic, legal and/or medical is experienced by disabled people. It is violence, or threats thereof, which reinforces power. Foucault does not acknowledge the importance of violence in determining the subjectivity of those upon whom it is directed.

3. CONCLUDING REMARKS

In rejecting the idea that power is primarily negative, Foucault is able to outline the complex network of disciplinary systems and prescriptive technologies through which power operates, particularly since the normalizing disciplines of medicine, education and psychology have gained authority. He demonstrates how disciplinary power operates at the local and immediate level rather than focusing on the supreme power of the state. Foucault is useful to us because he shows how disciplinary power forms through localized mechanisms of surveillance, regulation and classification, historical and cultural practices which constitute distinct forms of subjectivity.

This is crucial to an understanding of our present day perceptions of disability and disabled people, and must be acknowledged if we want to examine resistance.

Using a Foucauldian model to explore disability allows us to see how the body is produced through power and is, therefore a cultural rather than a natural entity. In identifying the body as the site of power, Foucault demonstrates how docility is accomplished and subjectivity constituted.

However a Foucauldian critique is not without its limitations. By emphasizing the effects of power in producing a disabled body, Foucault reduces social agents to docile, passive bodies. This has been criticised by many academics (McNay 1992, Butler 1990) as they claim it does not allow for any sense of agency or autonomy. Whilst acknowledging this as important and relevant I would like to emphasize the point that Foucault's model is useful in an analysis of disability and disabled people because so much of our subordination is produced through everyday practices of self-surveillance and self-normalization. This results in many instances of disabled people experiencing docility and conformity in terms of power and control.

I am not suggesting that disabled people consciously collude in our own subordination, but rather that we may experience a feeling of power whilst actually acting as docile bodies. That is to say that we might, on an individual level, feel empowered and potent, but it is our very docility to cultural norms which can give us this impression.

Foucault maintains that wheresoever there is power then there is the possibility of resistance. Whilst agreeing with this I think it is important to remember that resistance can itself become incorporated into the dominant discourse which defines the disabled subject. It is in this way that resistance can be robbed of its power and thereby become neutralized. This does not mean that there is no such thing as resistance, but rather what might be an act of resistance for the performer is not necessarily read as such by the audience.

Central to Foucault's work is an assumption that power is neutral. Yet violence as an instrument of power is not neutral. Disabled people are only too familiar with certain forms of violence which serve to augment power. By not giving a voice to those of us upon whom violence is exercised, Foucault is, in effect, denying an important aspect of disabled people's subjectivity.

Whilst Foucault can provide valuable insights in to an analysis of disability, we should remain circumspect in our use of him. However his methodology remains highly relevant for disability researchers; of particular interest is his theory of the subject.

It is for this reason that in the next chapter I shall turn to Foucault's later works. For it is in these texts that Foucault not only addresses some of the problems identified in his work in this chapter, and in particular his treatment of agency and autonomy, but now he turns his attention explicitly to the formation of the modern subject.

1. Foucault (1980:115) argues that power has traditionally been understood in one of two ways. The first understands power in terms of law and conceives its exercise in judicial terms of constitution and sovereignty. In general this type of analysis is politically to the right and found expression amongst early forms of political theory, such as Hobbes's theory of the state. The second analysis of power was largely inspired by Marx and understood the working of power through state apparatus and its ideological 'representations'. Foucault demonstrates that whilst there are surface differences between these two modes of analysing power, they share a fundamental similarity. Namely that both the sovereign and the subject exist prior to the exercise of power. Foucault terms these two forms of conceptualising power "juridico-discursive" thus reinforcing the similarity of this conception. Indeed he writes:

> Whether one attributes to it the form of the prince who formulates rights, of the father who forbids, of the censor who enforces silence, or of the master who states the law, in any case one who schematizes power in a juridical form, and one defines its effects as obedience. Confronted by a power that is law, the subject who is constituted as subject - who is 'subjected' - is he who obeys. To the formal homogeneity of power in these various instances corresponds the general form of submission in the one who is constrained by it - whether the individual in question is the subject opposite the monarch, the citizen opposite the state, the child opposite the parent, or the disciple opposite the master. A legislative power on one side, and an obedient subject on the other. (Foucault 1979:85)

2. For a fuller discussion of how medical knowledge both describes and constructs the body as an invariate biological reality see Armstrong 1983.

CHAPTER SIX

THE CARE OF SELF

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Abstract: *This chapter opens with an overview of Foucault's later works. In the second and third volumes of his trilogy: "The History of Sexuality" Foucault shifts his emphasis from being an enquiry into the historical conditions which make various types of quite specific and differentiated subjects possible, and turns now to an ethical enquiry centred not so much on the control of the subject by the external 'other' as on the internal relation of the self to the self. However, it is clear that these later works remain concerned with problems and forms of control. Foucault makes a clear distinction between the "californian self" and self-stylization. And, as I argue in this chapter, it is when we look at notions of self-elaboration and technologies of the self that we can begin to question the limits which have been placed on subjectivity. It is only by doing this that we can expose new domains to the ever-present possibilities of resistance. The second section of this chapter explores the implications of this work for disability theorists. I argue that a questioning of the boundaries of subjectivity is of crucial importance to us, and yet we must also be aware of the problems inherent to this work. Whilst I highlight some major deficiencies and difficulties with this work I conclude that it has immense possibilities in terms of resisting cultural dictates, on an individual and immediate level.*

INTRODUCTION

In this chapter I am going to critique Foucault's later works - principally *The Use Of Pleasure* (1985) and *The Care of Self* (1986), volumes two and three in his study of the history of sexuality. My aim is to see whether or not Foucault's notion of an 'ethics of self' can provide us with an alternative approach to the concepts of power and resistance. To this end I shall begin with a brief overview of his latter works and interviews and then go on to consider any implications his work has for us.

In 1982, when responding to the question 'Why study power?' Foucault says that it is not power per se which he is interested in, but rather his objective has always been

> ...to create a history of the different modes, by which, in our culture, human beings are made subjects. (Foucault 1982:208)

As we have seen in the previous chapter, in Foucault's earlier works this has been illustrated by modes of enquiry which "give themselves the status of sciences" (Foucault 1982:208). This can be seen, for example, in linguistics where the speaking subject is objectivized, or again in biology where the living subject becomes objectivized. The second mode explored by Foucault is that of the objectification of the subject by 'dividing practices'. By this Foucault means the subject is either divided inside herself or divided from others, as in the mad and the sane, or the abled and the disabled. And finally in what was sadly to become his last work Foucault turned his attention to examining the ways in which human beings turn themselves in to subjects. It is this last mode that I am particularly interested in in this chapter.

In these latter works Foucault shifts his focus from the body and redirects it to the self. This does not, as some critics maintain (see O'Farrell 1989; Ferry & Renaut 1990) signify Foucault's rejection of his earlier works, but rather Foucault now acknowledges the limitations of these texts, and hence develops his notion of practices of the self in order to overcome such shortcomings. That is to say that Foucault recognised the importance of counterbalancing techniques of domination with an analysis of techniques of the self. Moreover, it is clear that his ideas developed in works such as *Discipline and Punish* (1977) inform much of his later concepts.

In the preceeding chapter I have argued that understanding the rise of our disciplinary society gives us an awareness of our present understanding of disability. In the next section I wish to examine how our present perceptions of self and subjecthood have come about and to see if this has implications for disability researchers. As Foucault says:

> We have to know the historical conditions which motivate our conceptualization. We need a historical awareness of our present circumstance. (Foucault 1982:209)

Thus it is that I shall now turn from the body to the self and see how Foucault shows how our present perceptions of self are founded upon an ethics rooted in Christianity.

As in Chapter Five, this chapter is clearly divided into two sections. The first section is an exposition of Foucault's position and the second section looks at the validity and implications this work has for disability theorists. As in the previous chapter, it is not until the second section that I draw upon the empirical data to ground Foucault's thought in the everyday experiences of disabled people.

1. FOUCAULT'S ARGUMENT

1:1. PASTORAL POWER

Foucault claims that an ethics of the self is more than merely an analytical tool for investigating subjectification. An ethics of the self, Foucault argues, has truly emancipatory potential as he now acknowledges the individual's capacity for self-determination and autonomy.

In works such as *Discipline and Punish* (1977) and *Madness and Civilization* (1967) Foucault sees the individual as being ensnared in a normalising framework of law and medicine. The 'self' is an effect of techniques of domination, of prevailing discourses and mechanisms of power. Indeed it has been argued that Foucault deconstructs the self to such a degree that notions of autonomy, self-determination and freedom have little sway. In these earlier texts Foucault pays little heed to notions of ethics and normative justification. In his later works however, notions of freedom, agency and ethics are firmly placed centre stage. His focus now turns to practices, or techniques, of self. That is to say Foucault shifts from examining how the subject is constituted as an object of knowledge to an analysis of how the individual comes to understand herself as a subject.

This was not viewed by Foucault as a break with his earlier work but rather as a continuation of his analysis of the modes by which human beings are turned into subjects. As he says on this point:

> A theoretical shift had seemed necessary in order to analyze what was often designated as the advancement of learning; it led me to examine the forms of discursive practices that articulated the human sciences. A theoretical shift had also been required in order to analyze what is often described as the manifestations of 'power'; it led me to examine, rather, the manifold relations, the open strategies, and the rational techniques that articulate the exercise of powers. It appeared that I now had to undertake a third shift, in order to analyze what is termed 'the subject'. It seemed appropriate to look for the forms and modalities of the relation to self by which the individual constitutes and recognises himself *qua* subject. After first studying the games of truth *(jeux de verite)* in there interplay with one another, as exemplified by certain

> empirical sciences in the seventeenth and eighteenth centuries, and then studying their interaction with power relations, as exemplified by punitive practices - I felt obliged to study the games of truth in the relationship of self with self and the forming of oneself as a subject, taking as my domain of reference and field of investigation what might be called 'the history of desiring man'. (Foucault 1985:6)

Foucault wished to undertake then, a 'genealogy of the desiring subject'. In order to do this he had to trace the historical emergence of self as we conceive of it today. This led him to the notion of a 'deep self', a 'confessing self', which he saw as a dominant feature in western civilization since the era of Christianity. In order to arrive at a point in time where, Foucault maintained, this conception did not exist he undertook a study of antiquity and the ways in which sexuality and the body became the object of moral deliberation and control.

Christianity, it is believed, saw the emergence of a new code of ethics. Christianity and christian aesthetics demands the subordination of the individual's moral conduct to external, predetermined, normalising principles. The individual conforms, and autonomy is lost. Yet what is generally overlooked is that Christianity also brought into being an entirely new set of power relations. For the first time a religion organized itself as a church with a specific hierarchical order. Out of this came the figure of the pastor who was able to exercise a very particular type of power over the lay public. Firstly this power had as its aim, the salvation of individuals. Secondly, unlike sovereign power where individuals could be sacrificed for the sake of the king, pastoral power had to, if necessary, sacrifice itself for the sake of the flock. Thirdly this power looked after, not just the community, but each individual throughout her whole life. And finally this power was exercised through knowing the soul of the individual, by inciting to confess. In Foucault's words pastoral power:

> ...is salvation orientated (as opposed to political power). It is oblative (as opposed to the principle of sovereignty); it is individualizing (as opposed to legal power); it is coextensive and continuous with life; it is linked with a production of truth - the truth of the individual himself. (Foucault 1982:212)

Christianity no longer, in modern society, has the hold it once did, and hence for Foucault contemporary secular ethics, which are grounded in scientific knowledge of the individual have supplanted christianity. These secular ethics are in fact a form of power. The modern Western state, argues Foucault, has integrated in a new political shape, an old power technique which originated in christian institutions. This power technique is a new and distinct form of pastoral power.

There are two main aspects of this new form of pastoral power which need to be highlighted. On the one hand is the ecclesiastical institutionalization, and on the other, its function. The former has, since the eighteenth century lost much of its relevance and significance, however the latter has expanded and multiplied, spreading outside of its original ecclesiastical institutions. This new form of pastoral power is quite distinct from the old pastoral power from whence it originated. In the first place its objective has changed. As I noted previously pastoral power had as its aim the salvation of souls in the next world. Now salvation becomes an objective in the here and now. In this way the word 'salvation' itself has changed: from being the promise of eternal happiness it now denotes health, well-being, security, insurance. "A series of 'worldly' aims took the place of the religious aims of the traditional pastorate" (Foucault 1982:213). This change was relatively smooth as the aims of the pastorate traditionally had a welfare dimension. A second difference between the old and new forms of pastoral power is that of the ever increasing number of officials exercising this power. This includes both power that is exerted by state apparatus and public institutions, and also private ventures such as welfare agencies and philanthropists. Further, traditional institutions, such as the family, were employed to take on pastoral functions. Equally pastoral functions became inscribed into other complex structures such as medicine and hospitals. A third point of divergence is that as a result of the plurality of aims and agents of pastoral power

> ...the development of knowledge of man [was focused] around two roles: one globalizing and quantitative, concerning the population; the other, analytical, concerning the individual. (Foucault 1982:213)

Whereas the traditional form of pastoral power was firmly embedded within religious institutions, since the eighteenth century this new form of individualising power has become incorporated in state power. The modern state, in Foucault's words should be considered as

> ...a very sophisticated structure, in which individuals can be integrated, under one condition: that this individuality would be shaped in a new form, and submitted to a set of very specific patterns. (Foucault 1982:214)

Modern society does not function by disregarding the individual, rather it claims to have understood the "truth" of the individual. The modern individual cannot escape her own identity; she is categorised and marked by it, she is trapped in her own identity. "Everyday life," writes Foucault

> imposes a law of truth on him which he must recognise and which

> others have to recognise in him. It is a form of power which makes individuals subjects. There are two meanings to the word subject: subject to someone else by control and dependence, and tied to his own identity by a conscience or self knowledge. Both meanings suggest a form of power which subjugates and makes subject to. (Foucault 1982:212)

The State can be perceived as a "modern matrix" of individualization. Where there once was a pastoral power which was firmly linked to religious institutions, and a separate, sometimes competing political power, we now have a form of individualizing powers, such as in the family, education, psychiatry, employment and medicine.

1:2. AN AESTHETICS OF EXISTENCE.

From early christianity to the present day we live under the dictum "know thy self". We must search and reveal the truth of ourselves. For the ancient Greeks this rule was a means by which the notion of taking care of the self could be articulated. One's life should be a thing of beauty, a work of art, in which the individuals main responsibility to himself[1] is to realise the possibilities of reinvention of self.

This is possible because there was no moral dictum by which one was supposed to live. In distinguishing between a morality where the emphasis is placed upon the individuals conformity to imposed codes of behaviour, and a morality as:

> ...the real behaviour of individuals in relation to the rules and values that are recommended to them. ...the manner in which they comply more or less fully with a standard of conduct, the manner in which they obey or resist an interdiction or prescription. (Foucault 1985:25)

Foucault demonstrates that it is not *which* code one adopts that is important but rather the crucial difference lies in the ways in which these prohibitions are integrated in relation to the self.

This allows, argues Foucault for more individual freedom in that the individual is relatively free to interpret the spirit of the law. As Foucault puts it:

> From Antiquity to Christianity, we pass from a morality that was essentially the search for a personal ethics to morality as obedience to a system of rules. (Foucault 1988a:49)

Modern ethics, unlike those of the ancient Greeks and the early Stoics, is an elaborate attempt at normalization. Foucault argues that there is little evidence of normalization in classical Greece, because these earlier ethics were principally concerned with aesthetics.

In Greek ethics men were concerned with their moral conduct, with their relations with themselves. In addition ethics was not related to any social - or at least to any legal - institutional system. For instance the laws against any sexual misbehaviour were few and not very compelling. Moreover, as Foucault says:

> The third thing they were worried about, their theme, was to constitute an ethics which was an aesthetics of existence. (Foucault 1983:62)

So, for example, even where there are similarities between an interdict in Christianity and a moral code in Antiquity their ethical content might be quite different. Conjugal fidelity in Christianity is demanded as a rule, a law to be valued. Yet for the Classical

Greeks, although conjugal fidelity might be prized it is not simply obedience and conformity to a rule, rather it is an act of morality, which can be performed for different reasons. It can be for self mastery; to show detachment from the world; it can be to demonstrate control over passion, or it can be to gain salvation or immortality, in the sense that they will be remembered for having lived a beautiful life. In other words a moral act is an act of self formation as an 'ethical subject'. It is a process in which

> the individual delimits that part of himself that will form the object of his moral practice, defines his position relative to the precept he will follow and decides on a certain mode of being that will serve as his moral goal. And this requires him to act upon himself, to monitor, test, improve and transform himself. There is no specific moral action that does not refer to a unified moral conduct; no moral conduct that does not call for the forming of oneself as an ethical subject; and no forming of the ethical subject without "modes of subjectivation" and an "ascetics" or "practices of the self" that support them. (Foucault 1985:28)

In developing a hermeneutics of the self Foucault's aim was not merely to discuss the subject in theory, but rather he also wanted to discuss the subject in relation to a set of practices in late antiquity. I briefly mentioned earlier that these practices were constituted in Greek as '*epimelesthai sautou*':

> 'to take care of yourself,' 'the concern with self,' 'to be concerned, to take care of yourself'. (Foucault 1988b:19)

This precept has become obscured behind the Delphic principle '*gnothi sauton*' - know thy self.

Foucault argues that for the Greeks the canon 'know thyself' was not some abstract philosophy, but in fact it was a piece of practical advice to be borne in mind when consulting the Delphic oracle:

> 'know yourself' meant 'Do not suppose yourself to be a God'. Other commentators suggest that it meant 'Be aware of what you really ask when you come to consult the oracle'. (Foucault 1988b:19/20)

Thus in Greek and Roman texts the dictum 'know yourself' was always in subordination to the principle of 'care for self'. Indeed it is only through this principle of 'care for self' that the second principle could be utilised.

> It is implicit in all Greek and Roman culture and has been explicit since Plato's Alcibiades 1. In the Socratic dialogues, in Xenophon, Hippocrates and in the Neoplatonist tradition from Albinus on, one had to be concerned with oneself. One had to occupy oneself with oneself before the Delphic principle was brought into action. (Foucault 1988b:20)

Foucault outlines a number of possible explanations as to why there has been a reversal of the importance in these two principles. Firstly we now tend to view the idea of taking care of oneself as something bordering on immorality. It is seen as a refusal to acknowledge rules and maxims, a way of escaping them. Nowadays our morality is steeped in the Christian tradition which makes self-renunciation the condition for salvation. Equally we have a secular tradition which views external laws with deference. That is to say that since the sixteenth century we have understood social morality in terms of our relations to others. Thus it is that the idea of 'care of self' is not respected as 'to know thyself' has been the basis of all critiques of morality since the sixteenth century. Therefore, as Foucault says: "It is difficult to see concern with oneself as compatible with morality" (Foucault 1988b:22).

A further reason Foucault gives for the obscuring of 'care for self' behind the principle of 'know thyself' is that of our philosophical tradition. Since Descartes to Husserl, knowledge of the self is recognised as the primary principle in the theory of knowledge.

To summarise then:

> There has been an inversion between the hierarchy of the two principles of antiquity, 'take care of yourself' and 'know thyself'. In Greco-Roman culture knowledge of oneself appeared as the consequence of taking care of yourself. In the modern world knowledge of oneself constitutes the fundamental principle. (Foucault 1988b:22)

Nowadays, in contemporary Western societies, Foucault believes our problems can be seen as similar. Most of us no longer believe that ethics is founded in religion, nor do we want a legal system to intervene in our moral, personal, private lives. For Foucault, the problem faced by modern liberation movements is that they cannot find any principle on which to base the elaboration of a new ethics. The only ethics seemingly available is based upon so called scientific knowledge of what the self is, what desire is, what the unconscious is and so on.

This is not to say that Foucault is suggesting that we should all return to a golden age of an ancient world. Far from it. When asked by Paul Rabinow and Hubert L. Dreyfus (1983) if the Greeks offer an attractive and plausible alternative to our modern ethics, Foucault replies:

> No! I am not looking for an alternative; you can't find the solution of any problem in a solution of a different problem raised at another time by other people. (Foucault 1983:62)

The interesting point in studying ethics in antiquity is, for Foucault, that these ethics are focused around the notion of personal choice. That is to say Greek ethics were focused on an aesthetics of existence. So rather than considering problems relating to the existence or non existence of God, or of whether or not there was an after life, the Greeks centred their problems around notions of how to live a beautiful existence, a good life. And, the point is that these problematics became central points in the constitution of self.

> The idea that...ethics can be a strong structure of existence, without any relation to the juridical per se, with an authoritarian system, with a disciplinary structure. All that is very interesting. (Foucault 1983:64)

Having briefly outlined Foucault's genealogy of the subject, and in particular his reading of the Greek notion of care of self as an aesthetics of existence, I wish now to look at the 'caring professions' and in particular social work. For social work illustrates, quite appositely how it is that pastoral power functions today through the social construction of need.

1:3. THE SOCIAL CONSTRUCTION OF NEED

It is apparent that social workers are not in general agreement in defining their role. The primary tension for social workers seems to be between being an advocate for the down-trodden over and against helping people to conform to society's expectations and norms.

If social workers are viewed as being agents of the state, of policing the deviant elements of society, of enforcing normalization and preserving the status quo, then social workers function at the level of productive power and become vehicles through which disciplinary mechanisms are reinforced. This means that the notion of 'care' becomes incorporated into a regime of regulation and rationalization. This is very different from the idea of 'care for self' as it was understood in Antiquity. 'Care' today has been assimilated into the 'welfare state' and is no longer associated with an aesthetics of existence. It does not function as a means to self stylization.

Indeed, whether one holds that social workers are agents of the state, champions of the oppressed, defenders of the individual or if one views their role as problem solvers, therapists or providers the underlying notion of 'care' upon which their actions or inactions are founded has little to do with the principle of 'care of self' which Foucault maintains was the basis for an aesthetics of existence in Antiquity.

Care today has become conflated with 'need'. And 'need' as Foucault says: "is always a political instrument, meticulously prepared, calculated, and used." (Foucault 1977:26)

The benefits and 'care' that many disabled people receive from the welfare state do nothing to challenge basic structural inequalities. Quite the opposite in fact. They are supportive or system confirming rather than oppositional.

Social welfare issues are generally framed in such a way as to make 'needs' appear totally straight-forward and unproblematic. Nancy Frazer writes that this way of understanding needs:

> ...takes for granted the definition of the needs in question, as if they were self-evident and beyond dispute. It therefore occludes the fact that the interpretation of peoples needs is itself a political stake, indeed sometimes *the* political stake. (Frazer 1989:145)

She argues that it is only through a discourse aimed at the "politics of need interpretation" that there is any hope of challenging the dominant policy framework.

Needs talk, argues Frazer, is peculiar to welfare state societies. That is to say that it is only in late capitalist political discourse that needs talk has become articulated and institutionalised. Frazer goes on to argue that certain needs, "thin needs" may well seem self evident. But they always take the form of "'A needs X in order to Y'" (Frazer 1989:163). This appears veracious when considering thin needs such as food or shelter. However:

> as soon as we descend to a lesser level of generality, needs claims become far more controversial. What, more 'thickly', do homeless people need in order to be sheltered from the cold? What specific forms of provision are entailed once we acknowledge their very general, thin need? Do homeless people need forbearance, so they may sleep undisturbed next to a hot-air vent on a street corner? A space in a subway tunnel or a bus terminal? A bed in a temporary shelter? A permanent home? Suppose we say the latter. What kind of permanent housing do homeless people need? Rental units in high-rises in central city areas remote from good schools, discount shopping and job opportunities? Single family homes designed for single-earner, two parent families? And what else do homeless people need in order to have permanent homes? Rent subsidies? Income supports? Jobs? Job training and education? Day care? Finally what is needed, at the level of housing policy, in order to insure an adequate stock of affordable housing? Tax incentives to encourage private investment in low income housing? Concentrated or scatter-site public housing projects within a generally commodified housing environment? Rent control? Decommodification of urban housing? (Frazer 1989:163)

From what starts as a seemingly simple question, endless other questions flourish. Thus it is that Frazer argues that the nature of needs claims are "contextual and contested". The deeper we delve into needs claims the more questions are raised and, importantly, the more controversy is raised. As soon as these questions are raised in the course of political debates, further disagreements and further questions arise. For example, do we assume, when considering the needs of homeless people, that we are not going to challenge the basic ownership and investment structure of urban real estate? (Frazer 1989:163)

Frazer argues that the thin needs approach does not recognise the thick needs and therefore important political questions remain unproblematised.

Frazer identifies three types of need discourses that operate in late capitalist society. First is the 'oppositional' forms of needs talk. These arise 'from below'; from the politicization of subordinated groups and are crucial in the formation of new social movements or collective agents. Second is what Frazer terms 'reprivatization' discourses. These arise in direct response to the oppositional discourses. And thirdly there are 'expert' needs discourses. It is the polemical interaction between these three discourses of needs, argues Frazer, which structure the politics of need. (Frazer 1989:171)

Let us look a little closer at these three areas.

When oppositional discourses of need are articulated, for example, when disabled people contest their subordinate positions and roles, or when we demand that needs which have been previously unpoliticised, become political needs, then there are a number of consequences. First they call into question the prevailing boundaries between 'political', 'economic', and 'domestic'. Second they

> give alternative interpretations of their needs, embedded in alternative chains of 'in-order-to' relations. Third they create new discourse publics from which they try to disseminate their interpretations of their needs throughout a wide range of different discourse publics. Finally, they challenge, modify, and/or displace hegemonic elements of the means of interpretation and communication; they invent new forms of discourse for interpreting their needs. (Frazer 1989:171)

The politicization of needs does not go uncontested. By challenging oppositional discourses which have questioned the boundaries between 'politics', 'economics' and 'domestic' the reprivatization discourses attempt to re-depoliticize a need. So for example, the argument that civil rights for disabled people is not a legitimate subject of political discourse but is a private, domestic matter is an attempt to re-depoliticize need.

These discourses of reprivatization then, are utilised by dominant groups to deradicalise demands made by marginalised or radical groups or individuals. It is a way by which issues that may have only recently entered the public arena are put safely back in the private realm and hence they become depoliticized and are rendered harmless.

Discourses of reprivatization operate by blending the old with the new. It is not merely a matter of balancing traditional values with those that appear to be deviant discourses of need, but rather, by rearticulating these 'deviant' interpretations of need, they simultaneously modify them:

> Because reprivatization discourses respond to competing, oppositional interpretations, they are internally dialogized, incorporating references to the alternatives they resist, even while rejecting them. (Frazer 1989:172)

So, for example, although charities for disabled people, by their very definition are disablist, some of them incorporate in a depoliticized form discourses of rights and independence (see Chapter Seven).

Expert needs discourses are the means by which politicised needs open themselves up to state intervention and, inevitably, re-depoliticization. As has been argued earlier, Foucault details the manner by which knowledge production mechanisms contribute to administrative redefinitions of politicised needs. Expert needs discourses are obviously clearly related to institutions of knowledge production. Frazer argues that expert needs discourses are thereby normalizing, and as such redefine the individual whose needs are in question:

> They become individual 'cases' rather than members of social groups or participants in political movements. In addition they are rendered passive, positioned as potential recipients of predefined services rather than as agents involved in interpreting their needs and shaping their life conditions. (Frazer 1989:174)

It is important, as Foucault makes clear, that an idea of ethics of self is not concerned with finding hidden needs, but rather to deconstruct what is perceived as needs in order to discover new areas of experience. Disabled people lack an alternative ethics;

what is required is one which is not based upon a naturalised understanding of need, nor on a fixed definition of identity. (McNay 1992)

Foucault presents the principle of an autonomous aesthetics of the self as an antidote to techniques of domination and normalization. Foucault says that nowadays what we have to discover is not what we are, but rather to refuse what we are:

> We have to imagine and build up what we could be to get rid of this kind of political 'double bind'; which is the simultaneous individualization and totalization of modern power structures....the political, ethical, social, philosophical problem of our days is not to try and liberate the individual from the state, and from the state's institutions, but to liberate us both from the state and from the type of individualization which is linked to the state. We have to promote new forms of subjectivity through the refusal of this kind of individuality which has been imposed on us for several centuries. (Foucault 1982:216)

What Foucault is suggesting then, is that resistance is now possible. As we saw in Chapter Five, resistance to disciplinary techniques is problematic in that it can always be reinterpreted in such a way as to reinforce prevailing power structures. That is to say that in works such as *Discipline and Punish* (1977) and in the first volume of *The History of Sexuality* (1978), Foucault's notion of power is such that individual acts of resistance are transformed into acts of compliance to which new acts of resistance develop and become integrated in a similar fashion. From a Foucauldian point of view then, much of the work carried out by the 'caring professions' does little else other than augment an individuals position within a disciplinary power structure. As McNay says in regard to Foucault's stance on psychoanalysis:

> It serves to implicate individuals ever deeper in the network of

> disciplinary power by instilling in them the urge to confess. (McNay 1992:87)

The disciplined, confessing, 'docile' body cannot resist dominant power structures. Yet Foucault's notion of practices of the self allows for resistance which does not necessarily become incorporated into existing power relations.

I have argued so far that in accordance with our christian heritage modern individuals attempt to delve deep within themselves to find the hidden truth, to uncover buried secrets, to bring to light their essential, unique, core of being. In short, modern individuals are compelled to endlessly explore their inner selves. Yet, as Foucault makes clear, this does not lead to self knowledge but is in fact the result of a forgotten coercion. As has been argued, Foucault makes a clear distinction between this type of self-denunciation and the notion of self-stylization. In an article entitled "What is Enlightenment" Foucault expands upon this idea of reinvention or crafting of self.

1:4. THE MODERN INDIVIDUAL

In 1784 Kant wrote a short text under the title *Was ist Aufklarung?* "What, then," asks Foucault, referring to this text, "is this event that is called the Aufklarung and that has determined, at least in part, what we are, what we think, and what we do today?" (Foucault 1984a:32)

Until Kant's text of 1784 was published, philosophical theory which attempted to reflect upon its own present had taken three main forms: first the present could be depicted as being separate from other times either due to some inherent characteristics or being marked as separate from other times by dramatic events. Second the present could be analyzed in such a way as to decode signs of some forthcoming event. And the third way in which the present was traditionally analyzed was as a point of transition towards the dawning of a new era. (Foucault 1984a)

Kant, for the first time depicts *Aufklarung* in a different way. For Kant the Enlightenment deals with the question of contemporary reality alone. He is seeking to find difference:

> What difference does today introduce with respect to yesterday?
> (Foucault 1984a:34)

Kant maintains that the Enlightenment is negative, it is an 'exit', a 'way out'. By 'exit' or 'way out' Kant is referring to the notion of "immaturity", and the manner in which individuals can gain maturity. And by immaturity he means:

> ...a certain state of our will that makes us accept someone else's authority to lead us in areas where the use of reason is called for.
> (Foucault 1984a:34)

Kant, in his text, was able to articulate what other Enlightenment philosophers had long been suggesting in their polemics; namely that the Enlightenment was 'mans' assertion to be recognised as an adult, responsible, mature being. That is to say that through the use of reason the modern individual will attain maturity.

Kant has generally been understood as being a philosopher who seeks universal moral tendencies. However, for Foucault, as Habermas makes clear, Kant is the first philosopher who is:

> ...an archer who aims his arrow at the heart of the most actual features of the present and so opens the discourse on modernity. (Habermas 1986:105)

Thus the question *Was ist Aufklarung?* represents, for Foucault, the first philosophical deliberation of modernity.

In sum then, Foucault's interpretation of Kant's text prioritises the notion of critical self awareness. It is this that Foucault elaborates on to provide a better understanding of a modern ethics of the self.

In order to illustrate what he means by a modern ethics of the self, Foucault draws upon the figure of Baudelaire's *dandysme*. For here we see a truly self made man, a modern individual.

Baudelaire does not just see modernity as being a state of critical consciousness to the present, but rather modernity is also concerned with the relationship one fosters with oneself.

> The deliberate attitude of modernity is tied to an indispensable asceticism. To be modern is not to accept oneself as one is in the flux of the passing moments; it is to take oneself as object of a complex and difficult elaboration. (Foucault 1984a:41)

Foucault continues, using the asceticism of the dandy who:

> ...makes of his body, his behaviour, his feelings and passions, his very existence, a work of art....This modernity does not "liberate man in his own being"; it compels him to face the task of producing himself.
> (Foucault 1984a:41/2)

Foucault is advancing here a notion of liberty, of choice. As in the days of antiquity, the freedom of the dandy is not dependent upon religion or the state. It is a practice of the self, an ethics of existence which is about styling oneself as a thing of beauty.

So, whereas the dandy "makes of his life a work of art", nowadays individuals assign art to a specialized sphere where it has no relevance, no effect on our notions of self-elaboration.

The important point, for Foucault, is that once we acknowledge that there is no analytical, necessary nor given link between political, social or economic structures and ethics then, perhaps, we can start to build an ethics, an aesthetics of existence where life itself is viewed as a work of art. In other words, by seeing that the relations between ethics and other structures are only historical coagulations and not universal givens then, without utilizing notions of truth and knowledge the individual is free to create herself as a mature being.

Foucault is not borrowing from Sartre here. Although Sartrean existentialism, like a Foucaultian notion of the individual, does not hold with the idea that the self is given, ipso facto, it would seem that through the moral notion of "authenticity" Sartre

> ...turns back to the idea that we have to be ourselves - to be truly our

> true self (Foucault 1984b:351)

For Foucault the only expedient outcome of what Sartre has said is:

> ...to link his theoretical insight to the practice of creativity - and not of authenticity. From the idea that the self is not given, I think that there is only one practical consequence: we have to create ourselves as a work of art....we should not have to refer the creative activity of somebody to the kind of relation he has to himself, but should relate the kind of relation one has to oneself to a creative activity. (Foucault 1984b:351)

As Foucault himself notes, his views are much closer to those of Nietzsche than to those of Sartre. (See Nietzsche 1974)

Underlying Foucault's notion that the self should be elaborated as a work of art, is the idea of utilizing a 'limit attitude'. That is to say that the critical ontology of ourselves is characterised by a philosophical ethos which is concerned with limits. Limits which construct boundaries around what we think, what we do, who we are. Foucault maintains that it is by questioning these limits on subjectivity, by interrogating notions of universality, that new areas are opened up for possible forms of resistance:

> The point, in brief, is to transform the critique conducted in the form of necessary limitation into a practical critique that takes the form of a possible transgression. (Foucault 1984a:45)

Subjecting a historical ontology of ourselves to a critique involves analyzing and reflecting upon limits. Foucault maintains that we now should not be searching for "formal structures with universal values" (Foucault 1984a:46) but rather we should adopt a genealogical approach which considers how it is that we have come to

> ...constitute ourselves and to recognise ourselves as subjects of what we are doing, thinking, saying. (Foucault 1984a:46)

So, the critical attitude of modernity, argues Foucault, is both genealogical and archaeological. In it's design it is genealogical, in that what are thought to be universal, given forms of identity are questioned, and the historically specific and contingent nature of identity is brought to light. It is archaeological in its method in that knowledge which is thought to be universal is not sought, but rather

> ...it will seek to treat the instances of discourse that articulate what we think, say and do, as so many historical events. (Foucault 1984a:46)

New forms of identity, different areas for analysis and previously unexplored areas of self formation are, for the first time, open to interrogation. That is to say that limits, or boundaries to subjectivity, are no longer viewed as given or essential and thus the opportunity to go beyond traditional boundaries becomes established. And because of this transgression of limits, this possibility of opening up new forms of subjectivity, the critical attitude of modernity must also be an experimental attitude.

> I mean that this work done at the limits of ourselves must, on the one hand, open up a realm of historical inquiry and, on the other, put itself to the test of reality, of contemporary reality, both to grasp the points where change is possible and desirable, and to determine the precise form this change should take. (Foucault 1984a:46)

We must beware, warns Foucault, of global, universal changes because as we have witnessed during this century, they can lead only too easily to "the worst political systems". Rather it is the changes that have occurred in the last twenty years or so, the small specific transformations, maybe only partial, that have altered our ways of thinking and being that we should foster. For example relations between the sexes, relations with authority, and our understanding of insanity and illness. (Foucault 1984a:47)

By suggesting that we restrict ourselves only to local or partial transformations, Foucault acknowledges that we must abandon all hope of:

> ...acceding to a point of view that could give us access to any complete and definitive knowledge of what may constitute our historical limits. (Foucault 1984a:47)

In other words our actions are always limited and determined and thus we are continually in a position of starting again.

Having briefly outlined Foucault's theory of an ethics of the self I would now like to consider what value this might have for disability theorists.

2. REFLECTIONS OF THE VALUE OF FOUCAULT'S NOTION OF ETHICS FOR DISABILITY THEORISTS

It is the idea of transcendence; of going beyond the limitations of contemporary social conditions which makes Foucault's latter works appear so appealing.

For disabled people this means discovering new ways of understanding ourselves and each other. It is a refusal to accept the non disabled cultures' perception of us, as well as a refusal to accept the limits of subjectivity, which we are so familiar with. It is not that we need to be told *who* we are, but rather to become free from understanding ourselves in a certain negative fashion; that is to say we need to liberate ourselves from who we have to be and we need to understand how we came to think of ourselves in that way in the first place.

However, whist the notion that we can transcend normative social conditions, that we can go beyond traditional limits to subjectivity sounds all very well when we are considering theoretical notions of a 'philosophical life', we need to examine the implications this has for disabled people. What practical use can this work have when we think of the real lives, the lived experience, of disabled people? In other words how can Foucault's theory of an aesthetics of existence be utilised to promote equality for disabled people? Indeed, does his later work have any relevance for us today?

It is with these questions in mind that I shall now return to my empirical data with the aim of seeing in what ways Foucault's insights into self-creation and aesthetics of existence might be of relevance to us.

2.1 'DOING' DISABILITY

It has already been made clear that the majority of the disabled people I interviewed show an acute awareness of the general, non-disabled, publics attitudes towards people with disabilities. These comments are very typical:

> But I do think there should be more outside information to tell people
> that, you know, these people in wheelchairs are not mentally defective,

> they are not crazy, you know, they are just as clever in mind as what you are. You know, it's like the two go hand in hand - wheelchair and stupidity. I admit that when I was able-bodied I was a bit like that myself. (Debbie:48)

> Once you have legs which are no use for walking and you've got to use a wheelchair it is something that you have to come to terms with. But out and about it is other people who have the problem. They will always talk to the other person who is pushing the wheelchair. They never talk to me, it was always to Thelma. And I felt that was strange,it was me with the illness, it was me who had to be in the wheelchair, so why talk to Thelma, why not talk to me? That was strange. And it was other people who had the problem with the wheelchair, not me. (Eddy:64/5)

> Some people are embarrassed by the wheelchair, they, you know, step aside when they see you coming. You can see people that you've known years back, at school, they don't want to know, they don't want to be bothered. They move to the other side of the road. (Linda:93)

As I have already noted elsewhere in this text, Beth, for example, deliberately attempts to counteract disablist practices and behaviour by presenting a more positive image. She uses a "colourful", "sporty" wheelchair, wears trendy clothes and likes to appear happy. Kay, too, attempts to counteract and resist the negative image that, she believes, sight-impaired people have:

> I think I've made more of an effort in my dress now that I can't see. I want to walk in somewhere and people think: "Wow! She's blind and really nice!" That's awful isn't it? Richard says I shouldn't think like that, but I want people to look at me and think: "Gosh she's blind and she looks really nice!" That's why I had my hair all plaited up, I sometimes go to the beauty shop and have my make-up put on for special occasions, you know. But I want to make more of an effort, because I can't see, than I did before. (Kay:306)

Equally Rachel attempts to subvert the dominant cultural image of wheelchair users:

> I feel the need to be cheerful, even if I'm not. I don't want people to think that I am miserable in a wheelchair. I suppose that is on me all the time. And also I don't...if someone says: "Are you O.K.?" and I'm feeling pretty shitty that morning I would never say that I was not feeling too good. (Rachel:202/3)

To compensate for normals embarrassment and disablism many of the interviewees have learnt to:

> preempt people and over-compensate for the embarrassment. You know I try to be more out-going and assertive and speak first and that sort of thing - try to make people easy. (Beth:212)

Rachel explains how she protects her friends from the reality of living with a disability:

> When we go out...sometimes we go somewhere where it is a bit awkward and I say: "Well I don't feel like it". I never say I can't go because of the steps or whatever. (Rachel:195)

In other words Rachel and most of the other people I interviewed, are very aware of the way that they are perceived now, compared to how they were perceived before they became disabled. Beth, for example, has had to learn to manage encounters with normals in such a way as to make her "acceptable" and them feel "easy".

It could be argued that disabled people are fulfilling the requirements of the disabled role, or that they are responding to cultural dictates that define the disabled person as the 'problem'. They are, we could also argue, acting as 'docile bodies' in that they perceive themselves, through normalising power, as 'abnormal'. However, by utilizing Foucault's later arguments a further alternative possibility is opened up for exploration, that gives us the opportunity to see the way we manage, experience and 'do' our disabilities in a way which shows autonomy, self-creation and resistance.

Whilst Beth acknowledges that initially she often told herself: "I don't want to continue with my life if this is how I am going to have to be", she now feels that the experience of becoming disabled has " been overall very positive - what's come out of it". She does not deny the difficulties associated with being disabled, or that her goals and future plans have not had to be reassessed. However she says that:

> My goals are probably set higher now, I've been exposed to a lot of opportunities which I wouldn't have been exposed to before. For example, I've got involved in a lot of voluntary work and because of my experiences as a disabled person I've been invited to join committees which compose of statuary agents, service providers and you know there's a real need for user involvement and that's where I tend to come in. Because I'm pursuing a degree as well it somehow makes it a lot more acceptable. So I can say that I can go on to be a primary school teacher still, [Beth's ambition before the accident] but it looks like I might go on to do other things. I'm a lot more committed now than if I hadn't had my accident. [...] I think I still would have pursued things but not to the extent I have now. (Beth:216/7)

If we view the way that Beth 'does' her disability in 'the later Foucauldian' framework we can argue that Beth is utilizing her disability as an instrument of self-stylization. She readily admits that "I am making a career out of disability", but, as she goes on to say:

> It's like you can be a little fish in a big field or a big fish in a little field and in a way I don't really want to use the word 'duty' or 'obligation' but I think it is my responsibility to inform people and because I have done so much up till now it seems a shame to sort of abandon all that and go into an area where I am not so well recognised or appreciated and, as I say, there are the opportunities there and I would be foolish to turn away from them. There is this movement now towards user involvement and getting the client there to actually work with or be the policy makers and because it is an interest of mine now I feel I should do it. (Beth:225)

Beth is not alone in believing that the onset of her disability has opened doors and given her opportunities which otherwise would have remained shut and unavailable to her. Many of the people I interviewed talk about such things. David says he has become far more confident since the onset of his sight-impairment:

> I think I am more confident than I used to be when I was sighted. I think it, in a way, is because I can't see people's reactions. I can't see people's faces so I'm more confident in speaking. I do speak for guide dogs. Which I think if I could see the people there, I mean I went to one just before I came down here which were a hundred and twenty people I were talking to. There were no way one time of day, the thought of even getting up to speak to people like that...but because I can't see them...you know I just get lost in my own little world. (David:5/6)

He continues:

> I've done things I never would have done when I were sighted. I mean I had thise weeks down at Torquay, the rehabilitation. I mean there is no way I could afford nine weeks down at Torquay if I was sighted. I've had a month engineering course down at London, I've done a demonstration in gardening in Harrogate. Just things I would never have done. (David:6)

And Steven claims that becoming disabled has given him:

> A bit more relaxed attitude about life, you know. I was always doing something, I always wanted to do something quickly, getting there quickly, do that quickly...just doing lots of things all at once and it's stopped me doing that. You know I don't rush about and I don't worry...well, I do worry about things but I don't think 'Oh shit I haven't done that', well I do but not like I was rushing about all over the place. I wanted to do this, I wanted to do that, get this done, get that done, I have just become more relaxed really, a bit more laid back really. (Steven:251)

Linda is very involved with the work she does for the M.S. society:

> I'm on the phone twenty-four hours, on the help line for M.S. patients.

> If ever anybody gets stuck for anything, medically wise, or wants equipment and things, doesn't know what equipment, or who to turn to, or anything like that, I am there more or less twenty four hours. (Linda:87)

Thus, whether it is through working with 'their' specific charity, having more leisure time, or through a newly developed interest in disability issues, our conception of self is no longer unproblematic and taken for granted. When, as we have seen, we cannot mingle anonymously with the crowd, when our previously unquestioned notions of self are repeatedly called into question, 'self', for the first time becomes exposed as a fragile and changable construct. Self, in other words, now becomes something that we are actively aware of.

Hilary describes herself as "an M.S. person" (109), but as she says:

> I don't wake up and say every morning: 'Oh I've got M.S. what a horrible day I am going to have'. I mean that's it, unless it plays me up particularly I just come to terms with it. I expect it to be part of me now. I don't love it, I don't hate it, it is just part of me. (Hilary:109)

This obviously runs contrary to the prevailing view held by normals of disabled people. Equally Rachel is resisting this doxa when she says:

> They [the normals] don't know that I laugh half the time about the things I can and can't do and make jokes about it. There are limitations on the relationship before you start and until you tell everybody what is wrong with you and that it is not as bad and not as depressing as they might think. (Rachel:196)

It is only, and can only be, on this individual level that we can talk about self-stylization and resistance. Beth, and countless others like her, resist and subvert the prevailing truth of disability on an individual, continuous and immediate level. This is not to say that in all aspects, at all times in her life does Beth resist for, as she says: "I live disability and I would sometimes just like to forget it." However, as an issue of ethics, as an issue of the aesthetics of the self, Beth and those of us who continuously challenge the doxa of disability cannot escape our disabilities, for we cannot fail to take on board a notion of self which is constructed in response to the pressures from society to become one of The Disabled.

Having outlined the value and relevance of Foucault's later works to us, I wish now to argue in the following section that there are serious problems with Foucault's aesthetics of existence which cannot be ignored.

2:2. THE PROBLEM OF THE DANDY

As we have seen, Foucault concentrates upon the Baudelairean figure of the dandy as the paradigmatic modern individual:

> To be modern is not to accept oneself as one is in the flux of the passing moments; it is to take oneself as object of a complex and difficult elaboration: what Baudelaire...calls *dandysme* (Foucault 1984a:41)

The dandy then, for Foucault represents the modern individual: he does not search his soul to reveal some deep, hidden, essential truth, but rather he works upon himself in order to produce himself.

By placing Baudelaire's dandy at the centre of his argument for an ethics of self, Foucault, however, exposes himself to much criticism.

Although Foucault is aware of the ways in which Western humanism has privileged the experience of the Western masculine elite as it proclaims universals concerning truth, freedom and human nature, it is precisely this same elite which is embodied in the figure of Baudelaire's dandy. As Diamond and Quinby (1988) affirm Western humanism is not only problematic because it assumes an autonomous and universal self but

> ...that this particular self is the domain of privileged white men. The valuation of their narrowed and partial experiences and activities and the corresponding devaluation of women's and other subjugated groups' experiences and activities not only are central to Western humanism but are its way of maintaining subordination of the Other. (Diamond and Quinby 1988:Introduction)

The dandy is also problematic as it represents only one style of being. In order to resist the operations of normalising power Foucault calls for a "search for styles of existence as different from each other as possible". (Foucault 1985:12) This would seem to bode well for disability theorists, yet the dandy represents a singular, exclusive and specific style of existence. As McNay (1994) writes:

> ...the choice of Baudelaire raises the question of how...Foucault is able to celebrate, in a relatively uncritical fashion, a certain tradition which normalizes as *the* experience of modernity a *particular* and gendered set of practices. (McNay 1994:149 Authors italics)

In other words Foucault, by choosing to focus on Baudelaire's figure of the dandy as being representative of the modern individual, is reinforcing normalization rather than propounding multifarious styles of existence.

And, of course, once we are given a 'paradigmatic figure of the modern individual' all that is not that figure automatically becomes Other.

A further problem with Foucault's use of Baudelaire is that Foucault accepts the category of artist as a marginal, free floating figure with no consideration for his cultural and gendered construction. Griselda Pollock (1988), amongst others, has shown not only that Baudelaire's work is misogynist but how the very concept of the artist is

> a combination of the Romantic notion of the artist as 'Genius' and expressive theories of art. To the artist is attributed a heightened sensibility and even a visionary capacity to see beyond surface reality and to probe human experiences which are expressed through so great a creative ability that it is assumed that it must be innate...Thus the primary object of art becomes in fact the artist whose being is expressed in it. (Pollock 1987:83/84)

Pollock argues that historically the meaning attributed to the artist has developed with the growth of capitalism.

> A new notion of art gained meaning in historical opposition to industry, and in such polarities as fine art against useful arts, arts against technology. (Pollock 1987:84)

By demythologising the notion of the artist, Pollock and other feminist critics, have shown how the artist is 'mythically idealized' as the free agent of creativity. They proceed to show how, in fact the artist denotes an elitist and privileged few, from select class, racial and gender groups.

Foucault's 'desexualized perspective' (McNay 1994) has received much criticism from feminist writers (Morris 1988; Bradotti 1991; Bartky 1988; Grimshaw 1993), but the implications of his use of the Baudelairean dandy as the paradigm of modern ethics has considerable ramifications which weaken and deflect Foucault's explicit arguments.

As we have seen, for example, underlying the notion of creating ourselves as a work of art is the idea of employing a 'limit attitude'. By locating the frontiers of identity in the figure of the dandy however, Foucault is falling back, quite uncritically, on a masculine tradition which assumes the radicality of avant-garde literature, of high modernist art. Equally as we have already noted in Chapter Three, literature by no means certainly transgresses normative stereotypes of identity. Indeed, I would suggest that a more compelling and pertinent figure in a contemporary exploration of identity could be found in the disabled individual, who often finds that the only available identity to adopt is that offered by able bodied/white/male stereotypes.

However a paradigm in itself is not useful and it could be argued that it is antithetical to Foucault's notion of a fragmented and incoherent individual. Thus we should be moving away from the very concept of a paradigmatic figure. It would be more beneficial to look at the *experiences* of disabled people, not as they embody otherness, but because they illuminate the dependency that normalization has upon the formation of other. That is to say that there is an interdependency between normalization and that which is not normal. The category of 'other' relies upon a notion of what it is to be 'normal'. However what is generally overlooked is that equally the classification of normal ceases to be if there is no Other to which it can be contrasted. When Colin says: "My name is Colin Edwards, not Colin the blind guy" (Colin:31), he is referring to the way that normals focus on our differences from them to the exclusion of any other aspect of our identity. In other words for the normals it is the otherness of being blind that has become Colin's defining characteristic. Obviously this would become meaningless if the category 'sighted' did not exist.

This is not to say that the relation between normal and other is one of equality, but rather it is a power relationship which is heavily balanced in favour of the normalized individual. Foucault's notion of an ethics of self seems to imply that the Other is merely an instrument through which the self is stylized. This ignores the inherent power relationship between and within individuals which was central to his earlier works.

In antiquity, as Foucault acknowledges, women did not have the freedom to fashion their own lives, their own 'ethical substance'. Women could not interpret the ethical code in relation to themselves as ethical beings, rather they had to obey strict rules concerning their behaviour and conduct. Free men, as we have already noted, were able to use women merely as vehicles through which they could style their own lives. But this non-reciprocity also existed between free men. Homosexual relationships were highly problematic for the ancient Greeks. Theirs was a 'virile' society in which their main concern centred around the notion of being 'active' as opposed to 'passive'. As many commentators have pointed out, passive here is akin to 'feminine'. But for the Greek men it was important not to be seen as the 'passive' partner. Thus a lot of energy went into the careful orchestration of the relationship in order to avoid either one being perceived as passive. Foucault makes clear that the rationality behind this was simple:

how could a man keep his status as a dominant free male if he were also a passive and therefore inferior man?

> The problem was that they could not accept that a young boy who was supposed to become a free citizen could be dominated and used as an object of someone else's pleasure. A women, a slave, could be passive: such was their nature, their status. (Foucault 1983:63)

Concern with the other, in terms of emotion and intimacy is largely absent except in so far as it affects individual status and self formation. (Grimshaw 1993:68) The care of the other is always secondary to care of self:

> One must not have the care for others precede the care for self. The care for self takes moral precedence in the measure that the relationship to self takes ontological precedence. (Foucault 1988b:7)

2:3. THE POWER WITHIN

Power, in Foucault's latter works has undergone a transformation. Previously, as we have seen in Chapter Five, individuals were constructed as docile bodies. Now power resides in the individual. No longer are individuals vehicles through which power operates, but now individuals exercise power over themselves. Again this would appear to be a positive change, one that disability theorists should embrace as all too often we find we have no room for autonomy and self assertion. This comment from Debbie reflects a reoccuring concern of the interviewees:

> When you are talking to able-bodied people they look at you a bit ga-ga you know, she doesn't know what she's talking about sort of thing. Well I get that feeling though they do...I mean even my own doctor to a certain extent, I mean he's marvellous, I think though 'is it sinking in

> with him?' 'Does he think I'm crackers? And then I start to think 'Well, am I crackers?' (Debbie:46)

Thus Foucault's reconceptualizaation of power being located within the individual sounds a promising notion for us. However when we explore this new formation of power we find it sadly disappointing.

As we have seen, moral conceptions in Greek and Greco-Roman antiquity were directed more towards practices of the self than towards codefications of conducts and rigid definitions of what is permitted and what is forbidden.

> The accent was placed on the relationship with the self that enabled a person from being carried away by the appetites and pleasures, to maintain a mastery and superiority over them, to keep his senses in a state of tranquillity, to remain free from interior bondage to the passions, and to achieve a mode of being that could be defined by the full enjoyment of oneself, or the perfect supremacy of oneself over oneself. (Foucault 1985:31)

So here we have an individual who exercises full control over himself; to produce himself involves a taxing, punitive discipline. Yet this power lies within the individual and is directed upon himself, so, it would imply that this power cannot be tyrannical. Terry Eagleton writes:

> This position thus combines the best of coercion...with the best of hegemony: the subject has the autonomy of the hegemonic subject, but now in a more radically authentic manner. Aesthetic self-production is a question of explicit power, not of that treacherous dissembling of power which is hegemony; but since this power is directed upon oneself it cannot be oppressive, and so is distanced from the epoch of coercion too. (Eagleton 1990:391)

Power then, in Foucault's later works, is firmly installed within the self. This concept of power, on the face of it, should be of great interest and value to disability theorists. Many disabled people have great difficulty in experiencing any form of personal autonomy and thus notions of power as self-mastery and self-transformation along with ideas of the active production and formation of the self, and the centrality accorded to practices of the self and the care of the self would seem to be apposite for an emancipatory theory of disability.

As I have argued in the preceding work, central to much of Foucault's earlier texts is the notion that disciplinary techniques and mechanisms of power operate upon the individual by means of self-surveillance, internalized self-monitoring and normalization. This is a very useful concept in understanding disabled people's subordination. Now, in his late work, Foucault seems to have reformulated power to such an extent that individuals who before were docile, are now understood to be acting in an autonomous fashion. The power of the self over the self has replaced the docile, passive self:

> Suddenly...these practices of self-discipline and self-monitoring are no longer seen as disciplinary practices which undermine all notions of the autonomy of the self; they are seen, rather, as constituting autonomy. (Grimshaw 1993:66)

Foucault never makes it explicit, or indeed even addresses the question of when, and how we know, an individual action is the result of disciplinary techniques and when it is an autonomous act of self-creativity. Foucault writes about a small elite of free males in antiquity, but the problem here is that he simply assumes them to be free. He takes their freedom at face value, never considering whether it is a matter of self-mastery and autonomy or whether it is in fact a matter of internalized disciplinary techniques.

When should we see, for example, Hilary's concern with her bodily appearance and her daily exercises as an expression of creative self-mastery and autonomy, and when should we regard it as the result of internalized norms of what a women's body should look like, and a reaction to disablist cultural dictates? Equally should we view Steven's refusal to have any contact with other wheelchair users as an act of autonomy or as an act of docility?

Foucault argues that the only alternative to a morality based upon adherence to universal rules is one in which the individuals life is fashioned and created in isolation from the rest of society. He allows no space for interdependency, for mutuality, nor for any notion of reciprocity, sociability nor commonality.

In other words what Foucault's ethics of self fails to address is an idea of a morality which does not uncritically embrace 'universal' ideals, but which strengthens mutuality and collectivity as organizing principles of individual lives. We have already seen how resistance to many forms of universalism can, only too easily, be recuperated and reinterpretated so that it ends up serving that which originally was being resisted.

McNay (1992, 1994) argues that the problem with a notion of the self which prioritises self-mastery and self-control over and above relations with others is that by doing so Foucault is reinforcing traditional orthodox conceptions of the self rather than challenging conceptions of subjectivity. Traditional philosophy of the subject places an active self operating upon an objectified world and interacting with other subjects who are, by definition, objects or 'narcissistic extensions' of the primary subject. Foucault's conception of the self does nothing in the way of disrupting or subverting this view of the subject. Indeed, Habermas (1987) comments:

> To the objectivism of self mastery on the part of the human sciences there corresponds a subjectivism of self forgetfulness on Foucault's part. (Habermas 1987:294)

For Habermas Foucault's criticism of the philosophy of the subject is invalid as Foucault cannot escape its primary concepts of subject/object, nor can he free himself from the paradigm of the knowledge of others as objects.

Foucault states in 1985 that:

> ...there were two possible paths that led beyond this philosophy of the subject. The first of these was the theory of objective knowledge as an analysis of systems of meaning, of semiology. This was the path of logical positivism. The second was that of a certain school of linguistics, psychoanalysis and anthropology - all grouped under the rubric of structuralism. These were not the directions I took. I have tried to explore another direction. I have tried to get out from the philosophy of the subject, through a genealogy of the modern subject as a historical and cultural reality. That means as something that can eventually change, which is, of course, politically important. (Foucault 1985:388)

So, Foucault's explicit aim is a deconstruction of the philosophy of the subject. Yet he never fully achieves this as his idea of a lone subject acting upon the self in order to realize her identity falls back upon the traditional philosophy of the subject. In other words Foucault's conception of the active self acting on an objectified world does not break with traditional views of the self expressed in the philosophy of the subject. Yet Foucault does move away from some of the central terms in the philosophy of the subject. Foucault is, as we have already seen, very much an anti-essentialist thinker.

So, on the one hand he rejects any notion of liberating a true inner self, and yet at the same time he remains ensnared within the dominant dynamic of the subject/object relation.

2:4. THE SELF AND THE OTHER

Now if we return to our earlier criticisms of Foucault's conception of the other as being merely an instrument through which self creativity can be attained, it would seem likely that this approach runs the risk of advancing domination over the other. Foucault, however, when questioned on this replies:

> ...in the case of the free man, I think that the assumption of all this morality was that the one who cared for himself correctly found himself, by that very fact, in a measure to behave correctly in relationship to others and for others. (Foucault 1988b:7)

So, it would appear that Foucault is negating his own insistence that power is present in all social relations. As McNay puts it:

> ...practices of the self appear to be abstracted from any social context which may predetermine inequalities between the behaviour of individuals. (McNay 1992:172)

Foucault's conviction that by caring for self, care for others is automatic overlooks the fact that we are not all positioned equally in the social field. So for example, an able-bodied person caring for herself correctly might, by virtue of inequalities in society, dominate or oppress a disabled person who does not have access to the same strategies of resistance as the able-bodied person. McNay argues that such a position could be counterargued by Foucault who would claim that if this were the case then the dominant person would not be practising care for self correctly. However, she goes on to say:

> ...but until guide lines are laid down about what constitutes valid behaviour then Foucault's belief in the self-limiting nature of the care of the self seems untenable. Since Foucault declines to outline, even in the most general terms, what he considers to be a valid use of power and what constitutes an abuse, then there is no guarantee that care of the self would not lead to the domination or marginalization of the other. (McNay 1992:172)

Foucault though, insists that care of self is practised by free individuals. It is through this freedom, which is expressed through the capacity to resist 'the games played by others' that Foucault is able to maintain his position. In elaborating upon this Foucault says the following, rather disturbing words:

> ...there cannot be relations of power unless the subjects are free. If one or the other were completely at the disposition of the other and became his thing, an object on which he can exercise an infinite and unlimited violence, there would be no relations of power. In order to exercise a relation of power, there must be on both sides at least a certain form of liberty. Even though the relation of power may be completely unbalanced or when one can truly say that he has "all power" over the other, a power can only be exercised over another to the extent that the latter still has the possibility of committing suicide, or jumping out of the window or of killing the other. (Foucault 1988b:12)

Exactly what sort of resistance is suicide or murder? To me Debbie's suicide attempt, rather than being an act of resistance is a desperate attempt at escape from her thoroughly oppressive position in society. Equally, when Colin states:

> This sight thing is not...is not like anything else. It's as much psychological as physical. It's a really scary business. Got to be honest I was terrified. Nobody to talk to, you can talk to family, but nobody

> understands until it happens to them. You get the usual lines from people. My social workers, and I mean I'm not grouchy by any means, they had the usual lines about people being worse off, which does nobody any good. I got fairly angry. It was the first time I ever gave up[...]well, I did try to sort of finish it all, but I didn't make a very good attempt.[...] I don't think you can ever really make sense of it, to be honest, most of the problems are minor ones. Little stupid things, like nothing massively big happened to me [...] it was stupid little things like pouring a cup of tea. But when it happens day after day after day where you are missing the cup [...] And other people's attitude...(Colin:28/9)

Colin's suicide attempt was his reaction to the repetitive difficulties he has, both with dealing with the physical and social world in which he lives. Suicide, in these instances, cannot be viewed as acts of resistance, but rather they should be seen as attempts to escape the oppressive business of being disabled in an abled world.

Foucault, by simply having faith in the idea that care for self correctly will incorporate a care for others, looses sight of the overarching structures of inequality and disparity into which we are all positioned.

The version of the self that Foucault paints then, is strictly monadic. There is no sense of reciprocity or mutuality. But even more troubling is the formalistic nature of the ethic in question. One has always to be exercising self-mastery and a sagacious attitude over one's powers and pleasures. In *The Use of Pleasure* (1985) Foucault writes:

> It was not a question of what was permitted or forbidden among the desires that one felt or the acts that one permitted, but of prudence, reflection, and calculation in the way one distributed and controlled his acts. (Foucault 1985:52/53)

In other words the act itself cannot be 'good' or 'bad', what matters is the intensity of the act. This is to say that in antiquity, Foucault maintains that the important point was not that ones practices were inherently good or bad, but one should conduct one's practices with temperance and self control in order that ones vital powers were not sapped of energy. So, we are not talking here of ethics, but rather an aesthetics of existence. Eagleton asks:

> But it is surely not true that some sexual acts are not inherently vicious. Rape or child abuse are signal examples. Is rape morally vicious only because it signifies a certain imprudence on the part of the rapist? Is there nothing to be said about the victim? This is a subject-centred morality with a vengeance. (Eagleton 1990:394)

It would seem then that Foucault is propounding an ethics based solely on style or aesthetics. And as Eagleton pertinently asks: "What would a stylish rape look like, precisely?" (Eagleton 1990:394)

3. CONCLUDING REMARKS

In Chapter Five we saw how Foucault, in *Discipline and Punish* (1977) and in the first volume of *The History of Sexuality* (1978), presents a theory of power and its relation to the body which disability researchers can use to explain certain aspects of disabled people's oppression. In particular the idea that the body is produced through power and it is therefore a cultural rather than a natural entity is a powerful critique of essentialist notions of the disabled body.

As we have seen however, there are critical limitations to this work. The emphasis that Foucault places upon the effects of power on the body results in a reduction of social agents to passive bodies and does not explain how individuals might act in an autonomous fashion. In other words by insisting that the subject is a docile self-incarcerating body Foucault ignores notions of autonomy and self-determination.

It was with this in mind that I turned to Foucault's later works as I felt that here at last, he was going to address the question of the subject. However, as I have shown, Foucault's later work on ethics is problematic.

Whilst Foucault attacks the idea of ethics based upon a strict adherence to universal codes, the only alternative that he proposes is a stylized aestheticisation of life. Not only are there problems with this in regard to the misogynist and highly masculinist nature of the ethics he explores, but he seemingly ignores any notion of the self as being embedded and formed through types of social interaction.

Ethics of the self as outlined by Foucault privileges the self. That is to say that any notion of society and self acting together to produce the subject is lost.

Disability theorists should however consider the questions that Foucault raises concerning 'practices of freedom', the care of self and notions of personal transformation and self-creation. Foucault's final work on the government of individualization allows for an individual who is not simply reduced to a docile body through the normalizing mechanisms of biopower. In these works Foucault demonstrates how norms are imposed on forms of individuality, and, more importantly, he shows the numerous ways in which the individual can transcend these limits. The idea of self-reinvention and self-stylization as a basis for an ethics of the self is not wholly satisfactory as the underlying normative assumptions remain theoretically undeveloped. However this is not to say that we should disregard this aspect of Foucault's work out of hand. On the contrary. Foucault demonstrates how techniques for managing the self are sites for constituting distinct ethical subjects. And it is here that I believe that Foucault speaks directly to the individual as we "do" our disabilities.

The care of self, the aesthetics of self that Foucault outlines for us is a tactic, a strategy, a manoeuvre that enables us to resist on an individual level. Albeit this is a kind of 'romantic' resistance, but it is one that has been in existence in the theorization of disability and disabled people for a long time. If we consider the great resisting disabled figures such as Milton with his blindness, Beethoven with his deafness, Byron with his club foot, Rosa Luxenburg with her limp, or the crippled dwarfed hunchbacked figure of Gramsci or Toulouse-Lautrec we can witness how they constructed an aesthetics of themselves, an aesthetics of their existence. The question that remains to be fully explored then is how can this aesthetics of genius be translated into a practical aesthetics for people who are not great, for ordinary disabled people. I think that Foucault, in his final works has suggested ways in which we might be able to resist. This is not because he has returned to a notion of a spontaneous, creative self, but rather because he has looked at the ways in which people with a particular kind of self operate upon the world. It is not that we can talk about a 'disabled self' but rather that we can only construct a self out of the debris that is thrown at us.

In the next chapter I shall return to the work of Erving Goffman and explore the possibility of using both his work and that of Foucault simultaneously as resources to inform our understanding of disability. My intention is to explore the possibility of using Goffman in an attempt to retain some sense of agency and autonomy that is lost in Foucault's earlier work and which is problematic in his later work.

1. As Foucault acknowledges Greek ethics were linked to a male society in which women had no place. "They were the underdogs whose pleasure had no importance, whose sexual life had to be oriented only toward, even determined by, their status as wives..." (Foucault 1983:62)

CHAPTER SEVEN

FOUCAULT AND GOFFMAN: TOWARDS A SYNTHESIS

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Abstract: *The first section of this chapter outlines the similarities between Goffman's position regarding the subject and social organizations and that of postmodern relational epistemology. This leads to a direct comparison between Foucault's treatment of self, power and social control and that of Goffman. I argue that Goffman's theory of power is generally overlooked and that it is only through a careful and detailed reading of his work that we can see the parallels between his thought and that of Foucault. Both writers maintain that subjects are produced through social arrangements, and in the third section I investigate the role that impairment charities play in the construction of a disabled subject. By considering Foucault's notion of 'capillary power' and Goffman's concern with 'role distance' I argue that whilst there are substantial similarities between these two thinkers, their thought can never be totally synthesized. Foucault's work is at the macro level of investigation. He is concerned with how power becomes inscribed on bodies in general. Goffman, conversely, is concerned with how power operates at the individual, micro level of interaction. In the next section I examine the ways in which we "do" disability, using both Goffman and Foucault as theoretical resources. I conclude that for a theory of resistance to have relevance on the individual level we need to supplement Foucault's work with ideas informed by Goffman.*

INTRODUCTION

In Chapter Five I outlined how Foucault's 'genealogical' work can furbish us with an historical awareness of our present situation. This seems to me invaluable if we are to understand the prevailing view of disability and The Disabled, and hence consider possible modes of resistance. However, Foucault's notion of the self in this period remained one dimensional and thus problematic.

Following this, in Chapter Six I explored Foucault's later works to see if the ideas expressed in texts such as *The Use Of Pleasure* (1985) and *The Care Of Self* (1986) would give us a more rounded version of the self which could be of use in this study of power, resistance and disability. Whilst I concluded that there are some serious problems with Foucault's later works, they can still be of use to us. However, I am still very drawn to the theories of Foucault as expressed in *Discipline and Punish* (1977) and *The History of Sexuality, Volume One* (1978), and in this chapter I shall explore the possibility of supplimenting Foucault's analysis with theories of the self derived from the work of Erving Goffman.

So it is with this in mind that I shall now return to the work of Goffman which I examined, with particular reference to *Stigma* (1966), in Chapter Three. Goffman, it seems to me, has been largely neglected in recent years. As Tom Burns in his comprehensive survey of Goffman's work puts it:

> ...there has been a tendency to pass judgement on too narrow or too superficial an acquaintance with his work, perhaps on too hasty a suspicion of the swift popularity of his first publications. At all events, he has...been too often dismissed as entertaining, stylish, full of perspicacious insights and diverting comments, but essentially lightweight, uninterested in the weightier concerns of social science, not a true contender in the intellectual stakes at least at heavyweight standard. (Burns 1992:5)

Yet it has been argued (Battershill 1990) that Goffman in fact was the precursor to postmodern theories of the subject. This will be explored in the following section. However, the main thrust of this chapter is an attempt to draw together aspects of both Foucault's and Goffman's work to see if we can arrive at a concept of the subject, one which is more rounded and which will be of use to both disabled people and disability researchers. And, more importantly for this present work, to see if this will provide us with a means of questioning the prevailing notion of the disabled self.

In the first section of this chapter I am going to explore the idea that Erving Goffman was a forerunner to postmodernism. This will then lead on to a discussion of the similarities and dissimilarities between Goffman's and Foucault's work. In order to do this I will explore Goffman's theory of power, and I will look at the role that charities, as large organizations, play in the construction and maintenance of the disabled subject. In the final section I will explore the implications this has for our understanding of disability, power and resistance.

1. GOFFMAN AS A HARBINGER OF POSTMODERNISM

Erving Goffman's contribution to sociology is generally assessed by examining the structuralist trajectory of his thought, (Frank 1979, Kurzweil 1980) or by simply relegating it to the 'interaction domain'. Yet, in his influential text *The Postmodern Condition: A Report on Knowledge* (1984) Jean-Francois Lyotard cites Goffman's work as being of great importance in enabling him to compare institutions and society to rule-bound language games.[1]

Although Goffman later was able to acknowledge the methodological similarities between his work and postmodernism he did not explicitly set out to overthrow modernist epistemology. Indeed Battershill (1990) points out that Goffman's method is

> ...a result of a unique recombination of sociologically 'classic' modernist sources. (Battershill 1990:164)

Moreover, Goffman himself says:

> My belief is that the way to study something is to start by taking a shot at treating the matter as a system in its own right, at its own level, and, although this bias is also found in contemporary literary structuralism, there is an unrelated source, the one I drew on, in the functionalism of Durkheim and Radcliffe-Brown. It is that bias that led me to try to treat face-to-face interaction as a domain in its own right. (Goffman 1981:62)

Be that as it may, Goffman's treatment of personhood and social organization clearly has direct parallels with postmodern relational epistemology.

As we have noted elsewhere in this work, modernism's insistence on a unitary, knowable social reality[2] is upturned by Foucault and other postmodern commentators. Rather, they depict reality as a subtly changing, overlapping and limited series of realities, which are constructed through various discourses and knowledge. In other words social reality is understood to be relational.

It seems very obvious to point out that there is a direct correlation here between postmodernism and Goffman. Indeed Goffman's sense of social reality being primarily strategic and relational is clearly developed in *Presentation of Self in Everyday Life* (1959). The self we are presented with is one who inhabits a subtly shifting world, where meanings alter according to the 'reader', and management of self in terms of impressions intentionally 'given' and unintendedly 'given off' hold sway. Autonomy and free will are shown to be mere illusions created by society in order to render individuals obedient and normalized. In other words, identity and self-determination are fallacies employed by society to make individuals conform to its volition.

In his arguably most ambitious book, *Frame Analysis* (1974), Goffman gives us a detailed description of the de-centred subject. His aim in writing this book is:

> ...to try to isolate some of the basic frameworks of understanding available in our society for making sense out of events and to analyze the special vulnerabilities to which these frames of reference are subject. (Goffman 1974:10)

Or, to put in another way as he does later on in the book:

> My concern is to learn about the way we take it that our world hangs together. (Goffman 1974:440)

In this work then Goffman is interested in how we make sense of everyday life. This, he claims, involves compartmentalizing the world and our experiences of life. This happens both between the individual and the world and, as we shall see later, within the individual, resulting in a series of part-selves. Goffman returns to his dramaturgical model that he utilized in *Presentation of Self in Everyday Life* (1959), this time however, using it as a paradigm for social conduct rather than emphasizing its metaphoric nature. As the individual consists of a multiplicity of part-selves, Goffman suggests that theatricality is a necessary consequence of this capacity. (Burns 1992:239)

There are two main threads of concern in *Frame Analysis* (1974). Firstly Goffman outlines the 'different realms of being' we divide the world into, or that we simply assume it is divided into, in order to make sense of our lived experiences. This also involves looking at the mechanisms we habitually employ which enable us unproblematically to divide our experiences into these different realms. The second thread of *Frame Analysis* (1974) looks at the ways in which these different realms of being are anchored to our everyday, taken-for-granted world. We may temporarily or partially leave this commonplace world but we always return to it. In *Frame Analysis* (1974) Goffman makes it clear that not only can we make distinctions between different realms of being but that we can also move in and out of these realms by employing the mechanisms described in the first half of *Frame Analysis* (Goffman 1974). Goffman goes on to consider the manner in which we attempt to keep these different realms separate and also how these realities are constantly changing and shifting, and how:

> subject to assault by illusion, fabrication, pretence and deception is our capacity to discriminate between the different realms. (Burns 1992:240)

Before tracing Goffman's postmodern connections any further I am now going to look briefly at these mechanisms by which Goffman is able to articulate his theory.

Goffman suggests that when an individual responds to an event she employs one or more frameworks which he terms primary:

> ...a primary framework is one that is seen as rendering what would otherwise be a meaningless aspect of the scene into something that is meaningful. (Goffman 1974:21)

Whatever its degree of organization, each primary framework allows its user to identify, to locate, to interpret and to classify the numerous occurrences within it. The individual does not have to be, and is unlikely to be, aware of this ability to frame the occurrence. In the same way we are not hindered by our lack of conscious awareness of the features of the frame, but can operate easily and effectively, applying the rules within it. This can be seen plainly in my discussions with disabled people. For example, most people experienced consultations with their doctors as 'disempowering'. That is to say, and there is much sociological evidence to support this (see Silverman 1987; Hughes 1982; Fisher and Todd 1981; Roter and Hall 1992; Ainsworth-Vaughn 1992), that the primary framework of doctor/patient meant that the understanding of this frame dictated how both participants acted in relation to each other. Indeed Sarah felt that she was not allowed to question anything her doctors did or said:

> The doctors never used to say anything, they just used to look at me and they made me walk distances around the room and that was it - come back in six months - that's all I got. (Sarah:103)

So even though Sarah was unhappy with the way she was treated by her doctors, her understanding of the primary framework, that of doctor/patient, did not allow her to challenge her treatment.

The people I interviewed for this work are all extremely aware that the primary framework in operation during an initial interaction between them and non-disabled people is that of normal/abnormal. This frames the interaction on all levels. David recounts the following story:

> There was a place where you could mix with sighted people, supposedly. I went in one day and stood at bar: "Oh you're alright love,

> go and sit over there. I'll bring your beer to you." Says the bar maid. I says: "You what?" She says: "I'll bring your beer to you". "But I want to stand at bar." "Oh sorry dear," she says, "but everyone always sits in that corner, that's the place for the blind". (David:20/1)

Linda tells of times when she has been into the city centre with friends and they have decided to go to a cafe:

> ...and people saying no you are not allowed in here with the wheelchair. They say it is because there is not enough room, other people can't get by and things like that which is ridiculous. So we avoided those cafes, but for as many that refused us there was as many that opened their doors and made room just for us. (Linda:85)

The fact that Linda uses a wheelchair is the focal point for her encounters with strangers. Whether they are pleasant or rude to her is irrelevant in the sense that it is her difference from them that dictates what the primary framework will be. Again this is brought home to us when Chris says:

> 'Cos now I get people who come up to me in the street, seeing me walk, and they say: "Oh, What's happened to you? Oh I hope the Lord prays for you". And all this sort of stuff, and it just turns me off, you know. Or they stop me and tell me: "Oh I've got a bad knee, I've got arthritis in my knee". And they talk to me for ages and it drags on and drags on. I hate that. It really drags me down does that. Just because I walk with sticks they think they can intrude on me. Does your story help me walk into town? No. (Chris:262)

Throughout this work I have cited many examples from my data which attest to the fact that for us, as disabled poeple, the primary framework within which non-disabled people view us is one which highlights our differences from them. In other words our impairments are always perceived to be a, if not the, meaningful aspect of the interaction.

Numerous frameworks can, of course, be operating simultaneously.

By establishing the primary framework an individual establishes to some extent, what it is that is going on. There are, however, an untold number of occurrences which are removed or transformed from the primary framework, but based upon it. This, Goffman refers to as 'keying':

> ...the set of conventions by which a given activity, one already meaningful in terms of primary frameworks is transformed into something patterned on this activity but seen by the participants to be something quite else. (Goffman 1974:43/4)

Play activity of children, adults and animals is generally closely patterned after something that is meaningful in its own terms. We know, for example, that animals as well as people can play at fighting. In this case 'real' fighting acts as a model, a blueprint, a detailed guide to follow. Obviously the pattern is systematically altered in certain respects. Staying with the example of fighting we can see that there are many ways in which a fight can be rekeyed. A fight can be staged, fantasized, rehearsed, analyzed, recounted, ritualized and so forth.

When a keying is being performed it plays a crucial role in our understanding of what is going on. Whilst watching Macduff and Macbeth fighting on the ramparts of Dunsinane Castle for example, it might well seem that they are fighting, but the participants might say that the only thing that is going on is acting fighting.

Keying is not confined to occurrences viewed within any specific class of perspectives. Rachel, for example, describes, with some glee, how others have to rekey or adjust their understanding of the frame:

> ...being in the car is great because people can't tell that you are disabled, and you can stop at traffic lights and people look at you and you think 'Oh, they don't know'. That makes me laugh when you see their face! Usually I get my wheelchair out and I click it into position and their faces...! (Rachel:207)

Beth too, talks about her experiences of driving a 'normal' car:

> It's great! It's like a status symbol as well. I feel normal and I look normal. People don't appreciate that disabled people can drive and the fact that I've got a normal looking car. I find it very funny that as soon as I mention that I've got a car I can see people thinking: 'Oh this Robin Reliant type.' So I like to be able to say I've got a normal car with hand controls and you wouldn't think it belonged to someone like myself. You have this sense of power and control, you can beat people off the traffic lights, you can compete equally. (Beth:218)

Beth continues to describe how shocked people are when they see her get out of the car and into her wheelchair.

Obviously rekeying does not just occur when disabled people drive cars, but it does illustrate the point. On many occasions the disabled people I talked with tell of other people's embarrassment when they become aware of the disability for the first time. I have had much experience of this, particularly with my guide dog. When we arrive at a particular place, for example a pub, I remove her harness so that she can lie in comfort. As people seem to enjoy fussing dogs she receives much attention. It is only when we are leaving and I work her that people who have been petting her and talking with me, realize that she is a guide dog and therefore I must be blind. The general reaction to this is shock and embarrassment.

Yet rekeying does not just occur when a hidden disability is unexpectedly revealed. It happens when people make assumptions about who we must be, (generally negative). So, for example, when I accompanied an able-bodied friend to the hospital it was presumed that I, rather than Liz, was the patient.

Events can be rekeyed and rekeyed:

> While one thing may momentarily appear to be what is really going on, in fact what is actually happening is plainly a joke, or a dream, or an accident, or a mistake, or a misunderstanding, or a deception, or a theatrical performance and so forth. (Goffman 1974:10)

A society such as ours is replete with alternative ways of making sense of reality and as such, frames become increasingly subject to 'rekeying':

> Where, for example, the 'romantic dinner' is endlessly rekeyed in advertisements, soap operas, sit-coms, novels, songs and jokes. (Cohen and Taylor 1992:3)

This adding of layers to the original framework is termed by Goffman 'laminations'. The outer lamination or rim tells us what sort of status in the 'real' world the event has, whatever the complexity of the inner lamination.

Keying then, is one way in which an occurrence can be transformed. A second way in which a strip of activity can be transformed is by fabrication. This refers to the way in which one or more individuals deliberately give a false view to a person about what it is that is happening. I have already discussed in Chapter Three how many disabled people prefer to "pass as normal" even if this means placing themselves in painful and potentially dangerous situations. One women explains why she prefers not to use her wheelchair if possible:

> When I'm walking I definitely notice different reactions to when I am in my wheelchair. Because people think that you have broken your leg, you know, and they think 'Oh she's just broken her leg, she'll be alright in a few weeks', so it doesn't effect particularly the way they see you...(Rachel:200)

Amongst the disabled people I interviewed and from my own experience as a person with a sight impairment, it is very common to present oneself as an able-bodied person. In many instances this is a carefully organized fabrication involving planning and forethought. Kay describes how she used to hide her visual impairment so that she could keep her job:

> I mean I could do the job to a certain degree, like serving people, but it was only through my knowledge of being there a long time that I fobbed my way off before really. When I had the first haemorrhage I actually sort of looked through a spy glass to see prices and things but because I knew the till and I could feel it everybody thought that I could see more than I could. (Kay:272/3)

At other times it occurs as a result of having a 'hidden disability'. It may be hidden in the sense that the disabled person looks normal and/or if they are not displaying the appropriate sign to denote their difference. Fabrication, as with keying, is based upon a model, upon something that is meaningful in terms of a primary framework.

Fabrications vary considerably. They differ in intent, organization, length, and so on.

Fabrications can take the simple form of a tease or 'leg-pull', in which case it is unlikely to be a highly organised occurrence and often does not last even the length of an utterance, or they can be highly organized. Self-delusion, con tricks and tact are all forms of fabrication. In considering fabrication Goffman points out that it is necessary to bear in mind the limit or boundaries which govern the framework of the delusion. For example, playful fabrications such as leg-pulling have an obvious limit the breaching of which can lead to the questioning of the culprit's moral and psychological state.

Hand in hand with fabrication go suspicion and doubt, two distinctly different modes of operation. Suspicion arises when a person is unsure as to whether or not she has been allowed a full view of what frames her. Doubt arises when the individual is unsure of what framework or key is required or is fitting for the situation. Typically for newly-disabled people suspicion and/or doubt arises when we are unsure if our companions are fully aware of our 'new situation'. Kay talks of how difficult she finds it when she goes somewhere where there might be people she knows but who may or may not know of her recent sight impairment but:

> ...if people know then I find it fine and I am quite confident. (Kay:283)

Frameworks do not only organise meaning; they organise involvement. In any occurrence the participant not only has a sense of the framework, but there is also a sense, to a lesser or greater degree, of involvement. An individual can become engrossed, enthralled, and generally 'carried away' by the occurrence. The extent of the involvement obviously depends upon the organization of the frame. Some frames do not demand full attendance. Other frames demand more involvement. "Other frames", writes Goffman, "like that in which sexual intercourse is understood, prescribe involvement that is literally and figuratively embracing." (Goffman 1974).

Whilst limits are set as to what is the correct amount of involvement or what constitutes over-involvement, an individual cannot make a conscious decision to become engrossed. For as Goffman says:

> ...if a particular focus of attention is to be maintained, it cannot be maintained intendedly...since such an intention would introduce a different focus of attention, that of maintaining a particular one. (Goffman 1974:58)

If, in a particular strip of activity it becomes transparent that one participant is not sufficiently involved, or is not maintaining the prescribed attention, then this effects the other participants in that they become involved in thinking about the meaning of this lack of engrossment and thus, they themselves are no longer, to the same extent, involved in the original happening.

There are times however, when an event occurs that does not fit into the framework, and which cannot be ignored. These occurrences Goffman refers to as 'frame breaks'. "A break can occur in the applicability of the frame, a break in its governance". (Goffman 1974:46)

One type of frame break can be instigated by the human body, such as when an individual is dressed inappropriately, has an attack of wind or hiccups, falls over or whatever. Frame breaks can occur during any situation. However, scripted performances give clear examples of many different classes of frame breaks. The very nature of a stage performance is designed to engross the watcher. A frame break occurs when the actor steps out of her role. This can be in numerous ways: fluffing lines, laughing, having an accident with a prop,etc., etc. An interesting reversal of this type of frame breaking occurred recently in a London theatre. The show, a humorous, satirical look at circuses, involved a stooge in the audience stabbing one of the actors. Unfortunately, for the actor, the dagger failed to retract and entered his spleen. The rest of the company wanted to stop the show, but this proved to be very difficult. The more the injured actor moaned, the more blood there was, the more the audience laughed. The management stepped forward, but the audience believed this was still part of the performance and continued laughing. It seemed impossible to break the frame that the audience were in. It was only with the arrival of an ambulance and with the duration of time that it was eventually realised that this was 'for real' and not part of the show and that they needed to break frame.

For disabled people frame breaking may occur as a direct result of a disability. Steven talks of the time his sheath came off in a meeting and "then you just piss yourself really", and Beth talks of the time she was going to a conference, chatting "professionally" with other members of the conference but the building was not wheelchair accessible and so suddenly her disability was "very much the focus of attention". Equally frame breaks can occur when the able-bodied insist on talking about your disability even though it is irrelevant and ungermane to the situation.

As one moves from one realm to another frame breaks occur. From dreams to everyday reality; from a good book to the realization that you have missed your bus stop; from the world of the cinema to stepping outside into another reality; from 'playing at' to being. And of course, a common experience for disabled people, from feeling non-disabled to feeling profoundly disabled.

Alongside this exposition of the various ways in which we can frame our perception of the world around us, is the notion that our everyday reality is no more or less real than the unreal worlds which we construct out of its component parts.

As we mentioned previously, we maintain trust in the reality of everyday frames through the use of various procedures that anchor frame activity (Goffman 1974:247-51). As Philip Manning remarks:

> The fact that we almost always experience day-to-day life as a predictable and routine cycle of events is testimony to the heaviness of these anchors. It is psychotics and comics who cut the cord between anchor and frames, allowing them to drift in a sea of keyed and fabricated meanings. (Manning 1992:127)

Goffman articulated five such anchoring mechanisms. Namely, bracketing devices, roles, resource continuity, unconnectedness and lastly our own assumptions about what it is to be human, and to be a particular human. Basically, brackets delineate the beginning and end of a frame and also they suggest appropriate behaviour for that frame. So for example a nurse calling your name and ushering you into a consultant's room, and then seeing you out once the consultation is over can signal the beginning and end of a appointment with a doctor. This would be an example of an external bracket as it is not part of an on-going activity but rather tells us when it starts and finishes. An internal bracket is when a piece of activity is separated from the on-going frame but is still a part of it, or as Goffman calls them "temporary time-outs" (Goffman 1974:260). As we have already seen when we examined the disabled role, roles can anchor people to the activity and thus the frame. The more seriously people take their role to be, the less doubt arises as to the frame's meaning. Resource continuity refers to the way in which activities can be anchored over time. That is to say that past events can be verified and thus we believe in them. Unconnectedness is the recognition that many occurrences within a given frame are not recognised as important to our understanding of that frame. In other words the frame is anchored by acknowledging that many of the things that are going on within it are not relevant to our understanding of it.

The final anchoring device relies upon the assumption that human beings are a single entity which incorporates all the roles that we perform. It is these beliefs about the essential and constant nature of human identity which anchor a frame and limit its meaning.

The prevailing view held by the social interactionist school is that meaning is negotiated in situations. Burkitt (1991) argues that Goffman's interactionism stresses the notion that it is the individual who defines the situation and thus their own characteristics, and that this results in his work leaning towards subjectivism, for it:

> stresses the meanings that individual actors give to situations and the impressions they foster of themselves. (Burkitt 1991:69)

This then, results in individuals who can do nothing other than act in the way that they believe is expected of them. However, whilst Goffman agreed that 'the definition of the situation' is of central importance and that meaning can be created anew in each situation, he stressed that in actuality the meaning is embedded in the situation:

> Presumably a 'definition of the situation' is almost always to be found, but those who are in the situation ordinarily do not create the definition even though their society often can be said to do so; ordinarily, all they do is to assess correctly what the situation ought to be and then act accordingly. (Goffman 1974:1-2)

Following on from Jameson (1976), Battershill (1990) suggests that by attaching more weight to the situation as opposed to a notion of negotiated meaning, Goffman is close to:

> a post-modern stance predicated upon the perception of persons as subjects in and of various knowledge fields. (Battershill 1990:171)

In other words the modernist subject is de-centred by giving precedence to a socially-derived knowledge-structure over individual consciousness.

Goffman's notion of the frame, of its component parts, and of its function as the very organizer of social meaning suggests then, a way of analyzing everyday life and individual existence which has strong parallels with Foucault's notion of a disciplinary society producing docile bodies.

Having summarily outlined Goffman's postmodern connections I now want to focus on the points of convergence and those of divergence between Goffman and Foucault.

2. FOUCAULT AND GOFFMAN: A COMPARISON

2:1. ORGANIZATION MEN

A striking similarity between the work of Goffman and Foucault is to be found when we compare *Asylums* (1961a) and *Discipline and Punish* (1977). Both authors, who were unaware of the other's work, stress the similarities in seemingly disparate institutions and organizations, such as prisons, concentration camps, hospitals, schools and army barracks. Basically *Asylums* (1961a) is an account of the ordering of identities and work-relationships by modern organizations. The notion that citizens are disciplined, controlled, hierarchized, that identities are regulated by modern organizations is, of course, crucial to Foucault.

As has been said, it would appear that Foucault and Goffman were unaware of the other's work, and yet it has been suggested that Goffman's approach as to how organisations can produce the individual would have made an appropriate starting point for Foucault's far wider thesis. (see Burns 1992:162-6, Battershill 1990).

Goffman and Foucault argue that the purpose of institutions such as prisons and mental institutions is not to 'cure' or normalise deviant behaviour but on the contrary: these institutions serve to perpetuate deviant behaviour. Their function is to marginalize, compartmentalize and categorize. Indeed Goffman says that 'total institutions' function most of the time

> merely as storage dumps for inmates, but,...they usually present themselves to the public as rational organizations designed consciously, through and through, as effective machines for producing a few officially avowed and officially approved ends. (Goffman 1961:73)

And from Foucault we have:

> The prison was meant to be an instrument, comparable with - and no less perfect than - the school, the barracks, or the hospital, acting with precision upon its individual subjects. (Foucault 1980:40)

So in other words these institutions exist ostensibly to normalise its inmates but in actuality their function is to highlight difference, separateness and otherness. Concepts without which normalization could not be articulated.

It is when we examine issues of power and social control that we can appreciate the similarities between Goffman and Foucault. For both the writers the ways in which organizations and institutions control their 'inmates' and the people who work for them is dependent upon 'normalization'. Foucault and Goffman both assert that it is through this concept that power is able to exert its hold on the subject in modern society.

I wish now to concentrate upon Goffman's notion of power, in order to contrast it with Foucault's conception of power as considered in Chapter Five.

Although Gouldner (1970) maintains that Goffman fails to demonstrate how power functions in society, and in particular, how it is manifest in institutions I want to argue that this is not the case. Goffman never claimed to be a 'theorist of power', and yet power plays an important role in his work. Admittedly, in the main, power is *implied*, rather than made explicit, yet power resides in every strategic interaction. It should be remembered in any consideration of the state of power in Goffman's work that he is not maintaining that all phenomena which occur during interaction are closely linked to power. Rogers (1980) sees in Goffman's writing that:

> Intentionality serves...to specify a conceptual boundary separating power and closely related phenomena from other phenomena which are commonplace in social interaction. (Rogers 1980:104)

So intentionality is pivotal to an understanding of Goffman's portrayal of power.

We have already noted that Goffman distinguishes between impressions "intentionally given" and those "unintendedly given off". The distinction here is between strategic interaction and nonstrategic interaction. Strategic interaction refers to instances where the interactant is aware of a preferred outcome to the encounter, and, more pertinently, is also able to choose certain modes of behaviour which are more likely to facilitate that outcome. In other words strategic interaction is a specific class of interaction, a type of interaction, which involves conscious and deliberate moves of planned behaviour. The implication is that in all encounters there is a strong calculative, exploitative, and/or competitive element. Thus assessing other people's intentions and motives is crucial to all encounters. And it is in examining the mechanisms at work here that we are able to review Goffman's implicit theory of power.

Power, here, takes the form of *resources*. By this Goffman means each individual's specific capacity to affect the behaviour of others.

We have already seen how meaning is embedded in the situation, and how individuals judge the occasion and act accordingly. Now the resources that an individual can draw upon in her reaction to a given situation define in part one's power in that situation. Thus it is that Goffman claims that it is the situation itself which primarily delimits power. This is not to say that the individual does not affect the power within the interaction. On the contrary, Goffman's argument is that it is both individual-based factors and situation-based factors which set the parameters of one's power.

It is at the level of 'resource continuity' that individual-based factors function. As Goffman says in *Frame Analysis*:

> The resources we use in a particular scene necessarily have some continuity, an existence before the scene occurs and an existence that continues on after the scene is over. (Goffman 1974:222)

These different resources have been termed by Mary Rogers (1974) as instrumental and infra-resources. She sums them up thus:

> ...instrumental resources are the *means* of influence, those attributes, circumstances, and possessions which can be activated or invoked to reward, punish and/or persuade others. Infra-resources, on the other hand, are those attributes, circumstances, and/or possessions which *relative to a given situation* must be had before one's relative instrumental resources can be activated or invoked. (Rogers 1980:131)

In considering instrumental resources Goffman talks of "primary capacities". These are often interpersonal skills which contribute to one's power:

> ...certain capacities, certain properties of the make-up, appear to be of intrinsic or primary relevance: in high construction work, care and balance; in mountain climbing, 'condition' and stamina; in bull fighting, timing and perceptual judgement; in game hunting, aim; in gambling, a knowledge of the odds; and in all cases, memory and experience. (Goffman 1967:215/6)

These capacities are not necessarily so specific to a given task. They also refer to:

> the conditions which bear upon their exercise, such as innate human propensities, culture bound beliefs, social norms, the market value of labour and so forth. (Goffman 1969:3)

In addition to these various attributes which can augment one's power Goffman cites knowledge. Knowledge and its corresponding ability to affect the player's power. In *The Presentation of Self in Everyday Life* (1959) Goffman talks of "information control", "misrepresentation", and "strategic secrets" (1959:142), whilst in *Strategic Interaction* (1969) Goffman writes of "the individual's capacity to acquire, reveal and conceal information". (1969:4) And, more explicitly, in *Frame Analysis* (1974) Goffman talks of "information states":

> By an information state I mean the knowledge an individual has of why events have happened as they have, what the current forces are, what the properties and intents of the relevant persons are, and what the outcome is likely to be. In brief each character at each moment is accorded an orientation, a temporal perspective, a 'horizon'. (Goffman 1974:133/4)

It is clear then that knowledge is crucial in demarcating one's power in a given situation.

It is when Goffman turns his attention to "infra-resources", that is to say to perceptions, information and access, that he is able to discern the "power-relevance of people's subjective assessments" (Rogers 1980:105). In situations, for example, which are understood to be fateful, "consequential and problematic" (Goffman 1967:216) one's power in a given situation can become unstable:

> An individual's sudden sense of what might shortly occur can have a marked effect on his behaviour,...the principled behaviour he manages to exhibit during ordinary occasions may break down. The quick consciousness of what his principles are costing him at the moment may cause his wonted decency to falter...naked self-interest may obtrude...similarly in the matter of task performance, his imagining to himself the consequence of failing or succeeding can work strongly upon his capacity to exercise the primary capacities in question. (Goffman 1967:216)

The power one has in a given interaction then, is susceptible to one's definition of the situation, to the knowledge or information the player has access to, and to one's past experiences with the specific interactant, and also of one's past experiences of 'others of her kind'. The power one has in a given situation is also susceptible to the reputation of the other.

As an infra-resource, access to correct information is crucial to the working of power. The connection between role performance, information possessed and accessible regions are firmly, if not inextricably, linked:

> ...during the performance we may expect to find correlation among function, information available, and regions of access, so that, for example, if we knew the regions in to which an individual had access we would know the role he played and the information he possessed about the performance. (Goffman 1959:144)

Yet the relation between function, information and place is seldom this simple.

Goffman systematically outlines various discrepant roles which complicate matters. He defines these discrepant roles as "additional points of vantage relative to the performance" (Goffman 1959:145). These include "the informer, the shrill, the spotter, the shopper, and the go-between" (Goffman 1959:150) These terms are pretty much self-explanatory, but I will briefly expand on the 'informer' to illustrate Goffman's notion of discrepant roles and the power relevance of them. The informer is a person who joins a group with the explicit aim of learning their secrets, weaknesses and information that can be used against them. She gives the impression that she is a valid member of their team and thus gains access to 'back-stage' areas and can acquire destructive information, "and then, openly or secretly sells out the show to the audience." (Goffman 1959:145) An undercover police officer, a spy and many forms of criminal activity depend upon this discrepant role. But equally the role of informer can be more subtle such as when a person with a hidden disability discusses with an able-bodied person the role of disability without letting on that they are a member of this group. Furthermore, the role of the social worker, doctor and/or researcher may also fall within this category. As has already been made clear, disabled people are generally well-acquainted with these roles and more often than not we are familiar with people performing these roles, gaining trust and then often betraying us. Numerous people I talked to (and from my own experiences) were thoroughly disillusioned with the medical profession and more specifically with the social services who, in Sarah's words "are always promising to do things for you but they never do. *They pretend to understand but they do not*".

I have argued so far that power, in Goffman's work is understood in terms of resources. I now want to focus on power in terms of control.

We have already seen how power can be the direct result of the ability to influence the others' definition of the situation. As Goffman says:

> ...in all interaction a basic underlying theme is the desire of each participant to guide and control the responses made by the others present. (Goffman 1959:3)

In both *Asylums* (1961a) and *Stigma* (1963b) Goffman demonstrates how people can be so categorized or labelled that little control, power or autonomy is left to them. We saw what typically happens when a stigmatized person attempts to resist the "all-embracing identification"(Goffman 1961a:84/5. See also Chapter Three).

Goffman, writing in 1963 says:

> In our society, to speak of a woman as one's wife is to place this person in a category of which there can be only one current member, yet a category is nonetheless involved, and she is merely a member of it. Unique, historically entangled features are likely to tint the edges of our relation to this person; still, at the centre is a full array of socially standardized anticipations that we have regarding her conduct and nature as an instance of the category 'wife'. (Goffman 1963b:70)

It is the categorization, classification, naming and labelling of people which constitute mechanisms that generate control.

Throughout Goffman's writings we see the workings of this power. Everyday life is a catalogue of pressures, both subtle and blatant, which we either exert on others or others exert upon us. Indeed, any sense of an orderly life, of the smooth working of society, is dependent upon intricate principles of social control.

Like Foucault, who always allows for the possibility of resistance, Goffman is aware of the continuous possibility of disorder and chaos. I have already outlined the various mechanisms by which we habitually carry out corrective or remedial work, and I now want to say a little about the idea of self-control or as Foucault would term it "self-surveillance".

In order for smooth interaction to occur we are reliant upon a notion of intelligent self-control:

> The individual comes to appreciate the claims of himself and others and exercises his ability to manage his own behaviour so as to minimize infraction. (Goffman 1971:121)

The traditional or orthodox view of control, which includes self-control, is reliant upon normalization. It is through socialization that we get a sense of right and just action and also our sense of what is wrong and unjust and therefore not socially acceptable behaviour. We build a set of beliefs concerning laws we should uphold and the consequences due to us if we should break them. We become aware of the image we present to others and thus we become "decently concerned" (Goffman 1971:346) with our reputations and what others think of us.

Taking the notion of internalized norms as central, Goffman identifies three basic forms of "normative social control" (Goffman 1971:346) upon which the orthodox view of deviancy is based. First, and Goffman states, "no doubt most important" (1971:346), is "personal control" (1971:346), that is to say a person disciplines herself, she acts upon herself under the ever watchful eye of an internalised policeman. So, for example if a person acts improperly, she admits to it, judges herself and takes remedial action so as to reestablish norms and herself as a person who is respectful of them. Second, there is what Goffman terms "informal social control"(1971:347). This refers to those instances whereby a person begins to display some deviation towards the norm. As soon as this person starts to 'step out of line' others present warn her, and generally let it be known that remedial action must be taken immediately so as to reestablish and reaffirm normalacy. Third is the idea of "formal" social control. This refers to organizations, institutions and professions which are called upon to deal with the threat to social order created by the offender.

Both informal and formal social control depend, to a large degree upon personal control:

> For control that is initiated outside the offender will not be very effective unless it can in some degree awaken corrective action from within. (Goffman 1971:347)

Goffman continues his essay "Insanity of Place", (1971) however, by saying that this prevailing view of social control is too simplistic, for it "provide[s] a very narrow picture of the relation between social norms and social deviations" (Goffman 1971:347).

For a start Goffman says these forms of social control might be effective, not because of an individual's "moral concern" but because of "expediential considerations"

(Goffman 1971:347). That is to say the individual's assessment of what she might loose or gain are the stakes, rather than her moral sensitivity. Equally, offenses are not automatically followed by sanctions, and in the cases where they are this does not necessarily mean a reduction in offenses. It might simply mean that the offender chooses not to spend time with those she has offended by: "placing their social business with someone else" (Goffman 1971:348). By doing so, however, more than simply a negative sanction is constituted. This is a form of management in its own right.

In the case of formal social controls Goffman lists numerous reasons as to why it might be inadvisable to call upon these agents:

> ...the cost and time required to make a formal complaint and appear in court; the uncertainty of the legal decision; the personal exposure involved in taking official action; the reputation that can be acquired for being litigious; the danger of reprisal later by the offender. (Goffman 1971:348)

There are other possible outcomes which reveal that the apparatuses of social control are not necessarily advantageous. Offenders may be victorious, forcing others to toe the new line they have drawn:

> Some of the mutinies that occur in schools, prisons and ghettos illustrate the same theme. The social changes produced by the labour movement and the suffragette movement provide further examples. (Goffman 1971:349)

But even in instances where withdrawal from the offender or acquiesence to her does not occur, it does not follow that social control is inevitable. The very mechanisms of social control themselves - negative moral sanctions and the material costs of deviation may fix the offender more firmly to her offence.

Goffman continues his attack on the orthodox account of deviancy by suggesting that an offender will get away with her offence if she uses enough tact, circumspection or secrecy. And that the point in fact is not whether or not a person offends but rather not to be seen as offending because this is precisely the same as not offending:

> The issue is not merely (and often not mainly) whether he conformed or not, but rather in what relationship he stands to the rule that ought to have governed him. Indeed a significant feature of *any* act is what it can be taken to demonstrate about the actor's relation to such norms as legitimately govern it. (Goffman 1971:350)

The important point Goffman demonstrates is that social control of everyday behaviour and interaction with others is accomplished by *displaying* conformity to social norms. The crucial factor is how people interpret another's conduct. So long as the offender does not openly flaunt her offence, so long as its property or "sanctity" is not denied then social control is not necessary. Further, what usually occurs when an offence is committed is that the offender, rather than offering reparation, shows that her offence does not represent her true attitude towards the social norm:

> Social norms are not designed for the systematic control of the individual *per se* but of the relationships in which his membership of organizations and communities involve him. An individual, by acting in an offensive way, and in the absence of any remedial work, or subsequent show of repentance, seems to 'proclaim to others that he must have assumptions about himself which the relevant bit of social organization' (e.g. family, social gathering, work place) 'can neither allow him *nor do much about*.' (Goffman 1971:356 quoted in Burns 1992:174 emphasis added by Burns)

In treating power as a routinized on-going effect Goffman draws close to Foucault's conceptualization of power. Goffman provides a framework for identifying the relevance of ill-fame, negative labels, stereotypes, stigmas, ideologies, belief systems and the like, to power.

I have argued that Goffman conceives of power as a potential or a capacity comprising of resources and control. He looks at both instrumental and infra resources, primarily focusing on those available to middle-class Americans in the 1950's and 60's - for example, questions of access and information. Secondly he looks at specific strategies of power and influence, for example misrepresentation and sanctioning. And thirdly he examines how prevailing ideologies or beliefs are used to control and influence others. Indeed Rogers (1980) writes:

> Thus within his dramaturgical framework, Goffman offers a rather far-reaching, intentionality-based commentary on power and related phenomena. (Rogers 1980:110/1)

It seems clear to me having briefly outlined Goffman's implied theory of power, that there are many aspects of his work which converge with Foucault's conceptualization of power.

Both Foucault and Goffman are in accordance with the idea that mechanisms of social control do more than uphold social order and structures. They maintain that our very identities are constructed and created for us through such social arrangements. Goffman writes:

> The self...can be seen as something that resides in the arrangements prevailing in a social system for its members. The self in this sense is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by himself and those around him. This special kind of institutional arrangement does not so much support the self as constitute it. (Goffman 1961a:168)

It seems to me that Foucault could have easily taken Goffman's conception of the self being constructed through organizations and broadened the implications of this for his own research. Yet there is no evidence to suggest that either was even aware of the other's work. Burns writes:

> It is almost as if Foucault had taken up Goffman's interpretation of the process by which organizations impose an appropriate identity on their members and expanded it into a much wider thesis about how political power is exerted in modern society. (Burns 1992:160)

We have already noted how disciplinary power is exercised through essentially social institutions: "...the disciplines of the barracks, the hospital, the school, the factory" (Taylor 1984:159), and how in his later works Foucault included the disciplines of the family and everyday life. In other words it is primarily through internalising culturally and historically specific normative codes of behaviour that power operates. This is reinforced through mechanisms of social control; through inducement to behave, and penalties for rule-breaking. Techniques of social control are born out of the mechanisms of domination, and exist to reinforce them:

> ...one must be able simultaneously both to increase the subjected forces and to improve the force and efficacy of that which subjects them. (Foucault 1980:104)

This is, as I have remarked, similar to the workings of power within total institutions as witnessed by Goffman.

Foucault and Goffman have both attempted to lay the foundations for a base, a construction, from which the insidious workings of normative power may be analyzed. The two of them, in their endeavour to identify, observe and record the exercise of this power, chose to concentrate on dissidence and the various mechanisms for its control.

The apparatuses of normalization ensure that its operation is so commonplace that it goes largely unnoticed, unquestioned and unchallenged. It is this very familiarity with normalising power that enables it to have such strong disciplinary effects. We are all familiar with the 'disfunctional family', the 'delinquent teenager', and the 'maladjusted child', and by and large these categories, and others, are accepted as given and unproblematic.

We have seen clearly how schools, hospitals, the army all serve normalising power. Social institutions of whatever type have to deal with all sorts of 'misfits', and those institutions which are filled with 'deviant elements of society', be they mental patients, prisoners or whatever, are especially designed to handle refractory members of society. What is being challenged by these people is not just the law, or socially acceptable modes of behaviour, but normalising power itself. Thus they are potentially disruptive and subversive.

Goffman's work on total institutions can be seen then as an analysis of what happens to individuals who test the limits, or push boundaries of normalising power: "who test the forces of normalization beyond their limits of tolerance" (Burns 1992:165).

In Chapter Five I recognised that the effects of normalizing power were not as haphazard or indiscriminate as Foucault would have us believe. Equally Goffman's notion of the effects of organizations upon the constitution of the individual are not quite as straight forward as he would have it. The inducements to become "organization men" (Burns 1992:166) are more compulsive, coercive and concealed than Goffman gives credence to. In other words both Goffman and Foucault fail to acknowledge that the normalization process does not work in some random, haphazard fashion. On the contrary, it is resolute and determined. In the next section of this chapter I will be considering the role that charities, as organizations, play in the constitution of a disabled subject.

Foucault's analysis is concerned with identifying the limits of normalizing power through a consideration of what occurs once these boundaries are questioned. In this way he identifies the character, intent and magnitude of normalization. However, Foucault is theoretically distant from people's everyday lived experiences. That is why, for example, it has been very difficult to incorporate the voices of disabled people into the chapters concerning Foucault in this work. In Goffman, however, we see clearly Foucault's constructions being exercised in the particular. In his work on total institutions Goffman, in empirical terms at least, grounds Foucault's research in the everyday experiences of real people. Moreover, in *Stigma* (1963b) Goffman demonstrates how normalising power operates within the boundaries of tolerance. As we saw in Chapter Three Goffman argues that normalising power (not that he uses this

Foucaultian term) acts as an unseen arbiter in all social encounters.

If we no longer view power as negative and repressive but instead utilize Foucault's retheorization of power as positive and productive, we can then credit power with the ability to produce the cultural forms and social stratifications we are so familiar with in our society (McHoul and Grace 1993:82). A short exploration into charities for disabled people will highlight the ways in which these organizations function daily in terms of their own procedures and techniques. The particular configuration of power relations at work, upon which these charities depend, will be made manifest. Furthermore by analyzing charities as capillary sites for the exercise of power we can examine the effects of such power relations without having to explain why or who power serves.

2:2. THE HELPING HAND

In this section I want to examine the ways in which charities *for* various disabilities exemplify moral normalizing discourses *par excellence*. By concentrating on charity advertising I hope to illuminate the mechanisms by which organizations induce their members to identify with organizational goals and values.

Traditionally, at least, charities for disabled people have been one of the central agents of disabled people's institutional and representational oppression. Yet whilst these charities are the most prolific producers and distributors of negative disability imagery, they are, as we have seen in Chapter Three, by no means unique in their nihilistic portrayal of us. So, whilst I am focusing on the representation of disabled people in charity advertising I am not arguing that the imagery used here is somehow 'worse' than other portrayals of disabled people.

Whilst exploring Foucault's genealogical works (Chapter Five) it became clear that the historical development of charities cannot be separated from the backdrop of ever-increasing discipline, surveillance and segregation. The growth of institutions, asylums and charities was a direct result of the ever-increasing normalizing power. Charities distinguished between the 'deserving' poor, i.e. disabled people, and the 'undeserving' poor, i.e. the lazy. With the growth of charities the notion of disabled people as dependent was consolidated.

Finkelstein (1980) argues that this segregation of disabled people, whether in specialized schools, hospitals, institutions or colonies, allowed for the growth of a whole array of disability experts and professionals. Thus it is that Finkelstein (1980) asserts that these specialists, physiotherapists, occupational therapists, social workers, counsellors, and so forth are themselves dependent upon the dependency of disabled people.

Charities for disabilities operate in exactly this way. These charities highlight the impairment, siting it firmly within the disabled body, and stressing the dependent nature of disability. Without which, of course, charities themselves would not exist.

On the surface it might appear that recent charity advertising provides a more positive image of disabled people than used to be the case. Yet, as David Hevey, in his original work *The Creatures Time Forgot* (1992) points out:

> ...they are likely to show disabled people not as chronically unconscious dependants (or monsters) but more as grinningly happy dependants (or monsters). (Hevey 1992:11)

Disability charities emphasize the impairment. That is to say that any notion of a socially constructed disability is overlooked in favour of the image of an impaired, broken body. Note the stress, for example, on the impairment in the names of the following charities: "The Guide Dogs For The Blind"; "The Multiple Sclerosis Society"; "The Royal National Institute For The Blind"; "The British Epilepsy Association"; "The British Diabetic Association". This is to say that charities for disabled people whole heartedly subscribe to the personal tragedy theory of disability. A theory, as we have already noted, which negates any notion of a political theory of disability.

I am now going to look at the way advertisements for impairment charities operate. In doing this I am drawing upon the work of David Hevey.

2:2:1. THE THREE STAGE PLAN

According to Hevey (1992), charity advertisements, in the main, follow a clearly identifiable three-stage plan: branding; attitude change and functional state.

The purpose of the first stage of this plan is to create 'brand awareness'. That is to say that a photographic image of a particular impairment has to be produced which also subtly links the impairment with the charity. The image has to portray not only the impairment but its social effect. So what is created is a symbolic and also social identity for the impairment. The body of the impaired person becomes central as it is both the essence and the symbol of disablement. The object of this first stage then is, as Hevey (1992) remarks:

> ...to place the symbol of the impairment into a social orbit but labelled as the property or concern of the affixed charity. (Hevey 1992:34)

The purpose is to make the general (non-disabled) public aware of the particular brand of impairment. Ostensibly the charity itself is not proclaiming its own existence. It is not marketing itself, only speaking for those who, presumably, cannot speak for themselves. Yet in reality charities for disabled people have to compete, not only with other charities but also with other charities who claim to have the same members as each other.[3] If charities are to exist they need to secure voluntary funds, and they need to compete successfully with commercial advertising. But they must compete without appearing to do so. Impairment charities use a number of common devises to distinguish them from commercial advertising. The two principle differences are that whilst commercial advertisements tend to be colourful, charity advertisements are usually monochrome. The second noticeable difference is that commercial advertisements sell desire, charity advertisements sell fear. "Charities promote a brand not to buy, but to buy your distance from" (Hevey 1992:35).

Typically then in this first stage a black and white photograph of an individual with an impairment, placed in a non-social environment is shown and the message the public are supposed to receive is how this person and others of her kind are neglected by society. However, juxtaposed with this negative image is the text. This text supposedly challenges the bleak photographic message. Where the image is negative, the text is positive. Help is available. And it is the charity which can provide that help. The name of the charity is written small and modestly at the bottom of the advertisement.

We see here then that two separately located meanings exist simultaneously within the charity advertisement. One in the image - inducing fear and pity - and one in the text - help is at hand. Yet image and text are consumed as one. Hevey (1992) argues that this creates what he terms a "double bind". Here we have impairment depicted as dependent and despairing and we have the charity for the appropriate impairment depicted as active and empowering. In other words the double bind consists of oppressive image/textual hope.

This double bind continues into the second stage. Now it is assumed the public are aware of this particular impairment and so the advertisers can elaborate upon their earlier theme. That is to say that the connection between the dependent disabled person and the reliance upon the appropriate charity in terms of care and/or cure is consolidated. Whilst Hevey (1992) terms this second stage "attitude change" he is not advocating that this new awareness of the impairment and its corresponding charity will negate oppressive practices towards disabled people. On the contrary Hevey (1992) argues that this second stage, whilst ostensibly promoting change is in fact perpetuating the tragic nature and passivity of disabled people:

> 'Attitude change' is the charities' dream of social change without political action. (Hevey 1992:36)

This discourse of 'attitude change' as expounded by charity advertisements merely serves to perpetuate disabled people's oppression, and, furthermore, it 'blames' the disabled person if they do not help themselves. The charities portray the notion that they are attempting to challenge prevailing views of disability, yet in reality these advertisements do just the opposite. The photographic imagery is negative whilst the text purports to challenge this. The basic message in these advertisements is that without the charity disabled people have no future, no life worth living.

The imagery used in both stage one and two of charity advertising can be very similar: the dependent, despairing, flawed body of the impaired individual. The text however is different. In stage one the text is impairment-specific and 'factual'. It introduces the public to the horror of a particular impairment. In stage two the text gives its reader more insight into the impairment. This is either done through a personal account of the disability, and/or through challenging the negative photograph. However, what is stressed in this second stage is that the charity exists unquestionably for people who suffer from its particular brand of impairment.

The juxtaposition of seemingly contradictory messages between the photographic representation and the text involves the viewer in seeing just how dependent upon the charity this particular 'sufferer' is. It is this aspect that becomes further highlighted in the final stage, which Hevey (1992) terms the "functional stage". Now we see images of disabled people who have overcome the difficulties of their impairment. But, and this is the important point, they have only been able to do this through total reliance upon the charity. Again we see the use of the double bind: the image verses the text. This time however there has been a reversal. Now the image is more positive, the text more negative. The text has to stress that without the active involvement of the charity this person would be unable to do whatever it is they are doing in the photograph. In other words the disabled person's ability to function socially is dependent upon the charity and thus upon the public's generosity.

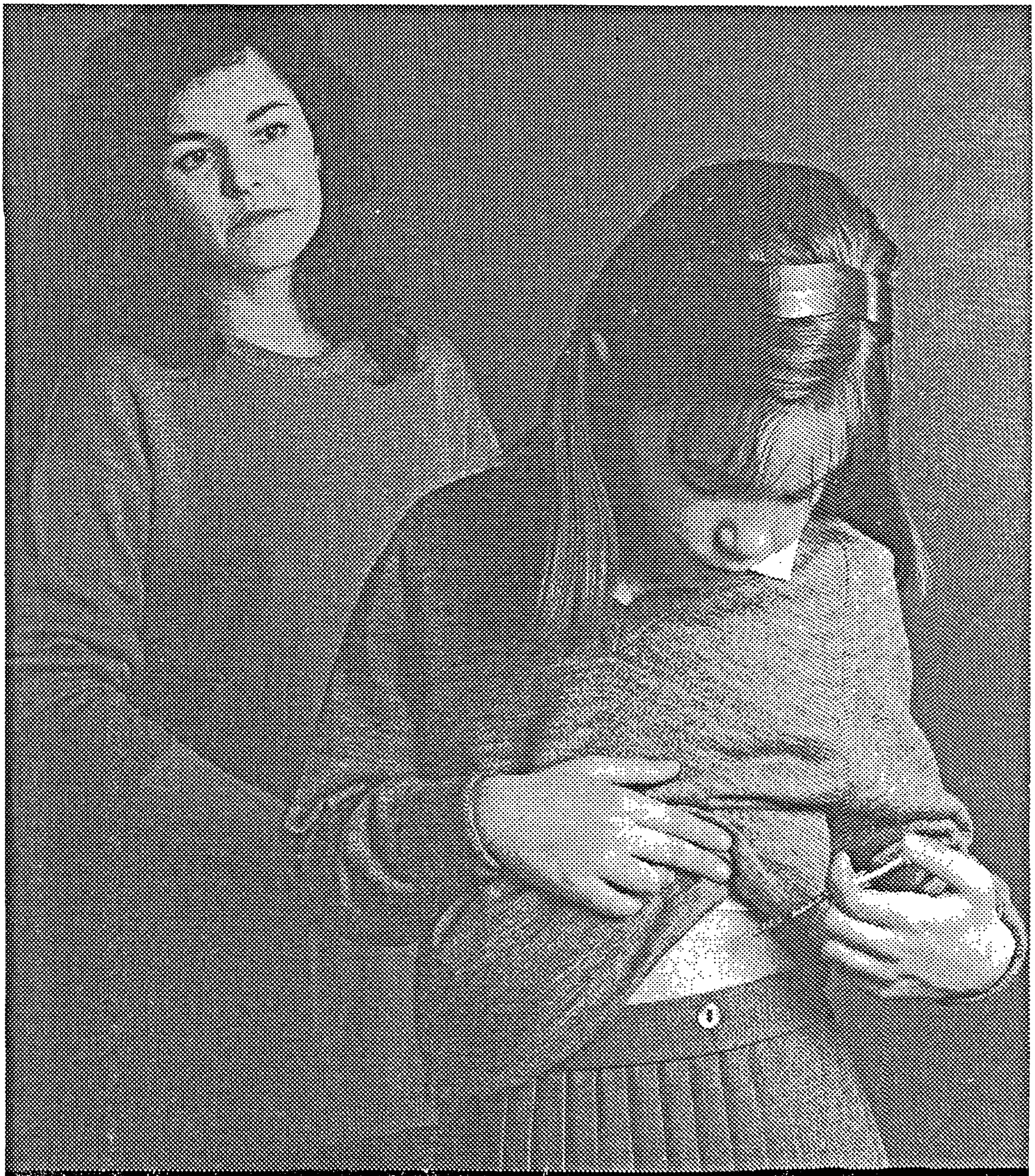
Throughout stages one, two and three the focus is on the flawed body. However, the final stage Hevey (1992) argues is a response to the growing politicalization of disabled people.

Hevey (1992) makes it clear that his three-stage plan for charity advertising is not all-encompassing, nor need charities be consciously aware of its operations. However he does stress that:

> ...the point I am making by outlining these three stages is to show the process that is common to many charities who wish to position themselves through advertising. It is likely that this trend will continue to grow. The notion of a *process* of charity image making is also important to grasp [...] because some people are being seduced into seeing the different stages as a 'positive' move on from the previous one. All charity advertising, in the final analysis, must somewhere in its poster posit the notion of its particular brand of impairment being dependent on charity. It is ridiculous to ask anything else of impairment charities. (Hevey 1992:41/2)

The advertisement on the following page for The British Diabetic Association fulfils all the criteria of Hevey's (1992) stage one of an advertising campaign. The photograph is black and white, showing an obviously anxious mother watching her daughter inject her flawed body. The text is factual: "recent reports show that the incidence of diabetes in children under 15 has nearly doubled in the last 15 years." At the same time the text highlights the horror of being diabetic: "injecting themselves with insulin at least twice a day, just to stay alive." But we need not despair - the Diabetic Association is at hand to conduct research into possible cures. As most people who have had diabetes for over twenty years know, the complications associated with diabetes, such as loss of sight, kidney failure, neuropathy, are far more serious than having to inject yourself. However, the general public's awareness of diabetes is generally restricted to the idea of having to inject oneself. This advert plays on the fear of injections that non-diabetics seem to have. So in fact the so-called factual text is not in itself particularly factual; rather it emphasises one aspect of this illness rather than trying to inform people.

The next advertisement illustrates the second stage as outlined by Hevey (1992). Again we have the black and white photograph depicting a flawed body, a tragic persona. But this time the text is less impairment specific. Now we hear the voice of this particular impaired individual, who is challenging the reader's understanding of cerebral palsy, and in this case her 'speech defect'. She has been "ignored" by society and she is "tired of it", as is her charity, Scope. And it is this charity who can give her hope, who can help. In other words she is promoting the charity rather than fighting for any egalitarian notions.



The parent of a child with diabetes learns to let go sooner than most.

When your child suffers from diabetes, there's a strong temptation to wrap them up in cotton wool.

Which is actually very dangerous. Because once children with diabetes start school they are responsible for injecting themselves with insulin at least twice a day, just to stay alive.

Diabetes is not a rare complaint. Over a million people in the UK suffer from this incurable condition. And recent reports show that the incidence of diabetes in children under 15 has nearly doubled over the last 15 years. (British Medical Journal, 1991, 302: p.443-7.)

The British Diabetic Association is the UK's single biggest contributor to diabetes research.

Please help us by sending a donation, joining the British Diabetic Association or remembering us in your will.

Because the only time this parent is going to feel confident enough to let go is when we find a cure.

To the BDA, 10 Queen Anne Street, London W1M 0BD.
Tel: 071-323 1531. A charity helping people with diabetes and supporting diabetes research.

I enclose a cheque/postal order* payable to the BDA £______

Debit my Access/Visa* Card by the amount of £______

Card Number ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Expiry Date ☐☐☐☐

Please send me more information and membership details ☐

Name ________________________

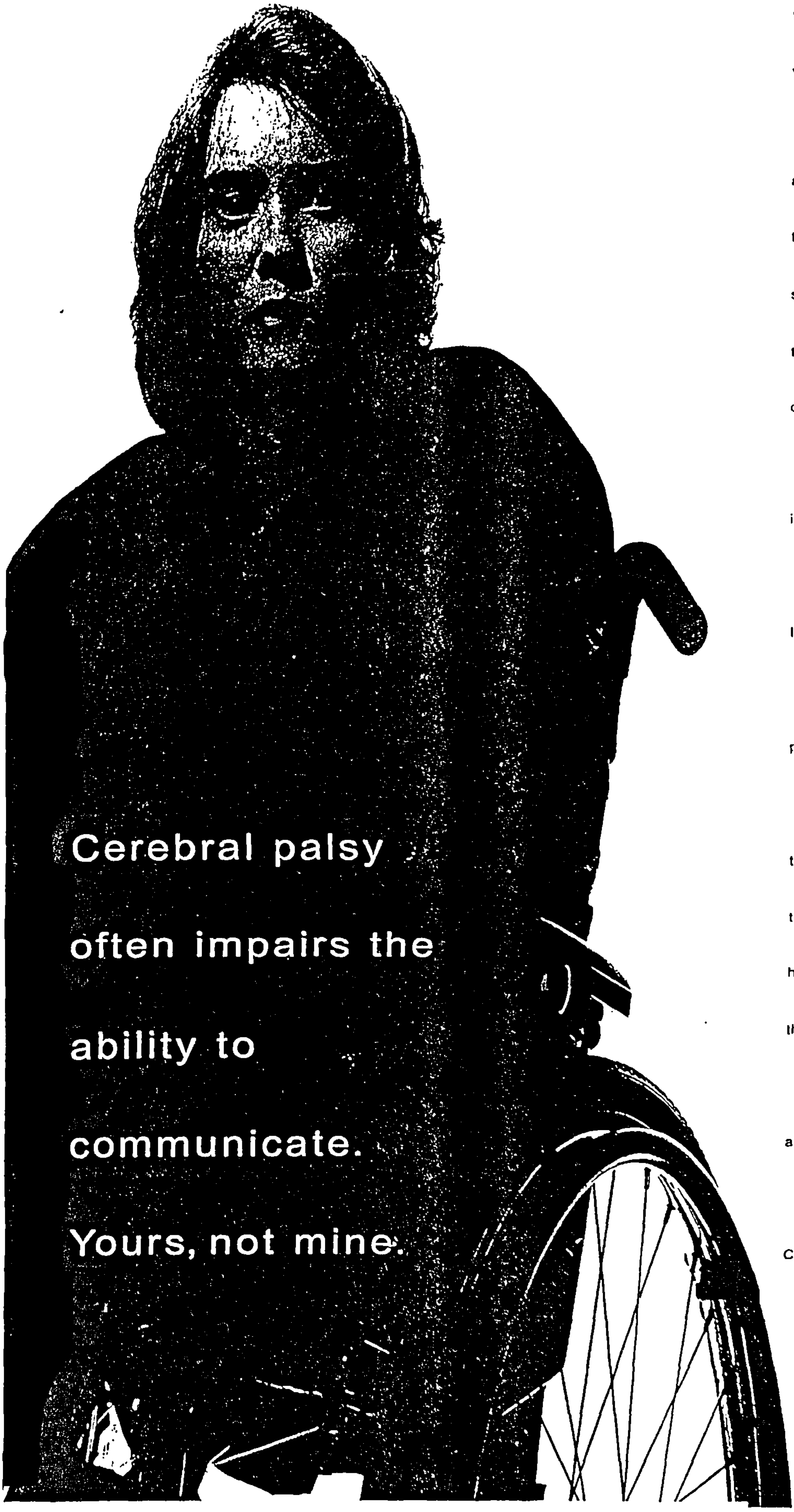
Address ________________________

Signature ________________________

*Delete which is applicable

Reg Charity No. 215199

BRITISH DIABETIC ASSOCIATION



I know it's difficult to understand what I say. But it would be easier if people tried.

It's the muscles in my jaw and my tongue that are affected, not my mind. That works as clearly as you're reading this.

And I don't care how many times you ask me to repeat myself. I'd rather you do that than just nod and pretend you understand. For all you know, I might have just told you that you've got a face like a bulldog sucking a wasp. Not that I would.

The worst thing is when people just ignore me and look the other way.

Schools, employers, local authorities. I've been ignored by them all.

And like everyone else with cerebral palsy, I'm tired of it.

So are the Spastics Society. That's why they changed to Scope. Because it's about time that everyone with cerebral palsy, however severely disabled, was allowed the scope to live normally.

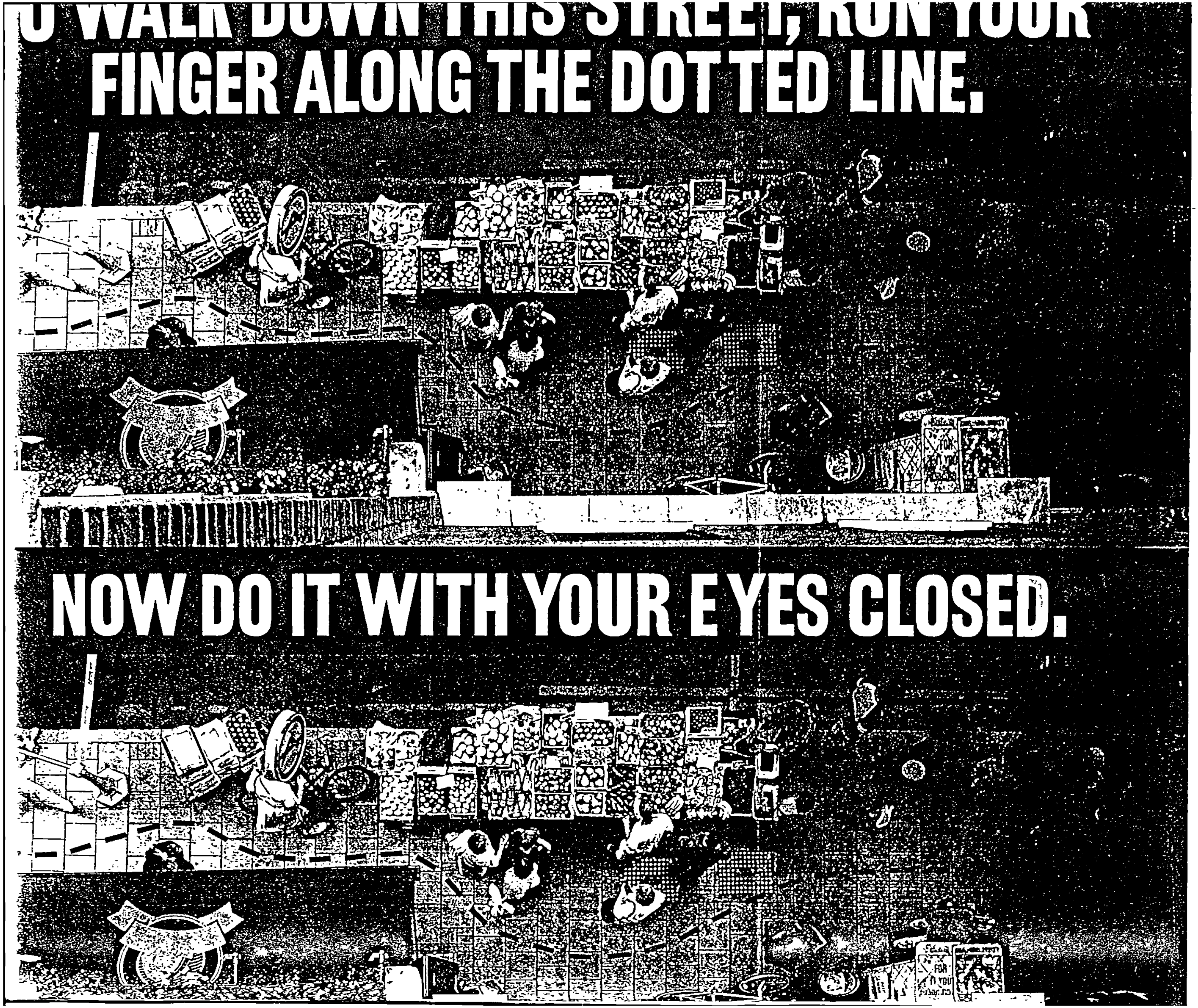
Which means not having our rights and abilities ignored.

Scope are as keen to talk to you as I am.

Call them, local rate, on 0645 486 487

SCOPE
FOR PEOPLE WITH CEREBRAL PALSY

Formerly The Spastics Society



Imagine being blind and having to do it for real. That's where being part of a guide dog team makes such a difference. Our dogs are trained to help their owners find the easiest, safest path through any maze of obstacles.

This training isn't achieved overnight. It takes around 2 years and a host of specialised people to train a single guide dog. But thanks to your donations and legacies, this fully trained guide dog costs a blind owner just 50p.

Anyone who is visually impaired and aged 16 or over can apply. And with no upper age limit they can be sure of our commitment for life.

A commitment that doesn't begin and end with training guide dogs.

We also provide daily living skills and mobility training. Everything from how to boil a kettle and learning braille to getting around with a long cane. Plus regular after-care visits to check owner and dog are running smoothly as a team.

In fact, anything we can think of to help a blind person lead a more independent life.

Please help. Run a pair of scissors along this dotted line.

I'D LIKE TO HELP GUIDE DOGS

Please send details of making a Covenant [illegible] Legacy [illegible]

Please send [illegible] ☐

☐ Enclosed is my donation for £ ____________

☐ Please charge my Access/Visa Card ____________ Expiry date ____________

Name ____________

Address ____________

____

[illegible] ____________ Signature ____________

GUIDE DOGS.
THE EYES OF THE BLIND.

[illegible]

In the third advertisement we learn how guide dogs for the blind can give independence to disabled people. The reader is asked to imagine that they are blind. They do this by shutting their eyes. Not only does this give a completely false impression of how the majority of sight-impaired people see, but it stresses the difficulties and promotes fear of blindness. The text however makes it clear that with a guide dog all is not lost. The charity enables blind people to be looked after for life, or to put it another way, the charity can make blind people dependent upon them for life. Not only can this charity give a blind person a guide dog, but in every aspect of a person's life this charity is ready to help: "In fact, anything we can think of to help a blind person lead a more independent life." This independency has a high price - total dependency upon the charity.

Having briefly looked at the way in which charity advertising operates I now want to focus on the affects of this upon the individual disabled person. In other words I want to focus upon how we collude with these perpetuators of negative representations of us.

2:2:2. THE FINANCIAL REWARDS

What is the purpose of charity advertisements? The answer would seem to be self-evident and commonsensical. Charity advertisements provide money for the charity. The advertisement goes out and money comes in. But is the relationship between charity advertisements and financial reward this straightforward? And if not, what purpose do these advertisements serve, when, as we have clearly seen, they portray a distorted view of us.

The total income of a charity can be divided between asset, trading and voluntary giving. Within the voluntary giving section approximately one third is received through legacy and the other two thirds of this sum comes from a variety of sources, including covenanted giving and the income generated by the charities' volunteers. The impression fostered by impairment charities is that they rely solely upon voluntary donations; they are clearly not businesses. As Hevey remarks:

> They portray themselves as the innocents of the commercial world, passively waiting for goodness to translate into income. Advertising is often viewed as the declaration of that goodness equalling an avalanche of financial admirers. (Hevey 1992:43)

A recent report by the Charities Aid Foundation looked into the issue of who gives to charity and in what circumstances. They found that the most successful means of raising money was through door-to-door collections. The report went on to say that:

> one of the least-used methods of prompted giving was responding to advertising appeals. Indeed, only 1 per cent were found to respond to this method.(quoted in Hevey 1992:44)

This radically challenges the prevailing notion that charity advertisements raise money. So what purpose if it is not directly financial, do these advertising campaigns serve?

Large national impairment charities depend on local support, or self-help groups. These are organised on a regional basis, and comprise an army of volunteers.

As we have seen, the most successful strategy for charities to employ in raising money is carried out by these volunteers. Door-to-door collections, raffles, sponsored events, 'flag' days, fetes, all play their part and all are dependent upon the charities' army of unpaid workers. The purpose of national advertisement campaigns is to speak to these people. It is to assure them that the work they do is valued and needed; that they do exist and that their cause is happening. In other words these advertising campaigns are a reward for the charities' workforce. It is telling them of a job well done.

Furthermore the national advertisement campaigns pave the way for the local branches and its volunteers to collect. The impairment has been branded and the three-tier campaign been followed. It is firmly linked in people's minds with that particular charity, fear of that particular impairment has been exploited and the dependency of the 'victims' upon their charity demonstrated. Now the volunteers can move in. The job of explaining who they represent and why, has been fulfilled for them.

The point I am particularly interested in here is why, given all the negative representations, disabled people volunteer for charity works.

There does not seem to be much available data in this area. However, my own research and experiences would suggest that people overwhelmingly work for impairment charities to which they feel they, or someone close to them, 'belong'. The branding is so complete that when people think "blind" they automatically think "Guide Dogs for the Blind", or again when they think "Multiple Sclerosis" they instantly think "M.S. Society". Out of the ten students training for guide dogs with me, I was the only person not to be involved in fund raising. So why is it that disabled people seemingly support oppressive impairment imagery?

I think to some extent I have already answered this. Because the impairment and its corresponding charity are so inextricably linked, and because of the lack of any viable alternatives, disabled people turn to 'others of their connate' and join the local branches of their charity 'to do their bit'. As we saw in Chapter Three, the relationship between an individual and "their own" can be ambiguous. However, the point to be stressed is that the 'branding', that is to say the link between the impairment charity and a particular impairment is so strong that people assume that the charity is working for them rather than colluding in our oppression.

Yet this picture is gradually changing. The disability movement is slowly gaining a voice. As disabled people 'come out', as we become more politicised, with charities <u>of</u> disabled people working for our rights, as opposed to charities <u>for</u> disabled people maintaining our dependency, then, I believe we will deconstruct the branding process and hopefully more people will challenge the agenda of impairment charities and the culture of dependency upon which they rely.

In this section I have attempted to show, through the example of impairment charities, how large organizations incite people to identify with a particular cause. I then went on to demonstrate how this is consolidated and how people are induced into sharing the goals and aims of the organization, even while the organization is working against any notion of independence.

In the next section of this chapter I am going to explore Goffman's notion of 'role distance' and Foucault's idea of 'capillary power' in relation to each other to see if these concepts can help us question the prevailing view of the disabled self.

2:3. ROLE DISTANCE AND POWER

In his essay "Role Distance" (1961b) Goffman develops ideas that he first touched upon in *The Presentation of Self in Everyday Life* (1956). That is to say, "Role Distance" is an exploration of the relationship of the individual to her several selves and their roles, with the individual as the central concern. Goffman suggests that the structure of social encounters is

> ...as something approaching mutual understanding reached between *individuals* who are engaged with each other in interaction, an understanding which conjoins the participants and steers the course which interaction follows. (Burns 1992:121)

Goffman draws a distinction between the exemplary idea we have of a role and the actual role performance. The prototypical notion of a role serves as a type of blueprint against which the actual role performance is measured. And the response too, has this idealised role within it. This allows for a certain degree of latitude in dealing with encounters with others, albeit generally speaking the number of appropriate options available to us is limited.

In "Role Distance" (1961b) the difference between role obligation and role performance then is clearly highlighted. It is the gap between these two, Goffman maintains that has traditionally been a source of trouble for sociologists:

> Often, they try to ignore it. Faced with it, they sometimes despair and turn from their own direction of analysis; they look to the biography of the performer and try to find in his history some particularistic explanation of events, or they rely on psychology, alluding to the fact that in addition to playing the formal themes of his role, the individual always behaves personally and spontaneously, phrasing the standard obligations in a way that has a special psychological fit for him.
> The concept of role distance provides a *sociological* means of dealing with one type of divergence between obligation and actual performance. (Goffman 1961b:115)

But what does Goffman actually mean by "role distance"? He states it thus:

> This "effectively" expressed pointed separateness between the individual and his putative role I shall call *role distance,* a short hand is involved here: The individual is actually denying not the role but the virtual self implied in the role for all accepting performers. (Goffman 1961b:108)

The term 'role distance' does not refer "to all behaviour that does not directly contribute to the task core of a given role" (Goffman 1961b:108), rather it refers to:

> ...those behaviours that are seen by someone present as relevant to assessing the actor's attachment to his particular role and relevant in such a way as to suggest that the actor possibly has some measure of dissatisfaction from, and resistance against, the role. (Goffman 1961b:108)

Goffman illustrates his point, principally employing an analysis of merry-go-round riders and an analysis of the behaviour of members of a surgical team.

In the first instance Goffman looks at people of different ages and considers how they sit and ride the wooden horses. This role, like many we perform, lasts for a very short period of time. Goffman studied the relative degrees to which the role was embraced. He was interested in whether or not the role fully absorbed the rider, or whether the rider can show some sort of irreverence towards the role. The description that Goffman gives shows the relative degrees of embracement and the relative degrees of role distance.

Goffman is not however claiming that in this way we can see the self peering round the edge of a role nor that there is anything truly individual about the way we choose to manage the role. On the contrary, the way in which the role is played or managed within a situated activity system is, claims Goffman, part of the role itself. That is to say that within all roles, whatever they be, there are various options available to us in order to manage that role.

Moreover, role distance can serve primarily conservative functions. For the sense that we have of not fully embracing a role is the very thing that allows us to continue playing that role. Thus role distancing allows us to remain locked within certain structural institutional arrangements. As Cohen and Taylor put it:

> The fact that we can regard with amusement the conventions of university or office life and our roles as teachers or managers, actually ensures that we remain within those conventions and these roles.
> (Cohen & Taylor 1992:56)

The point is that the distancing techniques themselves can become just as much a part of the role, and just as much a habit or routine, as the very thing that they are trying to elude.

> When the individual," writes Goffman, "withdraws from a situated self he does not draw into some psychological world that he creates himself but rather acts in the name of some other socially created identity. (Goffman 1961b:108)

In other words the attempts to escape from roles and routines are also patterned.

The second major instance that Goffman provides is that of a surgical team. The surgeon, one would think, is hardly going to deny the virtual self implied in her socially prestigious role as surgeon. Surely here we shall see a person fully embracing her role. Nevertheless Goffman shows that role distance is not only evident in the operating theatre but is also routinely expressed.

In her situated role as surgeon, the surgeon has to attend to the management of her working relationship with the other surgical team members. However the surgeon, like us all, is a multiplicity of selves with many situated roles. Whilst in the operating theatre these other situated roles may impinge and need attending to. In the surgeon's case these include:

> ...teaching, making future appointments through speaker-phone, rearranging the day's schedule. And there are other more 'social' claims which stem from his social identity (age, sex, social class, and the like), and from non-specific affiliations and obligation, such as those that apply to encounters which include strangers. (Burns 1992:134)

The way in which the surgeon handles these infringements on her situated role can necessitate role distance from her situated role as surgeon.

The important point that Goffman makes is that the smooth running and preservation of the situated activity is paramount. Thus any potentially disruptive demands are dealt with in such a way as to maintain and sustain the situated activity. This, Goffman makes clear, is not to suggest that the surgeon in her management of her role exhibits autonomy, or show signs of "personality", but rather she is, and can only, draw upon other, already existing socially contrived roles:

> In other words, one of the claims upon himself that the individual must balance against all others is the claim created by the over-all "needs" of the situated activity system itself, apart from his particular role in it. (Goffman 1961b:121)

Obviously role-distancing techniques are not restricted to surgeons or merry-go-round riders. Disabled people are experts at letting non-disabled people know that "they are not like other disabled people". But role distance is also routinely expressed by those experts whose role it is to 'care' for us. Doctors, nurses, social workers, physiotherapists, and so forth, all operate in the same manner as the medical team that Goffman so appositely investigated.

In short, I have argued that with his essay "Role Distance" (1961b) Goffman firmly claims the individual as a socially constructed product. He has been principally concerned with those instances, episodes and "expressive features" which are discrepant with the typical role performance. There are two ways in which these discrepancies within a situated performance may be managed so as not to cause the situated activity to break down. Firstly the individual attempts to disassociate herself from the role, and the second concerns the individual's failure to control completely the information others receive from her. In both cases the individual distances herself from the virtual self implicit in the role. What distinguishes Goffman from other writers on this topic is that he is not claiming that the individual, in her attempt to show dissatisfaction with her role, does not retreat to some self-styled psychological domain, but, on the contrary has to resort to other socially prescribed identities. "The liberty he takes in regard to a situated self, is taken because of other, *equally social* constraints" (Goffman 1961b:120 emphasis added).

Whilst this demonstrates Goffman's commitment to what has since been termed "the de-centred subject" by postmodern expositors, it does not, at first sight appear to be so very different from Foucault's 'docile' individual. However, the main tenet of Goffman's argument resides in a version of the self which, whilst being a social product, is clearly a multifarious, heterogeneous collection of selves.

Burns (1992) suggests that Goffman's main aim was discovery as opposed to the construction of a general explanation of society. Foucault on the other hand is attempting to articulate a much grander theory of modern society. So, inevitably, there exists differences between them. And yet underlying Goffman's classifications, identifications, and taxonomy of everyday life is, by definition, by default perhaps, a theoretical thesis. As any postmodern commentator would point out, the way we choose to order and classify subject matter is hardly neutral. Goffman was not the first to undertake a taxonomic analysis of social interaction, but what is most notable about Goffman's work is his ability to make his classifications and observations immediately recognisable to his reader. For Goffman:

> ...saw his task as illustrating an interpretation rather than proving an argument. (Burns 1992:358/9)

We can immediately see here the correlation between Foucault's conception of power and that of Goffman's. Neither writer conceives of power as something that can be seized, as a property belonging to an elite group. On the contrary, for both Foucault and Goffman power is diffuse, disseminated and diasporic.

In Foucault's work the mechanisms of power operate through a 'net-like structure'. Foucault explores the implications of this on a macro level. In Goffman we find an analysis which also defines power as 'web-like'. Yet in Goffman we see the exercise of power at the micro level.

Power, as we have seen, does not exist in a vacuum. It is always and can only be exercised through interaction with others. Whether it is directly in face to face encounters or through a technological or imaginative medium is irrelevant. By conceiving of individuals as docile bodies Foucault sees a person as non-interactive. Goffman, on the other hand, examines the enactment of power through interaction. Foucault sees the individual merely as a vehicle of power and thus he gives power some sort of autonomy which individuals are denied. For Foucault then, power is transmitted through the action of others and yet he ignores interaction, only acknowledging it in his later works in so far as others may be instruments of self-stylization (see Chapter Six).

So far I have been concentrating, in the main, on the similarities between Goffman's and Foucault's work. There are, of course, fundamental differences between these two writers. Goffman's work is that of an anthropologist and sociologist. Perhaps one of the most important influences on Goffman's thought can be found in the 'structuralism' of Durkheim. Although, as we saw earlier in this chapter, Goffman was to move away from the classic Durkheimian position, it still flavours much of his later research. Foucault's original training, on the other hand, is in philosophy and psychology. Foucault shows no interest in American pragmatics, derived from the work of G.H.Mead, nor in symbolic interactionism generally. Rather, he bases much of his work on European continental documentation. Foucault was, of course, highly influenced by the work of Nietzsche, Marx and Sartre. In the 1960's Marxist theories of political economy were being challenged. Marxism could no longer adequately account for the plurality, diversity and fragmentation of late capitalism. The classical Marxist model was increasingly deemed to be too mechanistic and deterministic. Equally, Sartrean existentialism was under attack. The idea of historical change and transformation being the result of the "irremediable freedom of individuals to create anew out of the 'raw material' from which they had been created" (McHoul & Grace 1993:8) was being problematised by writers such as Gaston Bachelard (1976) and Georges Canguilhem (1968)[4]. It was against this critical backdrop that Foucault's work emerged. Indeed Foucault's project challenges both the existential and Marxist positions which, in the 1960's, were so prevalent in French politics and philosophy. Foucault's work, in effect, was to question, or to re-establish, the entire foundations of Western human sciences. Foucault, in the final analysis, interrogates the very basis of western philosophy, and, indeed, sociology. Foucault's overall project is summarized by Dreyfus and Rabinow (1982) as that of going "beyond structuralism and hermeneutics". This is not a project shared by Goffman. Goffman's interest lies in the field of micro interaction, which is not to say that his work does not have institutional underpinnings.

Equally I am not suggesting that Goffman was unaware of the political implications of his work. On the contrary, in his introduction to *Frame Analysis* (1974) Goffman explicitly states that the central concern of this book is to show how we organize experience as opposed to "the core matters of sociology - social organization and social structure" (1974:13). It is not that Goffman thinks these topics to be of no interest, but, as he puts it:

> I personally hold society to be first in every way and any individual's current involvements to be second; this report deals only with matters that are second. [...] Of course, it can be argued that to focus on the nature of personal experiencing - with the implication this can have for giving equally serious consideration to all matters that might momentarily concern the individual - is itself a standpoint with marked political implications, and that these are conservative ones. The analysis developed does not catch at the differences between the advantaged and disadvantaged classes and can be said to direct attention away from such matters. I think that is true. I can only suggest that he who would combat false consciousness and awaken people to their true interests has much to do, because the sleep is very deep. And I do not intend here to provide a lullaby but merely to sneak in and watch the way the people snore. (Goffman 1974:13/4)

Having broadly stated Goffman and Foucault's radically different lineage I now shall return to the notion of power.

As we have seen, Goffman has been charged with having no theory of power. But equally, I have shown that this, in fact, is a false accusation. Goffman locates the institution as the labeller, the giver, the manufacturer of power. However, and this is a crucial difference between Goffman and Foucault, in Goffman's theory of power there is no real way in which power is translated into the body. It is Foucault who formalizes the body as the internalizer, the giver of power. Whereas Goffman has a very strong feeling, a passion for the peculiar intricacies of the way power operates on individuals, Foucault is not much concerned with this aspect of power. Foucault concentrates instead on how power becomes inscribed on "patterns" of bodies. So, for example, we see how power is inscribed on the bodies of prisoners, the bodies of soldiers, the bodies of hospital inmates and so forth. We do not see, in Foucault, the singular complexities of power operating on individuals.

Goffman never explicates a theory of hierarchical power. This is precisely because he takes the notion of power working 'from the top down' to be self-evident and unproblematic. Foucault's re-theorization of power, of course, attacks this notion of power acting from above. Yet while Goffman does not question the prevailing view of power *per se*, his work, in contemporary terms, shows an acute awareness of the discourse that is being undertaken. In short Goffman wants to witness how people 'do' discourse. Discourse here is to be understood in the Foucauldian sense. That is to say, Foucault "identifies discourses as historically variable ways of specifying knowledge and truth - what it is possible to speak of at a given moment" (Ramazanoglu 1993:19). Discourses are extremely powerful because they rely upon sets of rules which define the parameters of knowledge. So, for example, discourses constitute the 'truth' of insanity, disability or criminality. Those of us who have been thus defined are in the grip of power. In Foucault's words discourses produce truths and "we cannot exercise power except through the production of truth" (Foucault 1980:93).

Whilst Goffman is principally concerned with "the way we take it that our world hangs together" (Goffman 1974:440), Foucault concentrates on the historically specific production of truth. These two thematics, it seems to me, can be used to inform one another in a very fertile way.

Throughout this work I have drawn upon recent debates within feminism to highlight some of the problems identified with Foucault's work. A central concern amongst academic feminists is that whilst Foucault's analysis of power allows for a more productive understanding of the nature of power relations between women and men, his work, at the same time negates women's lived experience of these power relations.

Similarly, if we apply Foucault's conception of power to the production of the disabled self, we find that the actual experience of being disabled is rendered inconsequential and unimportant. Yet if we retain Foucault's position and add to it, or integrate with it, Goffman's concept of "how the world hangs together", I believe the end result could be of great benefit and importance to disability theorists and disabled people.

It is with this in mind that in the final section of this chapter I shall examine the ordinary, taken-for-granted view of how disabled people experience the world around us. I shall look at the events and activities which we initiate, participate in and watch. In short I want to look at the way we "do" disability. Yet I do not want to lose sight of the wider picture, the overall framework, the discourse and power relations, in which the experience of disability is located. This is to say that in the following section I want to use Goffman's theories to make manifest those of Foucault.

3. THE IMPLICATIONS OF A GOFFMAN/FOUCAULT SYNTHESIS FOR A THEORY OF POWER, RESISTANCE AND DISABILITY.

Goffman is principally concerned with the question: 'what is it that is going on when interaction takes place?' Foucault wants to understand how it is that we can speak the truth at a given moment. I want to suggest that if we can use these two ideas to inform and supplement one another then perhaps we can arrive at some sort of notion of power which is a power of bodies, a power of selves and identities, but which is also a power that is located within institutions.

In this section, therefore, I am going to draw heavily upon the interviews I conducted with disabled people with the aim of seeing what 'truth' of disability is being made manifest. In short I want to explore how it is that we define ourselves as disabled, or to put it another way: how we 'do' disability.

Thus in this section I shall demonstrate, by way of my informants, that we can discuss both Foucault's question: how is it that we can speak this truth at this present? and simultaneously ask Goffman's enquiry: what is it that is going on? In other words, what is going on in a situation can also be seen to be the effect of particular ways of exercising power.

Within sociology there is a well-founded tradition which addresses notions of power imbalances in interpersonal relations. However, I am not searching for some universal, underlying cause to explain disabled people's lack of power. From my own personal experiences and from my data it is clear that there is a knowledge of the external image of disability. But, more significantly, there is a knowledge of the gap between this image and the individual, which allows for the potential manipulation of identity and expectations on a day-to-day basis. We, as disabled people, are all too familiar with the stereotypes and expectations which surround disability; we have all, at some stage, been constrained and restricted by these. But, equally, at times we have used them to our own advantages.

The importance and relevance of drawing upon Goffman and Foucault then, is that they allow us to examine power relations as flexible, pliant and adaptable. Goffman uses the concept of negotiation to demonstrate that what is going on in a particular situation has to be arrived at through a 'working concensus'. Thus power relations are always open to the possibility of change and re-negotiation. And in Foucault we see the concept of resistance producing counter discourses which in turn produce new knowledge, speak new truths and so constitute new powers.

Throughout this work I have discussed notions of the stereotypical image of The Disabled. Similarly I have looked at how this image, in effect, reduces the life chances of disabled people. In other words we have seen how the stereotypical image of disability fosters an oppressive stance towards disabled people. In the remainder of this section I shall concentrate on the awareness, by disabled people, of a gap between the stereotype and their own self-image. Then I shall look at how we might use this gap to resist and challenge the prevailing view of disability and The Disabled.

3:1. EXPLORING THE GAP

The Disabled are a clearly defined, heterogenous group. However, as disabled people it is apparent that we do not classify ourselves quite as unproblematically as the able-bodied appear to do. Hilary says:

> I do not feel disabled on the scooter. I do not want to look like a disabled person...I don't want other people to class me as a disabled person. (Hilary:112)

Indeed, throughout the interviews it is clear that disabled people do not view themselves to be 'like other disabled people'. Most of the interviewees are aware that the non-disabled public view them simply as belonging to the category of The Disabled, but on an individual level they do not feel they belong to this group. However, it is clear that they have been defined, by others, as such.

Frank talks about how he realized that the only way for him "to make a fresh start", after the onset of his disability, was by moving out of his "over-protective" parental home:

> It wasn't an easy decision to make, because there is so much pressure within your family and within your friends to, like, convince you that you are an invalid and that you can't do things and obviously I had a lot of my own doubts as well... (Frank:160)

Later on in the interview Frank says that other people's attitudes towards him are:

> difficult to cope with and offensive...I suppose it's like gender stereotyping, in a wheelchair people impose a whole set of values and attitudes on to me which I don't like. (Frank:161)

Yet Frank does not simply accept these negative attitudes and act accordingly. On the contrary, Frank feels that because he does not conform to the stereotypical image of a disabled person he gains confidence and a certain amount of estimation:

> For example, if I come into a room I'll immediately be a person in a wheelchair and, yeah, there is a negative element in that. People impose stereotypical attitudes on people who are disabled. But on the other hand, it does, well as soon as I come into a room I am noticed, and people notice me, so I suppose it makes me a point of interest, the fact that I am a person who is disabled. I'm at university, I've got my own house, I drive my own car, I suppose to a certain extent people have a lot more immediate respect for me and for my achievements. (Frank:165)

Beth is also acutely aware of how 'normals' see her and she does her best to counteract this view:

> I keep myself busy deliberately, I mean I have always kept myself busy, but even more so now. It's a bit of diversion therapy I think. But also I think that if you're not busy you reinforce the myth about disabled people. You know they are only sitting at home watching television, with nothing to do - whereas if you are out in the public view and doing all these things it breaks down those myths I think. (Beth:221/2)

David too, knows what is expected of him by society at large:

> When I first lost my sight I were watching a programme on television. I think I had only been out of hospital a week, and a chap come on, one afternoon, and he were a blind person, and they asked what he did, and he were basket weaving. You know, it just suddenly went through my

> head - is that all I can do? Basket weaving? You know I just absolutely broke down, I mean there were just no way. I thought well, I'm not going to do basket weaving. (David:5)

But now David thinks that the stereotypical image that the able-bodied have of disabled people has also worked to his own advantage. David won first prize in a gardening competition that was open to everyone:

> If it had been a sighted person that won that competition nought would have been done. But because I was blind I mean everybody come. Papers, I mean first thing I knew about it when wife rang me up. I was down at newspaper, she said that all the papers had rang me up, and she was saying television ought to ring up, and the next minute television rang to come down! (David:7)

Kay talks quite openly about the way she 'uses' her sight impairment to get her own way:

> If he wants to watch something on the telly, for instance, and I want to watch something else, I'll make it an excuse: 'Well, I can't see and if I want to watch something that I want to enjoy...' You know, and 'I can't you go and make a cup of tea because I can't see'. Whereas other times I'll just make it. I do play on it. (kay:281)

So far I have been illustrating how we are aware of the way others see us, and how this can enable us, in some situations to draw upon this knowledge in order to manipulate what others expect of us on an everyday basis.

However, even though it is apparent that we, as disabled people, are aware of the homogenous, undifferentiated manner in which the 'normals' habitually classify us, knowledge of this does not, of course, amount to resistance. We have already looked at the problems associated with resistance in Chapter Five and I think David's comments illustrate both his experience of personal empowerment and also his collusion in perpetuating the myth of The Disabled. As with all the instances of experiencing personal empowerment, David's example appositely makes the point: if David, as a sight-impaired individual, had not been treated as different, as blind, he would not have received any media attention. It was his difference, and the public's understanding of this difference, that made his winning the contest news-worthy. So, in effect, the publicity he received consolidated the truth of disability as difference. At the same time, however, David personally experienced this as a positive event. So in order for us to be able to feel empowered by an interaction we are, at the same time, reinforcing our own negative image. In other words we must be aware of our complicity in the construction of the prevailing view of disability.

If we return to the methodology chapter (two) and look at the way I was able to find my data group it can be argued that I was colluding with the prevailing discourse on defining who fits this category of people. I wrote to 'experts', to health care professionals and to disability 'specialists', and they were able to put me in touch with some of The Disabled.

In order for me to have undertaken this research there had to be mutual assumptions, made by all the actors, concerning who we were, and what was going on. In other words a working consensus had to be arrived at so that both my informants and myself knew what was expected of us.

The question of myself as the interviewer operating within the categories able/disabled, and replicating them even whilst I was attempting to deconstruct them, is difficult. In the final analysis it comes down to the fact that, even before I had met my interviewees the interaction was shaped by this working consensus. This is to say that between myself and the interviewees there was a hidden agenda, a silent complicity, to continue rather than to challenge this game of identity construction.

We can witness this complicity at work throughout the interviews.

What we see happening is that in a Goffmanesque analysis the notion of disability as 'otherness', as difference, can be called upon as a resource to enable us to experience personal empowerment. In Foucault's language this can be seen as the workings of capillary power. Goffman's claim that in all strategic interaction power is being exercised does not necessarily mean that in all interactions between able-bodied people and disabled people, it is the able-bodied who hold this power. As we have seen in this chapter, the exercise of power depends on a number of factors.

From a Foucauldian standpoint however, notions of otherness and difference are the sites of our continual oppression. A notion of otherness is essential for the workings of normalization. And it is through normalization that power is able to exert its hold on the modern subject. This is not simply a matter of negation. That is to say that the concept of The Disabled is not only necessary to define The Abled, but that it is through the segregation, marginalization and compartmentalization of disabled people that the very idea of deviancy itself is perpetuated.

Hence, the discourse of disability, the 'truth' of disability, means that even whilst we might be able to manipulate identity on a day-to-day basis, the actual truth of disability remains unchallenged. In this way it would seem that it is only through our awareness of the negative image of disability that we can, on an individual level, resist. But the actual discursive truth of disability is compounded and consolidated by our very resistance.

In effect then, there exists a contradiction in which disabled people are locked: we are continuously in the process of empowering ourselves, yet simultaneously contributing to our very disempowerment.

There is a side of me that is very tempted to leave this work at this point. The experience of being disabled in an able-bodied world is monotonously difficult. And so many of the difficulties are connected with, and compounded by, the ways in which resistance is continually undermined, neutralized or turned against us. However, this is an unequivocally negative and pessimistic prognosis. Moreover I do not think it is a wholly accurate reflection of the experience of power, resistance and disability. I want to suggest that resistance is not, and cannot be, seen simply as a matter of legitimating the political rhetoric of disability. That is to say that resistance cannot be solely understood in terms of vindication for the consensual discourse of disability. For if this is the case then it must also hold true for all marginalised and oppressed groups. Obviously we all, to some degree, collude in our own oppression and this is true for all minority groups. But if this is the only conclusion to draw then we might as well throw in the towel and go home.

Thus it is that I now want to move away from this rather defeatist and immitigable position and consider resistance in terms of the social changes that disabled people have gained in the past few years.

3:2. A MORE OPTIMISTIC PROGNOSIS

The past fifteen years have seen a growing awareness, amongst disabled people, that we are being denied basic human rights. This change in attitude can be traced to the emergence of the disability movement. These organizations of (as opposed to 'for') disabled people have gradually gained a voice that demands to be listened to. A central tenet of such movements is the individual and collective empowerment of disabled people. The notion of disability as a medical problem which happens to a few tragic individuals is challenged and the idea that it is society which systematically disables people with impairments is promoted.

Increasingly disabled people are being mobilized into direct political action. More and more frequently we see on our televisions and in newspapers, and hear on our radios, politicised disabled people focusing the (presumably able-bodied) public's attention on our inequality. Images of disabled people chaining themselves to inaccessible public transport, to railings outside The Houses of Parliament, and vociferously demanding civil rights have become increasingly familiar.

Perhaps the most significant indication that disability has entered the political arena is the way in which institutions are now responding to disability issues. I am well aware that a lot of institutional change, in this respect, is merely surface dressing. Yet, in an optimistic prognosis, we can still argue that this is a change in the right direction. And indeed, simply to dismiss such institutional changes as insubstantial and empty rhetoric is to deny the real effects and benefits that have occured in institutions. For example, it is only relatively recently that universities have employed a disabilities officer; that employment equality is recognised as meaning, not just race, gender and sexual orientation, but also disabilities. We are all now familiar with tactile pavements which enable sight-impaired people to locate road crossings, disabled toilets, hearing loops, and ramps are much more in evidence than a few years ago. Indeed, the position of disabled people today is generally more high profile than it would have been even twenty years ago.

The point that I am making here is that resistance, at this level, is possible. No huge ruptures in the social fabric have occurred, The Disabled have not risen up and revolted against our inequality, but this is not what we expect. Rather, as both Goffman and Foucault make clear, resistance is possible. But we are talking about a local, partial resistance that is continually in the process of becoming.

These ideas will be explored further in the following, concluding chapter.

1. Lyotard refers to Goffman's "The Presentation of Self in Everyday Life" (1959) as one of his resources in conceiving of society as a series of overlapping, different meaning language games: "each language partner, when a 'move' pertaining to him is made, undergoes a 'displacement', an alteration of some kind that not only affects him in his capacity as addressee and referent, but also as sender. These 'moves' necessarily provide 'countermoves' and everyone knows that a countermove that is merely reactional is not a 'good' move" (Lyotard 1984: 16).

2. Not all modernist positions hold with this view. For example modernist social science is concerned with subverting and demystifying social reality.

3. There are, for example, eighteen epilepsy charities in the UK.

4. Canguilhem's (1968) prudent treatise on the history of biology showed that it could not easily be made subject to a universal theory of historical or 'ideological' change. Thus it called into question the progressivist and continuist views of science.

CHAPTER EIGHT

CONCLUSION

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1. THE ARGUMENT

In this work I have looked at various accounts and explanations of disability, with particular reference to oppression, and assessed their suitability and applicability as resources to inform a theory of disability. Whilst acknowledging, in Chapter Three, that role theory can play an important part in an analysis of stereotypes and cultural norms, I felt that it was problematic and unsatisfactory as a basis for an account and theory of disability, power and resistance. I then turned, in Chapter Four, to accounts of oppression: namely biological, cultural, psychological and class theories and found these too, to be unsatisfactory as explanations of the disabled experience.

The basic and insurmountable problem with any theory of oppression which relies on biological explanations is their underlying assumption that biology is destiny. I have argued that any account which attempts to explain the unequal and oppressive treatment of others on the grounds of biological difference cannot possibly be the basis for an emancipatory politics.

Equally cultural and socialization theories of oppression do not address the experience of disability. For if, as the socialization argument would have it, all that is needed to have a non-disablist society is to change certain societal values, then surely it would be a very straight-forward affair. The basic weakness of this line of thought is that issues of power remain unproblematised.

Whilst acknowledging that culture obviously plays an important role in our understanding and experience of disability, an emancipatory theory of disability cannot rely on a culturally deterministic approach. Our comprehension of disability is produced within a specific discourse. This discourse is informed by a particular bourgeois, liberal version of humanist philosophy and values. I have argued that we cannot escape the paradox which lies at the centre of this mode of thought. We cannot liberate ourselves from this because the very structures that are in place for our 'care' simultaneously ensure our oppression. That is to say that the position of The Disabled is solidified and given coherence rather than challenged or subverted. The liberal humanist position presupposes the existence of the categories 'able' and 'disable' (amongst others) as real and unproblematic.

I found psychoanalytical approaches to disability similarly disappointing. This approach assumes disability and impairment are an individual, tragic and medical problem. It then suggests that disabled people have to work their way through various stages of adjustment in order to become psychologically well once more. This, not only negates any notion of the social construction of disability, but also reinforces the notion that disability is a problem of personal and individual emotional and psychological adjustment Moreover, by emphasising a normalising framework individual experience is negated and resistance is reduced to a problem of non-acceptance.

A class analysis of disability obviously has relevance in a capitalist society. Yet, in itself, it cannot explain the experience of disability, other than in materialist terms. I am not doubting that disabled people's oppression has been strengthened by the capitalist mode of production, but our experiences cannot be reduced to an effect of it.

Following this I drew upon the work of Michel Foucault, and particular his concept of power, to see if I could use his analysis as a resource to inform a theory of disability.

Foucault has much to offer disability researchers. His understanding of power relations can provide us with new and productive ways in which to view our relationship with the able-bodied world, with one another, and with ourselves. Whilst most recent disability literature has been developing theories of the social construction of disability, Foucault has provided a new understanding of power relations. He retains a notion of social construction but in his version, he allows us, through a careful deconstruction of present day power relations, to depart from the rather mechanistic and reductionist theories of simple cultural constructionism.

Furthermore, Foucault challenges the very basis on which much disability theory, and other theories of oppression, are built. The implications of his argument suggest that most emancipatory theories are based upon a misconception, a misunderstanding, of power relations and thus they are bound to fail.

Moreover Foucault's interpretation of 'social constructionism' allows us to view the body as an historical effect of power which is constituted by shifting social forces rather than as a fixed, given entity. In other words by rejecting the view that our bodies, our physical being, dictates who we are, Foucault opens up a new domain for disability theorists to investigate.

Foucault challenges modes of thought which have prevailed since the Enlightenment. His perceptions concerning power relations, knowledge, truth, cause and effect, freedom and the nature of human agency have called into question assumptions which have not been seriously debated, in Western thought, since the eighteenth century. As Ramazanoglu comments: "Foucault intentionally disturbs and upsets what we have taken to be true." (1993:4)

Central to Foucault's conception of power is his rejection of the notion that if one is oppressed then there must exist a corresponding oppressor. This is not to claim that Foucault rejected any notion of domination out of hand. Rather domination, oppression and subordination are experienced as 'effects' of power rather than the outcome of a specific source of power. This is of utmost importance to understanding disabled peoples subordination.

However, as I made clear in Chapter Five, I do not advocate an uncritical embrace of Foucault's thought. There are problems and limitations principally around his conception of productive power, docility and resistance.

Foucault's last works, however, introduce a new focus of attention. In these texts he now concentrates upon the creation of the subject by the subject. His notions of self-stylization, self-creation and practices of self and freedom are extremely interesting for disability researchers. For, as I have illustrated in this thesis, the ways in which we 'do' our disabilities demonstrates not only our ability to fashion ourselves out of the cultural detritus, but, moreover to do so in such a way as to resist what we are told we must be. Whilst I believe that this period of Foucault's work has, potentially, great import for us, it is, as I made clear in Chapter Six, not without its difficulties and shortcomings which inevitably lead to its devaluation.

We cannot talk about resistance without being aware of its ambiguous status. I have illustrated in this work that resistance can always be interpreted in such a way as to render it impotent.

This does not, however, reflect the experiences of the disabled people I interviewed. The informants receive a strong feeling of empowerment on an interactional level from the very instances that disempower them on a collective level. This experience cannot be ignored. Neither can it be explained in a Foucauldian framework.

By utilising Goffman's conception of power I have attempted to show that the limitations inherent in Foucault's work can themselves be limited. As we have seen Foucault is extremely helpful in any analysis of power and resistance, but on its own it fails to show us any way out of the impasse that is created by acknowledging the precariousness of resistance. However, by returning to Goffman, whom, as I have made clear, shares many similarities with Foucault, we can hope to find a way out of this theoretical closure.

By analyzing resistance in a way that uses both Goffman and Foucault as theoretical resources I have attempted to show what forms of resistance might be possible.

We have witnessed how Foucault demonstrates the exercise of power on collections of bodies. This is, of course, extremely relevant to our understanding of how power is exercised on The Disabled. But on an individual level it is not so satisfactory. Goffman, however, is clear in his insistence that it is through interaction that power operates. These two perspectives do not necessarily cancel each other out. On the contrary, I have argued that they can be used, fruitfully, to inform each other, and thus provide us with a productive notion of resistance.

We have seen how the prevailing view of disability and The Disabled is very difficult to resist. Not only do we internalise the oppressive practices that render us as other, but all too frequently we collude in our own oppression. Understanding this is fundamental to an emancipatory politics of disability. The notion that we, as disabled people, collude in our own oppression, in the sense that we often exhibit symptoms of aversion and devaluation of others of 'our own', is crucial to understanding our oppression. I have argued in this thesis that this is a result of internalising the dominant cultural knowledge that defines us as 'not quite human'. In other words, we take on board the dominant subject position towards disabled people. But equally, we live a subjectivity which is different from the dominant subject position. In contrast to the prevailing understanding of The Disabled, this derives from positive identification with other disabled people and, increasingly, with an awareness of our own value and worth to society. I have already given many examples from the data which attest to the ambiguity we feel towards socialising with other disabled people. Beth, perhaps, summarizes these attitudes when she says:

> I can understand when disabled people don't won't to know other disabled people [...] When you asked me before [in the first interview] I think I was a lot more sensitive to being friendly with disabled people than I am now. But I do feel conscious of going out as a group of disabled people, and I personally feel better going out with able-bodied friends...that I might mingle in and not be so conspicuous. But having said that if the environment is right, if the situation is right, I am happy to go out with a group of disabled friends. I often have a better time with them than I can...we can relax and we can get on with one another and we have so much in common with one another. (Beth:231)

It is the dialectic between these two subjectivities, one the result of the dominant discourse which defines us as Other, and the second, deriving from our own experiences of ourselves as ordinary, normal and commonplace individuals, which makes our sense of self, our sense of our own subjectivity, fragile, contestable and heterogeneous.

Although I argue that we collude in our own oppression this is certainly not to suggest that we are responsible for our subjugated and unequal position within society. On the contrary, I have shown that it is partly through interactive habits, unconscious assumptions and stereotypes and shared feelings of awkwardness that our oppression is perpetuated. As Young (1990) puts it:

> Group oppressions are enacted in this society not primarily through official laws and policies but in informal, often unnoticed and unreflective speech, bodily reactions to others, conventional practices of everyday interaction and evaluation, aesthetic judgement, and the jokes, images and stereotypes pervading the mass media. (Young 1990:148)

We have already seen how the majority of the people I interviewed, as well as myself, have all experienced, in the course of our everyday lives, instances where 'normals' have treated us as if we were inferior, subordinate and unequal. This is clearly articulated by Sarah in the following remark:

> I'd like people just to treat us as normal, as normal people. It's just the way they look at you. People look at you and just look down at you, and that is one thing that really annoys me, when you are in a wheelchair people talk down at you. "Oh, do you want me to do this for you?" "Do you want me to do that for you?" I can do it myself. It is...if people just accepted us the way we are. I mean we are not from another planet or anything. I mean sometimes you would think we were. (Sarah:104)

Moreover, when we express any anger or indignation at being thus treated we are all equally familiar with the response this invariably elicits: "She didn't mean anything by it", "She didn't know better", "She was just trying to be helpful". In other words we are told that our anger, our moral judgement is inappropriate, unapt and inexpedient. We are told we must not condemn another's behaviour if their intentions are good. And yet, if these so called 'good intentions' contribute to our oppression, indeed perpetuate and sustain our oppression, then they must be judged as unacceptable and deemed morally and politically unjust and therefore they must be challenged.

In the past two decades we have also seen, however, changes taking place in society which have had many beneficial results for disabled people. This is not because disabled people have traditionally been docile. Indeed, disabled people have resisted and fought against our oppression, in numerous ways, for many years. For example, in 1920, in 1933 and again in 1947 sight impaired workers marched to London, from all over the country, to protest against low wages and poor working conditions. Ted Williams, a sight impaired man, remembers how he joined the 1933 march, when he was eighteen:

> There was more or less a national uprising. The whole of England and the whole of Scotland decided to have a march to London. The Scots came down marching all the way and picking up the English blind as they went. They arrived in Sheffield and all our workshop joined them and we marched down to London. I was jiggered, it seemed such a long walk to me, like it did to a lot of us. Salvation Army Halls we slept there, they took care of us for a night. And the people in the towns and villages they were very, very good and they used to troop out and bring us soup and sandwiches. Actually I am certain that I got more on that march than I got for a month at home. And every morning we pushed on a few more miles until we eventually got to London. We stood in Trafalgar Square and shouted for what improvements we wanted. We sent a deputation of shop stewards into Parliament and I might add that they got nowhere at all but it at least awakened people to our conditions. (Quoted in Humphries and Gordon 1992:117/8)

Yet these demonstrations, whist empowering on an individual level, did not touch the majority of people. Living in our 'information era', however, means that nowadays disability issues are reaching ever expanding numbers of people. This inevitably includes a large number of disabled people.

Increasingly institutions are taking disability issues on board. Admittedly, more often than not the way this is done is in a purely superficial manner. But as we can learn from other civil rights campaigns, this is the way institutional changes occur. Once we have a foot in the door, so to speak, the possibility of it opening wider is ever present. I do not want to argue that we are standing on the threshold of liberation, or that we are about to witness a social revolution in which equality for disabled people is guaranteed. Yet, it cannot be denied that there are fragmented and incomplete transformations happening. And it is in this way that we can talk about resistance.

We must not forget, however, the dangers implicit in resistance. I have already made clear the ways in which resistance can be neutralised, but equally deleterious to any liberatory politics is a form of resistance which takes on board the discourse of its own oppression. The politics, for example, of Louis Farrakhan, and his party "The Nation of Islam" has precisely taken on the form, the counter-image, of its own enemy. In their attempts to subvert the relationship between oppressor and oppressed they have merely reproduced the racist discourse which they purport to be disrupting.

According to Jesse Jackson race relations in America are in "a worsening condition".[1] Whilst it can be argued that important civil rights issues have been won, there is still great inequality between blacks and whites. "The Nation of Islam" is a sect which combines black nationalism with its own version of Islam. Farrakhan's message is very different from many traditional black leaders. Thirty years ago black and white people had marched together with Martin Luther King, sharing a vision of a "colour blind society". Their emblem was black and white hands joined together. This hope, this dream, is now on the wane. Like conservative America, Farrakhan argues that blacks should look to themselves, rather than to the government for a solution to their inequality. He reasons that white supremacy has produced a sick society. In his speeches he has attacked Jews as "blood suckers", and he has often threatened white society.

In October 1995 Farrakhan called for a million black men to march on Washington. It was a very different mood to the march thirty years earlier. The 'million man' march was less about bridging the racial divide, and much more about being separate, being black. Farrakhan urged black Americans to revive their own communities, but he also urged them to turn away from the dream of integration into mainstream America:

> We believe that separation ultimately would be the solution to the problem between the races. If we are unwilling to try to get along with each other in peace, with justice, then we have to separate and do something for ourselves. (Farrakhan 1995)

Whist on one level this can seem to be a logical and inevitable outcome of the experience of being black in America today: it has a reasoned and rational argument behind it - we are oppressed by white supremacy so we will have nothing more to do with it. On the discursive level, however, this is false resistance.

In attempting to resist their own inequality and subjugated position within American society "The Nation of Islam" has adopted the very same racist and oppressive discourse that it sets out to overthrow. So in this sense "The Nation of Islam" perpetuates inequality. The power which is constituted in this particular discourse has not been disrupted, subverted or indeed, challenged. Furthermore "The Nation of Islam" propounds sexist views. The "million men" march was exactly that: men were called upon to march, it was not an euphemism for 'people'. Women were denied participation in this demonstration. So in this way black women are further marginalized.

Any notion of resistance must be mindful of falling in to this vicious circle.

The danger of becoming locked into a discourse of oppression is not a flippant consideration. My experience in writing this thesis reinforces the dangers and difficulties inherent in an exploration of resistance. Whilst conducting the interviews I was acutely aware of the conceptions and consensual definitions surrounding disability. Obviously I did not want to reinforce these notions. Yet it proved to be impossible to resist the overpowering expert vocabulary, which in itself made it impossible to produce an alternative language. This is to say that both the interviewees and myself negotiated the discourse of disability which is ultimately extremely restrictive.

In addition to this problem I was presenting myself as the 'expert'. I was from the university, I was asking the questions, I was taping the encounter. So in one sense I was responsible for framing the interaction, for defining the situation. Yet, on the other hand there was a peculiar reciprocity between the informants and myself which was due to my own disability. Furthermore, as I noted in Chapter Two, the power exercised between us shifted within the interview.

This all illustrates that it is not only notions of power that are fraught with difficulties and inconsistencies. Resistance has to be seen as a fluid, intractable, ever shifting concept. As such it cannot easily be defined, catalogued and compartmentalised. Resistance, as I have clearly demonstrated, is not static, stable nor rigid. What counts as resistance in one situation, for one person, can count as oppression for another.

In short, this thesis has shown that by utilising a Foucauldian framework it can be demonstrated that the body, and more specifically in this instance, the disabled body, has been constructed through culturally and historically specific relations of power and discourse. I did not set out to do a genealogy of disability per se, but rather to document how disability and the disabled subject have been produced through mechanisms and technologies of normalization. This is particularily important because in using Foucault's work we can see how the medical model gained currency and became the dominant discourse of disability. Furthermore this allows us to understand why it is so powerful and ingrained in our thinking on this topic. The medical model of disability was born out of disciplinary techniques, that is, as mechanisms which create the disabled subject. I have shown how this is accomplished and consolidated through social institutions and cultural phenomenon. But equally, our own understanding of what it is to be a disabled person is strongly entrenched within this medical model. The only readily available identity for us is one which is dependent upon some notion of normalacy. Moreover, given that our identity is defined in terms of the normal, then we all too often have faith in a medical solution to our disabilities and we can thus afford to overlook any possibility of equality being achieved through social change. Equality becomes normalacy. When Sarah says that her goal in life is: "to get walking again, to get back to normal" (99), she is articulating what many of the interviewees suggest: that to be disabled is to be abnormal. And we all have plenty of experience of being treated as such. Sarah goes on to put it like this: "I don't like other people looking at me as if I'm some kind of wierdo just because I can't walk as well as them" (99).

I was further attracted to the work of Foucault because, through the notion that disciplinary power operates on all deviants and transgressors internally, through the process of normalization, he allows us to theorize and understand how we collude in our own oppression. We can experience empowerment whilst actually contributing and strengthening our own subjugation. Our desire to "pass as normal", to avoid the company of other disabled people, to denigrate ourselves so that normals feel comfortable with us, to spend both time and money on our appearances so as to make our impairment less evident, are, as I have illustrated in this work, real examples drawn from my data, of this phenomena.

Whilst there are some serious problems with Foucault's later works, the positive contributions he can offer us cannot be ignored. Notions of transcending the limits and boundaries of subjectivity are important for us, and we have witnessed how disabled people continually resist the normals definition of us. When, for example, Linda says:

> I still wear modern clothes like anybody else, things like that...I enjoy what I can do and I accept everything as it comes along. I have a catalogue which I have run for years, and I can see what are up to the minute fashions, if I fancy it I'll have it, if I don't I won't. I mean I made two skirts last year, winter skirts. Instead of wearing a blanket around your legs, like a lot of people do, I wear these skirts which are lovely, warm and feminine. You have still got your feet there and your stockings...and everything else! (Linda:91/2)

Linda is neither fulfilling the stereotypical asexual image that society expects of us, nor, more significantly, does she understand herself in this negative and marginalized way. Equally Eddy's thoughts of his future, suggest that he is resisting the normalizing gaze that defines us as 'less than human':

> Assuming that I get the O.U. degree that will not be the end. I am going to do two extra courses to make it an honours degree and then I hope to do a Ph.D. (Eddy:83).

I returned to the work of Goffman because, as I have illustrated, Goffman allows us to apply Foucault's macro analysis on a micro and individual level. I have argued that it is only by supplementing Foucault's thought with that of Goffman's that we can understand the workings of power, resistance and the experience of being disabled. Whilst Foucault allows us to question how it is possible to speak a given truth at a given moment, Goffman enables us to witness power at work on the experiential level. The two, together make it possible to understand power as being both embedded in bodies, in selves and identities and, at the same time, being embedded within institutions. It is only by applying both a Foucauldian analysis and a Goffmanesque one that we are able to understand that when Colin makes the following comments he is acknowledging the power inherent within the medical model of disability; an institutional power that is enacted through individuals on an interactional and experiential level. And it is on this level that Colin is able to resist:

> They just registered me as blind and I didn't know that I had a choice about it. I'd just been to see the guy and it was one of those situations where you would go in, they would check your eye sight, which was always a waste of time, and then you would wait for a while, then go and see the guy, and he would do the usual battery of looking in your eye, and on this particular day they raced me through like the queen mother. Went straight in, no waiting, and he said: "I've registered you blind, I don't need to see you any more, bye-bye". It was...I mean I knew it was coming but it was still a kick, I mean I was actually in total shock until I got home. I didn't find out 'till twelve months later I actually had a choice about it, but nobody explained that...But their attitude changed as well. I mean I have had diabetes for a long, long time. And although I don't know the technical terms I certainly know the condition as well as any doctor. I found the doctor who talked to me as a human being who had diabetes but who knew a bit about it, but now I went in as the blind guy who wanted everything explained to him. But they seemed to think that as I had lost my eyes I had lost my brain. I found out that it wasn't that much different. I could still be stroppy, I could still be the comedian, I could ask questions. But they had a problem. They never asked me how I felt, how I was, what I wanted. I

> didn't like that. I didn't know anything about my condition and to be honest their attitude was 'don't let it concern you, we are here to treat you'. I didn't like that at all. You don't need to know exactly why it's not working but it would be nice if someone sat down and explained why they were giving you certain treatment, why they were stopping certain treatment. Nobody ever thought about doing that. The one who was the most concerned with my eyes was me, and yet they ignored me. I mean they all come round, and clutter round the bottom of the bed and you catch four or five words out of a hundred and I used to say: "If you're going to talk about me would you mind doing it as if I am present. But if you want to talk as if I am not here, get completely away from me, where I can't hear bits, and have my own versions, and please talk in English and not in jargon".[...] I think I am [the same] as when I could see. A lot of the problems seem to be their problems.[...]I think I stand for far less nonsense than I used to. If someone insulted me before then I would just get up and walk away from them, but now my attitude seems to be,well, I just don't care. I mean people quite often come out with stupid remarks about blindness etc. etc. and they really should think before they open their mouths. And a lot of people say stupid things like: "Oh I wear glasses so I know what it's like!" Well, most blind or partially sighted people would love to wear glasses, watch the t.v. or read a book. And until somebody has actually got that situation they are never actually going to know what it is like. But again it's education. (Colin:37/8)

2. THE POLITICS OF POWER, RESISTANCE AND DISABILITY.

The present currency amongst the disabled movement is strongly steeped in the social construction model of disability. This model has proved to be very influential on disabled people. For the first time many disabled people were able to view their disability, not as a result of their bodily limitations, but as a consequence of an uncaring and disabling society. However, this model overlooks many aspects of living with an impairment. There is no room within this model for a discussion of pain, frustration or depression, which can be central to many disabled peoples lives. The reality of living with an impairment is reduced to issues surrounding access, demands for equal job opportunities, education and social assimilation.

I am certainly not denying the validity of such arguments. But the majority of those who propound such views allow no space for disabled people to express any seemingly negative aspects of being impaired. This, it seems to me, is in direct response to the individual and tragic model of disability. We have had to fight, and continue doing so, against this prevailing view to the exclusion of any other aspects of living with an impairment. To start talking now about our bodily differences can appear to contradict precisely what the disability movement has at its core: that disability is purely a social construction.

The struggle, for so long has been to move the focus away from the impairment, that it has become dangerous to acknowledge any difficulties that might not be overcome by removing disabling barriers.

In short, the emphasis has been on the social construction of disability. That we now need to recognise the real effects of an impairment might risk the reintroduction of the tragic flawed model of disability. As Liz Crow writes:

> We have become so afraid of being drawn back into the "personal tragedy" mould that we have polarized the social model. Impairment is no longer the total explanation; Disability is. We focus on Disability and pretend that impairment has no part in determining our experiences. (Crow 1992:6)

This highlights a major problem within debates surrounding power and resistance. The 'second wave' of feminism of the 1960's and early 1970's was exactly propounding such views. As we saw in Chapter Four, biological difference has been used to justify unequal and oppressive treatment of people. In response to this feminists such as

Shulamith Firestone (1970) advocated "the freeing of women from the tyranny of reproduction". (1970:221) Firestone argued that child-bearing could be taken over by technology leaving women free to join the labour force. Biological difference was denied in favour of arguing that women's condition was a result of the social arrangements within society. Not surprisingly this approach received much criticism, not least from other women who felt that their lived experiences were being undermined and rendered invalid. This resulted in the following wave of feminism placing undue emphasis on difference.

Yet, as we have seen, by highlighting separateness and difference we face other problems. Not only can the discourse of oppression be perpetuated, but, by promoting the idea of positive group specificity, of claiming that disabled people constitute an undifferentiated, homogenous coterie, the idea of The Disabled becomes solidified and unproblematic. Issues such as gender, sexual orientation, ethnicity and class cannot be addressed. However, at the same time we cannot ignore the fact that in everyday interaction and cultural imagery certain assumptions are made about The Disabled which are used to justify exclusion, avoidance and segregation. As Young (1990) argues, continued disablist institutions and behaviour create specific circumstances and environments for disabled people which, inevitably, perpetuate our unequal position within society. (Young 1990:164). In these conditions it then becomes equally oppressive to try and deny our differences.

This thesis has thus shown that both power and resistance are not fixed concepts. The highlighting of difference may in Foucault's terms be a way of creating a subject, an object of surveillance etc. but denial of that difference per se is not a route to resistance. Similarly in Goffman's terms, the highlighting of difference may stigmatise and disempower individuals, but in specific interaction difference alone does not dictate what that power relationship will be.

The social model of disability assumes that the removal of disabling barriers will result in our assimilation into mainstream society. Yet, as with any assimilative view, this line of argument fails to take account of lived experience and sets goals which are simplistic in the face of day-to-day interactions.

The synthesis of Goffman and Foucault presented in this thesis attempts to avoid such over-simplification and argues that we cannot polarise difference and assimilation, because the workings of both power and resistance are not contained within a single paradigm. Power and resistance constitute a discourse, experienced via interaction, which is always open to negotiation.

By utilizing Foucault's approach to political discourse we can begin to devise effective strategies to contest and resist the discursive operations of our contemporary disablist ideology. Foucault opens the way for us to analyze discourse strategically. That is to say in terms of what it does rather than in the traditional sense of what it says. I am not suggesting that the content of disablist discourse is irrelevant, for we need to be aware of what it says before we can analyze how and why it works, rather, we learn from Foucault:

> not to allow the truth or falsity of particular propositions to distract us from the power-effects they produce or the manner in which they are deployed within particular systems of discursive and institutional practices. (Halperin 1995:31)

Further research needs to be developed in which the oppression of disabled people is analyzed in terms of discursive power-effects. We need to examine strategies for deligitimizing 'compulsory ablebodyedness'. We do not need to only fight specific agents of oppression but rather our focus should shift to those ubiquitous and pervasive strategies of disablism that construct both private and public discourses, that saturate the entire field of cultural representation, that, like power in Foucault's formulation, are everywhere.

I have demonstrated throughout this work that resistance is always open to renegotiation and reappropriation by normalising disciplines. However if we refuse to engage with the content of a particular authoritarian discourse (such as disablist discourse) and to, instead, analyze discourses in terms of their overall strategies we can resist being drawn into what Foucault called *bavardage*[2].

In other words we have to recognise that by attempting to refute the 'truth' of disability, by engaging in the very discourse that defines us as other, we run the risk of consolidating this truth rather than challenging, subverting or resisting it.

Equally, there is no way in which we can talk about a homogenous, universal disabled self. This very notion is a myth which has been, and continues to be, constructed for us by normal definers, by normal enforcers, by normal interpreters. In other words the notion of the disabled self is constructed through normalizing agents. It follows then, that we can no longer talk about the disabled self waiting to be liberated by the dynamics of a liberating politics. For whatever our objections to post-modernist celebrations of multiple identities and de-centred subjects, it is certainly the case that there can be no way of discovering a common denominator in the construction and experience of disability. Hence all that we can say is that the discourse of normalacy is always parasitic on the hypostasisation of difference. That is, to put it plainly, that to be normal is not to be different. For those who play the game of normalacy, all disabled people constitute an universal other. It is unfortunate that this discourse becomes the ideology of both the normals and the abnormals.

1. The information quoted here concerning "The Nation of Islam" is taken from a Panorama documentary which was broadcast on 20.11.95 on B.B.C. 2.

2. Chatter - as in "the chatter of criminology". (Foucault 1977:304)

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