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CHAPTER 6

Psycho-emotional Dimensions of Disability and the Social Model

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Introduction

Within the disability world, many of the current debates centre on the nature of disability and on interpretations of the social model of disability, which posits disability as the externally imposed,

disadvantage or restriction caused by a contemporary social organisation which takes little or no account of people who have ... impairments and thus excludes them from the mainstream of social activities (Oliver and Barnes 1998: 18).

This social relational definition of disability extends the one created originally by the Union of the Physically Impaired Against Segregation (UPIAS 1976) to include all impairments rather than just physical impairments. In this relational model, disability is seen as a form of social oppression, like racism, homophobia and ageism, rather than as an individual problem caused by impairment (as in the individual or medical model of disability). Recasting disability in this light has been a vital part of the move towards the emancipation of disabled people within society and has been able to highlight and challenge the

social and economic disadvantage faced by disabled people (Barnes 1991).

In this chapter, I discuss the benefits of adopting the extended social relational model of disability proposed by Thomas (1999), which builds on the definition quoted above, to include both structural and psycho-emotional dimensions of disability. In this model, disability is seen as a form of social oppression that operates at both the public and personal levels, affecting what people can *do* as well as who they can *be*. I provide some examples of psycho-emotional disablism and show how this dimension of disability can leave some disabled people feeling worthless and ashamed, whilst removing others from the social world as surely as structural barriers. In the light of current debates about disability and identity, consideration of both dimensions of disability has useful implications for who is seen, and who see themselves as disabled.

However, although this extended model of disability allows for a more sophisticated and complete analysis of the ways in which both structural and psycho-emotional dimensions of disability are evident in the lives of people with impairments, there are compromises associated with adopting a more complex definition of disability. Nonetheless, more work needs to be done in order to raise the profile of the psycho-emotional dimensions of disability within disability studies and the disabled people's movement.

The extended social relational model of disability

One of the main criticisms of the social model of disability, with its emphasis on socio-structural barriers, has been that it ignores the cultural and experiential dimensions of disability (Shakespeare, 1994). Consequently, the focus has been on the 'public' experiences of oppression such as social barriers, at the expense of the more 'personal' experiences of oppression which operate at the emotional

level (Thomas, 1999). In her book, *Female Forms*, Thomas (1999) proposes an extended social relational definition of disability that attempts to address this criticism:

Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments *and the socially engendered undermining of their psycho-emotional wellbeing* (Thomas, 1999: 60; *emphasis added*).

This extended social model of disability takes account of the sociostructural barriers and restrictions that exclude and discriminate against disabled people in addition to the social processes and practices which place limits on the psycho-emotional well-being of people with impairments. In other words, this extended definition of disability which incorporates both structural and psycho-emotional dimensions of disability, includes the limits on what disabled people can both do and be – for many people, such as myself, it is this latter form of disablism which is the most restricting. The agents of this disablism can be close family members or individuals with whom disabled people have direct contact such as ‘professionals’, in addition to disablism experienced within society at large (Thomas 1999).

These psycho-emotional dimensions of disability can be considered to be the effects of psycho-emotional pathways of oppression which are sustained through imagery, cultural representations and interactions with others:

Going out in public so often takes courage. How many of us find that we can't dredge up the strength to do it day after day, week after week, year after year, a lifetime of rejection and

revulsion? It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility (Morris 1991: 25).

Thus, the experience of structural and/or psycho-emotional dimensions of disability can prevent people with impairments from participating within mainstream society.

Psycho-emotional dimensions of disability

The psycho-emotional dimensions of disability can be manifested in many different ways. However it is important to note that the experience of psycho-emotional disability is not inevitable or unchanging. Not all disabled people will experience this form of disability and it will change in intensity with time and place; whether or not it is more or less disabling than their experience of structural disability will vary and sometimes the two dimensions reinforce each other. I will now briefly describe three examples of this dimension of disability.

Responses to experiences of structural disability

For people with physical and sensory impairments, the experience of being excluded from physical environments reminds them that they are different and can leave them feeling that they don't belong in public and private spaces.

It tells us that we aren't wanted in the places that non-disabled people spend their lives – their homes, their schools and colleges, their workplaces, their leisure venues (Morris 1991: 26-27).

Fred, a research participant who used a wheelchair, talked to me about the problems he faced visiting a

counsellor in her inaccessible house - he had to be carried in, and once inside she made a show of needing to move furniture in order to accommodate him. As he said,

Here I'm supposed to be being helped, and I am just being made to feel more in the way (Reeve 2000a).

The counsellor's grudging admittance of Fred to her house, especially in the way that she failed to move furniture out of the way before Fred and his wife turned up for each of their appointments, reinforced the message that Fred was getting from society – that he was different and that he was not wanted here, he was out of place. Slack (1999) writes about her experiences as a wheelchair user and the anger and frustrations which arise from living in an inaccessible environment. She feels that her friends do not want her to make a scene when she is faced with physical barriers and that they do not want to recognise her experiences of oppression.

Whilst the suggestion by others that she should 'write and complain' is all very well, like many other disabled people, she could spend her entire life and energy complaining rather than trying to socialise or earn a living.

An important difference between the experience of disabled people and those from other oppressed groups in society is that the doctrine of 'separate but equal' is enshrined in law (Olkin 1999). At the start of the 21st century it would be unthinkable to make people from ethnic minority groups access a building through a different entrance to other people, and yet this is what disabled people do every day – entering an art gallery through a back entrance, using a goods lift to access a first floor classroom, travelling in the guards van on a train. Being forced to move within public space in this manner reinforces the feeling that one is a second-class citizen who is being tolerated, but only just. This manifestation of

psycho-emotional disablism describes the emotional costs of moving within these 'landscapes of exclusion' (Kitchin 1998: 351) which add to the oppressive nature of structural disability.

Social interaction with others

In addition to the daily battle with disabling physical barriers, disabled people also have to deal with the reactions of others within society. Many disabled people with visible impairments have to deal with the frank curiosity of other people.

We often experience the fascination that non-disabled people have with 'just how do you *manage?*' They have a consuming curiosity about how we pee, how we shit, how we have sex (*do we have sex?*) ... Our physical difference makes our bodies public property (Morris, 1991: 29; *emphasis in original*).

It has been suggested that non-disabled people may feel that they have the right to ask these kinds of personal questions because disabled people are occupying 'their' public space, and like children and elderly people, can be approached with less respect and reserve than the average adult (Chouinard 1997). There are also expectations about what disabled people 'look' like and this can cause difficulties for those disabled people who do not match the stereotypical image of being elderly and/or a wheelchair user, especially when using facilities set up for disabled people such as disabled parking spaces or accessible toilets.

Another aspect of interacting with others that is a potential source of psycho-emotional disablism, is the experience of being stared at by others. Whilst acknowledging that the ways in which disabled people respond to the gaze of others vary and are affected by

personal biographies and experience, nonetheless the experience of being stared at can leave disabled people feeling ashamed, vulnerable and invalidated. This is exemplified by one woman's narrative about her sexual experiences:

The look of revulsion on a man's face at the sight of my naked flesh does absolute wonders for my self-esteem. And then there are the 'freak show' types. Their motives range from mild curiosity to fully blown fetishism. It's great to hear, at the peak of an orgasm, 'I've never fucked a woman in a wheelchair before' (Ball 2002: 170).

This experience of being gazed on is obviously affected by what is visible to the observer and so the experience of this form of disablism is mediated by how apparent impairment and impairment effects are to others. Someone who is unable to hide their impairment is most likely to be seen as 'disabled' by others at the expense of any other personal attributes (French 1994a). Whilst someone with a hidden impairment is less likely to be stared at by others, there is always the risk that their disability status will be revealed and this fear forms the basis for 'the negative psycho-emotional aspects of concealment' (Thomas 1999: 55).

This discussion about the interaction between disabled people and others in society is not new to disability studies. Goffman's (1963) work on stigma provides a descriptive account of how disabled people interact with non-disabled people and has rightfully been criticised for failing to provide an account of the true nature of disabled people's oppression and for presenting such interactions as inevitable (Finkelstein 1980; Bogdan and Taylor 1989). Nonetheless, for many disabled people, it is the reactions of others which affect their psycho-emotional well-being and indirectly 'restrict activity'; therefore this should be

considered as an important part of the disablism present in society that needs to be challenged (Thomas 1999). As it is forty years since Goffman published his social interactionist analysis of stigma, it may now be appropriate to revisit this concept using a more recent sociological perspective.

Internalised oppression

The final element of psycho-emotional disablism I want to describe is that of internalised oppression. This can happen when individuals within a marginalised group in society internalise the prejudices held by the dominant group – the acceptance and incorporation of ‘*their values about our lives*’ (Morris 1991: 29; *emphasis in original*). This form of oppression is most effective when it is acting at the subconscious level, affecting the self-esteem of the individual in addition to shaping their thoughts and actions (Marks 1999). Disabled people are surrounded by myths and stereotypes which underpin prejudices experienced on a daily basis (Morris 1991); the dearth of positive disabled role models means that these myths are never challenged and remain in place supported by media and film images (Barnes 1994). Terms of abuse within everyday language use words related to impairment such as ‘too blind to see’, ‘out of your mind’, ‘words falling on deaf ears’, and ‘haven’t got a leg to stand on’ which all support the notion that to be of value, one must be physically, psychologically and mentally fit (Thomas 1995). Therefore, it is not surprising that disabled people can feel devalued and disempowered:

Somewhere deep inside us is the almost unbearable knowledge that the way the able-bodied world regards us is as much as we have the right to expect. We are not full members of that world, and the vast majority of us can never hope to be. If we think otherwise we are deluding ourselves (Battye 1966: 8-9).

In addition, internalised oppression maintains the negative stereotypes of disabled people that are prevalent within society. If disabled people accept the prejudices and assumptions held by non-disabled people, then they become what they have internalised and become the 'slave of their archetypes' (Fanon 1986: 35).

As mentioned earlier, the agents of psycho-emotional disablism can be family, friends, professionals or strangers. Disabled children may experience more acute internalised oppression because their less powerful position means that they are more vulnerable to the views of the wider society; in addition, their parents may be unwitting oppressors in the process, because their beliefs and expectations will be shaped by the professionals they defer to (French 1994b). This can result in children having low self-esteem, which in turn can render them more vulnerable to being abused. The negative social values placed on children with impairments creates a situation in which abusers can believe that it is all right to abuse a child who is 'worthless' and the child accepts the abuse because they believe that they are 'defective' (Kennedy 1996). For example, a young man with cerebral palsy who had been sexually abused commented, 'Why bugger up a normal child, I was defective already' (Kennedy 1996: 127). This abuse extends into adulthood with disabled men and women tolerating abusive relationships because of their low self-esteem about being disabled and hence unlovable (Gillespie-Sells et al. 1998).

Again, the experience of internalised oppression is not inevitable and is affected by an individual's biography. There is the phenomena of multiple/simultaneous oppression faced by disabled people who belong to more than one minority group, such as disabled women, disabled gay men, disabled Black people (Morley 1992; Vernon 1998). Also, whilst some people will resist and

fight internalised oppression, others will be unable to do so, either because they are isolated or unaware, or maybe because the support they receive is conditional on them being compliant and continuing to play the 'disabled role' (Thomas 1995). Despite the prevalence of negative stereotypes of disability within every aspect of society and the damaging effects internalised oppression has on the everyday life and health of disabled people, this phenomenon remains a currently neglected area of discussion (Marks 1999).

I consider internalised oppression to be one of the most important manifestations of psycho-emotional disablism because of its unconscious and insidious effects on the psycho-emotional well-being of disabled people and because it has a direct impact in restricting who someone can 'be'.

The relevance of the psycho-emotional dimensions of disability for a contemporary social model of disability

Whilst consideration of internalised oppression and social interactions are not new to disability studies, the inclusion of these oppressive relationships with the self and others within a social model of disability is innovative. I will now illustrate the contribution that inclusion of the psycho-emotional dimensions of disability within an extended social relational model of disability can make towards providing a more comprehensive account of disability and the related issue of identity.

Providing a more inclusive account of disability

Sometimes I don't go into my local town centre because I cannot manage the steps on that day, other times I don't go shopping because I cannot deal with the stares of others. Both of these have the same effect of keeping me out of a public space, both are the result of oppressive social relationships which require changes in the socio-structural and socio-cultural fabric rather than my

individual acceptance of disability. Like psycho-emotional disablism, the experience of structural disability is not identical to all people with impairments because its effects are mediated by other factors such as class, gender and ethnicity, in addition to impairment. For people with invisible impairments or those who can pass, structural disability may be present at some time in their lives; however, the experience of psycho-emotional disablism may exert a greater influence on their well-being (Thomas 1999). Therefore, as disabled people each experience their own different degrees of structural and psycho-emotional disablism, it would be more accurate for a model to include both dimensions of disability rather than focus on structural disability alone.

These two dimensions of disability can also interact to affect the economic disadvantage faced by disabled people. The existing UPIAS social relational definition of disability does take account of the many ways in which disabled people are excluded from participation in mainstream life because of the prejudicial attitudes of others - for example, there is ample evidence of institutional and direct discrimination against disabled people in the labour market (Barnes 1991). Whilst this discrimination is undoubtedly the greatest cause of unemployment and underemployment amongst disabled people, there will also be some disabled people who do not feel confident enough to apply for jobs for which they are eminently capable because they have internalised the negative value afforded disabled people in society – the end result is the same, no job with the associated poverty this brings. It is also possible that the experience of psycho-emotional disablism can further add to this level of poverty; for example, a disabled person who is feeling worthless and stressed because of the continual experience of being excluded from the built environment, may not have the emotional strength to then fight for the benefits to which they are entitled, and instead, attempts

to manage without. Thus psycho-emotional dimensions of disability can operate in conjunction with the experience of structural disability, further increasing the level of exclusion and material disadvantage experienced by people with impairments.

Whilst the Disability Discrimination Act and Disability Rights Commission are slowly improving access for disabled people to mainstream life, even in the utopian dream of a world free from socio-structural barriers, psycho-emotional disablism would still be present within our society because of the longevity of prejudicial attitudes and stereotypes about disability. Unfortunately the improvement of social attitudes towards disabled people will be a slow process if the experiences of women and minority ethnic groups are anything to go by – these two groups of people have been protected by legislation outlawing discrimination for many years and yet negative attitudes towards the members of these groups are still endemic within society (Corker 1999).

Finally, I want to briefly consider the relationship between disabled people and the medical profession. Within disability studies, criticisms have been made of the manner in which medicine advocates the pursuit of a 'normal' body at all costs and the way in which this locates the cure for disability with the individual rather than society (Oliver 1990). The treatment of disabled people at the hands of the medical profession can also have adverse effects on their emotional well-being, leaving them feeling ashamed, vulnerable and objectified (Marks 1999; Thomas 2001). Therefore, the use of a social model of disability which recognises dimensions of disability operating at the structural and psycho-emotional level allows for a more complete identification of the ways in which the actions and attitudes of health professionals disable people with impairments, in extreme cases rendering them more vulnerable to subsequent abuse by

repeated exposure to medical examinations and the experience of 'public stripping' (Marks 1999).

Extending the social model of disability in this manner enables a richer analysis of the ways in which structural and psycho-emotional dimensions of disability operate within the lives of people with impairments. I now want to consider the implications of this extended definition of disability for issues of identity.

Identity and disability

A recent study (Grewal et al. 2002) showed that just over half of the people with impairments who were surveyed did not identify as disabled. The reasons for this varied: some did not feel that they were ill or incapacitated enough to count as disabled, others felt that their health problems were part of illness or the process of ageing, rather than disability. The negative images associated with disability caused some participants to be too embarrassed to identify as disabled. This same study showed that disability was persistently believed to be connected with a physical impairment that typically affected mobility, was visible, led to dependency and incapacity and was a permanent condition. This image of disability was at variance with how many of the people questioned saw themselves and so they did not see themselves as disabled. For example, one woman did not see herself as disabled because although she had severe psoriasis, she was mobile and 'able to do things'.

During a recent Disability Equality training session I was running it turned out that two of the participants in the class both had the same impairment; only one of this pair felt that she was disabled and the reason given was that she received Disabled Living Allowance. This is not the first time I have come across people with impairments who feel that they are 'allowed' to count as disabled because they qualify for disability-related benefits or have a disabled parking badge. Also many people do not see

themselves as disabled because having an impairment is 'normal' for them and so they do not see themselves as different (Watson 2002).

Therefore, whilst having an impairment is an essential characteristic for someone to be able to identify as disabled, the presence of the former does not always lead to the latter. Even when people do identify as disabled, is it not a common identity for all such people – it varies from being associated with what someone is unable to do ('I'm disabled because I'm not able-bodied'), through to the 'I'm disabled and proud' identity associated with the disabled people's movement. Consequently, as Watson (2002) points out, this lack of a collective identity for people with impairments has consequences for who is actually being represented by the disabled people's movement and the associated organisations of disabled people. The issue of which individuals identify themselves as disabled, or are seen as disabled by others is not simple and clear-cut.

The issue of 'passing' is particularly interesting in this respect. Disabled people with less visible impairments have the option of passing, choosing whether or not to identify as disabled. Whilst this eases the strain of social interaction, especially amongst strangers, it can cause difficulties for the individual who is always at risk of exposure as described earlier. Unfortunately disabled people who do pass can be seen as traitors by others within the disabled people's movement – passing,

may defend an individual against the commonality of our oppression but it is dangerous in that it denies our very identity (Morris 1991: 37).

This assumes that passing involves the active rejection of a disabled identity without allowing for the possibility that someone is simply attempting to reduce their experience of psycho-emotional disablism in that time and

place (Kanuha 1999). Given the current debates about disability and identity, the issues of why, how and where people pass is of particular relevance. Consideration of the psycho-emotional dimensions of disability could contribute to a better understanding of the phenomenon of passing and its relationship to issues of identity.

Even people who do not pass, but who have visible impairments, can still experience difficulties having their disability identity accepted by others. It has been suggested that collective self-organisation is one way of developing a positive disability identity (Shakespeare 1996). Unfortunately this does not always happen; for example, the disabled people's movement has been accused of under-representing young disabled people and marginalising people with learning difficulties (Campbell and Oliver 1996). I have also come across cases in my own research where being part of an organisation of disabled people has been quite oppressive for some of the disabled people involved because of a perceived 'hierarchy of impairment' within that organisation. One of my participants did not feel she was seen as a 'real' disabled person because she was not a wheelchair user and did not have one of 'the biggies' like cancer, arthritis, multiple sclerosis or visual impairment. Consequently her identity as a disabled person was challenged by other disabled people in the organisation. The presence of a 'hierarchy of impairment' in which people with certain impairments are seen as being more entitled to identify as disabled does nothing to promote the growth of an inclusive disabled people's movement. Whilst this hierarchy has its roots in the way that society has traditionally divided disabled people up by impairment group, it is also maintained by internalised oppression, a psycho-emotional dimension of disability (Shakespeare et al. 1996).

Charlton comments that a disabled people's movement,

must recognise that the phenomenology of oppression is a totality of lived experiences – from poverty and isolation to cultural degradation and self-pity (Charlton 1998: 82).

Thus an extended social model of disability which includes pathways of oppression operating at both the public and personal level would appear to offer one way of meeting this challenge. Consequently, this broadens the definitions of what are considered to be legitimate disability experiences which changes who identifies as disabled in the political and personal sense. This could have particular relevance for people with invisible impairments (and who can therefore pass) or those for whom impairment does not restrict physical activity, such as facial disfigurement - whilst such people may experience structural disability at some point in their life, they are more likely to be affected by psycho-emotional disability. For example, although the woman with psoriasis described earlier did not see herself as disabled because she could 'do' things, she might view her experiences differently if the disabling reactions of others towards someone with a visible skin condition were explicitly included within a definition of disability.

There are many different reasons why people with impairments may or may not choose to identify as disabled, or be considered by others to be disabled. People may identify as disabled in one setting but not in others; one of my participants described how she identifies as a 'disabled person' at work, but elsewhere in her family and social life, her identity is that of mother and woman – her impairment and disability are not part of her identity in these other settings. Thus the process of identification is not fixed in time or place; it is also influenced by the complex intertwining of impairment effects and disability, in addition to other social identities

and personal biography (Thomas 1999). In addition, the manner in which disabled people choose to resist or challenge psycho-emotional disablism has relevance for the ways in which people identify (or not) as disabled and how they challenge the 'disabled role' defined by society (Reeve 2002).

Discussion

I have described some of the ways in which psycho-emotional dimensions of disability, the 'barriers in here' work alongside and in conjunction with structural dimensions of disability, the 'barriers out there'. Whilst the psychoemotional dimensions of disability act at the emotional level, leaving some disabled people feeling devalued and stressed, the material and physical effects of this form of disablism can be similar to the experience of sociostructural barriers which lead to exclusion and discrimination. This chapter has shown that the extended social model of disability suggested by Thomas (1999) which includes both structural and psycho-emotional dimensions of disability could offer a more sophisticated tool with which to understand the breadth of experience of disability and the associated issues of disability identity.

A powerful counter-argument to extending the social model in this manner could be that it weakens the campaigning power of the social model to effect material and political changes within society. I acknowledge that the social model of disability formulated by UPIAS in 1976, has been crucial to the fight against disabling barriers and discrimination as a means to improving the material and social lives of disabled people. I would agree that aspects of structural disability are easier to identify, challenge, and change than psycho-emotional dimensions of disability which are more deeply rooted in both the societal and individual unconscious. Therefore I can see how explicitly including a dimension of disability which operates at the emotional rather than the structural level could be

perceived as weakening the power of the social model of disability to improve the lives of disabled people. One of the strengths of the current social model definition of disability is that of its relative simplicity as a concept in helping disabled people see disability as a social, rather than individual construction. This simplicity could be compromised by adopting a more complex definition of disability which explicitly references both structural and psycho-emotional dimensions of disability.

Additionally it could be argued that one of the roles of a disability culture is precisely to challenge psycho-emotional disablism by providing alternative images of disability, a collective context in which to share ideas and feelings as well as a space in which to reflect on the experience of disability from the perspective of different groups of disabled people.

Taking part in the arts should also be viewed as a tool for change as much as attending meetings about, say, orange badge provision ... Introducing disabled people to the social role of artistic creativity and opening a debate about disability culture is a dynamic way of assisting disabled people to challenge their assumed dependency and place in mainstream society (Morrison and Finkelstein 1993: 126-127).

For people such as Finkelstein, the existing social model of disability already recognises both structural and psycho-emotional dimensions of disability as evidenced by the presence of both political activism and disability arts. On the other hand, other disability studies writers (such as Shakespeare 1996; Thomas 1999) would argue that whilst this might have been the intention behind the UPIAS social model of disability, the academic and political interest has been much more focussed on structural dimensions of disability, and consequently the psycho-

emotional dimensions of disability have received far less attention.

Importantly, if the social model of disability sets out to define what disables people with impairments, then it has to take account of structural and psycho-emotional dimensions of disability, which both have their origins in oppressive social relations. The question is, how should this be done? Should the social model of disability be extended to explicitly include psycho-emotional dimensions of disability as a way of bringing attention to bear on this neglected form of disablism? Or is it more appropriate to retain the political strength of a simple definition of disability and apply the social model of disability in its existing UPIAS-based form to clarify and explore psycho-emotional dimensions of disability? Whilst the extension of the social model proposed by Thomas (1999) offers a very valuable contribution to the development of a social theory of disability, it is less useful for the purposes of campaigning and effecting social change. On the other hand, the disabled people's movement must engage with some of the darker sides of the experience of oppression (Shakespeare 1996) - issues of internalised oppression and the related hierarchy of impairment. My concern is that it is easier for groups of disabled people to continue to avoid tackling these painful areas if they are not explicitly included within a definition of disability. The question about whether or not the social model of disability *needs* extending is complex and there is no obvious answer.

As part of the ongoing debates about whether or not the social model of disability should acknowledge the role of impairment in restricting the activity of disabled people, Oliver suggested that the social model of disability,

has been a pragmatic attempt to identify and address issues that can be changed through collective action rather than medical or other

professional treatment (Oliver 1996: 48).

Although the psycho-emotional dimensions of disability operate at an emotional level I would not suggest that this form of disablism can be 'fixed' by a visit to a psychologist or counsellor; such professionals generally work within an individual model of disability and are more likely to add to, rather than help resolve issues associated with the psycho-emotional dimensions of disability (Reeve 2000a; Reeve 2000b). Adopting this 'treatment of the individual' approach also supports the notion that people who are unable to participate in mainstream life because of the effects of psycho-emotional disablism are not 'really disabled' in the same way that, for example, a wheelchair user who cannot access the built environment is. Consequently their experiences of exclusion become their 'personal trouble' to overcome rather than something to be recognised and worked with collectively.

Given that psycho-emotional dimensions of disability emerge from oppressive social relations and cultural myths, then they are open instead to challenge by collective action in two ways. Firstly, experience of the disabled people's movement and disability culture can be more effective than individual counselling at challenging this hidden form of disablism through the provision of positive role models and exposure of the pervasive nature of prejudices and myths about disability. However, as indicated previously, the issue of how people identify as disabled and the ever-present hierarchy of impairment mean that even in such a collective context, some disabled people still doubt their right to be considered as a 'real' disabled person. Secondly, as socio-structural barriers within society are broken down, then it is reasonable to expect that the increasing presence of disabled people within mainstream society will slowly break down some of the stereotypes within our culture, thereby reducing still further levels of psycho-emotional

disablism.

Apart from providing a possible refinement to the existing social model of disability, explicitly recognising this psycho-emotional dimension of disability will also contribute to the continuing development of a social theory of disability. Finkelstein and French have previously advocated the construction of a new approach to a psychology of disability:

With the growth of new (social) approaches to disability, there is a need to develop fresh insights into the way disabled people, and others, make sense of, cope with, manage and overcome disabling social and physical barriers (Finkelstein and French 1993: 32).

In other words, there is a need to take account of the personal effects of living with disability in a manner which differs from the psychological models of loss which are more typically associated with the disability experience. This psychology of disability (rather than impairment) focuses on the psychological anxiety and distress caused by the social relations of disability and is therefore very closely related to the psycho-emotional dimensions of disability.

Finally, within disability studies there is a growing body of literature offering post-structuralist and post-modernist perspectives on disability, impairment and identity (Corker and Shakespeare 2002). Recently Shakespeare and Watson (2002) suggested that a social theory of disability would need to include all dimensions of disabled people's experiences – bodily, psychological, cultural, social and political – in order to make sense of the complex and situated nature of disability. I believe that consideration of both the psycho-emotional and structural dimensions of disability and how they interact with each other can

contribute to these post-structuralist debates; I have already used a post-structuralist approach to theorise the psycho-emotional dimensions of disability, and their interrelations with impairment and identity (Reeve 2002).

Summary

This chapter has illustrated how the extension of the social model of disability to include both structural and psycho-emotional dimensions of disability, as suggested by Thomas (1999), facilitates a sophisticated analysis of the manner in which people with impairments are disabled by oppressive social relations. I have shown how the experience of exclusion from mainstream life can have an adverse effect on the psycho-emotional well-being of a person with impairments, illustrating the complex manner in which structural and psycho-emotional dimensions of disability can be intertwined and/or mutually reinforcing. Internalised oppression or dealing with the reactions of others can exclude a disabled person as effectively as an inaccessible public space and therefore any discussion about barriers to participation in mainstream society needs to include reference to both dimensions of disability. The psycho-emotional dimensions of disability also have an important contribution to make in examining the different ways in which people with impairments see themselves (or not) as disabled people, because it operates along emotional pathways.

Whilst a focus on identifying and challenging structural disability has led to considerable improvements in the lives of disabled people, this emphasis on the barriers 'out there',

has the rather ironic consequence of leaving aspects of social life and social oppression which are so keenly felt by many disabled people (to do with self-esteem, interpersonal relationships, sexuality, family life and so on) 'open season' to

psychologists and others who would not hesitate to apply the individualistic/personal tragedy model to these issues (Thomas, 1999: 74).

For many disabled people, it is the barriers that operate 'in here', at the psycho-emotional level which have the most disabling effect on their lives. Therefore it is high time that this dimension of disablism, which operates along emotional and psychological pathways, is given proper attention within disability theory. Whether this should be done as part of an extended model of disability as Thomas suggests, or by working within the existing social model definition of disability remains to be seen.

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Bibliography

- Ball, K. F. 2002: Who'd fuck an ableist? ***Disability Studies Quarterly***, 22 (4), 166-171.
- Barnes, C. 1991: ***Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation***. London: Hurst and Co. and BCODP.
- Barnes, C. 1994: Images of disability. In S. French (ed.), ***On Equal Terms: Working with Disabled People***. Oxford: Butterworth-Heinemann.
- Battye, L. 1966: The Chatterley syndrome. In P. Hunt (ed.), ***Stigma: The Experience of Disability***. London: Geoffrey Chapman.
- Bogdan, R. and Taylor, S. J. 1989: Relationships with severely disabled people: the social construction of humanness. ***Social Problems***, 36 (2), 135-148.
- Campbell, J. and Oliver, M. 1996: ***Disability Politics: Understanding our past, changing our future***. London: Routledge.
- Charlton, J.I. 1998: ***Nothing about Us without US:***

- Disability, Oppression and Empowerment.*** Berkeley: University of California Press.
- Chouinard, V. 1997: Making space for disabling differences: challenging ableist geographies. ***Environment and Planning D: Society and Space***, 15, 379-387.
- Corker, M. 1999: Difference, confluences and foundations: the limits to 'accurate' theoretical representation of disabled people's experience? ***Disability and Society***, 14 (5), 627-642.
- Corker, M. and Shakespeare, T. (eds) 2002: ***Disability/Postmodernity: Embodying Disability Theory.*** London: Continuum.
- Fanon, F. 1986: ***Black Skin, White Masks.*** London: Pluto Press.
- Finkelstein, V. 1980: ***Attitudes and Disabled People: Issues for Discussion.*** New York: World Rehabilitation Fund.
- Finkelstein, V. and French, S. 1993: Towards a psychology of disability. In J. Swain, V. Finkelstein, S. French and M. Oliver (eds), ***Disabling Barriers - Enabling Environments.*** London: Sage and Open University Press.
- French, S. 1994a: Dimensions of disability and impairment. In S. French (ed.), ***On Equal Terms: Working with Disabled People.*** Oxford: Butterman-Heinemann Ltd.
- French, S. 1994b: The disabled role. In S. French (ed.), ***On Equal Terms: Working with Disabled People.*** Oxford: Butterman-Heinemann Ltd.
- Gillespie-Sells, K., Hill, M. and Robbins, B. 1998: ***She Dances to Different Drums: Research into Disabled Women's Sexuality.*** London: King's Fund.
- Goffman, E. 1963: ***Stigma: Notes on the Management of Spoiled Identity.*** Englewood Cliffs, NJ: Prentice Hall; Harmondsworth: Penguin 1968.
- Grewal, I., Joy, S., Lewis, J., Swales, K. and Woodfield, K.

- 2002: ***Disabled for Life? Attitudes Towards, and Experiences of Disability in Britain.*** Leeds: Corporate Document Services.
- Kanuha, V. K. 1999: The Social process of 'passing' to manage stigma: Acts of internalized oppression or acts of resistance? ***Journal of Sociology and Social Welfare***, 26 (4), 27-46.
- Kennedy, M. 1996: Sexual abuse and disabled children. In J. Morris (ed.), ***Encounters with Strangers: Feminism and Disability.*** London: The Women's Press.
- Kitchin, R. 1998: 'Out of place, knowing one's place': space, power and the exclusion of disabled people. ***Disability and Society***, 13 (3), 343-356.
- Marks, D. 1999: ***Disability: controversial debates and psychosocial perspectives.*** London: Routledge.
- Morley, L. 1992: Women's Studies, Difference, and Internalised Oppression. ***Women's Studies International Forum***, 15 (4), 517-525.
- Morris, J. 1991: ***Pride Against Prejudice: Transforming Attitudes to Disability.*** London: The Women's Press.
- Morrison, E. and Finkelstein, V. 1993: Broken arts and cultural repair: the role of culture in the empowerment of disabled people. In J. Swain, V. Finkelstein, S. French and M. Oliver (eds), ***Disabling Barriers – Enabling Environments.*** London: Sage and Open University Press.
- Oliver, M. 1990: ***The Politics of Disablement.*** Basingstoke: Macmillan.
- Oliver, M. 1996: Defining Impairment and Disability: issues at stake. In C. Barnes and G. Mercer (eds), ***Exploring the Divide: Illness and Disability.*** Leeds: The Disability Press.

- Oliver, M. and Barnes, C. 1998: ***Disabled People and Social Policy: From Exclusion to Inclusion***. Harlow: Addison Wesley Longman.
- Olkin, R. 1999: ***What Psychotherapists Should Know About Disability***. New York: The Guilford Press.
- Reeve, D. 2000a: Negotiation of disability and impairment within counselling relationships: a critical evaluation from the perspective of clients with spinal cord injuries. Unpublished MA Thesis, Leeds: University of Leeds.
- Reeve, D. 2000b: Oppression within the Counselling Room. ***Disability and Society***, 15 (4), 669-682.
- Reeve, D. 2002: Negotiating psycho-emotional dimensions of disability and their influence on identity constructions. ***Disability and Society***, 17 (5), 493-508.
- Shakespeare, T. 1994: Cultural Representation of Disabled People: dustbins for disavowal? ***Disability and Society***, 9 (3), 283-299.
- Shakespeare, T. 1996: Disability, Identity, Difference. In C. Barnes and G. Mercer (eds), ***Exploring the Divide: Illness and Disability***. Leeds: The Disability Press.
- Shakespeare, T., Gillespie-Sells, K. and Davies, D. 1996: The Sexual Politics of Disability: Untold Desires. London: Cassell.
- Shakespeare, T. and Watson, N. 2002: The social model of disability: an outdated ideology? ***Research in Social Science and Disability***, 2, 9-28.
- Slack, S. 1999: I am more than my wheels. In M. Corker and S. French (eds), ***Disability Discourse***. Buckingham: Open University Press.
- Thomas, C. 1999: ***Female Forms: Experiencing and Understanding Disability***. Buckingham: Open University Press.
- Thomas, C. 2001: Medicine, gender and disability: disabled women's health care encounters. ***Health Care for Women International***, 22 (3), 245-262.
- Thomas, P. 1995: Internalised oppression, ***Coalition***,

- February, 5-7. UPIAS. 1976: ***Fundamental Principles of Disability***. London: Union of the Physically Impaired Against Segregation.
- Vernon, A. 1998: Multiple oppression and the disabled people's movement. In T. Shakespeare (ed.), ***The Disability Reader: Social Science Perspectives***. London: Cassell.
- Watson, N. 2002: Well, I know this going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. ***Disability and Society***, 17 (5), 509-527.