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Chapter 7

Towards a psychology of disability: The emotional effects of living in a disabling society

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Introduction

The relationship between the disciplines of psychology and disability studies has been a troubled one at best. The proliferation of loss and stage models about how people with impairments 'adjust' to disability through a mourning process have been extensively criticised within disability studies for failing to reflect the lived experience of disabled people and instead providing a 'psychopathology of disability' (Finkelstein, 1990). This approach to understanding the experience of disability is not surprising given that psychology generally views disability as being the domain of rehabilitation psychology rather than part of mainstream psychology training (Olkin, 2003). This skewing of psychology research and theory is also problematic because most disabled people who seek psychological or psychotherapeutic help, for whatever reason, are seen in the community and not in a rehabilitation unit. However there are consequences to this rejection of the rehabilitation based models as a way of explaining how people with impairments 'come to terms' with disability. There appears to have been an avoidance of engaging with *anything* psychological within disability studies lest the individual tragedy model be re-invoked through suggesting that disabled people *need* some form of psychological help.

In a recent review of the literature looking at the mental health support needs of people with physical impairments, Morris (2004)

suggests that more research is needed to consider how the experience of disabling attitudes and environments affect the emotional well-being of disabled people. Whilst many disabled people have written about their experiences of disabling attitudes (such as Keith, 1996; Morris, 1991) there has been less discussion about the psychological consequences of being on the receiving end of prejudice and discrimination. Therefore there is still a need for a *psychology of disability*, which is based on how '*we make sense of our world according to the way we experience it*' (Finkelstein, 1990: 1; emphasis in original) rather than prioritising the imagination of non-disabled people about what it could be like to experience impairment (Oliver, 1996). This chapter will explore the contribution that an understanding of the *psycho-emotional dimensions* of disability can make towards a psychology of disability which is underpinned by a social model understanding of disability, rather than an individual model approach as reflected in the loss and stage models within psychology.

The psycho-emotional dimensions of disability

Recasting disability as a form of social oppression has been tremendously important in highlighting the social and economic disadvantage faced by disabled people. However, feminist writers in particular have pointed out that the focus of the social model has been on the 'public' experiences of oppression, such as inaccessible environments, at the expense of the more 'personal' experiences of oppression which operate at the emotional level (Thomas, 1999). Consequently, an extended social relational definition of disability has been proposed which attempts to address this criticism by explicitly including both the barriers 'out there' and those that operate 'in here':

'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 well-being.*' (Thomas, 1999: 60; my emphasis)

For example, someone may be disabled by a flight of steps or by being given information in an inaccessible format – these are examples of the structural dimensions of disability which restrict activity. On the other hand, psycho-emotional dimensions of disability would include being stared at or patronised by strangers, actions which can leave disabled people feeling worthless and ashamed, and may end up

preventing them from participating in society as effectively as physically inaccessible environments (Reeve, 2004b).

This particular dimension of disability which operates along emotional pathways is highly influenced by cultural representations and disabling images. Disabled people are rarely seen on television or in films as part of everyday situations and when they are part of the story-line, the focus is generally on their impairment. Negative cultural images and the rejection of impaired bodies from mainstream society have an effect on how disabled people see themselves, but also how they are perceived by others. Thus psycho-emotional disablism can be found in the ways that some disabled people internalise the negative social values about disability, or within their relationships with family, friends, professionals or strangers (Thomas, 1999). However, it is important to note that the experience of psycho-emotional disablism is not inevitable or fixed. Not all disabled people will experience this form of disability and it will be affected by time and place; whether it is more or less disabling than their experience of structural disability will vary and as I will show, sometimes the two dimensions reinforce each other. Disabled people often find ways of resisting this particular form of disablism, although this may have additional emotional costs. The experience of psycho-emotional disablism can also be affected by how visible impairment effects are and have an interaction with other aspects of identity such as gender, ethnicity, age and class (Thomas, 1999).

The specific inclusion of both structural and psycho-emotional dimensions of disability within an extended social model definition of disability contributes to the development of a psychology, rather than a psychopathology, of disability. Over a decade ago, a new approach to a psychology of disability was advocated because:

‘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, it was acknowledged that there is a need to take account of the personal effects of living with disability in a manner which differs from the traditional psychological models of loss and adjustment. 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.

Examples of psycho-emotional disablism

I will now illustrate several different forms of the psycho-emotional dimensions of disability by drawing on research which explored the ways that people with physical impairments negotiate disability within everyday life (Reeve, forthcoming). This PhD research used the free-association narrative interview method described by Hollway and Jefferson (2000) to generate narratives of people's 'disability experiences'. As well as indicating some of the forms that resistance took, I will show the longevity and cumulative nature of psycho-emotional disablism and consequent effects on the emotional well-being of these research participants. The pseudonyms used in the rest of this chapter are those chosen by participants.

The experience of structural disability

For many disabled people, the experience of being excluded from physical environments reminds them that they are different and can leave them feeling that they do not belong in the places where non-disabled people spend their lives (Morris, 1991). Robert talked at length about his experience of inaccessible environments, in particular shops and pubs. As a wheelchair user he finds it difficult to negotiate the doors to most shops on his own and so is forced to rely on the help of strangers to gain access.

'A lot of people see you want to go in, and they just walk past you. Or you ask them to hold the door and they just go on straight into the premises. You know, you just [pauses] how can I put it? Just feel like you're not wanted. They just look, everybody just looks down [their] nose at you.' (Robert)

This experience of moving within what Kitchin (1998: 351) calls 'landscapes of exclusion' reminds Robert that he is 'out of place' and that he somehow should not be shopping with everyone else. Consequently he finds himself apologising all the time:

'You say, 'Oh sorry for doing this', or, 'Sorry for doing that'. By the time you get home you think, 'Why should I say sorry?' But it upsets you that much - what do you do? You come home, you pop your pills, what you've got to take, and then you go and have a lie-down for an hour and it's still there, you know.' (Robert)

I asked him if he felt he had to present himself in a particular light in order to get help in shops and he agreed saying:

'[Y]ou've always got to put that false smile on, say, 'Oh thank you very much. Can you please pass me that? Can you do this please? Can you do that? Oh excuse me, can you move out of the way?' ' (Robert)

So Robert is aware that he is deliberately performing the 'grateful disabled person' role, simply to overcome the physical obstacles within the shop (a structural dimension of disability) and to deal with the reactions of others who look down on him (a psycho-emotional dimension of disability). This is an example of how structural disability can be compounded by the experience of psycho-emotional disablism because the inaccessible shop forces him to ask people for help and the way that these people ignore his request leaves him feeling unwanted and worthless. On top of this he is apologising for bothering people at the same time as feeling angry that he is being forced to ask for help in this manner - the result is considerable emotional distress. Additionally it may be more difficult for Robert to ask and receive help from strangers than for a disabled woman, because of the dissonance between the cultural representations of masculinity (strength and independence) and disability (weakness and dependence) (Robertson, 2004). This illustrates the manner in which the psycho-emotional dimensions of disability can be intersected by other identities such as gender.

Social interactions with others

An important source of psycho-emotional disablism comes from interactions with other people in society, relationships which can be affected by prejudice and myths about disability. One of the prevailing themes that Adinuf (so called because he had 'had enough') talked about was the way that friends and strangers avoided him once he became disabled – even crossing the road when they saw him coming in his wheelchair. This example of psycho-emotional disablism, being regarded by others as someone to be feared and avoided, left Adinuf feeling isolated and unwanted.

This avoidance was exemplified by the story he told about attending a computing course at the local college. When the tutor suggested that they all gather round to watch her demonstrate something on the computer, Adinuf found that no-one was willing to sit near him.

'I don't even know them and straight away they sort of identified me, 'Ah, stay away from him, he's got a disability, he's got a wheelchair - mustn't go anywhere near him'. [edit] Because people just don't understand disability. They think that, 'Oh, maybe he's going to ask me to do something for him'.' (Adinuf)

Adinuf felt that the source of people's avoidance of him was not only due to vague fears of contagion, but also because they were frightened that they might be called upon to help in unspecified ways. Social encounters are usually governed by culturally 'agreed' rules of engagement (Keith, 1996: 72), but the lack of such cultural rules for the interactions between disabled and non-disabled people can lead to anxiety and confusion about how one 'ought' to behave, with the result being avoidance rather than engagement as seen here. Adinuf's reaction to this behaviour is to take on the role of educator, to try and prove that people like him are not contagious, that there is nothing for them to be frightened of. Adinuf recognised that generally he took on this role of educating people about 'disability', feeling that much of the rejection he had experienced was simply due to ignorance and people not taking the trouble to talk to him over a cup of coffee, to see Adinuf rather than the wheelchair.

Another problem which many disabled people with visible impairments face is the issue of how to deal with the curiosity of others (Morris, 1991). Rose had surgery on her leg following polio as a child and her father's job meant she changed schools frequently. She was always planning how to answer the inevitable 'What happened to your leg?' question.

Rose: I would go through scenes in my head where I would think, 'What can I say? How can I deal with this? I know, I'll say, 'It was an accident'. Or I'll say, I'll just tell them. Or I'll tell - I won't say anything. Or, and' - and, you know, I tried all these things and none of them worked. I would go prepared to say such and such a thing, and nobody would say anything.

Donna: [Laughs quietly]

Rose: And I would think, 'Oh, A, they don't mind, B, they haven't noticed, anyway it's alright'. And then a bit later on they might say something, and it might be really unkind [hesitates] and all sorts of things.

Rose is attempting to retain control over what people know about her, which is difficult when impairment is visible. Like Adinuf, she is

'working' to manage the information which others have about her. Once she started dating men she became acutely conscious of how her status would change when they noticed her impairment.

'What did you do to your leg?' And you think, 'Oh, shit!' And immediately it reduces you, it takes you down to a different level - they've noticed that you're not perfect. Because when you're dealing with the opposite sex, you do put your best foot forward and you want to present as attractive a package as possible. And when that major flaw is the first thing, or one of the first things that they notice, it weakens your position. You feel that you have to apologise or make up for it in some way.' (Rose)

Rose's story makes explicit reference to the cultural representation of femininity (women as pretty and physically perfect) and the way in which she feels that she fails to meet the required standard because of her 'flawed' leg. Thus, like Robert, understanding how gender and disability intersect provides additional insight into how psycho-emotional disablism affects self-esteem.

In addition to direct questions or avoidance, people with visible impairments also experience being stared at by others. This action is not a value-neutral event, but is an act of invalidation based on public narratives of 'normality, truth, beauty and perfection' (Hughes, 1999: 164). Rose hated the way that people had stared at her since childhood:

'People would stare, they'd look and their eyes would drop and you knew - and they wouldn't even pretend to hide it and they would just sort of follow you round. And you'd turn round and you knew that they were turned round as well. And I just wanted to kill them, I can't tell you the anger I had inside me, all my childhood, for so long. I really wanted to kill them. I really wished I had a machine gun and I would blow them away.' (Rose)

Whilst disabled people are increasingly refusing to accept this invalidating gaze from society (Reeve, 2002), nonetheless the experience of being stared at can seriously affect someone's emotional well-being and self-worth as illustrated by Rose, and its effects should not be under-estimated. This is particularly true of an extreme form of medical gaze known as 'public stripping' (French, 1994).

'I had periodic reviews at Manchester. Mr G was very nice, but I mean, I used to go and strip down to knickers and vest and have to parade in front of a group of students [pause] which got increasingly embarrassing, the older I got.' (Rose)

This form of institutional abuse can leave a disabled person feeling vulnerable, exposed and humiliated and is an example of psycho-emotional disablism.

So far I have discussed social interactions which adversely affect the emotional well-being of a person with visible impairments – both Rose and Adinuf are identified by others as disabled because of visible difference. However, whilst people with hidden impairments are much less likely to be avoided, feared or stared at, there is always the risk that their disability status will be revealed and this forms the basis for the 'negative psycho-emotional aspects of concealment' (Thomas, 1999: 55). This is probably most marked for disabled people who have some form of incontinence, especially given the powerful social expectation that children and adults should be in control of bladder and bowels (Cavet, 1998). Finally, people with hidden impairments can also face difficulties when they attempt to use facilities which are reserved for disabled people. People who do not match the stereotypical image of someone who is elderly and/or a wheelchair user can result in their right to use facilities, such as accessible toilets or disabled parking spaces, being challenged by others. Consequently someone may choose to use a stick, to adopt a visible marker of impairment, in order to be able to use these facilities without harassment – but this may also have an emotional cost in publicly identifying as disabled (Reeve, 2002).

Internalised oppression

The final example of psycho-emotional disablism I want to describe is that of internalised oppression, which is a feature of any marginalised group in society. In this form of oppression, which acts at the unconscious level, individuals within the marginalised group internalise the prejudices held by the dominant group - the acceptance and incorporation of '*their* values about *our* lives' (Morris, 1991: 29; emphasis in original). Cultural representations of disability reinforce the myths and stereotypes which underpin prejudices experienced by disabled people on a daily basis; for example the increasing calls for voluntary euthanasia to be legalised and the current debates around bioethics give strong messages to disabled people about the value of their lives.

Thus it is not surprising that internalised oppression can leave some disabled people feeling devalued and disempowered (Reeve, 2004b). This form of psycho-emotional disablism also has a very direct effect on the decisions which disabled people take about their lives; for example someone may decide not to become involved in a sexual relationship because they have internalised the prejudice that people 'like them' are sexually undesirable to others.

The starkest examples of internalised oppression were recounted by Rhodri who had been born with cerebral palsy and was marked out from the day he was born as 'useless' and a 'burden'. The consultant at the hospital told his parents that they should leave Rhodri in the hospital and go home and forget about their baby because there was no future for someone with his condition.

'All my life, call it insecurity, or whatever you like to put on it, right, is that, 'What's the difference with me then? Why was I given up so early?' I hadn't had any chance to prove myself in any form and yet somebody in authority could say I was useless. [edit] I've got the tendency of going too negative-wards, I have, because 'I'm no good', going back to being a kid again. 'Nothing is going to become of this gentleman'.' (Rhodri)

This internalisation that he was worthless was made worse by the public humiliation he experienced at the hands of staff at a residential school.

'I was put out in front of the whole school when I was coming up to a teenager, and said, 'This will happen to you, if you wet your clothes'. And I had to go round in a dressing gown and pants and they were spares - so I was a spare person, wasn't I. Only by having a fragment of my life, you can see why I haven't got a lot of confidence.' (Rhodri)

Rhodri's impairment meant that he couldn't help having 'accidents' – but when he did, he was publicly humiliated by being made to go around in a spare set of clothes. For someone who already felt worthless, this reinforced to Rhodri that he was just a spare person, someone of no value, a message he carried throughout the rest of his adult life. The effects on Rhodri of the way his school handled his incontinence have also had a direct effect on his physical well-being. Because of the way that he was regarded as 'the dirtiest boy in the

school', he is reluctant to seek medical help for current continence problems which prevent him from leaving the house. So this childhood label has lasted forty years and now directly prevents him from participating in society as well as jeopardising his health. Thus the experience of past psycho-emotional disablism can have an impact on present-day impairment.

Another example of internalised oppression was seen in the way that Rose internalised the view that she was not valued as someone with an impairment. Her parents would not allow her to talk about bullying at school or even how she felt about being disabled – thus Rose became a 'supercrip', someone who works hard to pass as more than 'normal', in an attempt to make her parents proud of her.

'So I grew up trying to excel and pretend that there was nothing actually wrong. And I strove, as I got older, I worked harder and harder to try and hide this defect. I was very, very conscious of it - the older I got, the worse it got.' (Rose)

However this can be a lonely place to be - because she is then neither disabled or non-disabled, but inhabits a twilight world in between. If Rose's parents had been more able to listen to their daughter and value her for the person she was, her childhood and adulthood would have been much easier and she would have had more confidence and self-respect.

Discussion

I have described different aspects of the psycho-emotional dimensions of disability and shown how they can adversely affect the emotional well-being of disabled people. I have also illustrated the complex nature of this form of disablism, its longevity, as well as indicating the additional emotional costs paid when people did find ways of resisting its effects. Whilst I have presented accounts of people with physical impairments, this dimension of disability can affect any group of disabled people (see for example Marks, 1999). I now want to consider the implications this has for psychology, in particular for psychologists working with disabled people.

Professional responses to disability are not simply about making services accessible to disabled people by putting in a ramp. It is about understanding disability from a cultural, political, social and historical perspective and being aware of the complicated effects of this

particular form of social oppression which operates at both conscious and unconscious levels. An important issue, which is discussed elsewhere in this book, is that the psychologist needs to be aware of *their* attitudes and prejudices about disability otherwise these will be acted out within the therapeutic relationship which can have disabling consequences for the disabled client (Reeve, 2000; Reeve, 2004a).

The preceding discussion of the psycho-emotional dimensions of disability reveal important aspects of the disability experience which psychologists need to be aware of. Disabled people may seek help with emotional difficulties for a range of reasons which may or may not be disability-related. However it is important that psychologists remain alert to the *possibility* that there may be interactions between presented difficulties and past/present experiences of psycho-emotional disability. For example, someone might want help with issues of self-esteem and confidence which stem from problems in childhood. But, if this person has also grown up with impairment it is important that effects of societal/familial prejudice are not ignored. For example, in Rhodri's case, being part of a society with few positive role models and a legacy of negative expectations about his value as a person, clearly contributed significantly to his lack of self-worth and confidence. Unfortunately many of the professionals Rhodri currently deals with do not know his 'history' and accuse him of over-reacting in ways that are quite understandable if one considers his childhood. It is also vital that emotional reactions to the experiences of exclusion and discrimination are not pathologised (Olkin, 1999); for example, Robert's anger with inaccessible shops is a reasonable response to the experience of being excluded rather than an indication that he has failed to adjust to his disability as predicted by the loss and stage models.

Psychologists also need to take account of the strategies people employ to counteract this 'personal' experience of oppression which can involve 'emotion work' to either hide their own true emotions in line with cultural 'feeling rules', or to manage the emotions of others (Lupton, 1998). For example, Adinuf feels that he needs to patiently reassure, explain and educate others who are actively avoiding him, using *suitable* language so that they understand more about disability and are not so afraid of him. Thus he is carrying out emotional labour in order to deal with *their* fears and prejudices about him, as a disabled man. Similarly Rose works to devise a story about what happened to her leg, a story which gives her some control over what the other children know about her, but also in order to deal with the curiosity

of others about what is 'wrong' with her leg. In Robert's case, his adoption of the 'false smile' and fake expressions of gratitude mean he is behaving in the ways that society expects disabled people to behave. This act may well be conscious and gets him the help he needs (the alternative being to remain excluded), but it has emotional costs because the projected behaviour is at odds with his very real anger at being forced to behave in this manner. This 'emotional dissonance' is a recognised aspect of emotional labour which can lead to emotional exhaustion (Ashforth and Tomiuk, 2000). It could also be expected that such dissonance could have an adverse effect on the physical, as well as emotional health of a disabled person. Thus it is important that psychologists consider the emotional and physical effects of resistance to these psycho-emotional dimensions of disability.

The case of psycho-emotional disablism and disabled children is worthy of particular consideration. The definition of emotional abuse is the

'persistent emotional ill-treatment of a child such as to cause severe and persistent adverse effects on the child's emotional development. It may involve conveying to children that they are worthless or unloved, inadequate, or valued only insofar as they meet the needs of another person.' (Department of Health, 2001: 43)

The consequences of psycho-emotional disablism on the self-esteem and self-worth of disabled children are potentially very similar to those resulting from emotional abuse – children who believe they are worthless, inadequate and useless. Thus psycho-emotional disablism could be viewed as a form of emotional abuse. In the example of Rhodri who ended up feeling like a 'spare person', it is clear that this was caused by institutional practices in which disabled children were not valued as human beings. Disabled children's experience of internalised oppression with its impact on self-esteem may render them more vulnerable to being abused than non-disabled children. Given the negative social values which are placed on disabled children, it is not surprising that some children accept abuse because they believe they are 'defective' and abusers feel it is all right to abuse a child who is already deemed 'worthless' (Kennedy, 1996). This same author also quotes the experiences of one disabled adult who points out that the experience of 'public stripping' described earlier could be seen as 'grooming' for future sexual abuse – how, as a disabled child, do you draw the line between what a doctor asks you to do, or the porter?

The levels of abuse of disabled children are significantly higher than for non-disabled children and yet this issue rarely receives the attention it deserves from professionals (NWGCPD, 2003).

Finally, it is imperative that there is more training about disability on psychology courses, especially given the scarcity of disabled psychologists, teachers and students (Olkin, 2003). However this training has to cover more than basic Disability Equality Training, an introduction to disability as an equal opportunities issue; it is vital that it also includes information about the psycho-emotional dimensions of disability if the full impact of the experience of living in a disabling world is to be understood (Reeve, 2004a). The impasse that has existed between psychology and disability studies is one contributory factor to the lack of such training - a situation that needs urgent redress.

Conclusions

For many disabled people, it is the barriers which operate at the psycho-emotional level which have the most disabling consequences on their lives. I have indicated how the experience of exclusion, prejudice and the reactions of others can adversely affect someone's emotional well-being, a situation which can be exacerbated by the emotion work which some disabled people undertake as a way of resisting psycho-emotional disablism. The application of individualistic models as a means of understanding how people respond to disability ignore these psycho-emotional dimensions of disability, fail to take account of their long-lived and cumulative effects and additionally risk pathologising justifiable emotional responses to being excluded and discriminated against.

Consideration of the psycho-emotional dimensions of disability as part of a psychology, rather than a psychopathology, of disability would help bridge the existing gap between psychology and disability studies. Recognising the social, cultural, political and historical aspects of disability is vital if psychology is to stop being 'part of the problem', yet another disabling barrier created by the viewing of disability as an individual deficit (Finkelstein, 1990). There is an urgent need for mainstream psychology courses to include disability as part of their diversity training. Given the nature of the emotional level at which psychologists work, this has to include reference to the psycho-emotional dimensions of disability, recognising the pervasive and long-lasting effects this can have on the emotional well-being of

disabled people, affecting who they are and what they choose to do. Rhoda Olkin concludes:

‘Disability studies and psychology can join hands, but they haven’t yet.’ (Olkin, 2003: 303)

Recognising the impact of the psycho-emotional dimensions of disability on the everyday lives of disabled people goes some way to helping this happen, whilst maintaining the vital connection to disability as a social construction rather than as individual tragedy.

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