

Reeve, D. (2012) 'Psycho-emotional disablism: The missing link?', in N. Watson, A. Roulstone and C. Thomas (eds) *Routledge Handbook of Disability Studies*, London: Routledge, pp. 78-92.

This is the corrected version incorporating reviewer comments and has been paginated to match the published version. Small typographical differences may therefore exist between this and the published version.

PSYCHO-EMOTIONAL DISABLISM: THE MISSING LINK?

Introduction

Although early disability writers such as Paul Hunt (1966) documented the impact of stigma and internalised oppression on the psyche of disabled people, these problems have largely remained a difficulty for the individual to manage whilst the disabled people's movement addressed the more material forms of disadvantage such as exclusion from employment, education and the built environment. It was the naming of these personal experiences as *psycho-emotional disablism* which has allowed for a sociological analyses of these aspects of social oppression, rather than leaving them in the hands of psychologists and other professionals 'who would not hesitate to apply the individualistic/personal tragedy model to these issues' (Thomas, 1999: 74).

This chapter has two aims. Firstly it provides a description of psycho-emotional disablism and the different forms it can take. Secondly the rest of the chapter explores what the phenomenological concept of the 'dys-appearing' body offers to an analysis of psycho-emotional disablism. As well as enabling the concept of 'internalised oppression' to be unpacked into its two components, the chapter also highlights the relevance of impairment via cultural prejudices when looking at the experience of psycho-emotional disablism. Whilst mentioning impairment is taken by some in disability studies to be equivalent to reinforcing an *individual* model of disability (such as Barnes and Mercer, 2010: 96-97), the continued silence means that:

disability theory withholds moral recognition from (the wrong kinds of) disabled people as effectively as anyone who actively stereotypes them or denies that some kinds of disability identity exist. (Scully, 2008: 175)

Similarly Wendell (2001) has argued that disability studies needs to take more account of disablism faced by those with chronic illness – the so called 'unhealthy disabled' who do not represent the 'paradigmatic person with a disability [who] is healthy disabled and permanently and predictably impaired' (Wendell, 2001: 21).

Finally, I would like to be explicit about the scope of this chapter which draws predominantly on disability studies work which is based in the UK. Therefore my analysis of psycho-emotional disablism and the forms it may take is very UK-centric and it would be expected that

psycho-emotional disablism would look very different in other cultures, particularly those in the Majority world which are outside my area of expertise. In addition the chapter draws on data collected as part of my doctoral thesis where participants with physical impairments talked about their experiences of disablism (Reeve, 2008b). Whilst this means my conclusions can only be partial, I present this chapter to continue the discussions which are needed within disability studies to broaden the empirical and theoretical study of psycho-emotional disablism (Thomas, 2004).

Psycho-emotional disablism

The concept of psycho-emotional disablism was first introduced by Carol Thomas in her book *Female Forms* (1999); whilst initially the term 'psycho-emotional dimensions of disability' was used, more recently this has been changed to 'psycho-emotional disablism' (Thomas, 2007) to make connections with other forms of social oppression such as hetero/sexism, ageism and racism. In order to redress the balance between recognition of the public and more private forms of oppression, Thomas reformulated the UPIAS definition of disability (UPIAS, 1976) to produce an extended social relational definition of disablism:

Disablism 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, 2007: 73)

In other words, disablism can be experienced as two forms of social oppression: structural disablism and psycho-emotional disablism. Structural barriers are those that operate from outside the individual such as inaccessible environments, physical and social forms of exclusion, discrimination and the like, or in other words, the usual forms of social oppression acting on a person with impairments which are *implied* by a social model definition. What differentiates this extended social relational definition of disablism from the traditional social model definition is the *deliberate* inclusion of psycho-emotional disablism, disabling barriers which operate on the psycho-emotional well-being of people with impairments. Whilst the original UPIAS informed social model definition of disability did not exclude these 'inner' barriers, their specific omission meant that they were often overlooked in analyses of the lived experience of disability, in favour of the more visible 'outer' barriers. However, recently there has been increasing interest within disability studies on the psychological impact of disablism which is discussed further by Goodley elsewhere in this book.

As well as the differentiation between structural and psycho-emotional disablism, it is also possible to identify two sources of this latter kind of disablism (Reeve, 2008b). *Direct* psycho-emotional disablism arises from relationships that the disabled person has with other people or themselves and is the most important form of psycho-emotional disablism. However, it is also possible to identify examples of *indirect* psycho-emotional disablism which emerge alongside the experience of structural disablism. I will now discuss some examples of these two forms of psycho-emotional disablism using data collected as part of my doctoral research involving people with physical impairments (Reeve, 2008b).

Direct psycho-emotional disablism

Hughes (2007) argues that the 'disavowal of disability' can be found in the 'most mundane everyday words or deeds that exclude or invalidate' (Hughes, 2007: 682). Invalidation can take various forms: common examples include being stared at by strangers, having jokes made about

your impairment or having to deal with the thoughtless comments of others (Reeve, 2006; 2008a). Related to being stared at, is the opposite – that of being actively avoided because of a prejudice that ‘disability is catching’. Adinuf - self-named because he’d ‘ad enough – had a chronic illness called Reflex Sympathetic Dystrophy (RSD) and he described how friends would wave when they saw him in the street, but then cross over to avoid talking to him and he described how friends would wave when they saw him in the street, but then cross over to avoid talking to him. Once he started using a wheelchair it got worse. He said:

“They see me coming along in a wheelchair and they’re even more frightened. They are literally frightened to death to talk to me then, because they think that they’re going to catch something.” (Adinuf)

Adinuf talked a lot about the hurt he felt at being treated as if he were contagious and being avoided. This prejudice had not been helped by a neighbour spreading the rumour that Adinuf had AIDS. But Adinuf also experienced the reverse of contagion, when a stranger would ask invasive questions about his condition. Ginny, his wife described how she would try to tread the thin line between remaining polite yet retaining personal control over what was revealed to others. So Ginny described how she would respond to that inevitable question, ‘What’s wrong with him?’

“He’s just got a bit of a nerves disease’. ‘But what is it?’ and I’ll say [RSD], ‘I’ve never heard of that!’ And I’ll go, ‘No, well never mind’ and I’ll walk off and I won’t talk to them. ‘But what does it *do* to you?’” (Ginny)

It can be seen how the questioner keeps on pressing until they get to the ‘real’ question they want to ask which could be summed up by the “But what does it *do* to you?” question. The questioner needs to be reassured that Adinuf is not contagious, that it won’t happen to them and is a good example of how wheelchair users in particular can ‘generate[s] dis-ease in the fully mobile’ (Shildrick and Price, 1999: 439).

In addition, though, to this psychological ‘disavowal of disability’ – that is, the projection of the unwanted fears about mortality, dying and physicality onto disabled people (Shakespeare, 1994: 298) – Hughes argues that there is an ontological invalidation of disability as a ‘worthwhile existential status’ (Hughes, 2007: 681). So for example, Laura who has MS and who uses a wheelchair described an all too-common experience on the street:

“Then like a guy walking past me on the street, saying, ‘I’d rather be dead than be in one of those’ - Well, where do these people get off? All those sort of things can be very disturbing, can’t they?” (Laura)

This ontological invalidation undermines psycho-emotional well being. It is a comment informed by the tragedy myths of disability in our society, and is also seen in the current debates about assisted suicide in the UK. As can be seen here, it was also a comment which Laura found disturbing and difficult to deal with because of the hugely negative value accorded to her life as a wheelchair user - which was in stark contrast as to how she saw herself.

In these examples, direct psycho-emotional disablism is experienced at the point that the stranger reacts to the disabled person – either saying something inappropriate or avoiding the disabled person altogether. Being subject to these kinds of comments from strangers can be difficult to deal with and can undermine psycho-emotional well-being. But it is not just the encounter itself that is disabling, there is also the ‘existential insecurity’ associated with the uncertainty of not knowing how the next stranger will react. This uncertainty further compounds this example of psycho-emotional disablism (see Thomas, 2004: 38 for more discussion about existential security).

How people respond to direct psycho-emotional disablism varies with time and place. Although for many people with visible impairments, the experience of being stared at because of a failure to match the cultural 'normate' body/mind can be stigmatising and judgemental (Garland-Thomson, 2009: 87), others are able to resist the normative gaze and to manage the social encounter in productive ways. Sue, who also had MS, used a Zimmer frame to walk outside the house and described how she used her interactions with strangers as a means of education, by challenging assumptions about what disabled people *looked like*. For example, Sue said:

"I don't feel that I am stared at - I don't know, probably I am. I sometimes feel that with my walker, yes, I do feel people watching there. But I don't mind, I think it's something, yes I sort of feel, 'Well it's good for people to see younger people with one'." (Sue)

In this respect, Sue's pragmatic approach to seeing herself as educating people about what 'disabled people look like', is a way of returning the gaze. For her, it is one way of retaining control over the interaction, refusing to be rendered vulnerable to the stares of strangers. Not all disabled people can respond in this way as it takes a degree of self-worth and self-confidence, as well as energy, to be able to adopt this approach. It is likely that other aspects of Sue's life, such as being in paid employment, contributed to this ability to return the gaze.

One of the difficulties facing disabled people within social interactions is that there is a lack of culturally 'agreed' rules of engagement about how strangers should treat disabled people (Keith, 1996: 72). There are cultural rules about commenting on someone's size: it is acceptable to remark how slim someone is, but not to comment that they are fat. When it comes to people with visible impairments, there is often no such restraint as was seen in the case of Adinuf's persistent questioner. Another consequence of the lack of rules of engagement is that all too often, fear of 'doing the wrong thing' results in avoidance rather than interaction. So often it will be the disabled person who has to 'manage' the interaction with other people by undertaking 'emotion work', be it educating or reassuring the person that they won't catch anything (Reeve, 2006; 2008a) – the alternative would be to remain excluded and 'Other'.

A final important example of direct psycho-emotional disablism is that of internalised oppression which arises from the relationship someone has with themselves (Marks, 1999). It happens when a disabled person internalises prejudices about disability, thereby effectively 'invalidating themselves'. It is not just people who grow up with impairment who find themselves surrounded by a world in which they are not represented as disabled parents, disabled workers or disabled sexual beings. Non-disabled people also internalise norms about disability and so for those people who become disabled in later life, one consequence is that they have to overcome their own prejudices about disability, now that they have moved from the included to the excluded group in society. For example, Adinuf described how he "fought" for two years not to use a wheelchair because of the negative connotations he had internalised about the kinds of people who used wheelchairs, in other words, 'the disabled'. It was only when he fell over in town and people assumed that he was drunk, that he started using a wheelchair - being seen as disabled was preferable to being seen as drunk. I will discuss internalised oppression in more detail later in this chapter.

Indirect psycho-emotional disablism

Whilst all these acts of invalidation are examples of *direct* psycho-emotional disablism because they arise from a relationship that the disabled person has with other people or themselves, *indirect* psycho-emotional disablism can arise from the experience of structural disablism. So the experience of being faced with an inaccessible building can evoke an emotional response such as anger or

hurt at being excluded. Therefore the act of exclusion operates at both a material and psycho-emotional level because of the message being given to disabled people that reminds them that "you are out of place", 'you are different' (Kitchin, 1998: 351).

Spatial barriers affect disabled people's lives at all levels: inaccessible schools affect education, poor housing restricts choice of where someone lives, lack of transport impacts on employment options, inaccessible public spaces reduce social contact with others. Laura had eventually given up work with the local council because of the environmental barriers she faced at the building where she worked, once her MS had progressed to the point where she needed to use a wheelchair. She described how she got "flashbacks" about times when she was trying to get into the building when it was raining:

"And not being able to open the doors, waving to people to try and get them to come and open the doors, and you're getting soaking wet. It was amazing how things like that would really - I mean, now I don't let that bother me, but it was all so new then, and distressing, it was really distressing." (Laura)

The practicalities of learning how to use a wheelchair in everyday life were made more difficult by these access issues and caused her a lot of distress. Laura is describing how her experience of being excluded (structural disablism) also has a psycho-emotional part (indirect psycho-emotional disablism).

Whilst these different examples of (in)direct psycho-emotional disablism may appear as relatively harmless one-off incidents, it needs to be borne in mind that for many disabled people, these are experienced on a daily basis. Psycho-emotional disablism impacts on a person's emotional well-being and sense of self and so can have a cumulative negative impact over time on someone's self-esteem and self-confidence (Reeve, 2006). However it is not an inevitable consequence of having an impairment because of the interconnection with other aspects of identity including class, gender, ethnicity, sexuality and age, as well as other life experiences.

Phenomenology and the dys-appearing body

Phenomenological approaches have been central to the development of the sociology of the body, which seeks to overcome the Cartesian mind/body divide by viewing the body instead as both subject/object (Merleau-Ponty, 2005 [1962]). The world is perceived through the body; as embodied subjects, experience is not simply an 'inner' phenomenon but is at the same time related to involvement in a world which exists independently of someone's experience of it. In other words, there is a 'lived body' which 'simultaneously experiences and creates the world' (Paterson and Hughes, 1999: 601). In *The Absent Body* (1990) Leder uses phenomenological ideas to develop the concept of the 'dys-appearing' body showing how bodily awareness is absent most of the time (it *disappears*) and it is only when one experiences pain or stumbles for example, that the body is suddenly brought to the foreground. The hyphenated term 'dys-appear' is used quite deliberately; although the *dys* part comes from the Greek for 'bad', 'hard' or 'ill' as in 'dysfunctional', in Latin *dys* can mean instead to pull 'away, apart, asunder' (Leder, 1990: 87). At times of dys-appearance, whether due to illness or as the result of a changing body during puberty, the body returns to the foreground of awareness at the same time as being experienced as *away or apart* from the self:

In experiential terms, one becomes aware of the recalcitrant body as separate from and opposed to the "I". ... The self that takes note of the body remains a moment of the organism, an *embodied* self. (Leder, 1990: 88, emphasis in original)

Leder identifies two different ways that the body can dys-appear. The onset of pain which is an *intracorporeal* phenomenon, is a reminder of the physicality of our bodies - if I have twisted my ankle I will need to pay attention as to how I walk. In contrast, *intercorporeal* phenomena include ways in which the body dys-appears in interactions with the social world – be they people, environments or institutions; for example, wearing the wrong clothes to a social gathering or feeling that one is too thin or too fat.

In addition the dys-appearance of the body is associated with a 'demand' for attention; looking at one's reflection in the mirror or concentrating on the body during a yoga session are to some extent optional activities whereas the onset of pain or feeling overdressed at a social event brings the body *sharply* into focus. As well as an attentional demand, dys-appearance also disrupts at the existential level because of the way that the body is tied up with self-interpretation.

It is Leder's discussion of social dys-appearance, intercorporeal interactions between the body and the social world, which are of most interest here. Acknowledgement is made of the ways that dys-appearance is linked to aesthetic judgements which in turn are located in particular times and places. The loving look of a partner is different to the hardened stare in the street by a stranger:

As long as the Other treats me as a subject – that is, experiences *with* me to the world in which I dwell, mutual incorporation effects no sharp rift. But it is different when the primary stance of the Other is highly distanced, antagonistic, or objectifying. (Leder, 1990: 96, emphasis in original)

Like many other phenomenologists, Leder does tend to assume the 'normal and healthy body' (Leder, 1990: 86) and to therefore see illness and injury as dys-appearance. (For a thorough critique of phenomenology and impaired bodies see chapter five in Scully, 2008). However recognition is made about how ideology and power relations can influence where/when bodies dys-appear. In the case of disabled people, Leder observes that:

biological dysfunction may inaugurate social dys-appearance, such as is frequently experienced by the handicapped and disabled. The body is at once a biological organism, a ground of personal identity, and a social construct. Disruption *and healing* take place on all these levels, transmitted from one to another by intricate chiasms of exchange. (Leder, 1990: 99, my emphasis)

It is this concept of social dys-appearance and how it is revealed in the everyday lives of disabled people which will feature in the rest of this chapter.

The 'dys-appearing' body: Embodied disablism and/or sociology of impairment?

Hughes and Paterson (1997) have turned to phenomenology as a way of retaining the body as a fleshy object. This carnal sociology theorises 'the body as *the* place where self and society interact' (Goodley, 2010: 56, emphasis in original). For some disability studies scholars this represents a way out of the impairment/disability dualism, allowing for an account of an impaired body which has agency and activity and is not simply an object which is acultural and ahistorical (Paterson and Hughes, 1999). Subsequently, as part of their continuing project to understand the 'carnal politics of everyday life', Paterson and Hughes (1999) have drawn on the phenomenological concept of the dys-appearing body to add further weight to their arguments advocating a sociology of impairment.

Paterson and Hughes (1999) provide examples of how disabling barriers of all kinds cause the impaired body to 'dys-appear', to become the thematic focus of (unwanted) attention.

One can argue - applying Leder - that the disablist and disabling sociospatial environment produces a vivid, but unwanted consciousness of one's impaired body. Here, the body undergoes a mode of 'dysappearance' which is not biological, but social. For example, in the context of the ubiquitous disabling barriers of the spatial environment, one's impaired body 'dys-appears' - is made present as a thematic focus of attention. When one is confronted by social and physical inaccessibility one is simultaneously confronted by oneself; the external and the internal collide in a moment of simultaneous recognition. When one encounters prejudice in behaviour or attitude, one's impaired body 'dys-appears'. (Paterson and Hughes, 1999: 603)

The examples the two authors give here refer to what I have termed indirect and direct psycho-emotional disablism respectively; therefore the 'dys-appearing' body is also highly pertinent to a discussion of psycho-emotional disablism. At the moment of dys-appearance there is also a psycho-emotional response – which can include feelings of anger, frustration, shame, embarrassment, awkwardness. The previously-absent body comes to the foreground of attention because of the apparent dis-ease in the mind of the stranger, based on myths fuelled by the cultural 'tyranny of perfection' (Glassner, 1992 cited in Hughes, 1999: 159).

The experience of inaccessible buildings or the thoughtless comments of others can both cause the impaired body to dys-appear and are clearly examples of intercorporeal phenomena. The problem lies with a social and physical world which is set up to accommodate certain kinds of normate bodies; Paterson and Hughes suggest that part of the quest for citizenship is based around creating new environments which are more inclusive of diversity, so that people with impairments are no longer reminded that they are 'Other' each time their bodily difference fails to find a fit. In other words, 'a world in which their bodies do not 'dys-appear'' (Paterson and Hughes, 1999: 604), a world free from disabling barriers.

Paterson and Hughes use the concept of the dys-appearing body presented in Leder's particular version of phenomenology to support their call for a sociology of impairment which is linked to, but still separate from disability. This separation has surprised Thomas who points out that:

given their desire to transcend dualisms, Hughes and Paterson present this line of thinking as a route to developing a *social model (or sociology) of impairment* rather than as a route to developing a unified or integrated theorisation of impairment and disability/disablism. (Thomas, 2007: 129, emphasis in original)

Drawing on the examples which Paterson and Hughes use to support a sociology of impairment, I have shown that these can also be described as forms of psycho-emotional disablism. The dys-appearing body can reveal ways in which 'disability is embodied *and* impairment is social' (Hughes and Paterson, 1997: 336, my emphasis) which involves considering both disablism and impairment together (rather than either/or) which I will discuss later in this chapter.

Internalised oppression unpacked

I now want to discuss some further examples of psycho-emotional disablism which expand on the points raised by Paterson and Hughes (1999) in their discussion of the dys-appearing body. So far I have considered examples which looked at the dys-appearing body within *intercorporeal* encounters between the disabled person and other people – the invalidating stare or comment. As I indicated earlier, direct psycho-emotional disablism can also occur within the relationship someone has with

themselves, in the form of internalised oppression which is very difficult to challenge; it is often only through contact with other disabled people that one sees alternatives to the mainstream cultural lexicon which equate disability with loss and lack. I have written elsewhere (Reeve, 2006) about the long-term impact that internalised oppression can have on someone's psycho-emotional well-being, directly restricting the choices about who they can be, such as potential parent, lover, worker, student. This 'false consciousness' to use the Marxist term, represents a state in which the body never dys-appears because the individual has wholly internalised the stereotype, believing that is 'normal' that people like them don't have children for example.

Whilst not advocating that false consciousness is politically desirable for disabled people as a way of life because it is still a form of psycho-emotional disablism, it does have the benefit that one is living in 'blissful ignorance'. The next step towards enlightenment, which in my case was being introduced to the social model of disability, is that of moving into 'double consciousness'. Although this transition marks the first important step towards identifying disabling barriers, it can be quite traumatic:

While the subject desires recognition as human, capable of activity, full of hope and possibility, she receives from the dominant culture only the judgement that she is different, marked, or inferior. (Young, 1990: 60)

The experience of double consciousness, where one is defined by both a dominant and subordinate culture in this way, is what Young calls 'cultural imperialism' (Young, 1990: 58-61). This is one of the five faces of oppression faced by people marked as Other (for more information see chapter two in Young, 1990).

In comparison to false consciousness, the experience of double consciousness is associated with *chronic* dys-appearance because of the *continual* 'presence-as-alien-being-in-the-world' (Paterson and Hughes, 1999: 603) associated with cultural imperialism. Whereas Paterson and Hughes discuss what I would consider to be forms of direct psycho-emotional disablism which are intercorporeal and *intersubjective* events, these are discrete albeit frequent occurrences. Instead, here I am referring to an experience which is both intercorporeal and *intrasubjective*. A good example of this is provided by Lucy who had become disabled following a car accident. When she came to marry for the second time she described how she did not feel able to wear a white dress:

Lucy: Because I didn't want to walk down the aisle again, all in my perfect white dress, whatever I chose to wear, realising that I wasn't perfect anymore. Because on your wedding day – I had been married before and it was such a special day and you feel all - and I didn't feel I could do it this time – walk down the aisle and look special, because of my new-found disability.

Donna: So it wasn't because you were marrying for the second time –

Lucy: No. And I didn't feel perfect anymore, as you do when you're going down the aisle. That was quite an important thing I thought. [cut] I wanted a red dress. I went round everywhere, [friend] went with me – [city name], [city name] - everywhere, couldn't find a red dress.

Donna: Why red?

Lucy: Because I wanted to be shocking. If everyone was going to look, bloody look at my red dress.

Lucy now walks with a limp and she talked a lot about dealing with people staring at her; so "walking down the aisle" will be different now that she has an impairment. Lucy has also

internalised the prejudice that disabled women are *imperfect* women and she does not feel that she can match up to the image in UK society about brides in long white dresses gliding effortlessly down the aisle. This illustrates a gendered dimension of psycho-emotional disablism because she feels of less value than non-disabled women simply because she now has an impairment. Her solution – or reaction – to this problem is to choose a red dress to shock people, so that they have something else to stare at instead of her limp. Lucy has challenged the conventional image of the blushing bride by choosing a colour which is more usually associated with a brothel than a church, which is her way of dealing with feeling imperfect. Lucy is also using the colour as a way of concealing her impairment, so this is an example of how impairment can interact with psycho-emotional disablism (in this case internalised oppression) and influence the way that someone challenges their internalised oppression.

I would suggest that the red wedding dress can be seen as a form of resistance because Lucy has deliberately stepped outside the social 'norm' that brides wear white by creating her own rules about bridal gowns. Her red dress made her body disappear so that it no longer dys-appeared when seen by others. The red dress as a productive outcome to psycho-emotional disablism can also be seen as an example of how dys-appearance can produce healing rather than disruption (Leder, 1990: 99). Similarly, the way in which Sue described earlier how she used her encounters with strangers as a way to educate them what about what disabled people 'look like' could also be considered as a healing outcome of dys-appearance.

The term 'internalised oppression' tends to incorporate both these understandings of oppression – false consciousness and double consciousness – which I have tried to untangle here as part of the process of understanding the different actions of direct psycho-emotional disablism. In reality one may experience false consciousness in some areas of life and be troubled by double consciousness in others I would also suggest that people who seek to educate people with impairments about disablism need to remain alert to the emotional distress double consciousness can cause. Whilst disability equality training can be empowering, the 'road to Damascus' is not an easy path to take. In the same way that an abused child finds it easier to blame themselves than their parent (Miller, 1991), it can be easier to believe that exclusion from the social world is because of personal impairment rather than a society that makes normative bodies and minds the necessary passport for full inclusion. Finally, it could be argued that the term 'internalised ableism' is a better term than 'internalised oppression' because it specifically draws attention to the ableist stereotypes impacting on the lives of people with impairments (for more information see chapter two in Campbell, 2009).

(Re)producing the disabled subject

Up to this point I have been discussing examples where the dys-appearing body was related to finding oneself 'out of place' when failing to meet the carnal norms of an ableist world. I now want to consider the creation of disabled bodies when claiming disability related benefits and other concessions such as disabled parking badges (Porter, 2000; Shildrick, 1997). Disability Living Allowance (DLA) provides money for helping disabled people with their mobility and personal care needs. As part of the application process the claimant is required to report in detail how their body fails to meet the 'norm' and a successful claim is more likely if the language used matches that recognised by the government agency (Daly and Noble, 1996). The claimant is (re)producing the disabled subject and consequently only certain bodies and minds are considered as 'disabled' and eligible for benefits. Similarly, when using accessible toilets and parking spaces which are marked with the universal wheelchair symbol, those who fail to match the stereotypical

image of disability can be challenged by others over their right to use these reserved facilities. It has been argued that the current wheelchair symbol is problematic as a representation for disability because it reinforces a very narrow view of what disabled people 'look like' and ends up separating wheelchair users from other people with impairments who also need to use these facilities (Bichard, Coleman and Langdon, 2007). As part of the process of creating culturally recognisable 'disabled bodies', the disabled person is required to foreground their impairment, to make their own body dys-appear. So for example someone may "limp worse" in order to prove their right to park in an accessible space and to avoid being challenged by a passing stranger:

"I limp worse when I get out the car than I do normally [laughs] just to show people that I have got a disability, I can park in the bay. [cut] That's deliberate. It's probably subconscious now, but in the beginning [after the accident] it was deliberate. Because my husband's noticed it - because he says, 'What's the matter with you today?' And I say, 'Nothing'. 'Oh, alright then'. And then I forget and start walking then, once I've passed the bay, and people look [laughs]" (Lucy)

Here Lucy is describing a deliberate performance that she undertakes to assert her identity and rights as a 'real' disabled person; however this performance is 'leaky' and incomplete when she fails to maintain the limp until she gets into the shop and she becomes re-subject to the judgemental gaze of others. Similarly when claiming sickness benefit one has to reproduce the incapable body/mind and to identify as a disabled person incapable of work (Price and Shildrick, 1998). It can be psychologically difficult to have to describe oneself in terms of the medical and deficit discourses which underscore the application process.

As I indicated above, being forced to define oneself in terms of what one is *unable* to do, impacts on psycho-emotional well-being. In some cases being forced to describe the details of impairment can make it temporarily worse as the person becomes what they have described (Reeve, 2008b); this is particularly true for some people with mental health difficulties who have been advised to be positive about what they *can* do in order to manage their symptoms. Mental health difficulties are often fluctuating and are much more complicated to 'measure' than physical or sensory impairment. The stress and anxiety of going through the benefit application process can make mental health worse, particularly as the new Work Capability Assessment (which forms part of the Employment Support Allowance that has replaced Incapacity Benefit since 2008) has been described as being:

so riven with faults that it's hard to see what kind of mental illness would, under its terms, actually qualify someone for help (Williams, 2011: np).

Having to reconstruct oneself as disabled can therefore make impairment temporarily worse as one is forced to produce the dys-appearing body/mind within a harsh welfare system situated in a culture which labels disabled people as lazy or fraudulent.

(Re)producing the 'normal' subject

Finally, another example of how the dys-appearing body can be more consciously foregrounded occurs when passing – adopting 'norms' of behaviour and movement and 'passing' as non-disabled. In this example of social dys-appearance the body:

incorporates an alien gaze, away, apart, asunder, from one's own, which provokes an explicit thematization of the body. (Leder, 1990:99)

In other words, the body is behaving according to cultural norms of able-bodiedness rather than being free to adopt any mode of behaviour and movement which is 'normal for them'. This can protect someone with invisible impairments from experiencing the kinds of invalidation that those with visible impairments (and/or impairment effects (Thomas, 2007: 135-137)) experience, such as being avoided or stared at. However there is always the risk that their disability status will be revealed, in turn risking psycho-emotional disablism when their body dys-appears as they become subject to the prejudiced comments of strangers. This gives rise to the 'negative psycho-emotional aspects of concealment' (Thomas, 1999: 55). Similarly Lingsom (2008) argues that people with invisible impairments occupy a highly vulnerable position because they are continually managing whether to conceal or disclose information about their impairment. If someone chooses to pass as 'normal' then they will be expected by others to conform to conventional norms of behaviour and stamina – which can be particularly difficult if an invisible impairment is fatigue.

There can be difficulties disclosing an invisible impairment; for example a young person with a stroke may be disbelieved because this is 'seen' as an impairment affecting only older people. It can also be difficult to convince others about the reality of some impairments such as pain and fatigue, a problem faced particularly by people with chronic illness (Wendell, 2001). As mentioned previously, people with invisible impairments may also be challenged when attempting to use facilities reserved for disabled people because they do not match the stereotypical image of someone who is elderly and/or a wheelchair user. Therefore, like Lucy who will "limp worse", they may choose to use a stick, to adopt a visible marker of impairment, in order to use these facilities without harassment - but this may also have an emotional cost in publicly identifying as disabled (Reeve, 2002).

Leder (1990) argues that dys-appearance makes demands on both the attention and existential levels because of the way in which the body is tied up with self-interpretation. So it could be suggested that passing and exposure are both forms of dys-appearance because of the impact they have on self-identity as disabled, non-disabled or something in between. In addition, when someone adopts a visible marker of impairment without seeing themselves as a disabled person, this act risks producing a conflicted self because:

[t]he deployment of the denotation of disability strategically cannot be undertaken without some incorporation of internalised ableism, either at a conscious or at an unconscious level. (Campbell, 2009: 28)

So whether someone is describing themselves in terms of the medical format of benefit application forms or will "limp worse" when using an accessible parking space, then they risk internalising the culturally informed 'disabled' identity that they are performing.

The role of impairment in experiences of psycho-emotional disablism

Although someone needs to have (or have had) a perceived impairment in order to experience disablism, the social model of disability otherwise cleaves the experience of disability from that of impairment. The original UPIAS statement which underpins the conventional social model understanding of disability clearly states that:

[d]isability is something imposed *on top of our impairments* by the way we are unnecessarily isolated and excluded from full participation in society. (UPIAS, 1976: 14, my emphasis)

This has been politically very useful for challenging structural disablism by 'fixing' society, not the individual. Another consequence of the clear separation of disablism from impairment has been the assumption that 'disabled people share a common experience of oppression, regardless of impairment' (Shakespeare, 2006a: 31). However disabled people do not share a common experience of disablism: factors including class, age, sexuality, gender and ethnicity all impact on the consequences of impairment and therefore on the social and economic experience of disability (Shakespeare, 1996).

Within disability studies, the impaired body has been receiving more attention from a variety of theoretical angles (for a more detailed discussion see other chapters in this book as well as chapter five in Thomas, 2007). For the remainder of this chapter I want to consider the interplay between psycho-emotional disablism and impairment. This is an initial attempt to respond to the following statement:

I have come to recognise that psycho-emotional disablism – both its enactment and its effects – should be thought about as fully embodied. This form of disablism should not be treated as one that operates simply at the level of mind or consciousness. (Thomas, 2007: 152)

I have used the dys-appearing body to illustrate how psycho-emotional disablism is embodied as well as social and political, that 'disability is embodied' (Hughes and Paterson, 1997: 336). The accounts of people like Lucy and Adinuf reveal how impairment/impairment effects and the experience of disablism are intertwined and can impact on each other. I have shown how the experience of psycho-emotional disablism can make impairment worse. Similarly the physical difficulties caused by negotiating an inaccessible environment (structural disablism) can also make impairment worse (Crow, 1996).

I now want to take a step further by suggesting that psycho-emotional disablism allows an insight into the ways that impairment and disablism can be interconnected in more subtle ways. I need to stress that I am *NOT* suggesting that impairment *causes* disablism, but I want to suggest that the manner in which psycho-emotional disablism is enacted – the kinds of disablist comments and treatment that someone receives - is often associated with the type of impairment and impairment effects that are visible/known to the other person. (This is not denying that someone with an invisible impairment can also experience psycho-emotional disablism if they find themselves for example, in a group of people who are making jokes about that particular impairment). Psycho-emotional disablism is critically associated with the cultural representations of disability within the media and wider society. I discussed earlier how fears of contamination or beliefs about the inability or undesirability of impaired bodies underpin the invalidating responses of others towards people with impairments. The strong connection between cultural stereotypes and oppression was discussed earlier with reference to cultural imperialism, which is kept in place by stereotypes which are so embedded in culture that they go unnoticed and unchallenged (Young, 1990). For example, the ubiquitous wheelchair symbol ends up reinforcing the hegemony of particular kinds of impaired bodies which will be accommodated and recognised as 'disabled'.

Watson (2003) highlights the importance of understanding the processes whereby prejudice, and therefore oppressive stereotypes, are maintained and reproduced within contemporary culture, society and practices. As I discussed earlier, it is in the everyday interpersonal interactions

that much psycho-emotional disablism is enacted, based on prejudice and stereotypes. If psycho-emotional disablism is embodied, then it could be predicted that prejudice (which leads to disablism) is influenced by perceived impairment – that psycho-emotional disablism takes different forms depending on what is known/visible to the other (non) disabled person. For example whilst I am stared at by people because I walk differently with two sticks, I am not subject to the kinds of 'souvenir photography' that Shakespeare (2006b) experiences - because we have very different impairments.

Analysis of the 2009 British Social Attitudes Survey showed that the assumption that people hold either 'negative' or 'positive' attitudes towards disabled people was not borne out by the data. Instead, attitudes were related to the perceived impairment:

Respondents' demographic characteristics interact with both the situation in which a disabled person is encountered, and *the impairment that they have*, in influencing the attitudes people hold.' (Staniland, 2011: 72, my emphasis)

People were much more likely to be prejudiced towards people with learning difficulties or mental health difficulties than those with physical or sensory impairments. Similarly, the former two groups of disabled people experience a disproportionately higher rate of disablism hate crime compared to other groups of disabled people (Sin, Hedges, Cook, Mguni and Comber, 2009); this is not surprising if disablism hate crime is seen as an extreme form of direct psycho-emotional disablism. Prejudices about disabled people are based around hierarchies of impairment which are rooted in cultural myths about disability (Tregaskis, 2003). This differentiation of the relative value of disabled people by impairment type is also reflected in the prejudices held by disabled people (Deal, 2003). Deal points out that disabled people need to acknowledge their own prejudices before they can demand a wholly inclusive society because hierarchies of impairment end up further isolating and oppressing those disabled people perceived to be towards the bottom end of the hierarchy. This process can be complicated because people who acquire impairments in adulthood have to deal with the shift from being 'normal' to 'Other' which entails shifting internalised stereotypes and dealing with guilt when they reflect on how they themselves used to view disabled people in the past (Reeve, 2008b).

Conclusion

In this chapter I have provided an introduction to psycho-emotional disablism and showed how it can impact on the emotional well-being and self-identity of disabled people. As psycho-emotional disablism is enacted at the inter/intra-personal level, it is beneficial to locate the analysis at the point where the 'cultural constructions of disability and impairment are played out within and through the body' (Goodley, 2010: 56). To that end I have explored how the phenomenological concept of social dys-appearance highlights the embodied nature of psycho-emotional disablism and the manner in which it is mediated by impairment and impairment effects via the operation of cultural prejudices about disability.

Whilst the 'arid materialism of disability studies' (Paterson and Hughes, 1999: 599) has been very effective at challenging structural disablism, it quite deliberately does not engage with impairment and so does not allow for any theoretical engagement with the lived body. In response, some would argue that phenomenology has little to offer disability studies because it only provides interactionist accounts of living with impairment (Barnes and Mercer, 2010). The continued 'stubbornness of the 'real' body' (Thomas, 2007: 128) cannot be ignored when analysing psycho-emotional disablism because of the way in which impairment and prejudice

are interlinked within the cultural lexicon. Therefore I have used phenomenology as a way of providing insight into psycho-emotional disablism which retains an interconnection with the realities of living with physical impairment and experiencing disablism. Although much progress has been made in removing sources of structural disablism, the prevalence of prejudice about disability in mainstream society and culture means that psycho-emotional disablism will be much harder to eradicate. For example, disabled people are reporting increased rates of discrimination and harassment which are directly linked to the rhetoric about disability benefits in the media (Scope, 2011); psycho-emotional disablism, like the fleshiness of the lived body, is still very much alive and kicking. This is not surprising given that cultural imperialism is a key component of psycho-emotional disablism. Therefore even when legislation and policy exist to protect disabled people, oppression continues to operate via:

informal, often unnoticed and reflective speech, bodily reactions to others, conventional practices of everyday interactions and evaluation, aesthetic judgments and the jokes, images, and stereotypes pervading the mass media. (Young, 1990: 148)

This goes some way to explaining why psycho-emotional disablism is still a problem facing disabled people in the UK even after more than 15 years of the Disability Discrimination Act. Therefore psycho-emotional disablism is important – it is not just a ‘personal trouble’ but needs to be seen as a public issue caused by the ableism endemic in our society.

References

- Barnes, C. and Mercer, G. (2010) *Exploring Disability: A Sociological Introduction*, 2nd Edition, Cambridge: Polity Press.
- Richard, J.-A., Coleman, R. and Langdon, P. (2007) 'Does my stigma look big in this? Considering acceptability and desirability in the inclusive design of technology products', *Universal Access in Human Computer Interaction: Coping with Diversity, Part 1* 4554: 622-631.
- Campbell, F. A. K. (2009) *Contours of Ableism: The Production of Disability and Aabledness*, Basingstoke: Palgrave Macmillan.
- Crow, L. (1996) 'Including all of our lives: Renewing the social model of disability', in J. Morris (ed.) *Encounters with Strangers: Feminism and Disability*, London: Women's Press, pp. 206-226.
- Daly, M. and Noble, M. (1996) 'The reach of disability benefits: An examination of the disability living allowance', *Journal of Social Welfare and Family Law* 18(1): 37-51.
- Deal, M. (2003) 'Disabled people's attitudes toward other impairment groups: A hierarchy of impairments', *Disability & Society* 18(7): 897-910.
- Garland-Thomson, R. (2009) *Staring: How We Look*, Oxford: Oxford University Press.
- Glassner, B. (1992) *Bodies: The Tyranny of Perfection*, Los Angeles: Lowell House.
- Goodley, D. (2010) *Disability Studies: An Interdisciplinary Approach*, London: Sage.
- Hughes, B. (1999) 'The constitution of impairment: Modernity and the aesthetic of oppression', *Disability & Society* 14(2): 155-172.
- Hughes, B. (2007) 'Being disabled: Towards a critical social ontology for disability studies', *Disability & Society* 22(7): 673-684.
- Hughes, B. and Paterson, K. (1997) 'The social model of disability and the disappearing body: Towards a sociology of impairment', *Disability & Society* 12(3): 325-340.
- Hunt, P. (ed.) (1966) *Stigma: The Experience of Disability*, London: Geoffrey Chapman.
- Keith, L. (1996) 'Encounters With Strangers: The public's responses to disabled women and how this affects our sense of self', in J. Morris (ed.) *Encounters With Strangers: Feminism and Disability*, London: Women's Press, pp. 69-88.
- Kitchin, R. (1998) 'Out of place', 'knowing one's place': Space, power and the exclusion of disabled people', *Disability & Society* 13(3): 343-356.
- Leder, D. (1990) *The Absent Body*, Chicago, IL: The University of Chicago Press.

- Lingsom, S. (2008) 'Invisible impairments: Dilemmas of concealment and disclosure', *Scandinavian Journal of Disability Research* 10(1): 2-16.
- Marks, D. (1999) *Disability: Controversial Debates and Psychosocial Perspectives*, London: Routledge.
- Merleau-Ponty, M. (2005 [1962]) *The Phenomenology of Perception*, trans. C. Smith, London: Routledge.
- Miller, A. (1991) *The Drama of Being a Child*, trans. R. Ward, London: Virago Press.
- Paterson, K. and Hughes, B. (1999) 'Disability studies and phenomenology: The carnal politics of everyday life', *Disability & Society* 14(5): 597-610.
- Porter, A. (2000) 'Playing the 'disabled role' in local travel', *Area* 32(1): 41-48.
- Price, J. and Shildrick, M. (1998) 'Uncertain thoughts on the dis/abled body', in M. Shildrick and J. Price (eds) *Vital Signs: Feminist Reconfigurations of the Bio/Logical Body*, Edinburgh: Edinburgh University Press, pp. 224-249.
- Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', *Disability & Society* 17(5): 493-508.
- Reeve, D. (2006) 'Towards a psychology of disability: The emotional effects of living in a disabling society', in D. Goodley and R. Lawthom (eds) *Disability and Psychology: Critical Introductions and Reflections*, London: Palgrave, pp. 94-107.
- Reeve, D. (2008a) 'Biopolitics and bare life: Does the impaired body provide contemporary examples of homo sacer?' in K. Kristiansen, S. Vehmas and T. Shakespeare (eds) *Arguing about Disability: Philosophical Perspectives*, London: Routledge, pp. 203-217.
- Reeve, D. (2008b) *Negotiating Disability in Everyday Life: The Experience of Psycho-Emotional Disability*, PhD Thesis, Lancaster: Lancaster University.
- Scope (2011) *Deteriorating attitudes towards disabled people*, [Internet], Scope. Available from <<http://www.scope.org.uk/news/attitudes-towards-disabled-people-survey>> [Accessed 17 May 2011].
- Scully, J. L. (2008) *Disability Bioethics: Moral Bodies, Moral Difference*, Lanham, MA: Rowman & Littlefield Publishers.
- Shakespeare, T. (1994) 'Cultural representation of disabled people: Dustbins for disavowal?' *Disability & 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, pp. 94-113.
- Shakespeare, T. (2006a) *Disability Rights and Wrongs*, Abingdon: Routledge.
- Shakespeare, T. (2006b) *Snap unhappy*, [Internet], BBC - Ouch! Available from <http://www.bbc.co.uk/ouch/features/snap_unhappy.shtml> [Accessed 15 September 2011].
- Shildrick, M. (1997) *Leaky Bodies and Boundaries: Feminism, postmodernism and (bio)ethics*, London: Routledge.
- Shildrick, M. and Price, J. (1999) 'Breaking the boundaries of the broken body', in J. Price and M. Shildrick (eds) *Feminist Theory and the Body*, Edinburgh: Edinburgh University Press, pp. 432-444.
- Sin, C. H., Hedges, A., Cook, C., Mguni, N. and Comber, N. (2009) *Disabled People's Experiences of Targeted Violence and Hostility (Research Report 21)*, Manchester: Office for Public Management.
- Staniland, L. (2011) *Public Perceptions of Disabled People: Evidence from the British Social Attitudes Survey 2009*, London: ODI.
- Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*, Buckingham: Open University Press.
- Thomas, C. (2004) 'Developing the social relational in the social model of disability: A theoretical agenda', in C. Barnes and G. Mercer (eds) *Implementing the Social Model of Disability: Theory and Research*, Leeds: The Disability Press, pp. 32-47.
- Thomas, C. (2007) *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology*, Basingstoke: Palgrave Macmillan.
- Tregaskis, C. (2003) *Constructions of Disability: Researching Inclusion in Community Leisure*, London: Routledge.
- UPIAS (1976) *Fundamental Principles of Disability*, London: The Union of the Physically Impaired Against Segregation and The Disability Alliance.
- Watson, N. (2003) 'Daily denials: The routinisation of oppression and resistance', in S. Riddell and N. Watson (eds) *Disability, Culture and Identity*, London: Longman, pp. 34-52.
- Wendell, S. (2001) 'Unhealthy disabled: Treating chronic illnesses as disabilities', *Hypatia* 16(4): 17-33.
- Williams, Z. (2011) *It's the tests that deceive, not the people claiming benefits*, [Internet], The Guardian. Available from <<http://www.guardian.co.uk/commentisfree/2011/mar/10/tests-deceive-benefits-mental-illness>> [Accessed 6 May 2011].
- Young, I. M. (1990) *Justice and the Politics of Difference*, Princeton, NJ: Princeton University Press.