<u>'Encounters with Strangers': Psycho-emotional dimensions of disability in everyday life</u>

Donna Reeve
PhD student
Department of Applied Social Science
Lancaster University
(donna.reeve@lancaster.ac.uk)

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<u>Introduction</u>
The emotional effects of living in a disabling society have been well documented by feminist writers such as Jenny Morris (1989; 1991), Lois Keith (1996) and Carol Thomas (1999). In recognition of these emotional effects, Thomas has proposed an extended social relational definition of disability which considers pathways of oppression operating at both the structural and psycho-emotional level:

> '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, forthcoming).

This paper is inspired by the original chapter by Lois Keith called 'Encounters with Strangers' published in 1996, which described how the reactions of strangers to disabled women who used wheelchairs, affected their sense of self. My paper will draw on the accounts of two disabled men who used wheelchairs in order to illustrate these *psycho-emotional dimensions of disability* which arise from interactions with strangers – if you like, 'Encounters with Strangers: Part 2'. I will also identify the very real 'emotion work' which these two men ended up doing in response to the disabling attitudes and prejudices of others, further draining their emotional and physical resources.

<u>Research methods</u>
As part of my PhD research looking more generally at the psycho-emotional dimensions of disability, I have used the free-association narrative interview method described by Hollway and Jefferson (2000) to generate narratives of people's 'disability experiences'. This method explicitly recognises the manner in which both participant and researcher can be seen as 'defended subjects', protecting themselves from anxieties which arise during the interview experience. This is useful for a study of the psycho-emotional dimensions of disability because these particular dimensions can operate at both the conscious and unconscious level. Thus data emerges from the stories that are

told, the manner of their telling, as well as what is not said. Fractures within narratives are as valuable as linear narratives in understanding and revealing the effects of this dimension of disability.

I adopted a similar two-interview approach to that advocated by Hollway and Jefferson. The first interview provided a space for the participant to discuss the issues which were most relevant to them about the topic under investigation, in this case, their experiences of disability (whatever that meant to them). This is the 'free association' part of the method. I then returned a week later to carry out a second interview in which participants had the opportunity to change or add to what they had said previously. This second interview also provided me with an opportunity to follow up some of the issues which had been touched on previously and to check out my understanding of what they had been discussing.

This paper is based on my data analysis to date of interviews carried out with people with physical impairments and draws on the narratives of two disabled men with acquired mobility impairments. 'Adinuf' (a pseudonym he chose to reflect the fact he has 'had enough') is 48 and has been using a wheelchair over the last 10 years. 'Robert' is a few years older and has been using a wheelchair for the last few years when he is outside the house. Both men live in the same city with their families and are involved in various disability related organisations.

Fear and avoidance – Adinuf's story
One of the aspects of disability which Adinuf found most difficult to deal with, was the way in which, since he had become disabled, people avoided him because they were frightened of 'catching something', as he put it. He was especially hurt by the way that old friends deliberately crossed the road to avoid talking to him when they saw him coming in his wheelchair. This issue was returned to repeatedly in the interview, its importance apparent by the way it interrupted other stories he told. 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 (this was referred to many times in the interview), 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.

Consequently, in this computer room, there was at least a ten-foot wide space between the other students and where Adinuf sat in his wheelchair. He went on to describe how:

> 'And then when we'd finished, the one lady who was talking to me, from that distance, asking me about a package that I'd got for desktop publishing, she's bought one and if she's got any problems, can she ask me the questions next week? I said, 'Yes, no problem'. 'Put them on a bit of paper for you', she said. So I know if she comes in now next Monday, she's going to pass a piece of paper to me because she doesn't want to be near me! So I'm going to be in the situation of, 'Like to come over here so's I can explain this?' and I'm literally going to have to force her, to show her that there's nothing to be frightened of.' (Adinuf)

This description of the woman passing Adinuf a piece of paper, rather than risk getting physically close to him, illustrates the extent of her fears – reminiscent of attitudes towards someone with leprosy, 100 years ago.

Adinuf's reaction to this behaviour is to take on the role of educator, to try and prove to her that people like him are not contagious, that there is nothing for her to be frightened of. Adinuf recognised throughout the interview that generally he took on this role of educating people about 'disability'. He felt 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.

Whilst reacting to reactions of avoidance by seeking to educate is laudable, and in the case above will hopefully improve the relationship between Adinuf and his fellow student, it is still Adinuf who pays the price of such a public spirited response to rejection. Adinuf is already physically exhausted by impairment effects, and the role of educator is an additional drain on his limited energies.

I now want to look at a more complex example of psycho-emotional disablism and to show how it can be inextricably linked with structural disability.

Inaccessible shops – Robert's story
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.

> '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 in to 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)

This part of Robert's story reveals how structural disability can be compounded by the experience of psycho-emotional disablism. 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. This contrasts markedly with his experience of an accessible shop where he is fully independent and therefore not forced to rely on strangers for help:

'And you feel that good inside yourself, you haven't got to go into any supermarket and knock the window for them to open the door - the door is already open, with the sliding ramps.' (Robert)

Robert also talked about his frustration with the way in which some local businesses were interpreting their obligations under the Disability Discrimination Act (DDA). Disabled people, unlike any other oppressed group in society, have the doctrine 'separate but equal' enshrined in law (Olkin, 1999). Thus it is legitimate to force disabled people to enter a building through a different entrance to everyone else, or to sit in a different part of the cinema to their friends.

Whilst some shops had made their premises wheelchair accessible according to the DDA, Robert found the solution was often less than desirable:

'[T]hey're forgetting people like to go into shops upstairs, or they might go to a place where there's clothes and then there's a restaurant - but there's no lift. So what you've got to do, you've got to go into the kitchens, right through the kitchens, through their lift, to go upstairs, which will come out at the back of the counter, and then you go and sit down and have your meal. Then when you want to come out, you've got to go down all the same procedures. [edit] You know, we shouldn't have to do it.' (Robert)

He was upset that although the local city had received a lot of money to revamp the town centre, many of the 'improvements' failed to include lifts/level entrances as part of an inclusive design and instead forced him to access premises through back street entrances or staff areas – reinforcing the message that he was a second-class citizen. He was hurt by the 'not doing' as he put it, the failure of architects and planners to consider the access needs of people like him, when they improved the town centre. Thus, the experience of structural disability and the so-called 'reasonable adjustments' carried out by shops to meet their obligations under the DDA had a psycho-emotional dimension because it left him feeling worthless and invisible.

Discussion
I have provided some examples of psycho-emotional disablism, showing how the reactions of strangers and the experience of inaccessible environments, can undermine the self-esteem of people with impairments. I have also indicated the different ways that these two disabled men responded to this dimension of disability, and it is these 'technologies of resistance' (Reeve, 2002), or what Keith refers to as 'techniques of resistance' (Keith, 1996: 86), which I will now discuss in more detail.

In her chapter entitled 'Encounters with Strangers', Lois Keith describes several ways of dealing with the undermining responses of strangers which helped restore power, control and self-respect to disabled women. As well as taking on the role of educator, as Adinuf did, she also suggests actively taking the initiative – in her case, asking people if they would like to do their 'good deed' for the day by helping her up a steep curb or ramp.

But what is happening in Robert's case when he finds himself apologising to people for asking for help? The fact that he is a disabled man, rather than a disabled woman may change the ways of resisting that are available to him. The dissonance between hegemonic masculinity (men as strong and independent) and disability as weakness and dependence (Robertson, In press) may make it more difficult for Robert to ask and receive help from strangers than for a woman such as Lois Keith.

So instead, is he consciously behaving in this apologetic manner in order to get the help he needs albeit at an emotional cost to himself? Or is this a case of internalised oppression, when he unconsciously views himself as someone who should be grateful for any help he is given, gratitude being the gift in exchange for tolerance and the receipt of help (Morris, 1991: 108)?

French (1994) writes about the dangers of adopting the 'disabled role' in which disabled people attempt to make themselves acceptable by conforming to the behaviour expected by non-disabled people. At one extreme, there is the risk that disabled people accept unquestioningly the prejudices and assumptions about disability that exist within society, and become what they have internalised, or what Fanon would call the 'slave of their archetypes' (Fanon, 1986: 35). On the other hand, there is the possibility that disabled people *consciously* play the 'disabled role' in order to get their needs met (Thomas, 1995).

Earlier I described how Robert experienced an internal 'clash' between feeling obliged to apologise for asking for help at the same time as feeling angry that he was put in that situation in the first place. In the second interview 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). He is well aware that he should not be forced to behave in this way, but in the absence of accessible shops, the only other option would be to stay at home – and often he doesn't leave the house because, as he says, 'What's out there for me?'

But, like the education process Adinuf undertakes, Robert's performance as a 'grateful disabled person' has a personal cost. (You can hear the gritted teeth behind the false smile in this extract).

It is at this stage that I want to bring in two concepts from the sociological literature of the emotions. Given the way that psycho-emotional disablism operates along emotional pathways, the concepts of emotional labour and emotion management could offer some further depth of understanding of these individual accounts of dealing with prejudice and to fully recognise the disabling effects of psycho-emotional disablism.

For my purposes, I define 'emotion management' to describe the manner in which an individual constitutes emotions in line with what is expected in particular contexts, both private and public, according to the *cultural dictionary* (Hochschild, 1998: 6). So it is appropriate to be sad at funerals and happy at weddings. The term 'emotional labour' is linked to the *work* done within relationships, both personal and social, in

> 'dealing with other people's feelings, particularly as part of the goal of maintaining harmony with a social unit or workplace.' (Lupton, 1998: 127)

This requires people to assess and manage someone else's feelings (Hochschild, 1993) as well as regulating their own feelings (James, 1989). For example we do emotional labour when pretending to get along with someone as part of a job or when hiding anxieties to protect someone else (Lupton, 1998).

These sociological terms can be used to recognise the emotion work (management and/or labour) which both Adinuf and Robert have undertaken when dealing with the responses of strangers. For example, Adinuf feels that he needs to patiently reassure, explain and educate others, such as the

woman in the class, 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.

In Robert's case, his adoption of the 'false smile' and fake expressions of gratitude mean he is behaving in the ways that the cultural dictionary 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.

These terms, when applied to the 'technologies of resistance' discussed earlier, reflect the real work and effort that disabled people can end up doing when dealing with psycho-emotional dimensions of disability arising from encounters with strangers – these modes of resistance are not free, they have a cost for the individual.

I am not suggesting that it is acceptable that people like Adinuf and Robert undertake this kind of emotion work in order to reduce the disabling effects of psycho-emotional disablism. At 'best', and I use the word reservedly, this emotion work allows someone to somewhat 'manage' this form of disablism individually, diluting its adverse effect on their self-esteem and self-worth although still taking valuable energy and effort – as seen in Adinuf's response in taking on the role of educator. But in Robert's case, emotion work can end up adding still further to the negative effects of psycho-emotional disablism, leaving him feeling angry, frustrated and humiliated – in this case it is not such a helpful strategy.

The experience of psycho-emotional disablism along with any associated emotion work has ramifications for issues of identity. Although both these men used wheelchairs, and adopted an understanding of disability consistent with the social model, neither person identified as a 'disabled person'. Like some of the people in Watson's research (2002), these two men are not celebrating their difference, and in Robert's case, might be considered to be reinforcing a stereotype of how disabled people should behave. On the other hand, the deliberate actions of both men in response to the disabling attitudes of others seems to be their way of reducing their experience of psycho-emotional disablism in that particular time and place, by easing social interaction with non-disabled people. Or as Watson says, 'they are not reinforcing oppression, but trying to make difference *not* matter' (Watson, 2002: 522, emphasis in original).

Therefore it is not always possible to assume that someone who behaves in a stereotypical manner is subject to internalised oppression or 'false consciousness' – it may instead be a very conscious act to retain control over

a particular situation in order to overcome otherwise disabling barriers. It is necessary to consider the possibilities of strategies of both resistance and co-existence. However, as already described, performances such as that carried out by Robert can have a personal emotional cost when they entail emotion management and emotional labour, as well as increasing the likelihood that such performances become internalised and unconscious if repeated over time.

Conclusions

As Keith says in her chapter 'Encounters with Strangers':

> 'doing disability all day long can be an exhausting process … having to deal with a physical world which is historically designed to exclude me, and even more tiring, dealing with other people's preconceptions and misconceptions about me' (Keith, 1996: 71).

When interacting with the social world outside the home, for some disabled people, it is the experience of psycho-emotional disablism which is more exhausting than dealing with environmental barriers.

Thomas's naming of these psycho-emotional dimensions of disability within her extended social relational definition of disability enables a fuller understanding of the complex ways that people with impairments are disabled by oppressive social relations. The reactions of strangers towards Robert and Adinuf significantly affected their self-esteem and both men developed different forms of emotion management and emotional labour to counteract this source of psycho-emotional disablism. Whilst Adinuf found acting as an educator to be helpful if tiring, Robert had very mixed feelings about the way he felt forced to behave in a certain way, if he was to get the help he needed.

Whilst it is possible to imagine a utopian world without prejudice and discrimination, the reality is that disablism is going to be part of our society for years to come, especially if the experience of women and minority ethnic groups is anything to go by (Corker, 1999). Thus there is still a need to develop a psychology of disability providing:

> '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)

Through this brief revisiting of 'encounters with strangers', I have illustrated the burden of exclusion and denigration operating at the psycho-emotional level, as well as indicating the amount of emotion work undertaken by some people with impairments as a way of 'getting by' in a disabling world. Therefore any analysis of the psycho-emotional dimensions of disability also needs to consider the potentially disabling effects of the strategies people employ to counteract this 'personal' experience of oppression.

References

Ashforth, B. E. and Tomiuk, M. A. (2000) 'Emotional labour and authenticity: views from service agents', in S. Fineman (ed) *Emotion In Organizations*, 2nd Edition, London: Sage Publications, pp. 184-203.

Corker, M. (1999) 'Difference, conflations and foundations: the limits to 'accurate' theoretical representation of disabled people's experience?' *Disability & Society* 14(5): 627-642.

Fanon, F. (1986) *Black Skin, White Masks*, London: Pluto Press.

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, pp. 26-33.

French, S. (1994) 'The disabled role', in S. French (ed) *On Equal Terms: Working with Disabled People*, Oxford: Butterman-Heinemann, pp. 47-60.

Hochschild, A. R. (1993) 'Preface', in S. Fineman (ed) *Emotion In Organizations*, London: Sage Publications, pp. ix-xiii.

Hochschild, A. R. (1998) 'The sociology of emotion as a way of seeing', in G. Bendelow and S. J. Williams (eds) *Emotions in Social Life: Critical Themes and Contemporary Issues*, London: Routledge, pp. 3-15.

Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*, London: Sage Publications.

James, N. (1989) 'Emotional labour: skill and work in the social regulations of feelings', *The Sociological Review* 37(1): 15-42.

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: 343-356.

Lupton, D. (1998) *The Emotional Self: A Sociocultural Exploration*, London: Sage Publications.

Morris, J. (ed) (1989) *Able Lives: Women's experience of paralysis*, London: Women's Press.

Morris, J. (1991) *Pride Against Prejudice: Transforming Attitudes to Disability*, London: Women's Press.

Olkin, R. (1999) *What Psychotherapists Should Know About Disability*, New York: The Guilford Press.

Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', *Disability & Society* 17(5): 493-508.

Reeve, D. (forthcoming) 'Psycho-emotional dimensions of disability and the social model' *Implementing the Social Model of Disability: Theory and Practice (???)*, Leeds: The Disability Press.

Robertson, S. (In press) 'Disabled & male', in C. Barnes, S. French, J. Swain and C. Thomas (eds) *Disabling Barriers, Enabling Environments*, 2nd Edition, London: Sage Publications.

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*, Buckingham: Open University Press.

Thomas, P. (1995) 'Internalised oppression', *Coalition*, (February), pp. 5-7.

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 & Society* 17(5): 509-527.