

# **Psycho-emotional dimensions of disability within relationships between professionals and disabled people**

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## ***Introduction***

Within disability studies there have been many criticisms of health and welfare professionals and the adverse impact they can have on the daily lives of disabled people. Many of the criticisms relate to the way in which much professional practice is underpinned by power relations and the ideology of 'normality' (Oliver, 1993; Swain and French, 1998). Evidence from research together with the accounts of disabled people themselves suggest that the relationships between professionals and disabled people are varied, but can be experienced as dehumanising or abusive (French and Swain, 2001).

Whilst writers such as Jenny Morris, Sally French and John Swain have identified the ways in which medical/welfare professionals' attitudes and behaviours can have an adverse effect on disabled people's emotional well-being, I will be illustrating how these effects can last well beyond the actual professional encounter and how the effect of such encounters can be cumulative.

## ***The psycho-emotional dimensions of disability***

A vital contribution to the understanding of the disabling effects of many professional relationships was the development by disabled people of the social model of disability. In this paper I will be using the extended social relational definition of disability which explicitly includes pathways of oppression which operate 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)

Examples of the psycho-emotional dimensions of disability, those that undermine someone's psycho-emotional well-being, might include being stared at or patronised, activities by others which can leave disabled people feeling worthless, ashamed, devalued, literally 'invalid'.

Whilst the agents of psycho-emotional disability can include family, friends or strangers, the psycho-emotional dimensions of disability are particularly

relevant to a discussion of the relationships between professionals and disabled people, a key factor of which is the inherently unequal balance of power (French and Swain, 2001).

Thomas (2004) suggests that the following questions need to be addressed in connection with the psycho-emotional dimensions of disability:

- 'Who has the power and how is it wielded?
- What are the decisions made, the words said, the meanings conveyed, in these networks of relationships?
- And what are the effects on disabled individuals' sense of self, self-esteem and existential security?' (Thomas, 2004: 38)

As part of my PhD research looking more generally at the psycho-emotional dimensions of disability, I used the free-association narrative interview method described by Hollway and Jefferson (2000) to generate narratives of people's 'disability experiences'. I interviewed people with physical impairments and will now discuss some of the examples of the psycho-emotional dimensions of disability, both past and present, which were revealed within accounts of their relationships with health and welfare professionals.

I will show how psycho-emotional disability can result from the experience of active discrimination, prejudice or thoughtless behaviour by professionals and the way in which this can be exacerbated by internalised oppression or other forms of past psycho-emotional disability. Finally I will consider the consequences of professional behaviours which are experienced by all people, but which nonetheless can increase the impact of psycho-emotional disability for disabled people.

Throughout I will address the questions posed by Thomas to illustrate the power present within these professional encounters and to show examples of resistance to this power.

### ***Becoming a mother***

One obvious example of discrimination within the medical profession is when a disabled woman is refused the chance to become pregnant because of the prejudice that she would make an unsuitable mother (Thomas, 2001). Laura had experienced this when she tried to get IVF treatment after failing to conceive naturally. The first time she saw the female doctor she was told:

“ 'Of course the problem is this MS'. [cut] She said, 'No, if it was naturally you were conceiving then fine, but I don't know if I can ethically allow you to have treatment in case you develop mobility problems'.” (Laura)

What is interesting in this extract is the inconsistency of the doctor's reasoning – if IVF treatment is not recommended because of the risk of mobility problems, then why would pregnancy through natural conception be any less risky?

Laura decided to complain to the trust and eventually she had one IVF attempt which failed. Laura was then 'allowed' to have a second IVF attempt following a meeting between the fertility consultant and two neurologists – in her absence. As she said:

“Very, very kind, I'm so grateful to them, them deciding that I could have another attempt [laughs]. At that stage, that was quite significant because I suddenly thought, 'Where's my control? Where's my say in all of this?' They gave me the go-ahead and I thought, 'I'm not bloody going ahead with it now, I'll do it in my time thank you!' “ (Laura)

These two extracts can be examined bearing in mind the questions listed earlier. At no point did the doctor ask Laura what she wanted to do in the light of the perceived risks to her mobility of getting pregnant i.e. allow Laura to make the decision. Laura's decision to become a mother was not one she had taken lightly, she had done her own research and talked to other mothers with MS. In contrast this doctor takes the stand that it is *unethical* to support her request for this treatment; the use of this particular word is steeped in power and control, implying that Laura's desire to have a child is somehow immoral and unreasonable, and so she should not be offered any treatment which would facilitate the process of becoming pregnant. The powerful link between medicine and ethics makes it more difficult for a patient to challenge a medical decision apparently made on ethical grounds than one made on the basis of obvious prejudice.

Laura had been quite upset and frustrated by the idea of these three men, who she knew all had families, meeting to decide whether or not she should be allowed to have another IVF treatment. Her absence from this meeting meant that she had no control or input in this decision. Additionally, there was a strong sense that she should be grateful to these doctors for eventually allowing her to have the second IVF treatment. So maybe it is not that surprising that in the end she takes back some control of this particular medical encounter in the only way she can - by deciding that she would choose when she should have the next IVF treatment, not the consultants. Nonetheless these experiences left her feeling devalued and I will return to this theme in a later example.

It should be noted that it is not only disabled women who come under particular scrutiny about their 'suitability' to be a mother; discriminatory IVF selection practices also reproduce class oppressive, (hetero)sexist and racist social divisions (Steinberg, 1997). However, for women such as Laura, IVF treatment can be refused by doctors because of professional discourses about risk to the health/impairment of the disabled woman in addition to disablist attitudes about their ability to be a parent.

### ***Being treated as an 'invisible'***

A thread which ran throughout Rhodri's narrative was that of being devalued and worthless.

This experience of feeling devalued stemmed from birth, when the doctor suggested to his parents that they should leave their child in the hospital

because there was no future for someone born with cerebral palsy. This had led to a life-long insecurity about his value to the world he lived in. This internalisation that he was 'no good' and that 'nothing would become of this gentleman' had been made worse by the public humiliation he experienced at the hands of staff at the residential school he attended as a child.

Rhodri talked a lot about the different relationships he had with care staff who came into his house. He was fed up with having his private space invaded by many different care staff, especially when they passed judgement on his taste in décor or what he liked to read.

"I don't go into their houses and say, 'Can I go in your drawers a minute - Good God, do you read this stuff then?' Can you imagine? It's that whole attitude thing and that's what annoys me more than anything. The cheek of it in saying that I needed my house painting - I don't need the house painted, yet if I challenge, 'Oh, I was only joking'. But the idea is put there - I am not of value as much as you are, as the person who's giving the care." (Rhodri)

The concept of private space is tied up with the individual's ability to control what they reveal to others (Peace, 1998). For someone like Rhodri who has care staff coming into the home, this privacy and control is lost. He talked about how he won't let care staff tidy his desk because for him, an untidy desk is psychologically easier to deal with than having judgements made about his choice of reading material. Then his loss of privacy and therefore control is made worse by a lack of respect for his choices as seen in the extract – in this case, about the colour of his walls. In effect he is being robbed of the everyday decision making about how to lead his life. He does attempt to challenge the personal comments that are made by the care staff, but power is exerted again, when his challenge is deflected by the excuse that the speaker was 'only joking'. All in all, the result of the patronising attitudes of the people who are supposed to be supporting him end up leaving him feeling more devalued and disempowered as well as frustrated by the off-hand dismissal of his challenge.

His experience of the practice of 'double handling' also affected how he felt as a person because of the manner in which the two care staff would end up talking to each other instead of engaging with him.

"[I]t's like being dressed in the morning with double handling, isn't it. 'And where did you go last night?' 'Oh, I went to the pictures'. 'Did you go to Bingo?' 'Did you go to Bingo?' 'Yes, I went to Bingo'. And here I am - 'Have you got your sock - I'm putting your socks on', 'But you're putting them on wrong'. [long pause] And stuff like that. That's why I won't get double handling because I'm not going to be treated like an invisible." (Rhodri)

Whilst the care staff are not behaving in an overtly discriminatory manner, the fact that they are not talking to Rhodri, asking him how he wants his socks put on, means he ends up feeling like "an invisible". Rhodri already feels invisible

compared to the rest of society and it is ironic that even the topic of conversation between the two care staff is about a social activity he is excluded from because of structural barriers. This is another example of, at the very least, unthinking behaviour which has psycho-emotional effects and further undermines Rhodri's sense of self.

The problems of having paid care staff in the house are well documented. Jenny Morris's account of community care ten years ago contained very similar stories (Morris, 1993). If Rhodri could have direct payments and employ personal assistants then he would have more control and power over how he was handled – he would no longer be an invisible. As this is not a workable option, it means he is forced to put up with this 'nonsense' as he calls it, but unfortunately this 'nonsense' continually erodes his sense of self-worth and represents forms of psycho-emotional disablism.

Generally, paid care staff are unskilled female workers who are not paid much above the minimum wage and the jobs they carry out are seen socially as having low status (Davies, 1998; EOC, 2004). So in the absence of any formal training about disability in the sense disability studies would understand it, it is maybe not surprising that paid care staff working with people like Rhodri treat him in the same prejudiced manner that strangers in the street do – that he is dependent and child-like as reflected in the way they dressed him without talking to him directly, as you might a young child. Nonetheless, if these care staff had been trained about the importance of emotionally engaging with the person as well as the practical procedures of double handling, then Rhodri's experience of getting out of bed in the morning would not be so oppressive.

Finally, Rhodri's internalised oppression was made much worse by his experience of social workers who he felt continually undermined him. Whilst he wants to work with social workers to ensure that his care needs are met, he finds it difficult to work with professionals who are, as he says, "Devaluing the person who's already - whose devalued themselves anyway". Thus his internalised view of himself as having little intrinsic value is made worse by social workers whose treatment of him leaves him feeling further vulnerable and stressed. Whilst some disabled people would challenge treatment like this, Rhodri's history of institutionalisation coupled with his internalised oppression about his worthlessness make it really difficult for him to take back control/power from these professional relationships.

Nonetheless, Rhodri and others in my research also talked about the qualities they regarded highly in people they had experienced as 'good' professionals such as care staff. Typically these would be people who 'went the extra mile', were not 'distant' and who cared about, rather than for, the disabled people they were supporting. One important result of professional relationships with these particular care staff was that they valued the disabled person, counteracting the sense of invalidity and invisibility that people like Rhodri experienced from other people both inside and outside the home. In other words, these good care staff counteracted Rhodri's experiences of psycho-emotional disablism from other sources.

### ***Trust in the medical encounter***

Finally I want to talk about another experience Laura had with the medical profession in the shape of the neurologist she saw in connection with her treatment for MS. Laura was hoping to be put on a medical trial for interferon, so that her relapses would be reduced enabling her to return to work. When she described her symptoms, the neurologist did not believe she was still having relapses:

“What he says is that I'm having exacerbations, flare-ups of symptoms - and I said, 'Yes, but I thought that was a relapse'. And they're using a whole new load of words now.” (Laura)

After monitoring her relapses for a year, as requested by him, she returned to see the consultant. After a two minute consultation in which he did not even examine Laura, he decided that her MS was too progressive to be considered for interferon or any kind of drug trial. This left her feeling that she was of no interest to the medical profession and that:

“I feel like he's written me off. 'Oh, your MS is too progressive', he's said, 'I don't need to see you again, I only see people in the early stages of the disease'. He didn't even use little words like, 'I'm sorry, I only see people ...' [hesitates].” (Laura)

Whilst the decision the consultant made may be medically justified, she felt disempowered by the manner in which he increased his power over her medical treatment by changing the words used to define who was eligible for interferon. The manner in which Laura felt he was twisting her words, challenging any sense of understanding that she had about what was happening to her body, is a form of 'epistemic invalidation' (Wendell, 1996: 122).

Her quest for interferon was not simply about treating her symptoms, it also offered reassurance that she was worth treating, that she was seen as having some value to society. This existential insecurity is made worse by the postcode approach to treatment within her area – whilst she has been refused interferon and physiotherapy, someone else living 8 miles away in the same local health trust has been freely given both. Consequently her experiences of the medical profession over the last seven years have left her feeling unable to trust them (Lupton, 1997) - this was a theme several people talked about in their interviews. This mistrust in the medical encounter has significant consequences for disabled people's existential security, if the very people that are responsible for their care are seen as a threat (Marks, 1999).

She has fought back against this particular consultant by making a complaint about his attitude within the consulting room. And two and a half years further on, she has relinquished the quest for interferon or any other drug treatment, which freed her up to spend her energy doing more positive and enjoyable activities as well as taking back control over her own health – she swims regularly and feels much better for it. Therefore Laura eventually found her own way of resisting the negative consequences of medical power as well as

removing herself from dependency on an emotionally damaging medical relationship.

The literature about doctor/patient relationships is full of references to the power of the doctor over the patient. It is entirely likely that this consultant, irrespective of the speciality he worked in, would always treat his patients, both disabled and non-disabled, with little thought or respect. Because medical practices do not always recognise the subjectivity of patients, treatment can end up feeling dehumanising (Marks, 1999). However, in Laura's case, her prior experience of psycho-emotional disability within the work place, allowed the abrupt and dismissive attitude of the consultant to have a disproportionate effect on her emotional well-being, leaving her feeling even more devalued than the loss of friends and job had already caused.

### **Conclusions**

In these accounts of two people's experiences of health and welfare professionals I have attempted to illustrate some examples of the psycho-emotional dimensions of disability. Laura experienced the discriminatory attitudes of fertility doctors who were reluctant to help her become pregnant. In Rhodri's case he ended up feeling devalued and invisible by the thoughtless comments and actions of care staff entering his house. As well as reinforcing his social invisibility caused by disabling structural barriers, his reactions to feeling devalued by care staff and undermined by social workers were made worse by the messages he had internalised about his lack of worth to society which he had received since the day he was born – in other words, past experiences of psycho-emotional disability. This existential anxiety was also seen in Laura's experience of the neurologist who left her feeling that she had been written off by the medical profession, and again of no value to society.

Within these accounts I have illustrated some of the power dynamics within these relationships, the meaning to Laura and Rhodri of decisions made, language used as well as giving a flavour of the negative effects this had on their self-esteem, self-worth and intrinsic value to society.

These examples link into the existing literature about the difficulties caused to disabled people by prejudiced and/or unthinking health and welfare professionals. The concept of psycho-emotional disability allows for full recognition of the manner in which these relations with professionals, laced with power and control, affect and are affected by other forms of psycho-emotional disability such as internalised oppression. The experience of patronising and prejudiced professionals is not just an issue for the individual to deal with but is an important dimension of disability caused by oppressive social relations which needs to be given more credence and attention. There is a dire need for professionals to receive training about the psycho-emotional dimensions of disability, to improve their professional practice so that they don't further disable the people they are working with.

I have also indicated that 'good' professionals such as care staff who 'went the extra mile' had the possibility of counteracting the negative effects of

psycho-emotional disablism experienced within other relationships both inside and outside the home. The same could be assumed to be true of disabled people who had medical professionals who adopted a patient-centred, holistic approach which included recognition of their subjective experiences – an alliance with a minimal power differential (Baker, Yoels and Clair, 1996). In other words, health and welfare professionals need to work with disabled people as allies which means relinquishing their professional power (French and Swain, 2001). As well as reducing the incidence of psycho-emotional disablism as a result of poor professional practice, it might help reverse some of the damaging effects of past psycho-emotional disablism.

I now want to pose some questions for further debate. Disabled people experience psycho-emotional disablism from all quarters of society – friends, family, strangers and professionals. Elsewhere I have suggested that there are strong similarities between the experience of psycho-emotional disablism and that of emotional abuse (Reeve, forthcoming) – both result in the same feelings of being worthless, devalued and having low self esteem. Therefore it may not be surprising that institutional practices and behaviours which are experienced by all people, such as patronising or dismissive attitudes from medical professionals, may have more pronounced negative effects on disabled people who already feel devalued and worthless because of other experiences of psycho-emotional disablism. This was exemplified in Laura's experience of the dismissive neurologist which was made worse by previous experiences of disablism in the workplace. It could be argued that disabled people like her are getting a double dose of disempowerment and disenfranchisement.

How might these effects be theorised?

Is this an example of secondary psycho-emotional disablism?

As they say, this will be the subject matter of another conference paper!

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