

Sometimes I wish it was just all over

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Abstract

In this article I reflect upon having recently been invited to join a new departmental group being set up to talk about Equality, Diversity and Inclusion; at the same time having been told to remember that my perspective is just one among equally valid others. I reflect upon what Drake (1999) has described as the ‘fundamentally opposed’ natures of the medical and social models, and upon the absurdity involved in a requirement to give assent to both. I consider the unfortunate dualism involved in claims that people ‘have disabilities’, and suggest that Sartre’s dictum ‘existence precedes essence’ offers a way of thinking about disability that the medical model can’t begin to make sense of. I draw upon statements by disabled people about how they feel about themselves to challenge conventional personal tragedy assumptions.

I was recently asked by a senior member of staff if I would be interested in joining a new departmental group being set up to talk about Equality, Diversity and Inclusion. I was asked because it was known that I have strong views about disability and that I hold with the social model. “You would have to remember, though, that in this group your perspective would just be one among others,” I was told.

The point being made, I suppose, was one involving inclusive principles, the recognition of people’s rights to hold different beliefs, and for these to be heard as valid. I was being told that even if others in the new group expressed views and assumptions about disability that were divergent from my own, I should not make a problem about this because they are as entitled to their views as I am to mine.

Fair enough, in a sense you wouldn’t want to argue with that. But for me there *is* a problem here. Having been a member of the department for 13 years, I can anticipate the talk within this new group. When it comes to disability, there will be much discussion of ‘people with disabilities’, and whatever emerges will follow from this. There will be assumptions made that when we talk about disability, we refer to something that is *wrong* with certain people: to physical, sensory, emotional or cognitive blemishes that spoil who they are or who they might otherwise have been. This is fairly conventional. It follows a line of thinking established, for example, in the Equality Act 2010: ‘You’re disabled under the Equality Act 2010 if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities’ (GOV.UK 2023). It involves individual or medical model thinking in that it sees disability as the outcome of impairment, something that can only be experienced negatively, and as a departure from normalcy.

My objection isn’t simply to do with terminology. It is, rather, to do with the meanings underlying words, and the way these meanings shape possibilities for experience. As Titchkosky and Michalko (2014:101) have pointed out, disability is lived in the midst of the meanings given to it. The meaning of disability, they say, is given ‘whenever we speak of it, act upon it, or even think of it’. When disability is understood as something people ‘have’; something separate from who they are as

people but that they have to live 'with'; something that can only be experienced negatively; this has consequences not just for the ways disabled people are seen and treated by non-disabled people, but for the ways they relate to their own experiences and identities.

I object to the view that disability is something certain people 'have' because I understand disability as a form of social oppression (UPIAS, 1976; Thomas, 2007; Oliver and Barnes, 2012; Clifford, 2020). Coming from a social model perspective established several decades ago by disabled people in the UK Disabled People's Movement, I regard disability as a form of social oppression 'involving the restrictions of activity of people with impairments and the socially engendered undermining of their psycho-emotional well-being' (Thomas, 2007:75). Disability is about what people with impairments are prevented from doing because of poor access to physical environments and about the loss of opportunities resulting from this lack of access. It is about the way impairment is talked about, represented and made meaning of within everyday discourse, resulting in invalidating judgements and encounters which impose roles and expectations based on negative assumptions. Disability isn't something people *have*. It is something that is *done* in the details of life – in the words, the acts, in the repeated, apparently inconsequential, behaviours that make up the unremarkable background to our lives (Martin, 2003).

I agree with Drake (1999:14) who described these views – individual and social model views - as 'fundamentally opposed' ways of understanding disability. Disability is something *wrong* with some people, or disability is a form of social oppression. It seems illogical or nonsensical to suggest it can be both.

What problematises grasping the idea of disability as oppression is the mundane level at which this takes place. As Young (2022:41) observes, oppression takes place in the details of everyday life. Injustice is experienced by disabled people as:

a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions, media stereotypes, and structural features of bureaucratic hierarchies and market mechanisms – in short, the normal processes of everyday life.

It is not that non-disabled people see themselves as oppressors. Far from it, they would take offence at this suggestion. Quite the reverse, they 'care' for 'people with disabilities'. Their intent is to provide a welcoming environment – conditionally upon an unspoken agreement that these people have something wrong with them and will work hard to overcome their 'adversity' in order to fit in (Clifford, 2020). It needs to be observed that many disabled people, too, talk about 'people with disabilities' and hold a medical model view, but this is unsurprising. Oppression always works by recruiting the oppressed among its strongest adherents (Memmi, 2021).

One problem with individual model thinking about disability is that it involves a Cartesian approach, regarding personhood and embodiment as distinct from each other. It suggests that each person has a self that exists within a body, but that these are separate essences. The idea that a person 'has' disabilities, which can only be experienced negatively, implies that trapped within the pitiable, flawed body of each disabled person there is a healthy, 'normal' person lamenting their fate and yearning to be free of their unfortunate limitations. This is at odds with an existentialist view, which holds that existence precedes essence (Sartre, 1993:35). From an existentialist perspective, it is through our experiences and the choices and decisions we make in life that we become the people we are. For disabled people, the experience of impairments and the situations we have had to deal with in relation to these are often important factors in shaping the choices we have made about who we become. Many disabled people have attested to this, and have spoken of the value added to their lives by their experiences and the sense they have made of their experiences *as* disabled people. This isn't to suggest that there are not plenty of times when living with impairment can be

messy, inconvenient and painful, but is to make the point that this is not all life with impairment is about. This is something a medical model outlook cannot begin to understand. Among notes from my PhD interviews (Cameron, 2010, starred names are agreed pseudonyms) is a statement made by Mary*, a visually impaired trades union activist from Edinburgh:

Do I fundamentally want to change myself... and wish my impairments away... no, I don't. To me, they're just part of me... they're an innate part of me.

Notes from an interview with Lola*, a wheelchair user from London who is a writer of erotic disabled fiction and a burlesque dancer, include this statement:

I'm absolutely proud to be who I am and... of course, that includes being a disabled person.

Lottie Jackson (2023:3) talks about the value added to her life through her experience of being a wheelchair user:

No matter how challenging it feels to be restricted, I now have something hard won and irreplaceable: the way I connect with the world... I (see) my ability to extract human compassion, truth and beauty, even from the most unexpected places. This hasn't come about through chance. It has come about through struggle, defiance and unfaltering love – the sum of my experiences.

Reflecting on life experience before and after her diagnosis of MS, Surinder, a Scottish Asian disabled woman, said (Cameron, 2010:111):

I think as me as a non-disabled person in the past, no I wasn't happy... but then, I didn't know myself then... and didn't have that awareness that I have now.

Surinder describes her preoccupation with mundane and superficial things before becoming disabled and compares her situation then with now as someone who, as a disabled person, has had to deal with difficulty and to think more deeply about life:

I can't say for sure cos I don't have the evidence, but I suspect that I wouldn't have gone through all these experiences which have made me the strong personality that I am today.

Ben*, an autistic man from Coventry, remarked during an interview (Cameron, 2010):

Had things been different... I might have been a different person... but I wouldn't have been a better one.

I shall not be joining the new departmental group being set up to talk about Equality, Diversity and Inclusion. It is important to make choices about where it is worthwhile spending time and expending energy. Meaningful inclusion involves the respectful welcome of difference, not regarding difference as deficit to be compensated for. Impairment needs to be affirmed as a characteristic of human difference to be expected and respected on its own terms, as something that adds perspective to life, not regarded as a negative mark of misfortune to be accommodated as a disruption to normalcy (Cameron, 2010). But while an individual, medical model understanding remains dominant, individualistic, piecemeal responses will continue to be made to what is a structural issue. A recent psychological fad, for example, that is currently part of mandatory training for every staff member, 'unconscious bias training', returns us to the awareness training days of the 1990s with the idea that addressing discrimination is primarily about recognising and addressing ideas in our heads. From a disability equality perspective, this sort of thinking was refuted decades ago by Swain and Lawrence

(1994), who observed that simply 'changing attitudes' and taking action to remove real barriers involve very different approaches. It seems strange that, in order not to cause offence, as a disabled person I should be asked to keep quiet about what I regard as oppression within a group specifically established to consider issues like this. It seems absurd, but then, not much more absurd than anything else in life. The social model seems a very simple thing for people to understand if they wanted to, but for some reason they don't. Disability is oppression. Along with many other disabled people, I have been saying this for a long time now, but as is usually the case non-disabled people just nod patronisingly and carry on doing what they were doing anyway. Sometimes I just wish it was all over. Sometimes I wish oppression would just cease. But it doesn't work like that. There will continue to be talk, and lots of it, but little change. And I would be surprised if it wasn't more or less exactly the same in any other new departmental group being established to talk about equality, diversity and inclusion in any other university in the UK.

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