**The Affirmation Model: A New Tool for Making Sense of Everyday Life**

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My wife Maggie was away last week, delivering Disability Equality Training to a small group of disabled people who are going to become trainers for a Disabled People’s Organisation. Reflecting on this when she got home she said that, while all the group members had been able to get their heads round most of the concepts involved, there was one idea, disability pride, which some had found incomprehensible. She said that, while they agreed there is little good in spending our lives bemoaning our ‘misfortune’, the leap was just too great in moving from that thought to one which involves being pleased and proud to be who we are as people with impairments – which involves affirming our impairments as being an important and valuable part of making us who we are.

Why is it so difficult for disabled people to relate to impairment otherwise than negatively? In this paper I am going to address this question and to propose the affirmation model as a tool with which to make sense of this dilemma. I need to make it clear from the outset, though, that in proposing an affirmation model I am not suggesting a replacement or substitute for the social model. The social model is the keystone on which everything else is built. This having been said, it does what it was designed to do and should not be expected to do more. As Colin Barnes has noted ‘the social model is nothing more or less than a tool with which to focus on those forces, structural and social... that shape our understanding and responses to people with designated impairments’ (Barnes, 2007). The social model is an invaluable tool, but any handyperson will tell you that in order to do a range of jobs you need more than just the one. The affirmation model is proposed as a new tool.

As John Swain and Sally French have noted, ‘even in a social world where disabling physical barriers had been removed, it would still be possible that impairment could be regarded as tragic’ (Swain and French, 2000). There is nothing in the social model, in which impairment is identified by UPIAS as ‘lacking part or all of a limb, or having a defective, limb, organ or mechanism of the body’ (UPIAS, 1976) or by DPI as ‘the loss or limitation of physical, mental or sensory function on a long-term or permanent basis’ (DPI, 1981) to suggest that impairment might be regarded as anything other than deficit. While the social model establishes the need for access and inclusion this is a long way from recognising impairment as something to be valued on its own terms.

Building on an idea originally suggested by Swain and French in 2000, the affirmation model definitions I present here were the outcome of my PhD research, completed a couple of years ago now. In this I carried out a series of interviews and observations with sixteen disabled people from across Scotland and England – young and middle-aged, gay and straight, black and white, with and without religious faith, in cities and isolated rural environments, with a variety of impairments, and who either strongly embraced or rejected an identity as disabled or who regarded disability as something just to get on with. The observations involved situations in which people got on with the business of their ordinary lives. The definitions I emerged with were as follow:

Impairment:

physical, sensory, emotional and cognitive difference to be expected and respected on its own terms in a diverse society

 Disability:

a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those identified as normal

(Cameron, 2011)

In coming to these definitions, and drawing on the work of Judith Butler (1990), I identified disability as performatively produced and compelled by regulatory practices. Disability involves experiencing and acting out impairment as if this is inevitably an undesirable personal characteristic, and requires people with impairments to relate to their bodies in one of two ways. Both of these involve acceptance of the ‘common sense’ assumption that to be impaired is to be a victim of misfortune and acquiescence with devaluing expectations of what it must be like to be disabled.

The first involves passive acceptance of the discreditable status associated with disability (Goffman, 1968). The second involves distancing the self from impairment, attempting to minimise the significance of impairment, both in terms of one’s own self-concept and insofar as one can shape the gaze of others. We consider the words of Glenda Hyatt:

People have expected me to take the nicely paved path laid out for the disabled. They expected me not to try, not to accomplish, and not to succeed. That map was tossed out long ago. I have followed my own path as a person, a woman, who happens to have a physical disability (Hyatt, 2008:unpaged).

It is this ‘who happens to have a physical disability’ which is revealing. In relation to what Sheldon Stryker (2002) names identity salience, Hyatt gives impairment a low priority in terms of how she wishes to think of herself and how she wishes to be regarded by others. She perceives the disabled role as involving ‘giving up’, and as something to be avoided. Something similar is expressed by Sarah, a young wheelchair user I talked with during my research:

I don’t think I have accepted that I am a disabled person to be honest… saying that’s a bit weird, but to be honest, I don’t think I have… because I still get pissed off… and it’s not like I don’t accept it like I hate it, it’s just that I’m never going to be comfortable with it, I’m never going to be what people expect…I suppose that’s why I’ve done so many things like… that people go ‘wow!’ …cos people just don’t assume… that’s the reason I did the sky-dive, it was just cos, like, I wanted to do something totally random and, like, just… something completely… I’d always wanted to do it, but it was, like, people said “Oh, I don’t know if she should do it” …so I thought fuck it, I’m going to do it...

Sarah makes it clear that she wants to be recognised for something other than being disabled, as she finds other people’s expectations of her limiting and humiliating. Her way of letting those around her know that she is more than just her impairment has involved her in what might be regarded as ridiculous, over-the-top stunts such as sky-diving. Her actions speak off her determination to ‘overcome’, her refusal to be ‘limited by her affictions’. The same point might be made about those involved in the forthcoming Paralympics.

Yet it is precisely in this attempt to distance the self from impairment that conformity with disabling expectations is given expression. Attempting to minimise the significance of impairment in our own lives, to cover up or to pass as non-disabled involves us in a rejection of those parts of the self experienced as marks of abnormality and simultaneously within a narrative which prizes normality.

The purpose of the disabled role takes on meaning in the context of what Richard Schmitt (2004) has called the ‘economics of conformity’. Conrad Lodziak (2002) has observed that capitalism requires citizen consumers who prize their individuality but really don’t differ from each other very much – whose hunger for distinction is satisfied by what is offered for sale on the high street. Henri Lefebvre (2008:152) notes that bourgeois individualism

implies the dreary, ludicrous repetition of individuals who are curiously similar in their way of being themselves and of keeping themselves to themselves, in their speech, their gestures, their everyday habits (Lefebvre, 2008:152).

The link between conformity and normality is easy to make. Erich Fromm suggests that the normal person is ‘the person who is able to fulfil the social role he has been given and to work in the fashion that contemporary society requires of him’ (Fromm, 2001:119). Normality, like disability, is an oppressive role. The difference between the two is that normality is made to appear attractive, in Fromm’s terms, by ‘anonymous authorities like public opinion and common sense’ which have a profound influence ‘because of our readiness to conform to the expectations that everyone has about ourselves and our equally profound fear of being different’ (Fromm, 2001:91). Being normal is a process which requires people to engage in more or less constant self-evaluation and meaning making by comparing themselves with those around them. Norbert Elias remarks that

the individual can only be understood in terms of his communal life with others. The structure and configuration of an individual’s behaviour control depend on the structure of the relations between individuals... The individual is only able to say I if and because he is at the same time able to say we (Elias, 2001:61).

Being normal, therefore, involves a process of learning to want to act in the ways that society requires one to act and to be the kind of person society requires one to be. Describing normality as an oppressive relationship, however, does not necessarily mean that it is recognised or felt as oppression. There are many pay-offs for being normal and, depending on where one is situated within the intersection of roles and identities, most people seem to do well enough out of it. This is not to say that normality is experienced as being totally pleasurable, for as well as a sense of well-being it involves an awareness of mundanity, restriction and limitation of possibilities. While there may exist a sense that things are not all they should or could be, however, there is at the same time a reluctance to give up the security that normality offers. The shame, disapproval and condescension heaped on those culturally marked as abnormal makes normality seem a decent enough deal.

It is in the details of everyday life that disability is encountered: in the myriad of behaviours, decisions, and interactions taking place in the contexts in which disabled people make their lives. Disability is materialised in gestures and assumptions, thoughts spoken and unspoken. It is experienced in the discomfort aroused by being pitied, spoken down to, or not taken seriously, a sensation that can be experienced anytime any place, in the company of family members or others barely known; in the awareness of being watched and found wanting, regarded as deficient, incompetent and unfortunate. Disability is not just about what we are prevented from doing and being, as the social model explains, it is about what we are required to do and be instead. It is not just a restrictive relationship, but a productive relationship too.

Disability is an oppressive relationship because, at a cost to people with impairments, it involves payback in terms of validating the subject position of those identified and identifying as normal. This is the sort of thing that Iris Young talks about when she describes structural oppression in terms of ‘the vast and deep injustices that some groups suffer as a consequence of often unconscious assumptions and reactions of well-meaning people in ordinary interactions’ (Young, 1990:41). It is not necessarily the case that the normal actively intend to oppress; in fact, their intent might often be the opposite. Rather it is that their own sense of self is so thoroughly enmeshed with favourable self-measurement against disabled people that what are identified from an affirmation model perspective as oppressive behaviours are perceived instead as common sense and uncontroversial. As Young comments,

the conscious actions of many individuals daily contribute to maintaining and reproducing oppression, but these people are usually simply doing their jobs or living their lives and do not understand themselves as agents of oppression (Young, 1990:42).

Charles, another participant in my PhD research, commented after we returned from a meal out with a friend at a local restaurant:

...when I was talking in the pub with Erin and yourself tonight, with every sentence I wasn’t thinking oh, I’m going to say this sentence with a speech impairment… blah blah blah… now I’m going to say this with a speech impairment… blah blah blah… I’m going to move back, but I’m moving back in my wheelchair… you know… you don’t think… but when you catch somebody looking at you, and looking at the effects of your impairment, concentrating on your impairment… then you’re suddenly aware that you’re speaking differently…

Living with impairment isn’t necessarily a problem so much as it is made a problem. People with impairments are turned into disabled people in transactions for which they expected to pay the ontological cost. In identifying impairment as difference to be expected and respected, and disability as role, the affirmation model offers a new tool for making sense of disabling encounters and of resisting the meanings inherent in these encounters.

Normality needs to be recognised as an oppressive construct involving disciplinary restraint in order that we take care not to overstep the boundaries of what is required of us. The rejection of disability identity – expressed in bewilderment that impairment can be regarded as anything other than misfortune, certainly not a basis for an affirmative sense of self, and in the hope that if we try hard enough other people might be kind enough to overlook our impairments – involves disabled people in acquiescence with the idea that oppresses us. The affirmation model provides a framework which allows us to reject the meaning involved in disabling encounters and to say “We feel no need to apologise, to prove ourselves, or to play your absurd games.” As Paula Greenwell, a disabled woman from Newcastle, replies when asked whether she wouldn’t rather be normal, “Why would I want to lower my standards?” (Swain, French and Cameron, 2003:106).

Normality is a tangled web which imprisons the lot of us. Whereas for some it’s a bit like an open prison, others of us are more deeply incarcerated – and that’s why it’s important to keep fashioning and using the right tools with which to break out.

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