Social models of disability and other life strategies

By Tom Shakespeare

Abstract: The UK social model of disability (SSM) originated within a political context, which is both a strength and a weakness. Good social research has been conducted prior to, and outside, the confines of the SSM. The SSM is above all a brilliant tool for mobilising change. But it can be applied over-zealously. Since the 1990s, various critiques of the SSM have been developed, exposing contradictions and inadequacies. Equally, some of the parallels between disability and other social movements may need to be tested. Identity politics and psychology explain some of the fervour of SSM debates. To move forward, a social theory of embodiment is required.

Introduction

Having spent nearly fifteen years arguing about the British social model, it was a curious pleasure to arrive at the 2002 NNDR conference in Reykjavík to continue the conversation with a new group of colleagues. It was chastening to realise that there had been a parallel debate in the Nordic countries dating back to the 1970s, and interesting to hear similar criticisms and new insights from across the North Sea. It is arguable that the differences between different British theorists are larger than the difference between British disability theory, on the one foot, and Nordic disability theory, on the other. While this paper follows the same broad structure as my remarks at the roundtable, it has benefited from the discussions from the Iceland conference, and I am grateful for both the insights and the welcome which were offered by our Nordic colleagues.

Part of the problem for scholars trying to understand and develop the theorisation of disability in any country is the entangling of the academic and the political. It could be suggested that close connections between policy, practice and activism are both the strength and the weakness of the British model of disability, perhaps also the Nordic: much of what follows is aimed at substantiating this claim. Much of the analysis here is necessarily tentative and hypothetical: a contribution to a debate, rather than a final word.

The British social model, henceforth called the strong social model (SSM), originated within a particular stratum of the UK disability movement in the 1970s. In the document *Fundamental Principles of Disability* (1976), UPIAS (Union of Physically Impaired Against Segregation) defined disability not as an impairment or deficit of body or brain, but as a relationship between people with impairment and a discriminatory society. The influence of Marxist thought and labour movement traditions is clear in the work of UPIAS and the theorists who grew from its ranks (Finkelstein, 1980; Oliver, 1990). In *Capital*, Karl Marx defined capital and labour not as things but as relationships. Similarly, the key publications which developed the SSM - *Attitudes and Disabled People* (1980) by Vic Finkelstein and *The Politics of Disablement* (1990) by Mike Oliver – both developed the definition of disability as a relationship between people with impairment and a disabling society. The SSM provided the ideological foundation for the British disability movement which burgeoned through direct action and local community development throughout the 1980s and 1990s (Campbell and Oliver, 1996). After the formation of Disabled People's International in 1981, Finkelstein argued for the SSM on the global stage. From the start, the SSM was both a political and a theoretical tool. The tensions between the needs of a political movement and the requirements of an academic theory became clear in the mid-1990s, and continue to drive the disability debate today.

Being only ten years old at the time of the UPIAS formulation, I came late to these debates. Similar to many disabled activists and academics, I started trying to apply social theory to my own personal and political experiences before discovering the existence of the social model. In 1989, I wrote a Masters in Philosophy dissertation about disability without any awareness of the SSM. I had already embarked on a PhD thesis exploring concepts of disability when Mike Oliver's seminal account of disability was published in 1990. The experience of exploring the social scientific literature on disability and the various definitions used in research led me to three conclusions.

First, the invention of the SSM was not quite the watershed in disability research that many accounts suggest. Looking at the work of non-disabled researchers prior to Oliver and Finkelstein shows that many were coming to similar conclusions during the 1980s and 1990s. For example, David Locker (1983), Mildred Blaxter (1976) and others were beginning to argue that the social consequences and social context of impairment were as much or more of a problem than the impairment itself:

"The immediate context is handicapping where it presents barriers which must be negotiated, consuming reserves of time, money and energy in the process, or where the effort is such that the person decides not to bother and retreats into an enforced passivity. It is also

handicapping to the extent that it leaves the individual with no option but to rely on the help of others." (Locker, 1983: 90)

Substituting 'disabling' for 'handicapping' in this quotation produces a fairly good fit with social model perspectives. This literature cannot be said to be based on the SSM, but accounts often come pretty close to it. It could be argued that the major distinction is not adherence to the SSM, but the fact that these authors were non-disabled social scientists, rather than socially engaged disabled activists.

Second, it is quite possible to have a disability rights perspective without a strong social model approach. My own early work on disability in 1989 and 1990 used the term 'people with disabilities' and referred to the social and cultural dimensions of disablement, without redefining disability as the social and cultural dimensions of disablement. Other UK groups contemporary with UPIAS, such as the Liberation Network of People with Disabilities, developed understandings of disability oppression which did not depend on the SSM formulation. North American minority group approaches, the Nordic relational approach, and other international perspectives have produced important analysis and research without the strong social model.

Third, the strong social model is not the only social model in town. In fact, there are all sorts of 'social models', as David

Pfeiffer (2001) has suggested. As other contributors to this journal argue, the Nordic relational model is not an alternative to the social model, but another type of social model. By analogy, America was discovered over and over again: by Asiatic nomads, by Irish monks, by Leif Eriksen, by Christopher Columbus and by Amerigo Vespucci. Each had a valid claim to be the first and each took a different route to the prize. If a concept (or continent) is important enough, then many people are bound to reach it, eventually.

Ideologies are useful because they bolster movements and inspire change agents. For example, normalisation/SRV provided the ideological backbone for anti-institutionalisation, and for the campaigning mission of families and professionals working for the inclusion of people with intellectual difficulties in the mainstream. In a similar way, the SSM provided the ideological backbone for UK disability movement (Hasler, 1993). In comparing the Nordic relational model to these other approaches, perhaps the Nordic perspective suffers in comparison. When it came to policy, or to research, the relational approach was not operationalised: it is claimed that in practice there was a 'decoupling' from the relational understanding.

This perhaps provides a clue to some of the international perceptions and tensions in the disability debate. First, theories need to be robust enough to make a difference. Certainly, both the SSM and

Social Role Valorisation (SRV) are robust. Critics have claimed that SRV and its practitioners can come across like an evangelical cult. In the UK, some have experienced the SSM operating like an ultra-left ideology. Perhaps the Nordic model never had this dubious quality of inspiring fervour. For example, Oliver has dismissed competing approaches as "intellectual masturbation" (Oliver, 1992), and others from the materialist wing of the disability studies community have frequently been just as robust in their defence of SSM orthodoxy. Second, a vital issue of disability politics is whether the leadership of the movement, and of research, is in the hands of disabled people themselves, or of non-disabled allies and professionals. The importance of the SSM was that it was a disabled-led initiative, in contrast to the largely non-disabled professionals, academics and charities who had hitherto dominated the disability field. The UK disability movement has been characterised by an intense suspicion of the motives of non-disabled people who want to work in the field of disability. This derives from past experiences of being patronised, spoken for, and taken over.

Uses of the Social Model

It is not controversial to note the robustness of the strong social model. Frances Hasler (1993) talks about it as the 'big idea' of the disability movement, and it had an extraordinary political impact. This is partly because it was simple and direct and effective. Political tools have to be understandable, memorable and relevant. But the SSM was also very good for consciousness-raising. By redefining the disability problem, it enabled people who had felt in-valid, incompetent and dependent to relocate the problem of disability from themselves to the discriminatory society in which they lived. Rather than feeling shame, self-pity and frustration, people with impairments could legitimately feel anger, resentment and solidarity with others. As a result, it was adopted fervently by self-organised groups of disabled people across the UK.

But the most important reason for the impact of the SSM was the instrumental value of a barriers analysis. Mike Oliver presented a paper at a University of Leeds ESRC disability seminar entitled 'If I had a hammer' (Oliver, 2003), in which he argued that the social model should be regarded as a tool, an effective tool for remedying the injustices faced by disabled people, and relocating the efforts of service providers from individual solutions to the removal of barriers to participation in the mainstream.

A social model analysis shows the key priorities for action: barrier removal; citizenship rights; anti-discrimination legislation. The SSM mandates structural change in society, rather than medical or psychological correction of individuals.

As well as being robust, the SSM was a tool wielded by a self-organised movement of disabled people, who were fed up of being ground down, and who had begun to celebrate resistance and talk of disability pride. This suggests an implicit tension within the UK disability movement. On the one foot, a commitment to barrier removal and social model analysis, and on the other foot, a more conventional minority group politics, based on a strong disability identity, and arguing for a better deal for the disabled constituency: higher benefits, more provision, a louder voice. These two strands have always co-existed, and may often blur into one, but are subtly different in their emphasis and implications. A similar tension can occur in disability studies: is it about studying disabling barriers, or studying the experiences of disabled people? Some argue that the latter takes research back to the bad old days of top-down and unaccountable social science. But of course, the effect of disabling barriers is the restricted life chances of disabled people. In order to document exclusion, hearing the voices and demonstrating the impoverishment of people with impairment is vital. Structures impact on the lives of agents, as both Karl Marx and Anthony Giddens would remind us.

Despite clear limitations, some of which are outlined below, the SSM rapidly became disability orthodoxy in the UK. It has been the litmus test of disability correctness. Organisations and individuals are judged on whether they use the correct social model term 'disabled people' or the outdated medical model term 'people with disabilities'. An entire government public information campaign ('See the Person, Not the Disability') was boycotted by the disabled people's movement because it implicitly defined disability as impairment, not as the barriers placed on people with impairment. Even a vigorous defender of the SSM such as Mike Oliver has conceded that over-zealous disability equality trainers may have gone too far in applying a crude and deterministic version of the social model. The SSM has ostensibly supplanted the traditional models of disability within many areas of health, social care and research. But many professionals and agencies profess allegiance to the SSM while continuing with business as usual, while others have been frustrated and confused by the implications of such a starkly environmental rendering of the disability problem: captured in Mårten Söder's memorable phrase "contextual essentialism" from the 2002 NNDR conference.

Critiques of the Social Model

Proponents of the social model have always accepted that it is not a social theory of disability. But even as a basic definition, it began to be criticised during the early 1990s. Simple and direct also meant simplistic and possibly misleading.

Feminist disability scholars such as Jenny Morris (1991), Liz Crow (1996) and Sally French (1993) argued that the SSM excluded many dimensions of personal experience, particularly issues relating to impairment and identity. I have argued that the strong social model fails to correspond to the everyday experience of disabled people, many of whom experience physical and mental difficulties, as well as social barriers and exclusion. It would be wrong to claim that the SSM is sexist or gender blind: however, it undoubtedly recapitulates the public/private split which feminists have criticised. The application of the SSM has often failed to deal with the ways in which the 'personal is political'.

SSM proponents rejoinder that there is nothing to stop anyone developing a social theory of impairment, that the SSM was never intended to explain everything about disability, that it is a heuristic not a formal definition, and so forth. While this may be true, it could be suggested that the SSM is a victim of its own robust coherence, and that it does not leave much space for a consideration of personal issues.

In a political/psychological sense, the SSM became ideologically dominant precisely because it moved away from the individual and the personal and the psychological and the bodily: activists wanted to disown the tragedy theory and the victim-blaming explanations, and any feeling that they were flawed

or frail. How could the SSM then expand to include what had been disavowed?

As the movement matured and wider issues were added to the agenda, such as impairment, sexuality, and genetics, the social model has not proved adequate to analysis in these areas. Back to Mike Oliver's talk (2003), we can think of the old saying: 'if you give someone a hammer, all they see is nails'. The social model is a wonderful tool for identifying social barriers and mobilising many downtrodden people, but perhaps the wrong tool for the other tasks which a progressive disability politics requires.

Nor is the SSM able to motivate or mobilise all disabled people (Shakespeare & Watson, 2002). The disability movement has been dominated by people with physical and sensory impairments. There have been difficulties in including other groups in the disability community, for example people with mental health issues, people with intellectual difficulties, Deaf people, and people with AIDS/HIV. While important social model analyses have been developed in these areas, it could be suggested that sometimes the social constructionist/ relativist approach has gone too far. For example, in contradistinction to Szasz, Laing, Cooper, Goodley and others, the bulk of medical evidence suggests that many people labelled with mental illness, or learning difficulties, or dementia, have an underlying cognitive or psychological dysfunction. They are undoubtedly

further disabled by society, but there are also organic pathologies in brain anatomy or physiology which cannot be wished away by a social modellist redefinition. Equally, many people with HIV/AIDS have become treatment activists, lobbying for more and better medical research and development, and other disabled people have major personal investments in medical research. None of this is to say that a disability coalition cannot and should not be built including all these diverse experiences, only that the 1976 version of the social model is not adequate to capture the complexities of every impairment and the social relationships and identities which arise from it.

As well as differences between impairment groups, the relationship between impairment and disability is also very complex. Marx predicted that the proletariat would inevitably become radicalised, as capitalism developed and society became polarised into two classes, and it was the (Hegelian) destiny of the working class to overthrow the bourgeoisie. History shows the errors and omissions in this analysis, as social democracy and right-voting workers and the rise of the middle class complicated the original model of identity formation. The implication of early disability activism, that people with impairments were oppressed and their salvation came with collective identification and mobilisation, has also proved over-optimistic. Only a tiny proportion of

people with impairments have ever signed up to the radical campaign, and many have actively disowned it.

Aside from this problem of politics, there are theoretical difficulties with the model. For example, are all people with impairment disabled? What if an individual does not experience disablement, because their impairment is hidden, or they experience no barriers? What if, because of other dimensions of their experience, for example their wealth, they do not need to rely on public transport, public housing or welfare benefits? If they are not oppressed, are they then still disabled? Disability does not have the same salience for everyone with impairment. If used too crudely, the SSM risks ignoring other dimensions of people's experience, such as class, race, gender and sexuality.

The implication of the strong social model is that there is the possibility of a world without disablement. Society could be constructed without barriers, and people could be equal, despite their impairments (cf. Finkelstein, 1981). Disregarding the difficulties of reaching utopia, could such a situation actually exist? Could people ever not be disabled by society? One important response to this question has been formulated by Paul Abberley (1998). He points out that several dominant versions of the progressive project rely on removing barriers to disabled people's workforce participation. While many people with impairments who do not currently work

may, in a better world, be able to be productive, this cannot be a possibility for everyone. Therefore, Abberley argues that achieving utopia also means challenging the role of paid work in our society, and creating alternative ways of valuing and rewarding people. A sceptic might say that this sounds even more difficult than the construction of a barrier-free society.

Turning to the environmental question, operationalising the SSM approach raises difficulties. It is undeniable that an environment or communication method can enable or disable an individual. The problem is that environments are built for entire societies, and often it is the case that removing barriers for some means imposing them for others. Steps may be better than ramps for some people. Pavement kerb cuts for wheelchair users may be dangerous for blind people. Typefaces which work for partially sighted may not work for people with dyslexia. Is the concept of barrier removal always better than the concept of special provision? Context is important. But different people have different requirements, bringing us back to the individual's impairments, and their own way of dealing with these, and their individual interaction with the landscape. These are the simple cases. What would barrier removal mean for people with intellectual difficulties, particularly social impairments such as autism (Singer, 1999), and to what extent is such a utopia possible?

Elsewhere, Carol Thomas seeks to go beyond the social impasse, by replacing the 'barriers' version of the social model with a 'relational' interpretation which distinguishes between impairment and disability, the latter of which she argues should be defined as social oppression. This ingenious way of resolving the problem is not however an effective solution, in my view. It ignores the dominance of the barriers interpretation of the social model, both to the original framers and most subsequent applications of the strong social model. And by linking disability definitionally with social oppression, it begs the question which research is designed to test, as well as implicitly ignoring the fact that disabled people are oppressed to different extents and in different ways.

This is a brief summary of some of the more obvious critiques of the strong social model: each has been debated at length, and there may be ways of resolving some of these problems. But the conclusion which I reach is that the SSM is too universalising and too simplistic to serve as a model for the way in which disability works. The strong social model may well be practically and politically effective, but social theories of disability need a toolbox, not a single tool. As argued elsewhere (Shakespeare & Watson, 2001), the problems of the social model paradigm have accumulated to the extent that it is unworkable. We need a new paradigm.

The social model and its parallels

Implicit in this paper is the validity and value of certain parallels between social phenomena and social movements. Perhaps the time has come to question some of these assumptions.

A parallel has already been drawn between Marx's formulations of capital and class and the social model. Early theorists of disability drew, implicitly or explicitly, on the Marxist tradition. It might be noted that after Marx came a century of refinement, elaboration and development of Marxism, which was partly a reaction to the failures, inadequacies and lacunae of the original conception.

Another parallel which has important to my own work and that of others in disability studies has been with feminist theory. In thinking and talking about the social model of disability, I have often suggested that the impairment/disability relationship is analogous to the sex/gender relationship as conceived in the early 1970s (Oakley, 1972). Sex (male/female distinction) is biological and bodily and fixed, while gender (men/women, masculine/feminine) is a social relationship, which is historical and dynamic.

If this is a valid parallel, it points up a problem with the social model. Gender was defined in early feminist theory as the socio-cultural dimension, which in practical terms has often meant women's experience of the oppression. But oppression is not implied by the sex/gender distinction, which is neutral as to the socio-cultural experience of being masculine/feminine. But disability, in the social model, is defined as the experience of *oppression*, not just the socio-cultural *implications* of impairment. People are disabled by society, which is always implicitly negative. In other words, what will disability mean in a barrier-free society? Will there only be people with impairment, not disabled people?

This gives a clue as to the second problem when thinking about this parallel. The simple sex/gender distinction of early second wave feminism has been largely demolished during the 1980s and 1990s, because of the reliance on a dualistic separation of the biological and the social. That is, many theorists pointed out that sex is always already social. Judith Butler, for example, claims that sex is always perceived through the lens of gender (1990). What we take to be simple sexual difference – male or female – is always a product of our ways of thinking about gender.

Without generating unnecessary levels of complication, the simple point is that impairment is never just biological, but that impairment is created, defined and understood in social contexts. The danger of a strong social model formulation is that it accepts the

medical model of impairment, and fails to include the social and cultural dimensions of embodiment.

Impairment and disability are on a continuum, as are sex and gender. We cannot think in terms of dichotomies. Impairment and disability are not distinct social phenomena. In practice, it is difficult to know where impairment stops and disability starts, as anybody who has done qualitative research with disabled people rapidly realises: it is not a case of either/or but of both/and. Perhaps at this point, we might be reaching for the old concept of the dialectic.

A final point about parallels: the critic and lens-artist David Hevey once asked me: are we making a big mistake to see disability as parallel to gender, sexuality and 'race'? In each of the other cases, people can celebrate their difference. Sisterhood, Gay Pride, Black is Beautiful have all been slogans of other social movements. While it is possible to celebrate the solidarity, the resistance and the strength and creativity of disabled communities and individuals, this is not usually about a celebration of impairment itself. Hevey suggested that perhaps impairment/ disability is a phenomenon which is more like poverty. Outside religious asceticism, people do not celebrate poverty as a state or status. Few would voluntarily choose to be poor. Most people who are poor want to stop being poor.

Who wants to be disabled?

Implicit in this paper is my belief that the strong social model of disability has to be approached and understood not just as a matter of theory, logic or rationality, but as a psychological/political moment in the lives of people with impairments or people who identify themselves as disabled. Achieving self-respect, self-esteem and self-confidence is central to any individual's life project. Axel Honneth has demonstrated how the denial of these feelings through social exclusion and devaluing lies at the heart of many social conflicts (1996).

In the case of impairment/disability, the possibility for achieving positive personal identity is undermined, both by the social exclusion and devaluing in disabling societies, but also through the intrinsic experience of incapacity, vulnerability and dependency.

Researchers have begun to explore the psycho-emotional aspects of disablement: the ways in which the disabling society takes its toll on the individual psyche (cf. Reeve, 2003). But simply having an impairment, regardless of the social reaction or social context, can be psychologically damaging for many people. Creating and sustaining a strong sense of self is difficult for anyone, but particularly for one who has been born, or who becomes, impaired.

In this context, the strong social model plays an important psychological role for

many disabled people. It is a powerful way of denying both the relevance and the negativity of impairment. Individuals can say that their problem is not their deficit of body or mind, but the society in which they live. By combining with others who share this belief, their own self-image is reinforced, and they can achieve solidarity and self-respect. Within the movement, some go further than the social model, and make the relativist claim that there is no intrinsic problem with impairment: that it is just a different way of being, if only society would accept it and remove the barriers.

When it comes to impairment, I am not a relativist. I believe that most impairments of body or brain are real, and that many of them are pathological. I do not accept the negative valuation of impairment and illness in much of the medical literature, the so-called 'medical tragedy' model. I do not think that impairment makes a life not worth living. I do not believe impairment is necessarily a worse problem than other social obstacles. I do not even believe that impairment is more of a problem for people than the disabling society in which they live. But I do believe impairment prevention is desirable, and I can quite understand why people would rather not become impaired, and why many will actively seek a cure.

The psychological/political value of the strong social model to individuals and to groups seems clear. It has led to the formation of a powerful disabled political

identity. Strong social identities are attractive to many people. It is part of the human condition sometimes to feel lost or groundless or lonely. If people have oppression to fight against, they can feel strong, self-righteous, and significant. If people can fight oppression in a group, then they no longer feel alone or powerless or irrelevant. The disability movement therefore attracts many individuals, with or without impairments, who are looking for a cause to identify with and who need to bolster their sense of self. All social movements are the same, and many religions operate in similar ways.

If this claim about the psychology of politics is correct, it perhaps explains the vigour, verging sometimes on brutality, of political debates around the SSM. The British disability movement has found it very difficult to respond to criticisms or developments of the social model. Many activists have refused to countenance moving beyond the formulation of 1976, or doing different sorts of research, or asking different questions.

Identity politics, as Foucault has argued, can become a kind of prison.

Conclusion

This paper has no firm conclusions. The debate about models of disability will run on and on. It is a debate which raises two of the biggest questions for social science as a whole: the relation

of the individual to the structural, and of the biological to the social. Despite the claims of theorists such as Anthony Giddens, it does not seem that the circle has yet been squared. Perhaps we shouldn't feel too badly that we haven't managed it either.

But I can make some tentative suggestions for ways forward. The disability community needs to make safe spaces to explore the psycho-emotional dimensions of both impairment and disability. Recognising the experience of hurt and of oppression is important for people to be able to operate effectively, and to enable disability politics to become less acrimonious and divisive. Understanding the investment individuals make in social model theory and the need to offer alternative ways of identifying and healing is part of the way forward for academic analysis.

Carol Thomas asks whether the relational can be rescued in the social model? I am not so sure. Clearly the work that Carol and Donna Reeve have done on the inclusion of psycho-emotional dimensions of disablement is vital. But including psycho-emotional issues shows the fundamental problems of the unsustainable dichotomy at the heart of the strong social model. If individuals are experiencing distress, can this be put down to the effects of impairment, the effects of disablement (whether defined as barriers or oppression) or both? What sense would

it make to distinguish these different factors in the complexity of an individual psyche?

We need to move beyond the polarity of medical and social models. Disabled people do need medical interventions, and do often suffer bodily deficits. But none of us want to be defined by our medical conditions, and the disability movement wants to prioritise environmental and social change, not individual correction. There is a need for appropriate interventions at the different levels at which people experience the complex phenomenon of disablement.

Different problems need different approaches. This applies to research as well as to service provision. To understand my genetic mutation, molecular biology is needed. To solve my spinal problems, I resort to orthopædics, physiotherapy or Pilates. When I experience an environmental problem, I need to negotiate an accessible workspace and campaign for good transport provision. Theorists might call this 'Ontological holism but methodological pluralism': it's the same person we're talking about, but each question needs a specific answer. Perhaps there is a need for the sort of 'bio-psycho-social' model for which proponents of the new ICF have argued.

In my recent work with Nick Watson, we have built on Irving Zola's arguments about the need to universalise disability policy (Zola, 1989). The imperative is to

break the social separation between disabled people, defined by their flawed bodies, and non-disabled people, defined by their perfect bodies. The strong social model does this by denying the flawed body and claiming that what defines disabled people is oppression and exclusion. Perhaps an alternative is stop denying the flawed body. All human beings have flawed bodies. Embodiment is not some Platonic ideal, but a constantly shifting experience of physicality with an inextricable element of lack, disease, degeneration and suffering. That is to say, everyone is impaired, to varying extents, and at different times.

However, not everyone experiences disabling barriers or oppression, because many impairments are not subject to social stigma, and many people, despite their impairments, are not socially excluded or discriminated against. Impairment/disability is always already social, and the major problems for disabled people are social arrangements. But, like all humans, we are limited by our bodies and brains. Rather than a social theory of disability, we need a social theory of embodiment.

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