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A Reply to Tom Shakespeare and Nicholas Watson

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Shakespeare and Watson's paper is well conceived and argued. I particularly enjoyed the way that the debate about the social model was set in a wider context, as this contained some features that I had not previously fully appreciated. In many respects there is more to agree than to disagree with in this critique.

SETTING THE SCENE

Firstly, for the sake of brevity I will refer to the two papers upon which Shakespeare and Watson's critique concentrates as the SHI paper, (Pinder, 1995, 'Bringing back the body without the blame...'), and the B. and M. Collection Winder, 1996, 'Sick-but-fit or fit-but-sick? Ambiguity and Identity in the Workplace'). Secondly, as readers may have less easy access to the more arcane academic journals, let me retrace my steps in more detail.

In SHI, I explored the employment stories of two informants disabled with rheumatoid arthritis as they attempted to 'make it'-or not-in the workplace. One, whom I called 'Elaine', was forced out of her much loved secretarial job after the onset of arthritis; the other, 'Sally', despite substantial difficulties, was still managing to hold down her post as a systems analyst at the BBC. In the B. and M. collection, a similar technique was adopted (I, too, enjoy arguing from oppositions), which illustrated the work narratives of two more informants disabled respectively with rheumatoid and psoriatic arthritis. 'Philip' had been abruptly dismissed from a career in the police force he had set his heart upon since early childhood; whilst 'Lucy' was 'a disability consultant in a local disability organisation, a job which she had found after many difficulties with previous employers over the thorny question of sick leave. Although the social model of disability explained some aspects of their experiences, it left others unaccounted for.

Disability study critiques have emphasised the way in which medical sociologists' work on the experience of illness have often underplayed the influence of structures; and simultaneously how, in their desire to move away

from the individualised 'tragedy' model of disability, much of their own work has concentrated on structures, and rather less on the subtleties and complexities of lived experience. The Leeds Conference 'Exploring the Divide' in March 1996 was organised precisely to address these issues and to see if a more sensitive rapprochement might be found between the two. Both my papers were conceived in the light of these two polarities and have attempted, albeit modestly, to explore the agency-structure dialectic through the use of two detailed case histories apiece in a way which, to the best of my knowledge, had not previously been attempted. In my view, their strength lies less in any great claims to originality than in their usefulness in illustrating this dialogue, I'm glad that, despite criticisms, Shakespeare and Watson can see some merit in my efforts.

Shakespeare has argued elsewhere (1992) that one of the achievements of the Disability Movement has been to separate impairment from disability. Whilst I appreciate the force of these arguments, and their grounding in disabled people's experience of marginalisation and exclusion from mainstream society, my two papers argue that attempts to treat the two as discrete entities glosses over the complexity of individual lives. As fast as I pulled out one variable in analysing the data, another tugged at my sleeve. Rather than looking at them in isolation, the task, as I saw it, became one of illustrating how the variables interpenetrate and interweave. My argument throughout has been that if we want to fully understand the ambiguities of lived experience, we need to come to grips with the many interlocking webs of significance in which impairment and disability are embedded. On their own, neither tells the whole story. The picture I have tried to paint is a holistic one, avoiding both the 'undersocialising' of an individualistic psychologising approach and the 'oversocialising' of a more deterministic analysis (Williams, 1996). I stand by these arguments.

WHAT IS AT STAKE

Let me turn to the particular criticisms which Shakespeare and Watson have raised, and acknowledge the depth of feeling which the social model, as a source of identity and pride, as well as a strong political vocabulary which focuses and interprets disabled people's struggles, raises in a way that I had perhaps insufficiently appreciated prior to the Leeds Conference.

Criticism almost always has some kernel of truth in it, so a point of agreement is in order. Gillian Parker (1993), in a sensitive account of caring within marriage, speaks of her 'puzzlement' which the social model engendered in her own attempts to care for a partner with a potentially life-threatening illness: a happy word, and one which I gather is not altogether

unacceptable amongst disabled academics. My feelings can most honestly be described as ones of frustration, as I tussled to fit the refractory experience of some (but not all) of the informants studied into a model which sought to provide an explanatory framework for disabled people's lives. It was certainly not my intention to 'grind an axe' against the Disability Movement, and if this is inadvertently the way the texts reads, I regret that.

Neither was it my intention when I commenced this research for Arthritis Care to make exploring the social model my 'sole project' (and funding difficulties often preclude writing as fully on a research topic as one might wish). However, the more I learnt of people's experiences, the more this emerged as the 'proper' topic of investigation. Although some informants in the research positioned their lives fully within the social model, others found it less comfortable to relate to. My qualitative social scientific training has alerted me to pay attention to anomalies, or 'deviant cases' in any research 'study: they often tell us more about the world than those who are more 'typical'. Increasingly I felt it was important to give voice to those experiences which seemed to sit on the margins of disability discussions.

My critics claim not to be able to recognise the four informants' stories (I have not thought to defend case study methods here when Shakespeare and Watson so ably draw upon a similar methodology!). The lack of recognition seems to me to be telling: these are the stories of other people with impairments 'out there', two of whom found a 'social oppression' model of disability unable to account adequately for their predicament; and one of whom was, perhaps, only on the threshold of framing her experiences differently. I am puzzled if the fourth informant, 'Lucy', portrayed in B. and M., is not recognisable, working as she does as a disability consultant in a disability organisation. Her narrative focused on the way in which, with the question-for the moment-in a way that 'Philip' so conspicuously could not. legitimately speak for others, an issue I had started to think about in B. and Shakespeare and Watson support of the disability community, she has re-framed the sick leave It raises the important question of how far, and on what basis, we can M., stimulated as it was by debates about difference in feminism.

To a final point of misunderstanding I feel, rather than disagreement. Shakespeare and Watson refer to a phrase I use in SH regarding the 'limited usefulness' of the social model, when my intention was its use as an heuristic device. Oliver (1996, p. 40) suggests that

... models are merely ways to help us to better understand the world, or those bits of it under scrutiny. If we expect models to explain, rather than aid understanding, they are bound to be found

wanting ... we cannot assume that models in general and the social model in particular can do everything, that it can explain disability in totality.

No one way of classifying a phenomenon is appropriate to every purpose. I was certainly not commenting on the efficacy of the social model as a political tool: indeed, the many gains which have been made by the Disability Movement in raising awareness and legislating towards civil rights can only impact positively on my own disability situation. The fact that such misunderstanding arises in the first place seems to lie in a tension in disability studies, already ably debated (Barnes, 1996; Shakespeare, 1996), between the academic enterprise and political activism. Certainly there are some medical sociologists – and perhaps rather more medical anthropologists – who wish to put their analyses directly to work to improve the lot of those whose lives they study, to do action research. It is my own particular foible that I am more comfortable with ‘diagnosis’ than I am with ‘treatment’: whilst I can appreciate the arguments of those in the Disability Movement who feel that there have been understandings enough, in the ebb and flow of events, interpretations always beget new interpretations. The infinite variety of people's experiences never ceases to beckon.

Shakespeare and Watson have treated the two papers as though they were identical, and have made little allowance for the fact that we all travel between writings. My later B. and M. chapter reflected this journey, both in tone and in argument: above all I had found a framework for understanding the differences that I have tried to grapple with in a way that makes sense, both experientially and intellectually.

A BETTER CONCEPTUALISATION

Perhaps the tension that is highlighted most sharply by Shakespeare and Watson's critique is that between the search for clear-cut, univocal messages crucial for the success of any political movement, and the necessarily more complex and subtle reality of people's lived experience. As Levine (1985, p. 38) argues ‘the institutions and ideals of modern culture are seriously dependent on unambiguous modes of expression’. In the avalanche of information which characterises our contemporary world, people have neither the time nor the inclination to pursue the meanings behind the words, to sleuth for complexity.

Indeed, the search for that coherence and predictability we all struggle for to make sense of our world is bound up precisely in the way we establish boundaries between what is and what is not: we classify and re-classify, we

say a person is this or that. But the mind is simultaneously many things. As Perin (1988) and Sibley (1995) have argued (and Mary Douglas before them), the human tendency is not to look too kindly upon blurred boundaries. Yet, as Bauman (1991) argues 'ambiguity cannot be wished out of existence'. And to ignore it excludes the richness of difference. The informants' stories presented in my two papers are above all stories about mixed categories, about transition - with all the discomfort this may imply for those who are unequivocally and safely 'there'. As I see it, their narratives have put confusion on the map.

TOWARDS A COMMON GROUND

The pluralism and 'nuanced worldview' to which Shakespeare and Watson refer in their critique is where fruitful common ground may surely be found between us. I return to the universalising themes discussed particularly in my B. and M. chapter, which owe much to the works of the disability theorist, Irving Zola (see also Williams, 1996). Let me raise anew the question: cannot a more holistic version of the social model, one which fully recognises the way in which agency and structure are intricately knit together, and which acknowledges that we are both producers and products of our social and cultural world, enhance the impact of a Movement committed to valuing and enhancing human life? As feminists have discovered, the experience of difference-within-difference, the multiple voices which are in our midst, need to be more fully recognised. I wrote in B. and M. 'A more holistic definition of disability, of the way in which disability is intimately linked to other structural relationships which differentially disadvantage social actors, is the hallmark of a Disability Movement which has truly come of age'. We need to nourish both the clarity of message necessary for the achievement of political gains, *and* the ambiguity and complexity inherent in a sensitive appreciation of the many differences in our midst.

I came across this evocative piece by the German sociologist and 'philosopher in transition', Georg Simmel in Levine's book (op.cit):

'Whoever is not for me is against me' is only a half-truth. Only the indifferent person is against me-one whom the ultimate questions for which I live move neither to a For nor an Against. But whoever is against me in a positive sense, one who ventured onto the plane where I exist and combats me on that plane, that person is in the highest sense for me.

Does this not have much to teach us?

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REFERENCES

- BARNES, C. (1996) Disability and the myth of the independent researcher.
- BAUMAN, Z. (1991) *Modernity and Ambivalence* (Oxford, Blackwells).
- DOUGLAS, M. (1966) *Purity and Danger.- an analysis of the concepts of pollution and taboo* (London, Routledge).
- LEVINE, D. (1985) *The Flight from Ambiguity: essays in social and cultural theory* (Chicago, University of Chicago Press).
- OLIVER, M. (1996) *Understanding Disability: from theory to practice* (Basingstoke, Macmillan Press).
- PARKER, G. (1993) *With this Body: caring and disability in marriage* (Buckingham, Open University Press) .
- PERIN, C. (1988) *Belonging in America: reading between the lines* (Madison, Wisconsin, University of Wisconsin Press).
- PINDER, R. (1995) Bringing back the body without the blame? The experience of ill and disabled people at work, *Sociology of Health and Illness*, 17, pp. 605-631.
- PINDER, R. (1996) Sick-but-fit or fit-but-sick? Ambiguity and identity at the workplace, in: C. BARNES & G. MERCER, *Exploring the Divide: illness and disability* (Leeds, The Disability Press).
- SHAKESPEARE, T (1992) A Response to Liz Crow. *Coalition*, September, 1992.
- SHAKESPEARE, T. (1996) Rules of engagement: doing disability research. *Disability and Society*, 11, pp. 115-119
- SIBLEY, D (1995) *Geographies of Exclusion* London, Routledge)
- WILLIAMS, G. (1996) Representing disability: some questions of phenomenology and politics, in: C. BARNES & G. MERCER (Eds) (1996) *Exploring the Divide: illness and disability* (Leeds, The Disability Press).