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SICK-BUT-FIT OR FIT-BUT-SICK? AMBIGUITY AND IDENTITY AT THE WORKPLACE

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A PROLEGOMENON

> `I think arthritis is, in some ways, unique, in that it's a crossover between disability and illness, whereas other disabilities aren't like that. I think that people with arthritis tend to have more time off through illness than other disabled people because of this crossover, and perhaps that puts them in a more difficult situation than other disabled people. It is difficult ... (She hesitated, and then resolved the ambiguity) ... No, disability and illness are separate things'.

This is how one informant, Lucy *, wrestled with the problem of how to equate her understandings about disability with the refractory demands of her body which fitted less neatly with established ways of perceiving the world. My questions are, firstly, what implications do Lucy's comments have for disabled people trying to integrate into a tight labour force, and for the policies which might better facilitate this? And secondly, what does this `crossover' tell us about the way disability is currently represented by, and the future goals of, the Disability Movement?

A basic human urge is to impose order upon the world, to search for clear-cut lines and concepts. As Murphy (1987) notes:

> `.. it is an empirical fact that the mind seeks to impose systems of some kind of order upon all it surveys. It is a property of all peoples and all cultures ... We look for order because it makes predictability possible, and we see predictability to avoid danger in an essentially perilous world' (p. 29).

The quest for clarity and simplicity find expression in our social institutions, reflected, for example, in employment policies that require employees to be either sick or fit, and is mirrored in the rules governing receipt of invalidity benefit: therapeutic earnings apart, claimants cannot be partly well.

Experience at the margins which fails to tally with our known ways of classifying the world, is especially problematic. As Douglas (l966) argues:

> `Danger lies in transitional states, simply because transition is neither one state nor the next, it is undefinable. The person who must pass from one to another is himself in danger and emanates danger to others'(p.97).

THE SOCIAL MODEL OF DISABILITY: TAKING A BROADER VIEW

One such evolving cultural system, the social model of disability, is viewed as the definitive way of representing the lived reality of disabled people as they struggle for social as well as political rights. It has become the means of explaining why disabled people fare so disproportionately poorly in the labour market, as in other areas of social life, such as education and housing (Oliver, l990; Morris, 1991; Higgins, l992; Swain et al., l993). Firstly, disability is a problem of society, difficulties resulting from a disabling environment rather than from the defects or deficiencies of disabled people as individuals; and the term `disablism' has been coined to give voice to the marginalisation, if not exclusion, of disabled people from mainstream society. Secondly, as society has `manufactured' the problems in the first place, disability theorists argue, the onus is on society to change: impairment is, at most, a minor issue.

With a husband disabled by Multiple Sclerosis, I have considerable sympathy with these views: at one level I know what they mean. Collectively they represent an attempt to move away from representations of disability as defective body parts and disabled people as tragedies, focusing instead on the oppressive practices which disabled people feel stifle their chances to participate in society. The Leeds Conference * showed the profound unease which exists within the Disability Movement to the idea of re-introducing impairment into the debate, and its implications for returning to a `medical model' of disability against which it has campaigned so vigorously over the past three decades (Oliver, 1996). It would create an anomaly, and anomalies, as Douglas (l970) and Bauman (l99l) argue, are often defined as dangerous and polluting.

However, to rely primarily on the `barriers and facilitators' approach which is promoted provides only a limited understanding. As Bury (1996, chapter 2 of this volume) notes, `Without a working definition of disability linked to impairment, the strong form of relativism in the "social oppression" approach threatens to overwhelm any form of enquiry'. The reification of `disabling

environments' is as partial as the previous exclusive concentration on bodies-to-be-rehabilitated neglected the social structure. Whilst focusing on those common external structures which deny access to disabled people has proved to be a powerful unifying political force, such a focus represents only part of a much more complex, multi-layered picture.

Although a few disability writers such as French (l993) and Crow (l996) have given impairment an airing, neither adequately grapples with the relational aspects of disability and impairment in the context of wider economic and socio-cultural contexts. It is not simply a question of `a bit more impairment'. The body is embedded in a wider nexus of structures which render a view of disability as social oppression alone over-simplistic. We need to address the age-old problem of the relationship between agency and structure, or, as Freund (l988) puts it:

> `... the interpenetration of the biological and the social in order to avoid the rarefied idealist bias that pervades it... In actual, concrete existence ... (mind, body and society) ... are in process and are "mutually determining" and "interpenetrate" each other' (p. 860).

The very elusiveness of this interaction renders the focus on `oppressive environments', characteristic of much contemporary writing on disability so compelling - and at the same time so incomplete.

GOING SICK AT WORK

The tensions inherent in over-emphasising the social model of disability are highlighted when we consider the situation of people with long-term deteriorating conditions, such as rheumatoid arthritis, as they attempt to `make it' at work. Arthritis often involves periods of unwellness as well as disability, and sickness at work is often a focal point of unease for disabled people. However, as Douglas (l966) notes, `anomalies are good to think with'. The sick record cannot be discounted in the way those with a stable condition are able to claim highly dependable work attendance records.

The problem of determining whether disabled people are sick enough to warrant exemption from work or not, or too sick to merit continued employment, is fraught with uncertainty and contradictions. A balance has to be carefully gauged. Yet it is not just an individual decision. As Bellaby (l989) makes clear, `... what constitutes acceptable absence' from work or not `is secured only by the evolution of conventions' (p.424), which are themselves framed by fellow employees, employers, medical practitioners, and close

relatives in the context of particular economic and historical circumstances. Taking time off, he concludes:

> `...is a structured social process which is reducible neither to morbidity nor to individual reasoning in isolation from other people and from conventions of conduct' (p.437).

Moreover, the way in which time taken off sick in the past is construed as an indicator of future performance is also embedded in a set of meanings as to what sickness `is', and what disability at the workplace may entail in terms of productivity and reliability of performance in the workplace.

Going sick thus involves a particular set of economic and socio-cultural relationships which illustrate the difficulties involved in despatching impairment and disability into neat, watertight compartments. A useful framework for exploring the dialectic between them may be found in Scheper-Hughes and Lock's (1987) interplay between the `three bodies': first, the individual body, or the body as self; second, the social body, or the body as a natural symbol, whereby a healthy body represents organic wholeness and the body in sickness offers a model of disharmony and conflict; and third - and the most dynamic of the three - the political body which refers both to the control of bodies in times of crisis, and the reproduction and socialisation of the kinds of bodies society needs.

Using such a typology, this chapter explores some of the ambiguities of going sick at work for people disabled with arthritis, illustrating the way personal, social and cultural identity is both reflected in, and itself shapes, disabled peoples' working lives. Firstly, it argues that a proper understanding of disability at work means bringing impairment back into the equation. Secondly, the chapter demonstrates that we cannot understand the experience of disability at work, particularly for those with long-term deteriorating conditions, without taking the mutually constitutive nature of bodies, selves and society into account. Thirdly, if the Disability Movement is to be fully universal in the way envisaged by Zola (l989), this chapter argues that the social model of disability needs to be painted with a broader brush. Feminists have become increasingly aware of the dangers of presupposing some underlying sameness to women. As Moore (l988) notes:

> `...it has often seemed as if the existence of a shared feminine identity, the commonality of gender, has somehow transcended the existence of other forms of difference' (p. 189).

Similarly, the experiences and needs of disabled people have all too often been assumed to be universal. As this chapter shows, the meanings of disability are multi-vocal. If unacknowledged, that powerful single voice which has been the stuff of successful political activism may be in danger of re-producing the very inflexibility of a wider ablist society the Disability Movement so rightly perceives as unfeeling and unresponsive to its needs.

These aims will be accomplished through the narrative accounts of two informants disabled by arthritis, Phillip and Lucy, who formed part of a wider qualitative study on employment commissioned by the charity Arthritis Care *. After the onset of rheumatoid arthritis at the age of thirty-four, Phillip lost his dearly won place in the police force, and found himself trapped in his attempts to pursue a satisfying career elsewhere: he was fit-but-sick. Over her short working career, Lucy's psoriatic arthritis had necessitated periodic times off sick, resulting in many difficulties with her various employers. However, in her new post as co-ordinator in a local disability organisation, she was now challenging her line manager to take a less hostile stance: she was sick-but-fit.

Philip's dismissal

Phillip had set his heart on being a policeman ever since he could remember. Securing a place as a probationer had taken some perseverance on his part, as his first application had failed the Final Board. A second attempt had been rejected owing to a freeze on recruitment. With his third successful application, the probationary period had initially taxed him to the limits because of what he described as `difficulties with the bookwork'. That hurdle surmounted, the onset of rheumatoid arthritis towards the end of his probation was a severe blow. Events telescoped in his mind:

> `I've always wanted to do it. And I got there, and I made it. And then I got arthritis. That all went out of the window, and that really hurt'.

The story gradually unfolded:

> `I got called into the office and I was told I was finished because I had this arthritis. And because of the nature of the disease, there's no cure so you're never going to get over it, you're never going to be fit enough to remain as a policeman... It was all cut and dried before I knew anything about it. Basically the Medical Officer said that I wasn't fit and so that was it'.

The finality of the decision had profoundly affected his sense of self. Even his considerable personal skills - he talked with fluency and good humour at the interview and at the Arthritis Care group meeting where I first met him - had been to no avail: there was evidently little room for manoeuvre. Particularly galling was his consultant's letter, giving a fairly encouraging picture of his prognosis, - `they had caught it early' - to the Police Federation Medical Officer, which had subsequently been overturned. He expostulated: `This was a consultant. The Force's Medical Officer is only a GP, but he disregarded this report. He worked on the "if you've got arthritis, you're not capable. Out" '. Phillip found that medicine was, at best, an uneasy ally in his struggles to sustain a role within the Force.

Reflecting on the anomaly Phillip felt that, on the one hand, he understood their predicament:

> `I can understand their view because arthritis is obviously something you can't guarantee the future. You've immediately got a disadvantage, if you like. Anyone could walk under a bus. But if you've got arthritis, you're already half way there, aren't you! So why take the risk? You can get rid of him for nothing, rather than risking ... You never know, in five years' time I might be incapable of doing the job anyway. You can't tell, that's the trouble with this arthritis, isn't it, because there's no routine, no set pattern'.

The very ambiguities of the illness and its likely future course which, in one context gave rise to some optimism, in another setting worked against him. He was trapped both in the inconsistencies of his own body and in the contradictory response to it from others: rheumatoid arthritis was evidently in a different league from spinal cord injury where tolerably reliable predictions could be made: the future was highly uncertain.

On the other hand, Phillip was irked by the fact that his dismissal came at a time when, after a short period of sick leave, he was once more holding his own on daily patrols. He wrestled with the anomaly of being simultaneously fit as he saw it, but sick in the eyes of others, a contradiction to which he continually returned in the interview:

> `It was a shock, because what really got me is that they pulled me off the streets to tell me I wasn't capable of doing it! And I knew I was capable of doing it, because I'd been doing it for the last three months. I mean I can do ninety-eight per cent of what I could do before I had it. And that two per cent is really so small that it might restrict me a little bit, but not to the extent that I would call myself disabled. You see even

that two per cent which prevented me from staying in the police force wasn't something I couldn't do, because I was doing it. It was something that might happen. I think that's the percentage that kicked me out'.

RP: `So they were making decisions about possibilities, not probabilities?'

`Oh yes, possibilities. It was all what might happen. Nobody knows to this day what will happen with arthritis, because it's such a varying thing. Everyone's different. Oh yes, definitely a case of better safe than sorry. I said this to the recruiting officer and he said "well, you could be right". And that's all he could say, but obviously he wasn't going to commit himself one way or the other. But I got the impression that I'd hit it smack on the nail. That's what's so annoying'.

That crucial `two per cent' - it was such a small anomaly - and the inconclusive nature of his future prognosis cost him dearly: he was fit-but-sick.

Efforts to negotiate an extension of his probationary period for twelve months `just to see if I could manage', or to find a desk job in the police force, proved fruitless. Moreover, the failure of the Force to compromise on the ambiguities of employing a probationer ninety-eight but not one hundred per cent fit had important consequences. Future career prospects in an area already hit hard by the recession were bleak. Discharged with a `record', how was he to explain his departure from the police force to prospective employers? And how should he account for his impairment now? Phillip felt cornered:

`What do you put? If I put I got fed up with them (the police) then it doesn't look good, does it. If I put I was sacked that looks even worse, so the only thing I can put is I was discharged medically and "will explain in detail on interview". On application forms it always says "do you suffer from any physical disability?" and I've always put "no". As far as I'm concerned, I can do everything I could before, although I might be in a bit of pain now and again, but I can do it'.

The awkwardness of knowing how to classify himself in a way that would not jeopardise his career prospects dogged his efforts to obtain another post. The complexities of his bodily experience were at variance with the black and white requirements of administrative reasoning. Neither could he circumvent

standard selection procedures in order to demonstrate his competence on a face-to-face basis:

> `If you got to the interview, you could p'raps talk your way through it and explain the situation. You'd stand a chance. But you've got to get shortlisted, and that's the bit. I had one month sick when I initially had it. I've worked for years without time off. When I was a driving instructor, six or seven years, I probably had two half days. Since I've had arthritis, apart from that initial month, I haven't had any time off at all. I put "no time off sick since then" on the form. As far as future employers are concerned, you're going to be a pain in the neck. You're always going to be off ill, so they don't bother shortlisting you. That might be how people feel'.

The possibility of being seriously disabled in the future was only one of the problems Phillip had to contend with. His sickness record was affected by a host of other considerations, not least his lack of paper qualifications:

> `You see there's nothing on paper, and at the end of the day, the majority of interviews are done on paper, aren't they. I mean you get shortlisted and it's what you're taking with you on paper. I've got seven CSEs, and that's it. I mean I'm capable of doing a lot more than what I do, but it's getting there in the first place. You see the problem is not knowing whether it's the arthritis or not that's causing it.

His previous career in the Army where he had been a small arms instructor and, eventually, a tank commander had ill equipped him for Civvy Street. Able to turn his hand to `all manner of tasks', his application lacked the solid weight of educational qualifications. He was already disadvantaged in the labour market prior to the onset of disability. The frustration lay in not knowing what to attribute to his impairment and what to his lack of formal qualifications.

Matters did not end there. With a young family of three to support, how was he to retrain when:

> `You've got to be unemployed for twelve months before joining. So what am I to do? Not work for twelve months so I can get on the course, and hope I'll get a decent job at the end of it? It's a joke. Just impossible'.

He was forced to turn down an offer to join the Ambulance Service, which would have been a satisfying alternative for him:

`Because there's the money side of things. I mean the Ambulance Service pays about 8,000 a year and I've been on l5,000 and you've got to live as well, and these three kids cost a fortune'.

Thus the problems arising from Phillip's current, or future, impairment were embedded in a web of other social and economic structures making a concentration on `oppressive environments' alone as an explanation for his predicament oversimplistic. He was disadvantaged in a host of other ways relating to his comparative lack of educational qualifications, and his role as the major breadwinner in a young family. He was also a young man of his time: the high unemployment rate locally, where he was competing with an unknown army of able-bodied applicants, only compounded matters.

DOING NORMAL SICKNESS: LUCY'S STORY

Lucy knew the contours of her impairment in a way that Phillip was only dimly beginning to discern. Now aged 32, she has had psoriatic arthritis since her early teens, but it was only when she started work that `things started to accelerate'. Her first job as a printing assistant in a small local firm ended abruptly. The running sore with her employer over the question of her regular hospital appointments was aggravated by his refusal to grant her paid leave to attend her grandmother's funeral. Diffident by nature, she nonetheless lost her temper:

`Eventually I just blew my lid and went absolutely potty and told him all the things I'd been really unhappy about, and then said, " I'm leaving at the end of the week". It was good I was upset. I didn't really care what he thought'.

With a second job as a camera operator in a large corporation, her future seemed more settled when it transpired that her new manager also had arthritis. An immediate bond was established between them. `I was very lucky' she acknowledged. `I think if he hadn't had arthritis, I don't think I'd have got the job to be perfectly honest'. Initial apprehensions from her co-workers that she would not be able to pull her weight soon melted away, and despite periods of unwellness, Lucy was not unhappy.

However, with the arrival of a new manager, trouble brewed once more over the question of her sick leave:

`I had to have a day off every three months to hospital, and at one point several of the joints in my feet had dislocated, and my toes were quite badly mis-shapen, and it was difficult to get shoes that were comfortable. The shoes used to rub on the top of my toes. I got a really bad ulcer, and I was actually off work for about eight weeks, because I couldn't wear anything on my feet, and of course he wasn't very happy about that at all. He made it very difficult'.

Mistrust and animosity between the two escalated, and Lucy's numerous hospital appointments became the focus of his hostility:

`With my type of arthritis I've got a skin complaint as well. Although it's one particular disease, they don't treat it as a whole thing. You have to go to a dermatologist and a rheumatologist, and if you've got a problem with your stomach you have to have medical checks with a gastro-enterologist. So I'd have to have three days off at a time. That made it even worse. It was, "you went to the hospital last week, you can't be going again", sort of thing'.

The complexities of her impairment strained the limits of tolerance. Being disabled was one thing, but multiple impairments, requiring a series of hospital visits, raised serious questions in her employer's mind about the genuineness of her sick leave.

As in Phillip's case, Lucy enlisted the help of her doctor in the hope of calming the troubled waters, but her consultant's intervention only inflamed the situation. She explained what happened:

`I spoke to my rheumatologist about the difficulties I had in being able to come up to hospital and she wanted to know why. And she wrote a letter to the Personnel Department and the Manager saying that I'd got this particular illness and it was necessary for me to come to the hospital, and she gave an outline of how many times she thought it was likely I'd need to come a year. I presented him with this letter, and also presented it to his superior and the manager of personnel, and he completely changed, and he said to me "Why have you done this? It wasn't necessary". And I said "Well, because you were questioning my hospital appointments". And he said, "Well, I don't know where you got that impression from, it just wasn't necessary to do this". In a way it probably aggravated him even more. It made the situation worse because he was annoyed'.

Her consultant, although anxious to help, proved to be an equivocal ally in negotiating credibility at the workplace. Later Lucy reflected upon how little by way of careful negotiation had taken place between the hospital and her employer: it had evidently been a matter-of-fact, no-nonsense approach to the dilemma *.

Illness at work does not exist in isolation from the wider contexts in which disabled people live out their lives. Lucy's situation was complicated by the nurturing and caring role she performed for her parents and grandparents. Yet the close-knit family ties from which she too drew support and sustenance were taken away from her at a time when she most needed them.

> `I had a lot of problems in my personal life. My father died suddenly in 1991 and I became ill because of that. I was off work for three months, something like that. And I developed a stomach ulcer which I think is related to the drugs which I'd been taking over the years for arthritis'.

Absenteeism was difficult enough to justify to her new manager on the basis of her impairments. When overlaid with the emotional and physical problems of bereavement, her credibility was seriously jeopardised. Returning to work on a part-time basis, her efforts to negotiate a return to full-time employment were unsuccessful, and she was reluctant to risk further endangering a tricky position by `making a fuss'. The arrangement nonetheless had some advantages: she was able to spend the afternoons at home caring for her mother, now increasingly incapacitated. But the situation was too volatile. Shortly afterwards she was called down to the Personnel Office and, despite the obvious availability of work, was formally made redundant.

After a period of low morale and dwindling job prospects, a vacancy for a co-ordinator arose in a local disability organisation and, with the help of the (then) Disability Resettlement Officer, Lucy was given the job. Yet the continuing need to take time off for family as well as for medical reasons soon led to difficulties with her able-bodied line manager.

> ` I've been there two years or so, and in that time, a lot's happened. I had to go into hospital and have an operation on my other foot for three months - there were complications, - and in the summer my mother died. I've had quite a lot of time off and it's made it difficult with the line manager. She's saying that that amount of time off is not acceptable. She's happy with my work, but she's not happy about the amount of time I'm taking off. The committee of (disabled) people are supportive and on my side, but this particular person is powerful and she can be

quite manipulative, so there's a bit of confrontation going on there at the moment'.

RP: `So the sick record doesn't go away, does it?'

`No, it always seems to be the sticking point, promoting policies for disabled people when disabled people are ill. I don't quite know how to handle that'.

At her previous monthly supervision meeting, Lucy had been presented with the ultimatum:

`... to have the whole of November without having any time off! Which is impossible, whether you're disabled or non-disabled. I don't think it's possible for anyone to say, "oh yes, I'll definitely do that"...'.

At interview, Lucy was planning to challenge the line manager at her next monthly meeting. I telephoned Lucy shortly afterwards to find out how matters stood. The challenge had evidently been successful:

` It's a good outcome. She's been told that if people are off sick, it's not their fault. She's stopped hassling me. I'm much happier now about the sick record. I feel I've got the support of other people'.

Her sickness was `normal', like everyone else's. She had gained a temporary reprieve, and with it the possibility of re-framing the disability and sickness dilemma which opened this chapter. She was sick-but-fit.

WHO AM I NOW THAT THIS HAS HAPPENED?: QUESTIONS OF IDENTITY

The way that both informants crafted a sense of identity for themselves was continuously being shaped and re-shaped in response to events that befell them, with differing implications for their respective work lives. Phillip had been propelled into a sick role which accorded ill with his perceptions of his body and his job competence, leaving him profoundly at odds with himself. His experiences raised in sharp form the question of identity: was he disabled, ill or sick, or a mixture of all three? Phillip tussled with the dilemma:

`That's a difficult one. I don't know that I felt disabled as such, or just ill. To me, if you're disabled, you can't do something because something is missing. You've lost a hand, something like that. As far as I was concerned, I temporarily couldn't do something, but it's something

temporary that could be controlled with the drugs. I never got to the situation where I couldn't walk and knew I wouldn't be able to walk. That's what I would call disabled ... I suppose temporarily I was disabled when I couldn't get up and do things, but I've tended to look at it more as an illness'.

Phillip no longer felt confident about how to classify his new two per cent differentness: he fitted into no neat pigeonhole. The image of disability as the loss of a hand or the inability to walk, although temporarily relevant, did not beckon as a source of identity. The strain was towards identifying with able-bodied norms, but key figures in his able-bodied world had rejected him. I wondered how far he had felt discriminated against. The question irritated him:

> `Aaah (sighed). That's some word is discrimination. I think it's used much too often to be honest'.

And he proceeded to give a spirited example of how he felt the term had been overused at his local school where he had a seat on the Board of Governors. Nevertheless, he acknowledged that he had little direct experience of the difficulties of his more visibly impaired acquaintances, first encountered at the Arthritis Care meeting: this was unknown territory. Although encouraged by their evident ability to `cope', he had been shaken by the extent of their impairment and what this might entail for his own future. Summing up his resistance to being categorised one way or the other he concluded:

> `I want to continue on with my life and just work with this arthritis. Yes I've got it, but it doesn't mean I've got to have a label stuck on my head'.

Lucy, on the other hand, was finding her new job as disability co-ordinator stimulating and fulfilling, and her identity as a disabled person was becoming more secure. Nevertheless, despite her deepening involvement with the disabled community, the question of sickness still troubled her, interfering periodically with the image she wished to present of herself to the world. I encouraged her to reflect anew on the contradictions raised at the beginning of this chapter.

> `Disability is a separate thing to illness. But certain types of disability can be responsible for subsequent illnesses, so it is difficult to separate the two. It's very complex. I don't quite know how to go about it! It goes back to the illness bit of it really. And very often with a disabled person,

their disability is static. It doesn't change. But with arthritis, it changes from day to day. It's difficult to lump everything together and say "this is how it is for disabled people" '.

RP: `I got the feeling when I first met you that you felt that illness is somehow letting the side down?'

`I did, but I don't so much now. People think of disabled people as sick but that isn't necessarily the case'.

Prior to starting her new post, she had exemplified the very stereotype she most wanted to challenge. However, since the confrontation with her line manager, the ambiguities of her situation seem to have been, at least temporarily, resolved. She had succeeded in re-writing the script, and, for the moment, her career prospects were more settled. Only time would tell whether her stand could be sustained.

However, her new allegiance was not entirely without reservations. She reflected again on the question of physical difference:

`If I was offered a cure tomorrow, I'd definitely take it. Some disabled people say that if they were offered an alternative of being "normal", if you like, they wouldn't take it. I can't really understand that myself. If I was in a room with disabled people and I said that, a lot of them would feel very unhappy about it. I don't know why, I can't understand why disabled people wouldn't want to take a cure if that was possible'.

Whilst much of Lucy's experience resonated with the philosophy of the Disability Movement, the correspondence was not an exact fit. Nevertheless, her challenge at work had crystallised her determination to be a disabled person in her own right:

`No matter what people say, I know that on the whole, I can do most things that I want to try and do, and certainly the belief in myself as a disabled person to challenge other people is much stronger. I am much more confident than I was'.

Phillip had just embarked on a journey, the outlines of which he could only dimly envisage as applying to himself. His brush with the disabled world had been fleeting: he was in the process of becoming a disabled person, with all its painful searchings and oscillations between able-bodied and disabled cultures. Lucy, on the other hand, already had a fund of experience of being disabled and, occasional disquiet apart, was fully involved with, and

committed to, the social model of disability: the disabled community was her world. Where Phillip's and Lucy's interests coalesced lay in the fact that both were intent on putting the obduracy of their bodies as central markers of their identity to one side.

CONCLUSIONS: MAKING WIDER CONNECTIONS

This paper has explored the particular experiences of two informants with arthritis, one at the margins of disability and the other who, whilst thoroughly committed to a disabled identity, nonetheless cannot entirely integrate her experience into a social model of disability. A picture of overlapping categories has emerged. Different though Lucy's and Phillip's stories are in detail, their stories illustrate the difficulties of confining the lived experience of arthritis to one discrete domain or the other. It is not simply that the insistence on minimising the impact of impairment gives a lopsided view: their narratives indicate how deeply the body (and the self) are implicated in wider social, economic and political structures. Reducing the difficulties disabled people encounter in forging viable work lives for themselves almost entirely to a question of external environments is misleading. As Lock and Scheper-Hughes (l990) note:

> `The individual body should be seen as the most immediate, proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle' (p. 71).

A successful employment policy needs to address the complexity and ambiguity of disabled peoples' experiences, as well as draw upon the common threads which underpin their struggle to compete economically in an ablist society.

We have already seen how Phillip's position was constrained by his lack of formal educational qualifications, his family commitments and the particular employment difficulties of a small Midlands town hard pressed by recession. Lucy's situation was equally compromised by what Rosaldo (l974, p.35) refers to as `the structural opposition between domestic and public domains of activity' which characterise many women's lives in contemporary Western society (Dalley l988). Returning to the questions raised at the beginning of this chapter, this concluding section will firstly draw out some wider implications of the interplay between the individual, social and political bodies; and secondly, explore how experience at the margins might inform a

more holistic approach to disability as the Movement gathers momentum to face the challenges of the twenty-first century.

(i) The embodied self: Despite having similar impairments, Lucy and Phillip positioned themselves differently, with differing implications for their future work lives. As we have seen, Lucy now firmly allied herself with the disabled community, although the contradiction which opened this chapter was only partly resolved, and in one respect - the possibility of a cure - her former able-bodied self still beckoned. Phillip, with minimal impairment, regarded himself primarily as able-bodied, although he could no longer dismiss the uneasy question mark which hung over his future. To an extent both were partly ` "betwixt and between" ... the recognised fixed points in space-time of structural classification' (Turner, l967, p.96), although Phillip's position was more precarious than that of Lucy, who was able to draw on the strengths of a collective discourse to reframe her situation. Had the complex realities of their experiences been more neatly resolvable, Phillip's unceremonious ejection from the Police Force, and Lucy's earlier struggles to present a morally competent version of herself despite sickness might have been more readily addressed.

Thus we are dealing not just with the discomfort which still exists between disabled people and the wider able-bodied, or `Temporarily Able-Bodied' society (Zola, 1989, p.406), but between disabled people, wider society, and those with partial impairments who may occupy a liminal status between these worlds. Turner (1967, p.97) has argued that `...what is unclear and contradictory (from the perspective of social definition) tends to be regarded as (ritually) unclean. The unclear is unclean'. As Shakespeare (l996) recognises, both disabled and chronically ill peoples' identities are multifaceted, challenging the assumption that disability is everywhere constituted the same way. Lucy's recent bid for acceptance as `normally sick' reassures us that multiple renderings of disability can provide an important critical challenge to the orthodoxy of a healthist workforce.

(ii) The social body: Questions of identity are intimately implicated in the way the body and the self are symbolic of the wider social order. If, as Higgins (1992, pp. 30-3l) argues, disability is associated with moral blameworthiness, then the two narratives presented here indicate that the additional presence of sickness may carry more disturbing connotations. Phillip's `two per cent that might happen' was, in William James' (l901/2, p.2) celebrated phrase `matter out of place'. Douglas (l970, p.93) has drawn attention to the way in which the ailing or disabled body is a metaphor for the social system:

> `The social body constrains the way the physical body is perceived. The physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society'.

Bodies which are flawed, or, as in Lucy's case, conspicuously sick convey powerful symbolic messages concerning social order and disorder. As Williams (1983) and Pinder (1995) have argued, attempts to sanitise disability, to present it as something mechanical distinct from fundamental cultural beliefs about the representation of health as a virtue and illness as sinful, may not ultimately be helpful. If only intuitively, we recognise how intimately they are bound together. However, in trying to reframe a healthist model of the labour force which constrains both disabled and able-bodied people, we need to draw on our common strengths and vulnerabilities: sickness in the workplace is likely to affect us all. If employment policies are to capitalise on the rich potential disabled people have to offer, they need to reflect this ambiguity rather than negate it.

(iii) The political body: The relationships between individual and social bodies are intimately woven into the political domain, raising important questions about power and control. Neither Lucy's nor Phillip's struggles were trivial: they attest to the multitude of ways in which chronically ill and disabled people assert an alternative view of their bodies. Although both informants found their everyday lives difficult and frustrating at times, their struggles with the able-bodied world contain an important critical standpoint. Three issues are important here.

First, the question of genuineness ran like an invisible thread through the two informants' attempts to sustain a viable work role. Much as they wished to discount the significance of their physical differentness, it structured their relationships to the world of work in a new and problematic way. On the one hand, prior to her attempt to redefine her absences as `normal sickness', Lucy's working career had been characterised by a continuous struggle to legitimate herself as sick-but-fit. On the other, Phillip had failed in his attempts to persuade an inflexible police bureaucracy to take a chance on his future work capabilities as fit-but-sick. Both had continuously overstepped the `limits of tolerance'.

Dodier (1985) notes that, `Moral judgements made at work can be decisive for a career', as both informants discovered to their cost. Phillip's dismissal and Lucy's earlier redundancy were not simply straightforward practical decisions concerning their respective physical capabilities: they were laced with moral connotations, which were themselves embedded in wider shifting structural

relationships. In the contemporary economic climate of heightened uncertainty and job insecurity, both informants were caught in what Lock and Scheper-Hughes (l990) refer to as `a nervous vigilance about exits and entries', where anxieties about maintaining existing body boundaries and body purity may be exacerbated.

Second, in trying to negotiate credible versions of themselves, both informants became entangled in the ambiguous relationship which exists between medicine and capitalism. As Bellaby (l990) notes:

> `Medicine, as an institutional complex, sits uneasily between employer and employee. It is not an unequivocal ally of capital in the social control and reproduction of the labour force ... but neither is it necessarily the worker's friend, whatever the attitudes of the individual medical practitioner may be' (p. 60).

Both informants' search for credibility brought them face to face with the differing imperatives of the medical profession, with its stress on mind-body dualism, and the labour market, which emphasises productivity and performance. A morally adequate explanation of what to expect of arthritis in the formalised setting of the hospital clinic carried little credence in the specific context of Lucy's and Phillip's respective workplaces. The discipline of occupational medicine is still in its infancy. Stronger links between trade unions, disability employment advisers, the medical profession and the disabled community are vital if the careful assessment and negotiation of options for re-deployment, so integral to responsible work practices for disabled people, are to be fully considered.

Third, events fan outwards. Once `on the books', the sick record itself became an invisible form of discipline, blocking Phillip's career advancement and seriously jeopardising Lucy's earlier credibility. As a means of classifying illness behaviour and making unambiguous decisions about sickness or fitness, it was a symbol of unpredictability and unreliability. Foucault (l977, p.l90) has alerted us to the way in which records represent:

> `the fixing, at once ritual and "scientific" of individual differences ... (they are) a process by which an individual is linked by his status to the features, the measurements, the gaps, the "marks" that characterise him and make him "a case" '.

For both informants in this chapter, the record had functioned as a `thing out there', constraining and shaping perceptions and future possibilities. Yet, as

we have seen, it would be mistaken to characterise either Lucy or Phillip as victims: both wrestled actively with their respective situations.

Thus, to focus almost exclusively on a model of disability which fails to take into account the way the body and the self are inextricably tied to a wider web of economic, social and cultural relationships gives a misleading picture. The validity of Lucy's and Phillip's narratives will be strained unless we pay attention to the interplay between them: herein lie the seeds of creativity and change. As disabled people grow in confidence, the dialectic between agency and structure is constantly shifting.

My final observations concern the implications of these findings for the Disability Movement's continuing exploration of its own identity, and the development of policies which may strengthen its message. Douglas (l966) notes that cultural categories:

> `...cannot neglect the challenge of aberrant forms. Any given system of classification must give rise to anomalies, and any given culture must confront events which seem to defy its assumptions. It cannot ignore the anomalies which its scheme produces, except at the risk of forfeiting confidence' (p. 40).

For reasons grounded historically in its own struggles, the Movement is ill at ease with ambiguity. Chronic illness is still seen as `medical' and therefore falling outside its provenance. The voices of those who, like Phillip, may weave in and out of disability, have so far been comparatively muted.

Yet, the two stories presented here have shown that the contradictions inherent in relying primarily on a social model of disability to explain the difficulties chronically ill and disabled people face at work cannot be ignored. As Bauman (1991, p.73) notes, `Ambivalence cannot be wished out of existence'. Phillip's narrative has as much to tell us about what it means to be able-bodied with physical limitations as Lucy's more conventional story alerts us to the pressures of being disabled. If the Movement is to adequately reflect the lived reality of their work lives, the experience of difference-within-difference needs to be acknowledged too. Feminists have already paved the way in this respect: `The differences between women are important' writes Moore (1988):

> `and they need to be acknowledged because it cannot be part of feminist politics for one group of women to speak for and on behalf of another' (p. 198).

It would be tragic if, in sifting the `proper' from the `improper', the Disability Movement failed to gather under its wing the many elderly and chronically ill people who may have difficulty in relating to a social oppression model of disability, but who nonetheless share similar inequities of treatment. As Williams (1996) argues, there is a danger that unless the Movement confronts its own ambiguities and speaks to the many other injustices (age, class, gender, and race) that plague our society, it may cut itself off from more general issues of public policy. If the particular problems of disabled women - and increasingly women from ethnic communities - are now well established in disability theory, Phillip's story alerts us to the importance of attending to the other `variables' and their interdependence. However understandable in a young political movement still flexing its wings, efforts to tame variety can only restrict its influence. 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.

Before his untimely death in 1994, the disabled sociologist Irving Zola urged the Disability Movement to embrace a universal approach. He wrote:

> `Only when we acknowledge the near universality of disability and that all of its dimensions (including the biomedical) are part of the social process by which the meanings of disability are negotiated will it be possible fully to appreciate how general public policy can affect this issue' (1989, p. 420).

The dilemma for disability theorists is whether, in bringing into the fold `experience at the margins', the political momentum can be sustained. I believe it can only be strengthened and enriched. If Lucy's and Phillip's narratives have highlighted the more complex questions which will need to be faced now that the 1995 Disability Discrimination Act (however inadequate) is on the statute books, this chapter will have made a modest contribution to that debate.

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