

*This is a slightly amended version of an article I published in the academic journal *Disability & Society* in 2002 (vol.17. no.3). It concerns the divide between disability and illness and argues for a disability movement willing to include people who traditionally define themselves, and are defined, as 'sick', as well as those more usually defined and self-defined as 'disabled'. It contends that in the absence of an inclusive movement, chronically sick people will remain stigmatised, with their strengths unrecognised and social measures to improve their lives unformulated.*

I would have hoped that after all these years the article would have become outdated because the argument would have been won. Sadly, it appears not.

Private Tragedy in Social Context?

Reflections on Disability, Illness and Suffering

by Patricia de Wolfe

Introduction

The disability rights movement has placed in the public domain a perspective according to which disability is construed as an effect of social organisation, and has evolved a language which enables disabled people to formulate claims which may be made on social institutions and on individuals. Despite limited progress in implementing the demands of the disability movement, the elimination of disability as disadvantage has been constituted as both a possibility and a social responsibility. However, as some disability theorists have themselves argued, a divide remains between disability and illness, with social responsibility for the latter construed mainly in terms of provision of individual health care and personal support.

In this paper, I examine some reasons for this divide, and some implications of the way in which it has been constructed. I suggest that the distancing of the sick from the sphere of the social profoundly affects the way in which illness, and particularly long-term illness, is lived. I further suggest that that ambivalences towards illness within disability theory are linked to a reluctance to acknowledge, and indeed an

embarrassment about acknowledging suffering as an intractable feature of the human condition. This reluctance relegates to the realm of the private, both conceptually and materially, those whose suffering cannot be relieved by either medical intervention or social change. I argue that no firm boundaries can be drawn between those characterised as sick and those more usually termed disabled, and that attempts to do so have undesirable political consequences; and that despite divergences of experience and, sometimes, of priorities, alliances should be forged between these two (unstable) categories.

Background and Personal Issues

My interest in, and my perspective on the matters explored in this paper are informed by my own experience, and I therefore begin with a brief account of the events which crystallised these issues for me.

I am a long-term ME sufferer who whiled away several years of illness studying for a part-time PhD in medical sociology. My first encounter with the sociology of health and illness was through interactionist accounts – prevalent in the early 1990s – of the experience of chronic illness. Although the intention behind these studies was in a sense liberatory, aiming as they did to give a voice to the unheard and dispossessed, I found much of this literature profoundly depressing. It seemed to replicate the isolation of the experience of illness itself. Few links were made between theorisations of illness and wider sociological issues, and there was little exploration of the relationship between the experience of illness and the social context in which it took place. Relieving sick people's sense of exclusion was widely construed as primarily the responsibility of their medical advisers (e.g. MacDonald, 1988, p. 200; Scambler and Hopkins, 1988, p. 175; Locker, 1991, p. 91; Scambler, 1991, pp. 194-195), rather than of society more generally.

The discourse of disability activism, however, which I encountered through reading and hearsay rather than political involvement, also seemed to offer me little help in

understanding or improving my situation. My (admittedly sketchy) knowledge of the movement led me to conceive of it as the province of basically vigorous – and probably usually young – people with a fixed impairment (e.g. inability to walk, or to see), rather than someone like myself, frail, with fluctuating symptoms of tiredness and pain.

The relevance of disability activism to my concerns was, however, abruptly brought home to me when an extension was built to my university's information centre, and I arrived one day to find new doors between the issue desk and the main library. These doors were so heavy that I could not open them without injuring the muscles in my back. I resented asking for help on each occasion – and in any case, this was not always available. I could not accept that a resource so overwhelmingly important to me, which had previously presented me with no problems of access, had now been removed from easy reach. The construction of *new* disabling barriers seemed to me outrageous.

The saga – too complicated to detail here – which followed my complaint ended in success when, a year later, the doors were pinned back magnetically. In the course of this battle I learned unwelcome truths of different kinds: that the quality of life of someone like myself hangs by a thread, and may be destroyed by a simple act of stupidity; that an institution may devise an impressive equal opportunities code without it apparently having occurred to anyone to take any steps to implement it; and that the words 'disability' or 'disability rights' induce a recognisable reaction in all too many people: a kind of dismayed gulp, followed by two steps backwards.

I also became acutely aware of how unthinkable it would have been to take a stand on a matter like this without the success of the disability movement in achieving some acceptance of the justice of equality of access, however great the gap between theory and practice. I myself would probably have construed my inability to open the doors as a personal problem, to be endured in silence: Wendell (1996, p. 46), also ill with ME, relates her slowness to recognise that the weight of the door to her own building

(which, as in my case, was causing difficulties for people other than herself) could rank as an issue of access. But I also knew – and this made me uneasy – that in normal circumstances, I would describe myself, and think of myself, not as disabled, but as ill. Disability felt like a category of which I did not have legitimate membership (c.f. Ravetz, 1998, p. 224). It seemed, however, the only the category of which I could avail myself in order to argue for what I needed. The notion of admitting to ME (a chronic illness) rather than ‘a muscle disorder’ (a disability) made me cringe. The idea of claiming a right of access to the library – or indeed any concession other than permission to go home to bed or to seek medical help – on grounds of *illness* seemed almost an absurdity. But why?

Disability, Pain and Illness: contested divides

A discussion of illness in the context of the thinking of the disability movement touches on the vexed question of whether disability theory has taken account of the intrinsic pain of impairment, and indeed whether it should do so (see e.g. Barnes and Mercer, 1996). In this section, I examine specific aspects of this debate. I focus on three sets of issues: political efficacy; the difficulties and contradictions of reconciling a project of accommodation with one of cure; and a Western cultural emphasis on the controllability of the body, which fosters a denial and stigmatisation of frailty and suffering.

First, a brief contextualisation of the discussion. Disability activists have understandably been wary of any shift in perspective that might signal a return to traditional models of disability as private tragedy, and thus as individual, rather than social responsibility; and as condemning the 'sufferer' to a restricted and unhappy life. They may, therefore, be reluctant to acknowledge the resistance of certain bodily problems to purely social solutions; or they may acknowledge the existence of these problems, but regard them as falling outside their domain. Thus, Oliver (1996, pp. 48-49) argues that the disability movement has not, as is sometimes alleged, denied the pain of impairment, but rather considered it to be beyond its purview, being solely concerned with matters amenable to change by means of collective action. Swain and French (2000, pp. 571-572) specify a firm distinction between disability on the one hand, and chronic illness and pain on the other: non-disabled people, they state, may experience both of the latter, as may their disabled counterparts. They go on to argue (*ibid.*, p. 577) for an affirmative model of disability which can serve as the basis of a strong group identity.

On the other hand, the construction of disability as purely social has attracted a range of critiques and qualifications. Some writers have suggested that disability theory fails to theorise embodiment, and that it therefore effects an illegitimate split between body and society. Phenomenological perspectives in particular stress that we apprehend the world through our bodies – and, conversely, that the (impaired) body is made meaningful through culture (Hughes and Paterson, 1997, p. 335). These theories propose a focus on ‘lived experience’ which unites our perceptions of a range of domains, and thus transcends dichotomies between body, emotion and society (ibid., p. 336).

Other objections to a purely social construction of disability are made on political and ethical grounds. Thus Crow (1996, p. 58), referring to what she terms the ‘SuperCrip’ images of some of the movement’s campaigns, draws attention to what she regards as the political dangers of neglecting embodied experience, and hence of creating a hierarchy of the impaired, headed by those whose impairments can, at least in principle, be rendered irrelevant by means of social change.

Empirically, too, it has been pointed out that what is generally construed as disability is often accompanied by sensations of pain and by fatigue, themselves the effects of disease and of ageing (Morris, 1993, p. 68); thus, the experience of disability and that of illness are often inextricably intertwined. Poststructuralist writers (Price and Shildrick, 1998; Corker, 1999) have taken issue with the project of dividing experience into segments, of denying its fluidity, and of specifying a stable disabled identity. Thus, Corker (1999, p. 633) points out that in everyday talk, disabled people allude to a complex existence that occupies the space between health and illness, disability and normality. Indeed, my personal account at the beginning of this paper might be thought to testify to the inadequacy of fixed categories of illness, disability and ‘normality’.

In the light of these general considerations, I now discuss the topics mentioned above.

Political Efficacy and Simplicity

As already noted, the disability movement has transformed the way in which disability may be perceived, and has been instrumental in the introduction of legislation which, however imperfect, aims to endow people with impairments with rights, and assist their integration into everyday life. Further progress, as with all social changes which make demands on public and private resources, is likely to require persistent and concerted efforts from campaigners. It is easier to formulate demands around issues which are clear-cut: the justice of the argument 'scholars with weak muscles should not be debarred from entering libraries' is patent. Elaborations to the effect that the scholar in question was in any case in pain and had a very poor quality of life because of tiredness might not have been helpful to my cause. Activists seeking to promote the cause of disabled people understandably prefer to convey a plain message: that disability does not equate with tragedy and exclusion from mainstream life, and that a society which accommodates disabled people can transform their lives. To raise and publicise considerations of experienced bodily pain and weakness (not to mention, for example, mourning for a former more active self), which are resistant to changes in social arrangements, could understandably be considered unhelpful to the objectives of the movement.

A political movement is also more likely to succeed if it is founded upon commonalities of experience which can mobilise and unify potential adherents. Unity may in any case be problematic: some of the divisions between different sets of people who would generally identify as disabled (as opposed to ill) will emerge in the next section. Attempting to incorporate into the disability movement people who suffer a wide variety of chronic illnesses might be thought to risk fragmenting it beyond all usefulness. There is, however, a countervailing point: would-be activists may currently be excluded from the movement because, for example, limited energy prevents them from attending meetings or other events. Thus numbers might be swelled if alternative modes of participation were developed (Crow, 1996, pp. 59-60). I shall return to issues of unity and diversity at the end of the paper.

Accommodation Versus Cure

Disability activists construe their bodily state primarily as the subject of social accommodation rather than medical attention. This is not to say that they reject all therapeutic intervention: the disability movement claims equal access for all disabled people to treatments which alleviate pain and suffering (Disabled Peoples' International Europe, 2000). However, the characterisation of a bodily problem as an illness or disease, places it, more or less by definition in Western society, under the auspices of medical practitioners and researchers who aspire not only to improve quality of life, but to rectify or prevent what is construed as a disorder. Relief of suffering is thus a mere interim measure pending a more fundamental solution.

The project of prevention/cure is not only antagonistic to that of accommodation, but it may seem to hold out the promise of a society of people with flawless bodies – a promise which, in the meantime, may appear to carry the implication that only the physically 'perfect' should be accorded full social membership. It thus makes acceptance within and integration into society ever more difficult for those whose impairments or disorders remain uncorrected. The genetic project in particular may be seen as a eugenicist movement aimed at ridding the world of imperfection (see Shakespeare, 1999, pp. 678-683). Disability activists have voiced profound disquiet at the possibility of the elimination of valuable human diversity and have stressed the right to life of all, regardless of type and degree of impairment (Disabled Peoples' International Europe, 2000). Scientific medicine may further be politically divisive, involving as it does costly research into individual conditions, and hence fostering competition for funds between groups of people with differing pathologies, rather than encouraging links based on a common social disenfranchisement (Zola, 1983, p. 212).

However, although reservations are frequently expressed about various aspects of the medical enterprise (other controversial issues include the use of animals in research, and the extension of infertility treatment to older women), few people would advocate the wholesale abandonment of the (scientific) project of cure for everybody. Further, it would seem impossible to claim clear-cut logical criteria for drawing a distinction

between those bodily states which are the proper subject of medical remedy or prevention and those ranking as impairments to be accommodated by means of social change. The issues involved in trying to specify such a distinction are complex.

First, the rejection of bodily 'improvement' is not universal even amongst those who identify as disabled rather than ill. People who attribute their impairment to the effects of poverty, pollution or dangerous substances will understandably demand that its cause be addressed (Stone, 1996, p. 480): it would surely not be appropriate to 'accommodate' the people affected by thalidomide without also prohibiting the drug or penalising its manufacturer. Moreover, because of the diversity of bodily conditions which may be construed as impairment, differing groups of people may respond with varying degrees of enthusiasm or indignation to the prospect of being reconstituted as curable clients of medical science. While some, such as Deaf people, may celebrate their difference, and reject curative procedures in favour of 'normality' within a Deaf community, and while others may regard their impairment as more or less irrelevant to the quality of their life given suitable social arrangements, it is inevitable that some will experience their condition as undesirable, or even intolerable, and seek its rectification. It is impossible to claim, from some neutral vantage point, that either group of people is 'right' or 'wrong' – although to take extant preferences as evidence of truly 'free' choices may be equally problematic, since these choices are made in a particular climate of opinion, and under particular material constraints.

Second, for those who suffer what they consider to be bodily disorder or anomaly, whether they identify as sick or as disabled, accommodation and cure do not necessarily present as mutually exclusive strategies. If this dichotomy were to be sustained, it would appear to follow that people who regard cure as the optimal solution to their plight are not entitled to claim arrangements which will foster their social integration. Their only entitlements would relate to occupancy of the sick role: medical care, withdrawal from work, entitlement to social security benefits. It must be remembered, in this context, that cures for conditions deemed diseases may be very slow in coming - or chronic (or indeed fatal) illness would not exist. To pronounce a bodily condition a suitable case for medical treatment is not to ensure that such

treatment will become available. The allocation of funds for medical research is a contested and political issue; and, even given these funds, the success of researchers' efforts is to some extent a matter of chance. Pending this success, people have to live with their bodily condition as best they can.

Most people who feel continuously weak, tired, giddy, in pain, will inevitably construe themselves as potential clients of curative medicine. By contrast with certain impairments discussed by disability activists, illness often does constitute tragedy, both for its victims and for those close to them. It can turn minuscule daily tasks into draining chores; make valued activities impossible, or ruin enjoyment in them; abort short- and long-term plans; strain relationships to breaking point. Many of these problems result from the bodily condition of the sufferer, and no amount of social accommodation can totally compensate for lost quality of life. This does not mean, however, that social arrangements and atmosphere do not make a great difference to the experience of illness.

The demands which sick people as a social group might make in this regard remain largely unstated. Patient activism – difficult in any case for those struggling with incapacitating illness – has tended to be organised around specific medical conditions, and to focus on the provision of better medical services and the need for medical research. Whilst sick people have occasionally campaigned around specific issues, such as the laws governing social security benefits (Adams, 1998), there is no political movement of sick people as a whole which is primarily aimed at *social* transformation, as opposed to the transformation of individual bodies. One might, therefore, ask which issues, medical research and cure apart, could inform the demands which sick people might make on society – and also what impediments exist not only to their implementation, but to their very formulation. One such obstacle is the increasing social tendency towards control of the body, and belief in the possibility of this control (Shilling, 1993, pp. 36-37). I now consider this in relation to illness and the disability movement.

The Control of the Sick Body

While there is no single perspective in Western societies on either the aetiology of illness or on the preservation of health, there are numerous discourses on health and illness according to which illness may be either avoided or remedied provided the (potential) sufferer takes appropriate action (de Wolfe, 1996). Rapid developments in medicine have resulted in a growing expectation that medical science will cure or alleviate all life-threatening or seriously disabling medical conditions. Those sceptical about the benefits of orthodox medical intervention may rely on alternative therapies; or on strategies of self-care; or construe physical health as the outcome of emotional well-being (Hay, 1988). All these constructions imply the need for activity around illness, and appear symptomatic of an impatience around the sick body. There seems to be little social legitimation for accepting illness as a regrettable, but sometimes unavoidable, part of life, or even allowing the body, once ill, time to recover.

This intolerant stance towards the body in illness emerges in the contrast drawn by Hoffman (1989, pp. 50-52) between the mores of her adopted homeland, the USA, and those of her native Poland. She notes the pressure in American society to discipline the body, and specifically the sick body. She recalls the notion, prevalent in her youth, that a sick body is cured by being coddled and preserving energy. Thus, as a child in Cracow in the 1950s, she was prescribed a year off school, and bed rest, for a form of anaemia; compare this with the predicament of British youngsters with ME in the 1980s and 1990s, some of whom were forcibly removed from home by social services because their parents withdrew them from school (Proctor, 1989; Harman, 1991; *Rantzen Report – M.E.: The Secret Epidemic*, BBC1, 5 August 1996). She relates that in the USA, where running, swimming and aerobics are the order of the day, her doctor issues warnings against staying in bed too long with flu. She also notes the indefinite sense of shame associated with illness.

People whose illness is intractable therefore suffer from a social atmosphere in which illness is regarded as an aberration, as a temporary and avoidable breakdown of a normal state of good health. If their ill-health persists, they are frequently assailed by

exhortations to undertake ever more obscure – and sometimes costly – therapies in order to regain their health (Duff, 1994, pp. 39-40; Wendell, 1996, pp. 97-98). Undertones of blame frequently lurk in this approach: it is taken for granted both that it is our duty to overcome illness (Herzlich and Pierret, 1984, pp. 283-288), and that it is always in our power to do so (Duff, 1994, p. 41). Assumptions about the controllability of bodily disorder, and hence condemnation of those who endure it, are embedded in social institutions (the workplace, the social security system), generating and legitimating structural forms of exclusion. They also pervade interactions between sick people and their families, friends and neighbours, as doubt is cast on the *bona fides* of those who fail to recover. The long-term sick may be suspected of seeking attention, or of avoiding normal responsibilities or relationships.

The disability movement does not explicitly address the issue of the controllability of the body, but its message is targeted at those whose bodies can, in fact, be controlled, in the sense of being subsumed into the social. It may hence be seen as (unintentionally) complicit in the marginalisation and stigmatisation of the incurably long-term sick. The ‘disappearing’ of the body for which phenomenologists criticise disability theory (Hughes and Paterson, 1997); the (arguably impractical) project of separating out and privileging bodily impairment which can be rendered irrelevant by social change (Oliver, 1996, pp. 48-49) – all this contributes to the notion that integration into society is contingent on absence of suffering, on a particular kind of physical and mental vigour.

It is in this respect that, despite its hostility to many aspects of the medical enterprise, the disability movement might be said to share its ethos. In his discussion of Foucault’s *The Birth of the Clinic* (1973), Rose (1994, pp. 68-70) argues that the medical enterprise is an intrinsic, indeed foundational component of a general social ethic in which suffering has no place. He claims that the work charts the emergence of a certain kind of clinical thought and practice implicated in the elimination of the metaphysical and spiritual meaning of suffering in favour of an ethic of health and happiness. To recognise this, Rose suggests, is not to condemn it, but merely to pose questions about the costs of organising our experience in this way (*ibid.*, p. 70).

Some of these costs are inevitably borne by those whose suffering cannot be entirely eliminated by either social or medical means. In arguing for a 'deprivatisation', and, in a sense, rehabilitation, of suffering (c.f. Hughes and Paterson, 1997, p. 336), I am not advocating a transition to an ethos where pain is glorified, or sought out for its spiritual benefits. It would be perverse to prefer illness and misery to health and happiness. Whatever meaning may be found in bodily suffering, and whatever narratives – and therefore sense - may be constructed out of illness, virtually anybody, as one chronicler of his own illness points out (Frank, 1995, p. 135), would rather be well. Illness should not be romanticised. It ruins lives.

I am contending, however, that suffering should not be rendered unspeakable or shameful: this compounds it by isolating and stigmatising the sufferer. It should be acknowledged that people who live with illness require social recognition, inclusion and support. It should also be acknowledged that long-term illness is not weakness, other than in a physical sense: those who live with illness need, and are usually obliged to acquire, many practical and emotional survival skills. They may even have something to teach the healthy. But neither this support nor this acknowledgement will be forthcoming if illness is – as has traditionally been the case with disability – construed as a purely individual problem. But what alternatives exist? And what might relations be between the chronically sick and the disability movement?

Disability, Illness and the Construction of 'Otherness'

The taboos which surround the topic of long-term illness, and which inhibit the discussion of the experience it generates, make it hard to formulate suggestions about the social changes which would make it more tolerable. Even those with an interest in promoting such a discussion may find that they are floundering to express needs and concerns for which they are unable to find words. (The notion of sick people arguing for 'illness rights' akin to 'disability rights' seems almost embarrassing, raising the spectre of a kind of whingers' charter.) The situation is further complicated by the complexity of the situations and emotions involved. Illness, like disability, may take

many forms; the extent of its severity varies, and it may, in a single person, improve or deteriorate, fluctuate or stabilise. Moreover, people may, even at a given level of incapacity, experience tensions between the wish to join the world of the well, and the wish to be granted exemption from it.

Some of the complexities regarding the promotion of a sense of worth and belonging in people who are ill become apparent in a discussion of work. Work is a major issue for both sick and disabled people, for in contemporary Western society, occupational status is central to identity, so that the inactivity necessarily associated with much illness often becomes tantamount to social death (Herzlich and Pierret, 1984, pp. 222-224). People excluded from work through bodily disorder frequently crave not only the companionship, but also the sense of social place which paid employment affords them.

It is, therefore, understandable that disability activists should have pressed for changes to enable the integration of disabled people into the workforce. Strategies of integration into the labour force are also important to some people who would normally identify and be considered as chronically ill, rather than disabled – although the concerns of the former might on occasion differ from those of the latter, focussing less on issues of access and motor skills. For example, patterns of work could be remodelled to accommodate some of those with fluctuating or limited capacity. Affordable help in the home would release energy for work. Reliable transport would reduce the strain of travelling. The structure (as well as the level) of social security benefits is crucial: a system is needed which is adapted to people who opt in and out of employment, without giving rise to endless bureaucratic complications, or generating the fear that occasional ability to work will result in permanent loss of sickness-related benefits. All this is, in principle at least, achievable, even though such changes will in practice be hard to implement, and slow in coming.

But even given some degree of transformation in the conditions of work, the possibilities of integrating *all* people with bodily disorder into the workforce are limited. Sustaining a sense of worth and membership of the social world in those permanently

unfit for work is far more complex. Abberley (1997, pp. 38-42) recognises these difficulties in relation to disabled people. He argues that a truly liberatory theory of disability requires a profound cultural shift, challenging 'production-based instrumental rationality', and severing the prevalent conceptual link between human value and capacity to participate in the workforce. The acceptance that some people, whether identified as sick or as disabled, might remain unable to work – or might indeed in some cases decide that the work open to them is an unrewarding use of limited energies (is it worth exhausting every iota of strength and ingenuity in order to work in a call centre?) – is particularly important in a political climate where the desirability of 'welfare to work' has become integral to government policy.

In such a climate, the possibility of achieving the cultural shift called for by Abberley on behalf of people with disabilities seems remote. A cultural change which would promote the social inclusion of the long-term sick appears even more elusive. Human value would need to be divorced not only from economic productivity, but from other, less tangible social values: activity, measurable achievement, vigour, bodily control. The necessary change in ethos is hard to imagine, let alone convey in words.

Without this change, however, the conceptual and social divide between those construed as disabled and those construed as normal is not abolished, but merely shifted. Shakespeare (1997, p. 217) terms disabled people 'dustbins for disavowal', suggesting that they serve as unwelcome reminders to the able-bodied of their own physical vulnerability and mortality, and that they represent the inevitable failure of Enlightenment ideals of self-perfectibility and capacity to triumph over nature (*ibid.*, pp. 234-235). According to this view, disabled people embody, literally, human physical frailty, and are the bearers of the terrors which this frailty may generate. They are therefore consigned to oblivion.

However, perspectives which insist on a distinction between disability and illness do not challenge this splitting off of the 'other', but simply relocate the line between social inclusion and exclusion. People whose impairment is amenable to social accommodation are reconstituted as (at least potentially) 'normal'. They are able to

join the ranks of the vigorous, become 'us', part of the world of the active and healthy. Those who are defined, or define themselves as ill, by contrast, remain excluded both from everyday life and from wider social consciousness. Their bodies are irredeemably flawed, reminders of potential disintegration and certain mortality, and of the sheer awfulness of unremitting physical suffering. They are hence deemed repulsive, contemptible and best consigned to the privacy of the family or the consulting room. The terms of the split between disability and illness are also resonant of an (implicit) divide along gender lines. Strength, as well as full membership of society and culture, are conventionally male preserves. Women are more likely to be considered physically weak and vulnerable; and also imperfectly socialised, being bound to nature by the demands (defects) of their bodies.

Conclusion: the possibility of alliances

If the political force that is the disability movement is to avoid constituting itself as located on the 'right' side of a barrier – leaving those on the 'wrong' side in social and conceptual limbo – a redefinition of its scope is needed.

I have already noted that poststructuralist theorists problematise the notion of a stable and unified disabled identity. From a modernist perspective, too, it can be questioned to what extent the definitions of activists represent the complex and manifold preoccupations and self-perceptions of the populations they claim to represent – an issue bedeviling many political movements. These objections can be met only by an acknowledgement that there are differences of interest – as well as a multiplicity of overlapping and interlocking interests – between people with various bodily 'differences', 'difficulties' or 'impairments', and that these people will also have differing and shifting relationships not only to each other, but to what counts as the world of 'normality'. Thus, some sick or disabled people will wish to fight for the right to work, or to participate in other 'normal' social activities, perhaps claiming special arrangements to enable them to do so; while others will demand exemptions: the right to an income without working, and the right to rest. Many people, no doubt, will veer

between these two positions, depending on their social situation and physical condition at the time. Even those in 'objectively' similar bodily states may differ amongst themselves in their understanding of their situation, with some seeing medical intervention as an optimal solution, and others prioritising a change in social structures and an end to discrimination.

What chronically sick people would gain from this broadening of the disability movement is inclusion in a political forum in which they could begin to articulate their social needs, ranging from respect for their experience and endurance to material arrangements which would make their lives less difficult. Disabled people, on the other hand, might benefit in feeling free to 'include all of their lives' (Crow, 1996). It is impossible to know how many adherents of the disability movement grapple with some sense of not truly belonging, because, for instance, they experience weakness and pain which conflict with a stereotype of a 'true' disability activist; nor can anyone know how many people are alienated from any kind of disability activism for the same reason.

The disability movement in the UK has only recently begun to address issues of difference and diversity in relation to gender, race, class and sexuality, amidst concerns that an exploration of these matters might lead to fragmentation (Fawcett, 2000, pp. 36-37). Extending the scope of the movement to include the interests and experiences of the chronically ill might compound this danger. There is genuine cause for concern about whether an influential political force can be forged out of what might become more like a network of sympathetic alliances than a unitary movement. There are also many unanswered questions about the practical operation and co-ordination of such a network. A major shift in thinking would be required on all parts, with 'sick' people focusing less on the specificities of their particular condition, and 'disabled' people more open to an understanding of various bodily discomforts and their effects. The result, however, might be a wide-ranging and radical challenge to the organisation and values of a society increasingly obsessed with bodily perfection.

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