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## **REPRESENTING DISABILITY: SOME QUESTIONS OF PHENOMENOLOGY AND POLITICS**

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### **INTRODUCTION**

The business of writing about disability has become a hotly contested terrain in recent years. Parallel discourses have developed with scarcely any cross-fertilisation of ideas. There are many reasons for this absence of dialogue. There are long-standing differences in the terms people use for describing disability. Indeed, language of disability itself has become the object of political analysis and dispute, and it is increasingly difficult to use terms to describe chronic illness and disability innocently (Zola, 1993).

There is, therefore, no neutral language with which to begin the process of discussing chronic illness and disability, and language itself is central to any discussion of how we approach the problem of dealing with 'disability'. In short, disability is fundamentally a problem of 'representation'. It is a problem of representation in the sense that there is no language to talk about it that is untainted. It is a problem of representation in that the language and categories we use influence both the definition of the problem and the size of the problem as an epidemiological phenomenon. And it is a problem of representation in the sense that there is continuing dispute about who are the legitimate representatives of the experience and reality of disability in the modern world.

At the heart of the dispute over representation lies the question of how one construes the relationship between the experience of 'impairment' and the 'environment' that constitutes the reality of the experience of chronic illness and disability. The relationship between the environment and impairment is a core issue in much of the work that has been undertaken in disability theory, sociology, and rehabilitation. However, the nature and direction of the relationship has been approached very differently within these fields. Within rehabilitation, the environment has been defined for the most part as a physical phenomenon, a set of discrete obstacles or barriers, which add to

and amplify the problems of impairment afflicting individuals. Within disability theory, the environment is regarded as the expression of power, a universe of discrimination and oppression within which disability is created. The sociological study of chronic illness and disability has tended to define the environment as something arising out of the symbolic and social interaction that takes place between individuals and their worlds as they negotiate their everyday lives.

These varying conceptualisations of the relationship between disability and the environment lie at the heart of the disputes that have arisen between people working in these different fields. Focusing too much on the impairments is seen to deflect attention from the systematic way in which the environment excludes people from participation in civil society. Placing too much emphasis on the politics of exclusion may be regarded as a way of underplaying the real effects of different impairments and the complex, 'negotiated' aspects of everyday life, thereby creating a spurious homogeneity. Focusing on interaction and the negotiation of identity can lead the investigator to be sucked into a bottomless pit of phenomenological analysis where the structures which underpin or destroy identity are lost from sight. As well as reflecting the organisation of different interests in the disability field, these varying approaches also reflect diverse perspectives on the nature of social science and the relationship between social science and political action.

The dilemmas posed by these different definitions of the situation have been spiced by the current ferment in the movement for the civil rights of disabled people. For those who are on the front line of the political battle currently taking place, the niceties of sociological analysis may seem an undesirable luxury or an irritating irrelevance. However, using the work of the American sociologist and disability activist Irving Zola as an example, I will argue that it is possible to be politically committed without being sociologically one-dimensional and that a multidimensional understanding of 'the environment' is required if ways are to be found of making civil society less oppressive and more homely.

## **IMPAIRMENT AND REHABILITATION**

The medical model that informs traditional approaches to disability takes the biological reality of impairment as its fundamental starting point. The focus of the analysis and the intervention is on the functional limitations which an individual 'has' and the effect of these on activities of daily living. Although rehabilitation practitioners may make reference to the way in which disability

affects the 'whole person' or 'all aspects of an individual's life', the nature of this wider context is rarely built systematically into analysis or recommendations for intervention (Gloag, 1985; College Committee on Disability, 1986). There is a recognition of the crucial role of 'the environment', but little if any attempt to develop a phenomenological or political analysis of the constitution of the forces which make up the environment for the individual or groups of people who 'have' the impairment or 'live with' the disability. The environment is something added, almost as an afterthought, to the basic project of dealing with the impairment. From the early 1970s onwards, those professionally engaged in the rehabilitation world recognised the need to move away from the highly reductive conceptions of functional limitations focusing on deficits in limbs and organs which had traditionally characterised physical medicine and physical therapy. This new 'holism' was enshrined in official reports, with the promulgation of broader definitions of rehabilitation as 'the restoration of patients to their fullest physical, mental, and social capability' (Mair, 1972; Tunbridge, 1972).

Increasingly, broader definitions of health status in patients with chronic illness and disability were used for two main reasons (Williams, 1987). First, to assess needs for treatment, therapy, services, or benefits; and secondly, to provide a baseline from which to perform more realistic evaluations of change in the health and functional status of patient, both informally and as part of research. The focus of these evaluations was still very much on the individual, but with a recognition that it was the person who could or could not perform certain kinds of activities rather than the organ, the limb, or the body conceived abstractly as a bundle of capacities and incapacities. The most common type of descriptor consists of assessments of performances in daily living stressing those activities which are purportedly carried out habitually and universally (Williams, 1987). There is no doubt that measuring directly a range of daily activities is an improvement on the conventional clinical measures of 'functional capacity'. However, the fact that they are deemed to be universal rather than context-bound implies that they can be used across multiple settings without any substantial reconsideration of their validity, and without consideration being given to the meaning of the items for the person with the impairment. The Barthel Index, for example, asks only whether a person can walk 50 yards on level ground regardless of whether he or she wants to, needs to, or has anywhere to go (Granger et al., 1979).

In other words, such traditional assessments provide a picture of 'activities of daily living' devoid of any phenomenological grasp of the individual's own experience and any political analysis of the structures and contexts within

which the activity takes place. In line with the positivistic underpinnings of medical science the emphasis of traditional assessments is on some universal definition and measure that can be applied by appropriately qualified people without reference to the disabled person's own perspective, the roles they occupy, the relationships in which they are embedded, the circumstances of their milieux, or the wider political context of barriers, attitudes, and power.

In research on rehabilitation within this perspective, the environment and the experience of the individual may exacerbate the consequences of impairment, but the focus remains very much on the impairment:

Lower-limb amputation represents a formidable handicap whatever its cause. The young man who loses a leg following a road traffic accident becomes impaired at a time when occupational and financial responsibilities may be heavy....The social problems experienced by the disabled are generally slow to resolve, and current health and social services policies fail to recognise these difficulties (Thompson and Haran, 1983, p. 165).

Both medical sociology and disability studies have in different ways attempted to develop a critique of such traditional models of the relationships between disability and the environment, in the context of the experience of individuals in relation to their milieux and the wider structures. In that sense they are both a critique of positivism, but they vary in the emphasis which they give to subjectivity and structures.

## **SYMPTOMS AND SITUATIONS**

The numbness in my hand is getting very trying...The Baby puts the lid on it all. Can't you see the sordid picture? I can and it haunts me. To be paralysed with a wife and child and no money - ugh!' (Barbellion, 1984, p. 253).

Sociological research on chronic illness and disability has focused on the meaning of illness in its context. The depth of the exploration of meaning varies depending partly on the extent to which the analysis focuses on one or other of two senses of meaning identified by Bury (1991). Bury argues that the meaning of an illness can be defined in terms of its 'consequences', which refers to the impact it has on practical aspects of the person's roles and relationships in everyday life; or in terms of its 'significance', which

relates to the cultural connotations, the symbols and significations, surrounding different sorts of illness and disability.

Both these forms of analysis of the meaning of chronic illness and disability have the notion of embodied experience at their centre, but rather than attempting to define functional incapacity or activity restriction in biomedical terms, they explore the ramifications of the experience from the point of view of the person affected. In other words, while the biomedical model has disease or dysfunction at the centre of its picture, the sociological perspective focuses on illness as something whose meaning and reality vary depending on the biography of a particular individual and the circumstances in which they find themselves.

W.N.P. Barbellion, the pseudonymous nineteenth century diarist (who the 'experts' believe had what would nowadays be diagnosed as multiple sclerosis), illustrates very nicely how important both senses of meaning are in understanding the experience of chronic illness, and how they interact. The numbness in his hand is upsetting for him because of what it might signify about him; and what it might signify about him is dependent upon his circumstances - a new father with financial responsibilities in the context of British society prior to the development of a health service and a welfare state. Taken together these represent a 'sordid picture' in his own mind. Regardless of the fact that his symptoms at the time he was writing were limited in the sense that he was not restricted in most activities of daily living, from his point of view and situation the symptoms were highly significant and consequential.

The attempt to understand the meaning of experience by looking at it in its context lies at the heart of the medical sociological project. The focus on chronic illness and the experience of disability associated with it can be seen as an attempt to move away from the rehabilitation models which were rather static, in addition to their being reductive and focused on the mechanics of functional limitations and activity restriction. While the experience of 'adaptation' to a limb amputation or some other trauma-induced impairment clearly has its own dynamics, influenced by personal, situational and treatment factors, chronic illness adds a new dimension of enormous variability and unpredictability (Bury, 1982; Strauss and Glaser, 1984). Moreover, the experience of different chronic illnesses is - to tempt tautology - clearly a very different experience. While disability might have certain common features, sociologists have been interested in both subjective variation in responses to the 'same' illness and impairment and variation in the meaning (in the second of Bury's senses) of different kinds of symptoms in society. Explorations of breathlessness, raging skin, inflamed joints, heart

problems, end-stage renal failure and many others have allowed sociologists and anthropologists to explore the seemingly infinite permutations of the experience of being physically different in a highly normalising society (Anderson and Bury, 1988; Strauss and Glaser, 1984).

Some of these sociological analyses are phenomenologically `deep' or `thick', others are more inclined to skate over the surfaces of meaning, but nevertheless deal with the interaction between symptoms and situations. The hallmarks of this kind of work are, therefore, its focus on the symbolic and material interaction between the individual and society, and the interpretative processes whereby individuals construct meaning from their experiences. The environment focused upon is that which emerges in the meaning-giving processes of interaction between the individual, their milieu, and the wider society. It therefore follows from this that disability (or `handicap') in the World Health Organisation's (1980) sense is the product of complex processes of interaction between an individual with an impairment and the discriminating, disadvantaging, stigmatising and prejudiced wider society. It is neither `in' the individual nor `outside' the individual `in' society:

`The extent to which functional limitations and activity restrictions constitute a problem, or are otherwise handicapping, is not only variable historically and culturally but is also somewhat dependent upon more immediate contexts; their meaning is not the same across different social and environmental settings' (Locker, 1983, p.5).

The point for Locker, therefore, is that `disability' or `handicap' as a social reality of people's experiences is caused by neither the externalities of the environment, nor by any `facts' of biological trauma or deterioration. This kind of analysis is primarily concerned with meaning as consequences rather than meaning as significance, though it may - as Locker does - explore at some level the `significance' of symptoms to individuals in terms of some notion of `felt stigma' (Scambler, 1989).

With this shift in focus from the individual with an impairment to the meaning-giving nature of interaction there comes a shift in the nature of the intervention that may be appropriate. If the problem is not the need of the individual to adapt to the impairment, but rather the complex process of negotiating the interactions out of which daily life is created, then the role of professional experts as people who do things to the impaired body is clearly limited. Much more important may be a supportive milieu of lay people who can help the individual renegotiate their place in the world (Williams and Wood, 1988).

The notion of re-establishing a place in the world is at the heart of some of the more phenomenologically deep analyses of the meaning of chronic illness and disability. These too may concentrate on the interactions within the mundane world, but there is a sense in which the purpose of these interactions can be interpreted as having rather more transmundane qualities. Such analyses lead us away from the empirical features of the impaired individual's interaction with the material world back into the individual's `self' and `body'. The focus of the problems shifts from interactionism to the exploration of the lived body, the body incarnate, drawing its theoretical inspiration less from symbolic interactionism and more from philosophical phenomenology.

In some of the work of Charmaz for example, she talks of the process of `immersion in illness' which `means experiencing the vulnerability of one's body' (Charmaz, 1991, p. 80). The process of living with chronic illness becomes so highly personalised that it leads us further and further away from any sense of the society in which the anguish of experience is embedded; and, as a consequence, the processes through which the response to chronic illness and disability emerge become less and less social and collective and more and more rooted in the psychological, cognitive and existential world of the individual. There is less exploration of the interaction between the person and the `environment' in the presence of the disruptive effects of chronic illness, and more searching the constitution of the self in the presence of a disordered body.

Some of the most powerful phenomenological analyses come from individuals, usually middle class and often academics or writers themselves, who have tried to explore autobiographically the depths of their own experiences of cancer, neurological disease, heart attack or whatever else (Murphy 1987; Frank 1991). The best of this work gives pre-eminence to the ill person's perspective, emphasising the `illness' (the social experience) above the `disease' (the physiological processes). However, the aim within this project to attempt `...to consider illness stories as embodied also deconstructs the distinction: the illness experience is an experience in and of a diseased body' (Frank 1995, p. 187).

In much of this work the storied or narrative nature of illness and disability is emphasised. The exploration of the experience of illness becomes a vehicle for exploring basic questions about the nature of the self in the world, the fundamental meaning structures in a person's life. The concept of a narrative is a powerful framework for analysing the experience of chronic illness for a number of reasons: it provides a vehicle for exploring the temporal nature of illness; it describes a life as both a sequence of events and as unified around

some purpose or purposes; and it moves back and forth between the subjective experience and the world in which the experience is lived out. If the chronic illness and disability can be seen as experiences which disrupt 'biography', making problematic the relationship between the individual and the environment, it makes sense to regard the experience of having a chronic illness or disability as part of a process of 'narrative reconstruction' (Williams, 1984).

There are now too many examinations of narratives of chronic illness and disability to do justice to the range and complexity of such work here. It is a body of work which has many origins. It is partly to do with a growing interest in narratives, across a range of disciplines and beyond the specific issues of illness and disability (MacIntyre, 1981; Ricoeur, 1991). It is also a form of discourse about illness which has been given a high public profile by the history of HIV and AIDS where the intersections of personal identity and the history of a societal response to disease, disability and death have, of course, been particularly sharply defined. While some of this work emphasises the materiality and the historicity of such narratives - the political economy of illness (Radley, 1993) - other research engages more and more deeply with the subjectivity of the experience - the negotiation and renegotiation of identity through talk, the rediscovery of self in the chaos of illness and so on (Sacks 1985). Some have explored with great skill and empathy the different kinds of narratives which can be constructed about the experience of chronic - often terminal - illnesses (Frank, 1995; Mathieson and Stam, 1995).

In the end, however, the danger in much of this work is that it loses sight altogether of the structures which make the experience take the shape it does. History and even biography are dissolved in ever deeper phenomenological penetration into the interstices of self and world. What started out as a sociological analysis becomes part of a quasi-religious or spiritual quest for the truth which illness is supposed to reveal. So profound is the truth of illness that even the person experiencing the illness is merely a vehicle for allowing the body to speak of its suffering. This is truly the body incarnate:

'The body is not mute, but it is inarticulate; it does not use speech yet begets it. The speech that the body begets includes illness stories; the problem of hearing these stories is to hear the body/ speaking in them' (Frank, 1995, p. 27).

While Christian theology and the learning of other world religions certainly provide rich languages for exploring questions of ultimate concern: life and

death, suffering, guilt and redemption, they can also - if we are not very careful - reduce the individual to a body, and limit the experience of illness and disability as a personal quest for meaning and truth. The politics and history of illness and disability become marginalised. The realities of health and social care become forgotten. All that is left is the individual engaged in some abstract process of overcoming bodily 'failure' and 'coming back' to normality:

'Coming back is the process of returning to a satisfactory way of life, within the physical/ mental limitations imposed by a disabling condition .... To come back is a very personal experience. Although others can provide assistance, only the individual can come back' (Corbin and Strauss 1991, pp. 138-139).

While it is certainly not the intention of this sociological analysis to produce a prescription for what is to be done that denudes the situation of its politics and material basis, it does show how difficult it is to explore the experiences of individuals while remaining alive to the politics of the situation.

## **THE POLITICS OF DISABILITY**

Against this background, it is not surprising that those working from within the movement for the rights of disabled people should want to distance themselves from sociological contributions to the study of chronic illness. It is not my intention to review the work of disability theorists and activists in any detail (they are well represented in this volume and can speak for themselves). Let me just provide enough of a commentary on their work to provide a clear counterpoint with what has gone before.

I have tried to show how sociologists have responded to the limitations of traditional rehabilitation perspectives on chronic illness and disability. They have done this by emphasising the need to move away from professional definitions of impairment and disability in order to explore the ways in which people with chronic illness and disability defined the relationship between their symptoms and situations. Using various forms of qualitative method they have attempted to reconstruct from people's own accounts of their experiences the reality of chronic illness and disability as something which emerges out of the relationship between the person and the environment. The World Health Organisation's Classification (1980) illustrates at a conceptual level what most of these studies attempt to accomplish at an empirical level. The concept of 'handicap' is used to describe a reality which

is relational or interactional, and most of the studies of chronic illness and disability within sociology echo that conceptualisation.

However, I have also indicated how the relational can at times slip into a phenomenological analysis in which the individual or even the body returns to the centre of attention, albeit constructed in a discourse somewhat different from that employed within rehabilitation medicine. While explorations of the lived body can illuminate experiences of extreme situations, once detached from the political economy and history of disability and its relationship to State and society, they can become an unhelpful form of self-analysis. The consequence of this is that what began as an attempt to see chronic illness and disability as the product of the complex relationships between individuals, milieux and social structures becomes a picture in which the illness is portrayed as something which causes certain social consequences.

This is in stark contrast to the work of many disability theorists in Britain and elsewhere for whom the prime mover in causal terms is most certainly not the illness, nor the individual in a state of tragic adaptive 'failure', but the oppressive society in which disabled people live. If disability is seen as a personal tragedy, disabled people are treated as the victims of circumstance. If disability is defined as social oppression, disabled people can be seen as the collective victims of an uncaring, discriminatory society (Oliver, 1990). This fundamental position is that which underpins most of the writing by disability theorists in Britain. It is a line which leads to a very different picture of, for example, the nature of dependency. Let me contrast two quotations in order to give a flavour of the difference between some medical sociology and the work of disability theorists:

'Certainly physical dependency, if not also social and economic dependency, can result from illness' (Charmaz, 1991, p.80).

'Dependency is created amongst disabled people, not because of the effects of functional limitations on their capacities for self-care, but because their lives are shaped by a variety of economic, political and social forces which produce it' (Oliver, 1990, p. 94).

The problem to be overcome is not anything within the individual's body, mind or soul. There is no personal road to redemption and salvation. It is, as I indicated in looking at the work of sociologists like David Locker, to do with the resources in society. However, in this case, the relationship between the individual and society is much more clearly stated: disability and dependency are caused by society. On this analysis '...hostile environments and disabling barriers - institutional discrimination' are seen as the 'primary cause of the

problem' (Barnes, 1992, p. 20). Proponents of this `social model' of disability argue that disability is caused by society, and if you change society you can eliminate disability.

The causal relation is reversed and, as a consequence, the traditional models and practices of those engaged in rehabilitation come to be seen as part of the problem. If the dominant ideology of the medical model informing rehabilitation defines the focus as what has happened to an individual and what can be done `for the patient', attention is distracted from the primary structural causes; and the medical profession and those working alongside them become key figures in the perpetuation of oppression. Sociologists who concede any primary role to the bodily disorder or impairment are seen to be participating in an oppressive ideological practice, and the WHO classification which (as far as I can judge) was put forward to socialise and collectivise our understanding of `disablement' becomes transformed into an extension of the medical model. Sociological analysis of what disability is like, from the point of view of someone with an impairment or disability - the phenomenological or interactionist exploration of the construction of reality - becomes another ideological justification for the oppression of disabled people.

My arguments against this position are well known (Williams, 1983; 1988; 1991). It seems to me that the oppressive quality of everyday life for many disabled people is without question, and the origins of much of this oppression lie in the hostile environments and disabling barriers which society (politicians, architects, social workers, doctors and others) erect. However, the processes whereby discrimination takes place are often extraordinarily subtle, for three reasons. First, most disability in modern societies emerges from chronic illness, and illness, unlike ethnicity or gender, emerges slowly over time. Secondly, someone who is able-bodied is only temporarily so. Disability is therefore a category theoretically open to everyone, and as populations age, one that becomes a more likely end-point for any given individual. Thirdly, disability is, at some level, undeniably to do with the pain or discomfort of bodies, and this is a dimension of the oppressive quality of chronic illness and disability for large numbers of people. While civil rights movements are therefore a powerful response to some aspects of the oppression of disability, they are not the whole story. In the final section I examine briefly the work of one of the very few social scientists, also an activist, who managed to retain a phenomenological and interactionist analysis of disability within a collectivist framework.

## **REPRESENTING DISABILITY**

Irving Zola was one of the key participants in the self-help and disability rights movements in the USA. He was also a medical sociologist who had written extensively on the relationship between culture and illness and the nature of medical power. Zola had experienced polio as a young child and a serious road traffic accident in his teens. These experiences had made him aware of his body, the extent to which he was treated differently, and the roles and activities of professional experts. Although Zola had a long-standing involvement in politics and had written penetratingly about the dangers of medical power (1972), he did not apply these twin concerns to his own experience of disability and the reality of life for disabled people until he was well into his career. These experiences have been written about by Zola with considerable autobiographical insight (Zola, 1982; 1983), and much of his writing was a blend of the personal and the political:

‘What I have produced might well be called a socio-autobiography, a personal and social odyssey that chronicles not only my beginning acknowledgement of the impact of my physical differences on my life but also my growing awareness of the ways in which society invalidates people with a chronic disability’ (Zola, 1982, pp. 6-7).

Zola was concerned to represent the interests of people with disabilities, and to explore new ways in which those interests could be represented. He preferred to talk about ‘people with disabilities’, putting people first, but he emphasised that in choosing certain terms he was ‘...not arguing for any “politically correct” usage but rather examining the political advantages and disadvantages of each’ (Zola, 1993, p. 171) and, in Zola’s view there was no single, unequivocal authentic voice of disabled people (Zola, 1988a), nor is there any set of definitions of the universe of disability which can or should be adopted as some kind of secular gospel.

Zola’s writing on disability has a number of different aspects. His early work drew on his own personal experiences and his involvement in the self-help movement in order to develop a critique of the rehabilitation system and its models of adjustment and adaptation. Along with many other activists Zola was concerned with two interrelated problems: first, that the rehabilitation process was not producing the kind of ‘adjustments’ that actually enable disabled people to live independently in society. Secondly, that even with good rehabilitation, the determinants of independence for disabled people were more to do with the organisation of the physical and social environment than with any professionally managed adaptation process.

During the early 1980s, Zola recognised that while his politics had to be unwavering in the articulation of demands for independence and an end to discrimination, there was more to a sociological analysis of disabled people's oppression than an empirical identification of environmental barriers conjoined with a conspiracy theory regarding the interests of professionals engaged in rehabilitation. In line with many other activists in both Britain and the USA, Zola recognised the undermining power of the dominant ideology of disability which regarded 'it' - that is the thing from which the individual 'suffers' - as a personal tragedy. However, in contrast to much of the work in this field, Zola recognised that the oppression experienced by people with disabilities was a complex matter.

Contrasting disability with race, for example, he argued that:

'...the social invisibility of people with a disability develops more insidiously. Children spontaneously express an interest in wheelchairs and leg braces, but as they grow older they are taught that: "...it's not nice to ask such things"....But why all this effort? Why this distancing of the chronically ill and handicapped? Why are we so threatening that we must be made socially invisible?' (Zola, 1982, p. 200).

The threat to be removed, Zola suggests, lies not just in society's failure but in the inevitability of one's own:

'When the "able-bodied" confront the "disabled", they often think with a shudder, "I'm glad it's not me"... The threat to be dispelled is the inevitability of one's own failure. The discomfort that many feel in the presence of the aged, the suffering, and the dying is the reality that it could just as well be them' (Zola, 1982, p. 202).

In some of his later work, in particular, he discussed the enormous implications of ageing societies peppered with chronic illnesses for the development of the disability movement (Zola, 1988b), pointing out that the processes of ageing were something that linked the interests of 'the able-bodied' to those of 'the disabled'. However imperative it may be politically to define people with disabilities as a minority group, it is a curious minority which will include us all if not today, then tomorrow, or the day after, and that:

'....only when we acknowledge the near universality of disability and that all 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' (Zola, 1989, p. 420).

It was Zola's `...conviction that it is impossible to create a society without disease and disability' (Zola, 1988b, p. 380). There is no all-encompassing master-slave narrative, there is no simple schema - Marxist, Freudian, or Foucauldian - which will illuminate the matrix of power and knowledge within which disability exists, and there will be no simple revolutionary change in medicine or in politics which will deliver liberation. The oppression is not easy to see or articulate, and people speak in different voices:

`If one has been oppressed for thousands of years, one does not gain a voice overnight. One of the features of oppression is the loss not only of voice but of the tools to find it...It will take us time to speak out, to learn what we have lost, to articulate what we need. But as I have tried to state here and elsewhere, the numbers trying to speak out are ever growing and the chorus of voices is increasingly diverse' (Zola, 1994, p. 65).

In place of the monochrome languages of the `medical model' on the one hand and the `social model' on the other, we find in Zola a willingness to examine disability from many points of view, and a desire to understand the contribution the different voices have to make to our discussions about disability. In the context of an occasionally intolerant debate over the correct language to use in talking about disability, Zola's work was a bold attempt to hold firm to the politics of disability while remaining free to explore its darker phenomenological waters. He wanted to place at the forefront of any discussion of disability the bleak realities of economic deprivation, disenfranchisement, and marginalisation, while insisting on the continuing need to find a place for research in clinical rehabilitation and an interpretative social psychology of the personal worlds of people with disability and chronic illness. Zola believed, in short, that you could not deal politically with disability without confronting it personally. He was committed to a civil rights perspective on disability, but he recognised that an understanding of disability also required an anthropology of the body and the emotions.

What marked Zola out was his willingness to be pluralistic without losing sight of the need for taking a position on issues of moral and political importance. He recognised that neither the life of a disabled individual nor the history of disabled people could be understood without understanding both. Neither medical sociology nor disability theory were of any use unless they made connections with the world of policy and politics on the one hand and the realm of personal experiences and narratives on the other. The `voice' which was so important to Zola within the disability movement, was the voice which told a story that connected with other peoples stories, providing the

foundation for a collective identity, a common agenda, and a shared strategy for social change.

## **CONCLUSION**

In this paper I have described some of the complex issues to be addressed in writing about or representing disability as a social phenomenon. Like other areas of social and political analysis, there is a tendency to veer towards either an 'undersocialised' or an 'oversocialised' conception of human life. Moreover, these conceptualisations are not neutral. They reflect fundamental interests, and one cannot pretend that these interests do not have implications for the way in which people are likely to be treated on the basis of them. It seems to me that the medical model is reductive. It is rooted in biology and it serves the interests of the medical profession and those professions and other economic and political groups allied to it. It is an intellectually and politically limited model for responding to the problems covered by the term 'disability' in the modern world.

It is limited for two reasons. First, it neglects the subjective experience of illness and impairment and reduces it to a set of discrete problems requiring technical interventions. In this sense the clinical approach to rehabilitation is dehumanising. Secondly, it deflects attention from many of the material and social bases of the difficulties people experience. In these terms it depoliticises disability. For this reason, the critiques of both medical sociologists and disability theorists are important. However, they too have their pitfalls. I have shown that the work of many sociologists starts off by viewing the experience of chronic illness and disablement in its context of social and economic circumstances, but gets side-tracked into increasingly solipsistic explorations of identity and self. With regard to disability theory, many of those writing from the perspective of the 'social model' seem so concerned to retain a tough political line on social oppression, that they are unable to accommodate the subtleties of social experiences of chronic illness.

In the struggle for equality in an unequal world simple positions need to be taken. However, we should not allow the strategic imperatives of disability politics to deflect our attention from the many needs experienced by people with chronic illnesses and the multiple perspectives they bring to bear on their situations. These perspectives reflect differences in bodies, interpretations and the degree of social exclusion and disadvantage people experience. In the harsh and uncertain welfare world of the late twentieth century we need to go beyond the fragmentation of post-modern political

radicalism and forge new alliances across bodies, experiences and socio-economic structures.

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