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## **SOCIETAL RESPONSES TO LONG-TERM DISABILITY**

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Whatever the fate of disabled people before the advent of capitalist society, with its coming they suffered economic and social exclusion. As a consequence of this exclusion, disability was produced in a particular form-as an individual problem requiring medical treatment. Old age suffered a similar fate. The transition to late capitalism ( or the "post-industrial society" as some writers have called it) has led to demands for the inclusion of those previously excluded. Consequently, the production of disability as an individual medical problem has increasingly come under attack and attempts to produce disability in a different, social form commensurate with inclusion, have been appearing upon the societal agenda.

Before proceeding further, it is perhaps necessary to explain the terminology used in this chapter (see Appendix). Underpinning it is a materialist view of society: To say that the category "disability" (or ageing or any other social category) is produced by capitalist society in a particular form implies a particular world view. Within this world view, the production of the category disability is no different from the production of motor cars or hamburgers. Each has an industry, whether it be the car, fast food, or human service industry. Each industry has a work-force which has a vested interest in producing its product in particular ways and in exerting as much control as possible over the production process. The production of disability can therefore be viewed as a set of activities specifically geared toward producing a good - the category "disability"- and which are supported by a range of political actions that create the conditions to allow these productive activities to take place and underpinned by a discourse that gives legitimacy to the whole enterprise. This chapter is part of an attempt to produce disability in a new form; an attempt which stems from disabled people themselves.

In order to understand societal responses to long-term disability, it is necessary to understand that the production of disability is in transition. In this process of transition, the move away from an individualised, medical view of disability does not imply that there is no role for medicine

in the world to which we are moving, Clearly, part of the experience of disability will remain an individual one. But in order to develop more appropriate societal responses to disability, it is important that we all understand-health care professionals and disabled people alike- that this is a partial and limited view. Our complex and difficult task is to understand that this process is one of transition from one world view of disability to another. This process is what Kuhn would call a "paradigm shift" (1).

There are three basic levels at which we can approach this task: the ontological, the epistemological, and the experiential In other words - What is the nature of disability? What causes it? And how is it experienced? These basic questions raise different sets of issues at different levels of abstraction. The ontological level requires issues to be addressed in terms of grand theory.<sup>1</sup> The epistemological level requires issues to be addressed in terms of middle range theorising.<sup>2</sup> The experiential level requires issues to be addressed in terms of developing an appropriate methodology for understanding the experience of disability from the perspective of disabled people themselves.

These levels do not exist independently of each other except in a conceptual sense. Rather, they interact with each other in producing what might be called the totality, or indeed, the hegemony of disability.<sup>3</sup> The hegemony of disability (Table 20.1), as it is produced by capitalist society-and it should be emphasised that other societies have produced

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<sup>1</sup>Examples of grand theory would include the following works: Parsons T, *The Social System*. New York: Free Press, 1951; and Marx K, *A Contribution to the Critique of Political Economy*. Chicago: University of Chicago Press, 1913.

<sup>2</sup> The need for middle range theories stems from the work of American sociologist R Merton. See his work *Social Theory and Social Structure*. New York: Free Press, 1968.

<sup>3</sup> Hegemony, as it is used here, describes the ways in which the ontological, epistemological, and experiential levels interconnect with each other to form a complete whole. It is borrowed from the work of Antonio Gramsci, an Italian sociologist and political theorist. For an introduction to his work, see Boocock R, *Hegemony*. London: Tavistock, 1987.

disability in different forms<sup>4</sup> - stems from the ontological assumptions it makes about the pathological and problem-oriented nature of disability.

These ontological assumptions link directly to epistemological concerns about the causes of disability in individuals with a view to eradication through prevention, cure, or treatment. Hence, the assumption in health terms is that disability is pathology, and in welfare terms that disability is a social problem. Treatment and cure are the appropriate societal responses to pathologies and problems. Finally, these assumptions and concerns exert a considerable influence on the way disability is experienced by non-disabled and disabled people alike - to have a disability is to have a problem, to have a disability is to have "something wrong with you."

In recent years, the hegemony of disability has been under a sustained and persistent attack in late capitalist society. At the ontological level this has led, not to a denial of the problem-oriented nature of disability, but of its assumptions of pathology. At the epistemological level, middle range theorising has been turned on its head; disability is caused not by the functional, physical, or psychological limitations of impaired individuals but by the failure of society to remove its disabling barriers and social restrictions. At the experiential level, disabled people increasingly are seeing their problems as stemming from social oppression (2) and institutionalised discrimination (3). In other words, disability is something wrong with society.

Thus, the argument that the problems of disability are societal rather than individual, and that these problems stem from oppression by society rather than from the limitations of individuals, is an essential part of developing an understanding of societal responses to long-term disability. Further, there is plenty of evidence to show that most policy and practice in this area has failed because it has been based upon individual rather than social models of disability (4,5); the individual model being a product of exclusion, the social model currently being produced by demands for inclusion.

However, in attempting to understand the hegemony of disability, the ways in which the individualising of disability is interconnected at the

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<sup>4</sup> For examples of the production of disability in different cultural forms, see Oliver M, *The Politics of Disablement*. Basingstoke: Macmillan 1990. and St. Martins Press. 1990 (Chapter 2).

levels of society, policy and practice, and personal experience is crucial. These interconnections are critical in the attempt to reformulate disability as an issue for society and develop a more appropriate social understanding of policy responses, professional practice, and personal experience.

The individualising of disability permeates all three levels and connects them in that disability is seen as a personal tragedy which occurs at random to individuals, that the problems of disability require individuals to adjust or come to terms with this tragedy, and that research has used techniques designed to "prove " the existence of these adjustment problems. The alternative view suggests that disability occurs in structured ways dependent upon the material relations of production (6); that the problem of adjustment is one for society, not individuals; and that research should be concerned with identifying the ways in which society disables people, rather than identifying the effects on individuals" (7,8).

Critiques of both the dominant way of understanding disability and the alternative formulation will be discussed in what follows and are summarised in Table 20.2.

### **GRAND THEORY: PERSONAL TRAGEDY OR POLITICAL ECONOMY?**

Grand theory , in sociological terms, is concerned with providing an all-embracing explanation of particular phenomenon at the highest level of abstraction. Undoubtedly, in terms of the phenomenon of disability, the dominant grand theory has been that of personal tragedy. This suggests that disability is a tragic happening that occurs to unfortunate, isolated individuals on a random basis. It further influences compensatory policy responses and therapeutic interventions designed to help individuals come to terms with tragedy. At the level of individual experience, many disabled people come to see their lives as blighted by tragedy.

The problem is that the personal tragedy theory does not provide a universalistic explanation of disability; in some societies disability is seen as the ascription of privilege, as a sign of being chosen by the gods (9). In others it is seen as bringing important social benefits such as bilingualism, as illustrated by the pervasive use of sign language throughout the community of Martha's Vineyard (10). Further, even within some capitalist societies, policies are moving away from

compensation and towards entitlement. Therapeutic interventions are also moving away from adjustment and toward empowerment. Finally, with the developing of a politics of personal identity, the experience of disability is being reinterpreted in positive rather than negative terms (11).

Political economy, on the other hand, suggests that all phenomena (including social categories) are produced by the economic and social forces of capitalism itself. The forms in which they are produced are ultimately dependent upon their relationship to the economy (12).

Hence, the categories of both ageing and disability are produced in their particular forms by these very economic and social forces. Further, both ageing and disability are produced as an economic problem because of the changes that result in the nature of work and the needs of the labour market within capitalism. The political economy perspective points to the structural dependency of the aged arising from conditions in the labour market and the stratification and organisation of work and society. (13)

Table 20.1 The Hegemony of Disability

Level Ontology	Questions What is the nature of disability?	Way of Understanding Grand theory
Epistemology Experience	What causes disability? What does it feel like to be disabled?	Middle range theories Methodology

Table 20.2 Exclusionary and Inclusionary Visions

Way of understanding Grand theory	Dominant Personal tragedy	Alternative Political economy
Middle range theories Methodology	Adjustment/Disengagement Positivist/Interpretive	Social adjustment Emancipatory

In other words, old people no longer play a key role in the process of production and no longer participate in the labour market. The same is

true of disabled people and has been so, except in times of severe labour shortage, since the time of the industrial revolution.

The speed of factory work, the enforced discipline, the time-keeping and production norms-all these were a highly unfavourable change from the slower, more self-determined methods of work into which many handicapped people had been integrated. (14)

Hence, the economy, through both the operation of the labour market and the social organisation of work, plays a key role in determining societal responses not just to ageing and disability, but also to ageing with a disability. Both old people and disabled people are forced into situations of dependency (15,16) because they do not participate fully in the processes of production. However, it would be wrong to assume that old disabled people simply experience a double dose of dependency; to put the matter simply, to be old and disabled is not twice as bad as merely being old or merely being disabled.

Critically reflecting on the author's work on ageing with a disability, common sense assumptions pointed in the direction of double handicap or double disadvantage, backed up by other work, notably in the area of gender and disability which made similar assumptions.

Both in analysing data and in looking at other views, it has quickly become clear that such notions were over-simplistic and indeed, oppressive. As one disabled woman argues,

It is not very helpful to talk about disabled women experiencing a "double disadvantage." Images of disadvantage are such an important part of the experience of oppression that emancipatory research (research which seeks to further the interests of "the researched") must consistently challenge them. Therein lies one of the problems with examining the relationship between gender and disability, and race and disability in terms of "double disadvantage." The research can itself become part of the oppression. (17)

Further, such additive approaches have also been criticised by black disabled people who argue that their experience of disability can only be

understood within the context of racism. Thus according to one black researcher,

In my opinion, the concept of double discrimination, as propagated by white disabled feminists is an inadequate framework within which to understand racism within disability...on the contrary, I suggest that racism within disability is part of a process of simultaneous oppression which black people experience daily in Western society. (18)

Whether simultaneous oppression offers a more adequate way of understanding disability is something that only further, more developed emancipatory research can show. Whether such a concept can cope with old, black, gay, disabled people remains an open question. So, too, do its links with middle range theorising and grand theory. Such questions indicate that, after 10 years, the work is only just beginning.

Thus, it is necessary to return to the crucial question of what is meant by political economy and whether it is possible to have separate political economies of ageing and disability, or indeed race, gender, welfare, or any other category. The generally agreed upon definition of political economy is:

The study of the interrelationships between the polity, economy and society, or more specifically, the reciprocal influences among government...the economy, social classes, state, and status groups. The central problem of the political economy perspective is the manner in which the economy and polity interact in a relationship of reciprocal causation affecting the distribution of social goods. (19)

There are two problems with such a definition. To begin with, it is an explanation that can be incorporated into pluralist visions of society as a consensus emerging out of the interests of various groups and social forces. Further. it fits materialist theories of society which, in the last instance, see economic factors as determining social relations. Such political economies often themselves become oppressive in that they

divide experiences into an arbitrary set of socially constructed categories, such as old age, race, gender, and disability.

Political economy, as it is used here, takes a particular theoretical view of society; one which sees the economy as the crucial, and ultimately determining factor in structuring the lives of groups and individuals. Further, while the relationship between various groups and the economy may differ in qualitative ways, the underlying structural relationship remains.

The convergence and interaction of liberating forces at work in society against racism, sexism, ageism and economic imperialism are all oppressive "isms" and built-in responses of a society that considers certain groups inferior. All are rooted in the social-economic structures of society. All deprive certain groups of status, the right to control their own lives and destinies with the end result of powerlessness. All have resulted in economic and social discrimination. All rob (American) society of the energies and involvement of creative persons who are needed to make our society just and humane. All have brought on individual alienation, despair, hostility, and anomie. (20)

As is usual in discussing the oppressions for which "isms" become shorthand, disablism does not merit inclusion. The reason for this is simple; even those writers who have specifically examined oppression have internalised the dominant, individualised world view of disability and have failed to conceptualise it as social oppression. Equally importantly, such theorising about oppression leaves the relationship between the various "isms" as non-problematic; with the exception of Abberley (21) there have been no attempts to analyse the similarities and differences between the oppressions of disability, race, and gender.

The "politics" part of political economy comes in the ways in which ageing and disability are constructed as particular kinds of problems. Any society wishing to appear "civilised" must make provision for those groups and individuals who cannot provide for their own needs through work (22) or resources built up through previous work (23). Hence, both ageing and disability are socially constructed as "problems."

Earlier it was suggested that producers of categories have an interest in shaping the ways they are produced. Both disability and old age are constructed as social problems because of the needs of the welfare system and the professionals who operate it, rather than the needs of old disabled people (24). Both are constructed as health problems because of the needs of the health care system and because of the imperialism<sup>5</sup> of the medical profession, which has proclaimed a whole range of social phenomena from crime, to homosexuality, through addiction, and onto naughtiness in children as problems requiring medical intervention (25).

#### MIDDLE RANGE THEORY: PERSONAL ADJUSTMENT, DISENGAGEMENT, OR SOCIAL ADJUSTMENT?

Middle range theories are usually concerned with linking the abstract concepts of grand theory to the specific experiences of particular phenomena. In terms of ageing and disability, loss has been the dominant metaphor for developing these perspectives. They have been operationalised in the study of ageing in terms of middle range disengagement theories and in the study of disability in terms of middle range adjustment theories. A critique of each will be provided before attempting to summarise recent work on social adjustment.

Until recently, the field of gerontology - the systematic study of ageing - has been dominated by theories that sought to explain how individuals react to the ageing process. Firstly, there are a range of individualist and psychological models which are primarily preoccupied with explaining "normal" and/or "successful" ageing - that is, adaptation to old age. Here, ageing is viewed as part of an ordered life process moving from birth to death, with each stage (adolescence, early adulthood, etc.) having its own set of expectations and behaviours (26). From this perspective, successful adaptation to ageing is represented by an individual accepting the changes that he or she has experienced and,

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<sup>5</sup> There are disputes between those who would claim that the medical profession is aggressively imperialistic, for example, Illich I, *Medical Nemesis: The Expropriation of Health*. London: Marion Boyars, 1975, and those who claim it is reluctantly imperialistic, such as Stone (22). What is important for the argument here is not *why*, but *that* medical imperialism is a potent force which has shaped the production of the categories of disability and ageing in particular ways.

ultimately, accepting the inevitability of death. At the same time, failure to undergo such change is often taken as evidence of pathological personality development (27).

One of the most influential models of ageing has been disengagement theory. This theory suggests that the life course is marked by stages such as "young old age," "middle old age," and "old old age." Here, the main emphasis is on "social roles" rather than personal psychology. From this perspective, ageing is characterised by various patterns of "disengagement" whereby - "as people grow older their behaviour changes, the activities that characterise them in middle age become curtailed, and the extent of their social interaction decreases" (28).

These developmental approaches to ageing have a certain usefulness in that they focus on individual experiences over the totality of the life course. There are several reasons, however, why theories based on disengagement and role change do not provide an adequate analytic framework for studying the experiences of ageing with disability.

First, the models of ageing implicit in these theories take little or no account of social factors which are external to individual psychological states or interpersonal behaviour such as the levels of pensions paid or social attitudes to ageing. Second, ageing is usually conceptualised in terms of an inevitable and pathological process; consequently, older people are viewed as victims lacking control over their own lives. These theories do not, therefore, take account of individual differences in attitudes, expectations, and resources. All of these factors may have a significant effect on how anyone individual may experience ageing - either positively or negatively (29).

Apart from these conceptual objection! to such theories, it is important to note that much of the existing research evidence indicates that the experiences of many older people simply do not match the kind of experience predicted. A major research study of ageing in three countries (30) showed that the majority of older people - given good health and adequate financial resources - do not experience a significant reduction in the scope of their activities, as disengagement theory would predict. More recent studies have also indicated that, where it does occur, any reduction in social involvement is much more closely associated with infirmity and poverty than with age itself (31). In other words, if some older people are less socially active, it is due to these external social factors which vary independently of chronological age. Because the individualistic approaches to ageing do not take sufficient

account of factors external to the individual, they make the basic error of assuming that the observable association between such problems and old age are actually caused by ageing itself.

Just as studies on ageing have been dominated by middle range disengagement theories, so have studies of disability been dominated by middle range adjustment theories. The argument suggests that when something happens to an individual's body, something happens to the mind as well. Thus, in order to become fully human again in order to form a disabled identity, the disabled individual must undergo medical treatment and physical rehabilitation as well as the process of psychological adjustment or coming to terms with disability (32). However, the conceptual framework provided by middle range adjustment theory has been severely criticised on theoretical grounds (33) as well as on the grounds that it does not accord with the actual experience of disability. Thus, alternative frameworks such as social adjustment (34) and social oppression (35) have been developed. But it is not just disabled people who have provided theoretical and experiential criticisms of this framework; researchers also have found it difficult to provide empirical evidence.

Our view of the available literature suggests that a great deal of variability exists in individual reactions to negative life events both within a particular life crisis and across different crises. We have found little reliable evidence to indicate that people go through stages of emotional responses following an undesirable life event. We have also reviewed a substantial body of evidence suggesting that a large minority of victims of aversive life events experience distress or disorganisation long after recovery might be expected. Current theoretical models of reactions to aversive outcomes cannot account for the variety of responses that appear. (36)

Initial work on the long-term effects of spinal cord injury suggested that the occurrence of a disability as a significant event in an individual's life is only a starting point for understanding the practical and personal consequences of living with disability. The work further suggested that the social environment, material resources, and - most importantly - the meanings which individuals attach to situations and events were the

most important factors to be considered in developing an adequate conceptual model, which has been called social adjustment.

For us, then, understanding the consequences of spinal cord injury involves a complex relationship between the impaired individual, the social context within which the impairment occurs and the meanings available to individuals to enable them to make sense of what is happening. (34)

In a subsequent study on ageing, this basic approach has been built upon to consider the longer term experiences of people who are ageing with a spinal cord injury. As previously, the concepts of "significant life events" and "career" are essential components in the conceptual model being developed. Before proceeding, therefore, it is necessary to explain what is meant by these terms and how they have been used in previous work.

While much of the existing work which has utilised the concept of life events has focused on negative life events (37), there is no logical reason why it cannot be applied to positive aspects of people's life experience. The only essential criteria are that a life event should be disrupting or have the potential to disrupt (38), and, that this should have some significant meaning for the individual (39). This means that a whole range of life events can be considered, including leaving school, working, marrying, having children, getting divorced, and losing one's job, as well as, of course, the range of life events often associated with ageing, such as retirement or the death of a spouse.

Since understanding the significance of ageing for older disabled people has been a central concern, the concept of life events provides a very useful conceptual tool. However, it is not a matter of simply being concerned with understanding the significance of life events associated with ageing in isolation from people's previous experiences and future expectations. Thus, just as the occurrence of a spinal cord injury is not simply a single, isolated event (34), so the intervening impact of ageing cannot be considered as a self-contained life event, or even as a series of discrete life events.

Consequently, the concept of "career" is a further essential component of the model as it allows consideration of people's experiences throughout their lives including, but not restricted to, their experiences of disability and, subsequently, ageing with a disability. Equally important,

and this relates back to a point made in the previous section, using the concept of "career" does not require the experiences of ageing and those of disability to be conceptually or experientially discrete and separate.

The concept of "career" as an aid to the analysis of life experiences was developed by the American sociologists Strauss and Glaser (40,41) and has subsequently been used in a variety of contexts such as education, work experience, and marriage, as well as in some studies of the experiences of disabled people (42,43). The main utility of the concept of a "disability career" is that it focuses not only on the experience of disability, but also on the interaction between this and other aspects of an individual's total life experience (44).

The concept of social adjustment was developed both to link together the concepts of life events and career and to facilitate an understanding of the wide variety of personal responses to spinal injury:

Understanding the consequences of SCI involves a complex relationship between the impaired individual, the social context within which the impairment occurs and the meanings available to individuals to enable them to make sense of what is happening. This is what we mean by social adjustment; it is more than simply the functional limitations that an individual has or the social restrictions encountered; it is a complex relationship between impairment, social restrictions and meaning. (34)

The experience 'of spinal cord injury, therefore, cannot be understood in terms of purely internal psychological or interpersonal processes, but requires a whole range of other material factors such as housing, finance, employment, the built environment, and family circumstances to be taken into account. Further, all of these material factors can and will change over time, sometimes for the better and sometimes for the worse, while giving the experience of disability a temporal as well as a material dimension.

Hence, the personal responses of individuals to their disabilities cannot be understood merely as a reaction to trauma or tragedy but have to be located in a framework which takes account of their life histories, their material circumstances, and the meaning their disability has for them; in

sum, social adjustment. Therefore, it is important to develop appropriate research methodologies which enable society to understand people's material circumstances from their own point of view.

## **METHODOLOGY: INTERPRETING OR UNDERSTANDING THE EXPERIENCE OF DISABILITY?**

The central methodological issue concerns the purpose of research and whether this is undertaken to interpret or understand particular phenomena. As far as disability research is concerned, most has gone for the interpretive approach. The problem with this approach is that it has been located within the medical model, with its in-built positivistic assumptions that view disability as individual pathology, rather than the social model of disability, which, as articulated by disabled people themselves, views disability as social restriction or oppression. Consequently, most of this research is considered at best irrelevant, and at worst, oppressive (45).

The persistent lack of fit between able-bodied and disabled people's articulations of their own experience has implications for both the provision of services and the ability of individuals to control their own lives. As Davis (46) points out, research on disability has consistently failed to involve disabled people except as passive objects for interviews and observations designed by researchers with no experience or sensitivity to the day-to-day reality of disability - a situation which, while it may be of benefit to researchers, does nothing to serve the interests of disabled people (45). Thus, many disabled people have become alienated from disability research; a not uncommon problem for research subjects, according to one commentator (47).

The term alienation, in its original Marxist sense, referred to the process of labour whereby workers became estranged from the products they produced. In a powerful critique of most of what passes for social research, Rowan argues that alienation is the outcome of the process of this research. By this he meant

... treating people as fragments. This is usually done by putting a person into the role of "research subject" and only then permitting a very restricted range of behaviour to be counted. This is alienating because it is using the person for someone else's ends - the person's actions do

not belong to that individual, but to the researcher and the research plan. (47)

Hence, attempting to separate people's experience with ageing from their experience with a disability in order to provide services organised on the basis that the two are separable, is itself alienating.

The recent history of disability research, in Great Britain at least, can certainly be seen in the terms described above. The national disability survey undertaken by the Office of Population Censuses and Surveys (OPCS) on behalf of the British Government is a good example of such alienation. Since the publication of the findings of this research (48,49), despite promises to the contrary, the Government has failed to take any coherent policy initiatives based upon it. OPCS has not taken it further, considering that they have done what they were contracted to do. Disabled people and their organisations have either ignored it or disputed both its reliability and validity (50,51).

Much of this was predictable in advance because of the alienation of disabled people from the process of research. They were not consulted about the research in advance - what issues should be investigated, how the research should be carried out, and so on. Further, in Rowan's terms, the researchers and the researched were alienated from each other in the way the research was carried out. Disabled people either filled in a postal questionnaire or were interviewed, not by the principal OPCS workers but by part-time interviewers. Further, it is in the nature of the interview process that the interviewer presents as expert and the disabled person as an isolated individual inexperienced in research, and thus unable to reformulate the questions in a more appropriate way. It is hardly surprising that, by the end of the interview, the disabled person has come to believe that his or her problems are caused by their own health/disability problems rather than by the organisation of society. It is in this sense that the process of the interview is oppressive, reinforcing onto isolated, individual disabled people the idea that the problems they experience in everyday living are a direct result of their own personal inadequacies or functional limitations. (6)

The research experience for all concerned was an isolating one, reinforcing the dominant idea of disability as an individual problem. Finally, according to Abberley (52), it attempted to "depoliticise the unavoidably political, to examine the complex and subtle through crude and simplistic measures."

This alienation from the most extensive and most expensive disability research ever carried out in Britain is not simply an isolated example but symptomatic of a wider crisis that exists between disabled people and the research community. As disabled people have increasingly analysed their segregation, inequality, and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than as part of the solution (7,8,52). Disabled people have come to see research as a violation of their experience, as irrelevant to their needs, and as failing to improve their material circumstances and quality of life.

This disillusion with existing research paradigms has raised the issue of developing an alternative, emancipatory approach in order to make disability research both more relevant to the lives of disabled people and more influential in improving their material circumstances: The two key fundamentals on which such an approach must be based are empowerment and reciprocity. These fundamentals can be built in by encouraging self-reflection and a deeper understanding of the research situation by the research subjects themselves, as well as by enabling researchers to identify with their research subjects (53).

The importance of emancipatory research, therefore,

is in establishing a dialogue between research workers and the grass-roots people with whom they work, in order to discover and realise the practical and cultural needs of those people. Research here becomes one part of a developmental process including also education and political action. (54)

Such an understanding is an essential prerequisite to providing a redefinition of "the real nature of the problem." This process has been succinctly captured in a commentary on research on black issues.

It was not black people who should be examined, but white society; it was not a case of educating blacks and whites for integration, but of fighting institutional racism; it was not race relations that was the field for study, but racism. (55)

This quote, 10 years later, applies exactly to the "state" of disability research; it is not disabled people who need to be examined but non-disabled society; it is not a case of educating disabled and non-disabled

people for integration, but of fighting institutional disablism (7,8); it is not disability relations which should be the field for study but disablism.

So the argument has come full circle. If the category disability is to be produced in ways different from the individualised, pathological way it is currently produced, then what should be researched is not the disabled people of the positivist and interpretive research paradigms but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society.

## CONCLUSIONS

This chapter has suggested that understanding societal responses to long-term disability is no simple task and requires us to analyse ourselves and the discourses we use in order to talk about our world. It has argued that disability is produced as a social category and that in order to understand disability production we must develop a materialist discourse. Such a discourse involves a re-evaluation of our ontological, epistemological, and methodological assumptions about disability. Finally, and central to this re-evaluation, we can only comprehend, challenge and change the hegemony that is disability by understanding the interrelations between these ontological, epistemological and methodological levels.

Just as we can produce red cars or blue cars or black cars, or cars with three, four, or six wheels, or hamburgers made with beef, or ham, or soya beans; so too with disability. We do not have to continue to produce disability as individual pathology and a welfare problem. We can produce it in other forms. Do we want to?

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## **APPENDIX: A NOTE ON TERMINOLOGY**

Using a materialist language [or discourse, as Foucault (56) would have called it] may make the intellectual work of understanding the argument difficult for non-materialists, but the alternative of opting for a non materialist discourse is to collude with other world views, whether they be pluralist, liberal, reactionary, radical, or whatever. Hence, a materialist discourse necessitates the use of terms like capitalist or late capitalist society. For non-materialists such terminology may appear to be pejorative, but it should be pointed out that for materialists, terms like industrial or post-industrial society are equally imbued with political connotations.

To relate the specific nature of particular discourses to this book, it has been suggested that the term "people with disabilities" should be used in

preference to "disabled people." This fits with the world view of liberal professionals who prefer to think about people first who just happen to have disabilities. Disabled people, on the other hand, know that disability is an integral part of their identities and it is a denial of reality to use language to pretend that it is not. Further, the term "disabled people" is the choice of the major representative organisations of disabled people throughout the world and to use other terminology is to deny authenticity to the collective voice of disabled people. The terminology used in this chapter will neither attempt to deny the reality of disability nor engage in political confrontation with representative organisations of disabled people.