

DEVELOPING AN UNDERSTANDING OF SOCIETAL RESPONSES TO LONG-TERM DISABILITY

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Introduction

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. As a consequence of this, 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, has been appearing upon the societal agenda.

Before proceeding further, it is perhaps necessary to explain the use of terminology in this chapter. 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 workforce which has a vested interest in producing their product in particular ways and in exerting as much control over the process of production as possible.

Using a materialist language (or discourse as Foucault (1) would have called it) may make the intellectual work of understanding the argument difficult for non-materialists, but the alternative of opting 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 by the editors and the publishers 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 its not. Further, the term disabled people is the choice of 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.

The production of disability therefore is nothing more or less than a set of activities specifically geared towards producing a good - the category disability - supported by a range of political actions which create the conditions to allow these productive activities to take place and underpinned by a discourse which 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 this process; that is the process of transition from one world view of disability to another. This process of transition is what Kuhn would call a 'paradigm shift' (2).

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 (3). The epistemological level requires issues to be addressed in terms of middle range theorising (4). 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.

FIGURE 1: THE HEGEMONY OF DISABILITY

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

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 (5). The hegemony of disability, as it is produced by capitalist society - and it should be emphasised that other kinds of society have produced disability in different forms (6) - 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 is, in health terms, 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 both able-bodied 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 lead, 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 are increasingly seeing their problems as stemming from social oppression (7) and institutionalised discrimination (8). In other words, disability is something wrong with society.

Thus the argument that the problems of disability are societal rather than individual problems and that these problems stem from oppression by society rather than 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 (9); the individual model being a product of exclusion, the social model currently being produced by demands for inclusion.

However, in attempting to understand hegemony of disability, the ways in which the individualising of disability is interconnected at the levels of society, policy and practice and personal experience is crucial. These interconnections are crucial to 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 (10), the problem of adjustment is one for society, not individuals and that research should be concerned to identify the ways in which society disables people rather than the effects on individuals (11).

Both the critique of dominant way of understanding and the alternative formulation will be discussed in what follows and can be summarised as follows;

FIGURE 2: Exclusionary and inclusionary visions

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

Grand theory -personal tragedy or political economy?

Grand theory, in sociological terms, is concerned with providing an all-embracing explanation of particular phenomena at the highest level of abstraction. Undoubtedly, in terms of the phenomenon of disability, the dominant grand theory has been personal tragedy theory. 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 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 (12). 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 that was Martha's Vineyard (13). Further, even within some capitalist societies policies are moving away from compensation and towards entitlement. Therapeutic interventions are also moving away from adjustment and towards empowerment. Finally, with the developing of a politics of personal identity, the experience of disability is being reinterpreted in positive rather than negative terms (14).

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 (15).

Hence, both the categories of ageing and disability are produced in the particular forms they appear by these very economic and social forces. Further, they are produced as an economic problem because of changes in the nature of work and the needs of the labour market within capitalism; and that this is true of both ageing and disability separately.

"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". (16)

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 coming 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". (17)

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 consequently also to ageing with a disability. Both old people and disabled people are forced into situations of dependency (18) 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 disabled (19).

In order to explain this, 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 following is a generally agreed definition of political economy,

"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 " .(20)

There are two problems with such an agreed definition. To begin with, it is an explanation which can be incorporated into pluralist visions of society as a consensus emerging out of the interests of various groups and social forces as well as materialist theories of society which, in the last instance, see economic factors as determining. In addition, such political economies often themselves become oppressive in they divide up the experiences into an arbitrary set of socially constructed categories; old age, race, gender, disability etc.

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". (21)

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 (22) 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 (23) or resources built up through previous work (24). 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 (25). Both are constructed as health problems because

of the needs of the health care system and because of the imperialism 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 (26).

Middle range theory -adjustment, disengagement or social adjustment?

Middle range theories are usually concerned to link 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 which 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 - i.e. adaptation to old age. Here, ageing is viewed as part of an ordered life process moving from birth to death, with each stage (e.g. adolescence, early adulthood etc.) having its own set of expectations and behaviours (27). From this perspective, successful adaptation to ageing is represented by an individual accepting the changes that he or she has experienced and, ultimately, accepting the inevitability of death. At the same time, failure to undergo such change is often taken as evidence of pathological personality development (28).

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 'middle old age', 'young 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 characterize them in middle age become curtailed, and the extent of their social interaction decreases*' (29).

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.

Firstly, 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 the social attitudes to ageing. Secondly, 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 (30).

Apart from these conceptual objections 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 (31) 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 (32). 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 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 studies of disability have 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 (33). Further, in order to adjust satisfactorily, the individual may need to grieve and mourn for lost ability and pass through a series of stages before adjustment is complete.

However, the conceptual framework provided by middle range adjustment theory has been severely criticised on theoretical grounds (34) as well as on the grounds that it does not accord with the actual experience of disability and alternative frameworks such as social adjustment (35) and social oppression (36) 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." (37)

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. " (35)

In a subsequent study on ageing, this basic approach has been built on 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 (38), 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 (39), and, that this should have some significant meaning for the individual (40). This means that a whole range of life events can be considered including leaving school, working, marriage, having children, getting divorced, losing one's job as well, of course, as the range of life events often associated with ageing (e.g. retirement, the death of a spouse, etc.).

Since the understanding of 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 (35), 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 importantly, 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 as 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 (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). 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 (43).

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. " (35)

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, hence 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.

Methodology -interpreting or understanding the experience of disability?

The central methodological issue concerns the purpose of research and whether this is to interpret or understand particular phenomena. As far as disability research is concerned, most has gone for the interpretive approach but the problem is that it has been located within the medical model with its in-built positivistic assumptions which see disability as individual pathology, rather than the social model of disability, as articulated by disabled people themselves, which sees disability as social restriction or oppression. Consequently, most of this research is considered at best irrelevant, and at worst, oppressive (44).

The persistent lack of fit between able-bodied and disabled people's own 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 (45) 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, whilst it may be of benefit to researchers, does nothing to serve the interests of disabled people (44). Thus many disabled people have become alienated from disability research; a not uncommon problem for research subjects, according to one commentator (46).

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". (46)

Hence, attempting to separate out peoples experience of ageing with a disability in order to provide services organised on the basis of the assumption 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 (47), 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 (48).

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". (10)

Hence the research experience for all concerned was an isolating, individual one reinforcing the dominant idea of disability as an

individual problem. Finally, according to Abberley (49) 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 and isolated example but symptomatic of a wider crisis that exists between disabled people and the research community. As disabled people have increasingly analyzed 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 (11 and 49). 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 (50).

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". (11)

Such an understanding is an essential pre-requisite to providing a re-definition 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". (52)

This quote, ten years later applies exactly to the 'state' of disability research; it is not disabled people who need to be examined but able-bodied society; it is not a case of educating disabled and able-bodied people for integration, but of fighting institutional disablism (11); 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 inter- relations 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?

1 Foucault M, The Archaeology of Knowledge. New York: Pantheon, 1972.

2 Kuhn T, The Structure of Scientific Revolutions. Chicago: University Press, 1961.

3 Examples of grand theory would include Parsons T, The Social System. New York: Free Press, 1951 and Marx K, A Contribution to the Critique of Political Economy. Chicago, 1913.

4 The need for middle range theories stems from the work of American sociologist Merton R, Social Theory and Social Structure. New York: Free Press, 1968.

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

6 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 Two.

7 Sutherland A, Disabled We Stand. London: Souvenir Press, 1981.

8 Barnes C, Discrimination and Disabled People in Britain London: Hurst and Co, 1991.

9 Oliver M, Social Work with Disabled People. Basingstoke: Macmillan 1983 and Borsay A, Personal Trouble or Public Issue? Towards a Model of Policy for People with Physical and Mental Disabilities, Disability, Handicap and Society. 1986 Vol. 1 No.2.

10 See Oliver M, The Politics of Disablement. London: Macmillan, 1990 Chapter 3.

11 It is in these areas that I and colleagues have been working in recently in an attempt to develop an understanding of both societal responses to, and the experience of disability. For nearly ten years now we have been attempting to document the experience of disability, looking at its long-term effects and inevitably focusing on the experience of ageing with a disability. However this empirical focus has not led us to neglect the other issues which we regard as essential to understanding both the experience of and societal response to disability. central to this have been our attempts to develop theories about disability and an appropriate methodology to enable us to really understand the experience of disability.

In terms of theory, we are currently working in two separate but interconnected areas; developing middle range theories in which to locate the experience of disability in social context and grand theory to

enable us to understand societal responses to disability. In terms of methodology, we are attempting to develop a set of non-disablist research techniques commensurate with building an emancipatory research paradigm which challenges current approaches to research. Oliver M, Changing the Social Relations of Research Production Disability, Handicap & Society. (in press) and Zarb G, On the Road to Damascus: First steps towards changing the Relations of Research Production Disability, Handicap & Society. (in press).

12 See Hanks J and Hanks L, The Physically Handicapped in Certain Non-Occidental Societies. In: Phillips Wand Rotenberg J (Eds) Social Scientists and the Physically Handicapped. London: Arno Press, 1980.

13 Groce N, Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard. London: Harvard University Press, 1985.

14 Morris J, Pride against Prejudice. London: Womens Press, 1991.

15 Marx K, A contribution to the Critique of Political Economy. Chicago, 1913.

16 Estes C, Readings in the Political Economy of Ageing. Swan J and Gerard L (Eds) New York: Baywood, 1984.30.

17 Ryan J and Thomas F, The Politics of Mental Handicap. Harmondsworth: Penguin, 1980.

18 Oliver M, Disability and Dependency: A creation of Industrial Societies. In: Barton L Disability & Dependency. Brighton: Falmer Press, 1989 and Walker A, The Social Creation of Poverty and Dependency in Old Age, Journal of Social Policy. 1980, Vol.9 (1):45-75.

19 Critically reflecting on our own work on ageing with a disability, our own common sense assumptions led us 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 analyzing our own data and in looking at other people's views, it has quickly become clear that such notions were over- simplistic and indeed, oppressive. As one disabled woman argues, Morris J, Personal and Political: A Feminist Perspective in Researching Physical Disability Disability, Handicap & Society (in press).

"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, race and disability in terms of 'double disadvantage'. The research can itself become part of the oppression".

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 Stuart O, *Race and Disability: What type of Double Disadvantage* Disability, Handicap & Society (in press).

"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".

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 theorizing and grand theory. Such questions indicate that, after ten years, our work is only just beginning I hope we have begun to address some of the right questions even if we haven't found any of the right answers.

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