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Parasites, pawns and partners: disability research and the role of non-disabled researchers

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*(This article first appeared in the **British Journal of Sociology**, 1996, Vol. 47, No. 4: 699-716).*

**Abstract** Important methodological questions are raised by the act of researching disablement. Disability research has attracted much methodological criticism from disabled people who argue that it has taken place within an oppressive theoretical paradigm and within an oppressive set of social relations. These issues are of heightened significance for non-disabled researchers and bear many similarities to those faced by researchers investigating barriers to the social inclusion of women, Black and 'Third World' peoples. Such challenges have led to the development of an 'emancipatory' research paradigm. Six principles of emancipatory research are identified and the authors' own research projects are critically examined within this framework. A number of contradictions are identified and an attempt made to balance the twin requirements of political action and academic rigour.

## **Introduction**

### ***Research and the Social Model of Disablement***

The dominant sociological and cultural representation of disabled people (in western societies and in some areas of the developing world) is underpinned by a conceptualization of disablement in terms of tragedy, the impaired body and Otherness. In this way it is consistent with oppressive representations of women and black people which also locate the 'problem' within the body (rather than within a patriarchal or racist society). By contrast, social models of disablement locate disability firmly within the structures of society including its values, mode of production, political economy, physical environment and 'welfare' system (Oliver 1990).

In line with this analysis, disabled people and disability theorists have sought to identify a new methodology commensurate with fighting the social oppression of disabled people. That concern has intensified over recent years with the articulation of an 'emancipatory paradigm' for conducting disability research: witness the 1992 special edition of *Disability, Handicap and Society*, and the more recent, if less radical, North American contribution, *Disability Is Not Measles* (Rioux and Bach 1994). The importance of these contributions amounts to far more than the 'methodology mania' which grips every self-respecting sociology-based discipline at some point in its development. It is the logical and vital next step in securing acceptance of the social model within mainstream sociology.

### ***Aims***

Our aims in this paper are threefold. First, we set out the key challenges which have been levelled at researchers contemplating disability research under the banner of 'emancipatory research', and in so doing we hope to locate disability research within wider methodological debates. This is inspired by the realization that disability research methodologies still have much to gain from feminist, anti-racist and development research.

Secondly, having highlighted the key principles of the emancipatory paradigm, we question our own ability to meet those challenges in conducting empirical research which is centred around field study. Our research projects are still in their formative stages and accordingly our personal perspective is one of anticipation (of difficulties and contradictions) rather than justification of research already undertaken.

Finally, as researchers interested in disablement, we believe that we need to make ourselves more accountable to disabled people by opening up our research rationale to the widest possible scrutiny, along the lines suggested by Stanley and Wise (1983: 206)

A major consequence of making available the reasoning procedures which underlie the knowledge produced out of the research is 'vulnerability'. We believe that this is the only satisfactory - because effective - way of tackling fundamental

features of the power relationship existing between researchers and researched.

This is particularly important for non-disabled researchers because the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world. Thus the present article is in part an attempt to introduce more 'vulnerability' into our own research projects.

### ***Condemning parasites and challenging partners***

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:

... 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.  
(Oliver 1992: 105)

The major critiques of disability research are grounded in experiences of oppression. Decades of 'scientific' research have perpetuated the marginalization of disabled people, justifying segregationist policies, eugenics, and the systematic denial of human rights (Rioux and Bach 1994). Researchers within the interpretative paradigm have also been criticized for compounding oppression (see Hunt's (1981) vitriolic 'Settling Accounts with the Parasite People', Finkelstein's (1980) condemnation of Goffman's *Stigma*, or Abberley's exposé of the oppressive rationale behind the 1988 national disability survey by the Office of Population Censuses and Surveys). Add to this list personal accounts of alienation, imposed passivity and betrayal at the hands of researchers and the call for a new research paradigm seems long overdue.

What, then, do proponents of the emancipatory research paradigm advocate to transform 'the parasite people' into partners? The discussion below identifies six key principles of emancipatory research concerning theory, the goals of research and research practice.

## **1. Choosing an Epistemology**

As noted above, disability research has been condemned where it has conceptualized disability as an individual pathology, a medical problem to be treated, or a personal tragedy to be pitied. Such conceptualizations are inseparable from the tendency of rehabilitation professionals to define the self-concept, goals, and inner motivations of disabled persons and determine their 'real wishes and potential

... without asking the individuals about their problems, preferred solutions, and alternatives or by openly disregarding all information received from the disabled persons themselves about desirable goals and solutions. (Safilios-Rothschild 1981: 5)

Academics working within the dominant paradigms for disability research (positivist and interpretative) have followed suit, casting themselves in the role of expert and 'knower' - a role which implicitly (and, on occasion, explicitly) maintains that the knowledge and experience of disabled people does not count. It is hardly surprising, then, that many disabled people and their allies have concluded that disability research has at best marginalized and at worst exacerbated the experience of disabled people (Abberley 1987: 5).

Disabled people and radical disability theorists have rejected the individualistic, 'personal tragedy' models that positivist and interpretative research have spawned. In their place, a new epistemology of disablement has been formulated whereby disability is understood as a social relationship (Finkelstein 1980), created by a disabling environment and disabling attitudes (UPIAS 1976), 'socially constructed and culturally produced' (Oliver 1990), and a form of structural oppression (Abberley 1987).

This view has been articulated as the standpoint of disabled people and the disability rights movement for nearly two decades and has profound implications for the production of disability research (Felske 1994). In particular, where disability is defined in social and material terms, the focus of disability research will have less to do with the ability of disabled people to 'cope with' or 'adapt

to' their situation and more to do with the identification and removal of disabling physical and social barriers. Thus, when researchers in the 1990s still fail to locate their analysis within the epistemological framework of the social model, their research cannot but be deemed oppressive (Abberley 1987).

This, then, is the first principle of disability research and represents a radical epistemological shift from the models adopted by positivist and interpretative perspectives (Felske 1994). The second principle develops the critique of the positivist paradigm, and finds resonance in the burgeoning literature on new social movements and the role of the researcher.

## **2. Surrendering Objectivity**

In redefining social relations, new social movements have *de facto* redefined many of the mores of social research. Probably the most significant attack has been directed against the dominance of positivism as a paradigm for social research (Smith 1988; Stanley 1990), particularly where a new social movement is itself the subject of research. In such a context, Touraine (1981: 29) insists that understanding can only be attained by the student who identifies with and becomes committed to the movement, who adopts an 'agitator's function' (assisting the group's own self-analysis) and a 'secretary's function' (recording the substance of group processes in a critical way).

For Touraine, research intervention in social movements is a means of 'raising their capacity for historical action and hence increasing the strength and elevating the level of their struggles' (1981: 145). Participant observation can only provide 'superficial information'; 'committed research' provides results.

The primacy of committed research has become a mainstay of emancipatory disability research. Zarb (1992) looks to a time when disabled participants' own research priorities are no longer subordinated by a dominant, positivist research paradigm which values and claims objectivity. Such claims have been exposed by Hunt (1981) who writes as both critic and research subject regarding his own experience of being researched as a Le Court Cheshire Home resident. Hunt condemns the researchers' self-imposed and hypocritical obsession with 'detachment' - hypocritical

since the researchers maintained distance from the disabled residents whilst siding with staff and experts. For Hunt, claims to 'detachment' and 'objectivity' - where the context is one of oppression - are inherently flawed.

Commitment on the part of the researcher, both to a social analysis of disablement and to the development of the disabled people's movement, must therefore form the basis of emancipatory disability research.

The first two principles of emancipatory research outlined above establish an epistemological standpoint for the disability researcher and eschew notions of detached objectivity as falsely premised, if not inherently oppressive. The third principle demands that the researcher does not sit comfortably within the academy but confronts the accusations of irrelevance which have flowed from disabled people and their organizations. What will the research achieve in terms of improving the lives of those whose selves become 'sources' and whose meaning becomes 'material'? Will it achieve any more than furthering academic careers and publication lists?

### ***3. What's in it for Them***

Irrelevance and benefit are recurring themes within social science research and particularly pertinent to research which focuses on oppressed groups (whether Black people, women or marginalized peoples in the 'Third World'). In disability research, criticisms of positivist and interpretivist research paradigms for their failure to effect 'immediate improvements in the material conditions of life for the disabled research subjects' (Oliver 1992: 109) have determined that the researcher must be judged by the practical relevance of her/his research to the lives of research participants. In line with the social model, relevance means the identification and removal of disabling social and physical barriers.

Thus the political standpoint of the researcher is tied to political action in challenging oppression and facilitating the self empowerment of disabled people. The researcher engages in processes of emancipation, rather than merely monitoring them from sympathetic sidelines. Moreover, the nature of that engagement should be determined by disabled people. It is at this



point that the principles of activism become incorporated into the fourth (and arguably most fundamental) principle of the emancipatory paradigm.

#### **4. Reversing the Social Relations of Research Production**

Oliver, considering the failure of feminist and third world research to effect practical change, considers that

[i]t is to what can only be called the social relations of research production that the failures of such research can be attributed, and indeed, it is to these very social relations that attention must be focused if research, in whatever area, is to become more useful and relevant in the future than it has been in the past. (1992: 102)

If research is to be relevant, and if the researcher is to demonstrate commitment in actions as well as words, then anti-oppressive practices must begin with the research production process itself. There must be a radical reversal of the social relations of research production, whereby the researcher engages in the emancipatory struggles of disabled people *by* disabled people through laying her/his research skills 'at the disposal of disabled people' (Barnes 1992: 122), 'for them to use in whatever ways they choose' (Oliver 1992: 111).

In understanding the importance attributed to reversing research hierarchies, it is vital to recognize that disabled people as a group are in an oppressed position and that research is conducted within a wider context of oppressive social relations built upon the privilege and power of non-disabled people. It is thus inappropriate to consider disability research production as an activity discrete from its social context.

Regarding the researcher-researched relationship, Abberley (1987: 141) has noted that disabled people have in the past been treated predominantly as 'passive research subjects'. This has been true not only of large-scale quantitative surveys (such as those carried out by OPCS in 1985) but also in traditional approaches to research interviewing which have tended to accept rather than challenge the existing disempowerment of research subjects. In so

doing, research may reinforce existing feelings of passivity or exclusion (a tendency well-documented within feminist research, for example Oakley's (1981) paper on 'interviewing women').

Ramcharan and Grant (1994) conceptualize the process by which powerful individuals and institutions have marginalized disabled people (through assuming the right to choose and speak on their behalf) as 'commodification'. They advocate 'reverse commodification', whereby 'disadvantaged individuals are themselves facilitated to 'commodify' the research process to their own ends' (Ramcharan and Grant 1994: 239), 'turning the researcher into a resource for their new employer' (op. cit.: 237). Only when disabled people and their organizations are at the apex of the research hierarchy (and this includes control of the financing of research) can research be deemed 'emancipatory'.

### ***5. Personalizing the Political and Politicizing the Personal***

The fifth principle of the emancipatory paradigm is perhaps the most contentious within the paradigm and signifies the beginnings of divergence amongst the core of disability theorists. Several authors point to the importance of differences in the personal experience of impairment and disablement (French 1993) and to the primacy of such experience as research data (Morris 1991). This approach is reminiscent of much feminist and anti-racist research.

The disability movement needs to take on the feminist principle that the personal is political, and in giving voice to such subjective experiences, assert the value of our lives. We can insist that society disables us by its prejudice and by its failure to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our own oppression. (Morris 1991: 183)

According to Morris, disability research should give space to present the subjective realities of individual disabled people. Morris (1992: 159) is wary of the use of either medical *or social* models to frame research and analysis since 'the use of models as an analytical tool comes from theory and research which treats us as objects'. However, there is a danger that such an approach can

obscure the collective nature of disablement as a form of social oppression. Morris thus combines her commitment to the personal as political with her commitment to a social model of disability (based on commonality). In this way, disability research design may recognize both commonality and difference in the experience of disablement.

Several advocates of emancipatory research attach still greater importance to collectivizing rather than individualizing experiences of disabled people in the OPCS surveys individualized the experience of disablement. The effect, Abberley argues, is to further disempower disabled people by reinforcing a personal tragedy model of disablement. Morris agrees that disability research can itself contribute to the perpetuation of negative images. Thus:

Images of disadvantage are such an important part of the experience of oppression that emancipatory research... must consistently challenge them. (1992: 162)

Finally, Felske (1994) argues, as have many feminists, that the emancipatory paradigm must move beyond the 'knowing of individual realities' and locate personal experiences within a human rights analysis if it is to avoid regression into mere description.

## **6. Qualitative and Quantitative**

Those who have offered critiques of existing disability research from anti-positivist and feminist perspectives have generally expressed a preference for the use of qualitative over quantitative data. Morris (1991) notes the importance of an oral tradition in the early stages of collective struggle by other oppressed groups (notably the feminist movement) and thus employs a qualitative approach to her study using interviews with eight disabled women.

Indeed, 'emancipatory' research (as with feminist and anti-racist research) is often regarded as synonymous with the use of qualitative data. However, such an association is problematic since there can be no simple causal relation between the use of qualitative data and the removal of disabling barriers. Some of the most vehemently criticized disability research (such as Miller and

Gwynne 1972) has been based on qualitative data. The problem here is not the qualitative nature of the data but the theoretical paradigm which guides its collection and analysis. Furthermore, it is likely that the identification of disabling barriers may be greatly assisted by the use of quantitative research designs. Abberley (1992) argues that if a social model of disability is to be incorporated into disability research then large scale and detailed empirical work needs to be done on the material conditions of disablement, and he concludes that a plurality of approach and method is required to satisfy the need for both macro- and micro-level understanding of the oppression of disabled people and their needs. Barnes (1992) also advocates the use of both qualitative and quantitative data within the emancipatory approach.

These arguments indicate that it would be misguided to equate emancipatory disability research with any one approach to data collection since both qualitative and quantitative methods can be used in an oppressive or an emancipatory context. While it is important to give primacy to the personal experience of disablement, the central issue is how this experience can be used at an early stage in the formulation and *choice* of appropriate research methods.

### ***Summary of Emancipatory Principles***

We have identified six core principles of the emancipatory research paradigm:

- the adoption of a social model of disablement as the epistemological basis for research production
- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers
- the evolution of control over research production to ensure full accountability to disabled people and their organizations

- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

The radical and uncompromising stance adopted by those advocating the emancipatory paradigm confronts the would-be researcher with a daunting task - all the more daunting given that none of the advocates of the paradigm have yet laid claim to the achievement of truly emancipatory research *within the context of a field study*. However, as researchers who have decided to explore disablement, we believe that it is vital to face up to these challenges and that, where we anticipate contradictions and difficulties, we might use them as a point of entry into a more critical analysis of the emancipatory paradigm. This is an ongoing and reflexive process and the second part of this paper signifies only the beginning of our engagement with emancipatory methodologies.

### **In Anticipation of Doing Emancipatory Research**

As mentioned at the outset, it is a purpose of this paper to relate the challenges of the emancipatory paradigm to our own research practice and thereby to introduce a greater 'vulnerability' into our current research projects. Therefore, the following discussion problematizes methodological aspects of our work in relation to the principles outlined so far. In doing so we seek to contribute to recent attempts within feminist research to admit imitations and to bridge gaps between abstract notions of what research should do or should be like and the frustrating practicalities of conducting empirical research.

### ***Background to the Studies***

The two studies in which we are involved are both being undertaken in the process of submitting for doctoral degrees in the Disability Research unit at the University of Leeds and, at the time of writing, are at a relatively early stage in their development. One

of us is examining a conflict of values between British community care policies and the goals of the disabled people's movement using a case study in Derbyshire; the other is concerned with the applicability of western concepts of disability and rehabilitation in China with reference to international 'development' projects.

The Derbyshire study arose directly from the concerns of disabled people involved with Britain's first centre for independent/integrated living (the Derbyshire Centre for Integrated Living). The centre, which is run and controlled by disabled people, has a long history of partnership with the local authority and now provides community care services under a purchasing contract with that authority. The implementation of recent purchaser-provider reforms has highlighted a conflict of values over the design and delivery of personal support services for disabled people in the local community. Under the contracting legislation, services designed by disabled people within a social model of disablement are evaluated with reference to quality standards derived from the individualising and medicalising value-framework of disablement policy makers. The study seeks to address this issue by exploring value conflicts at the local level and by using action research methods to facilitate the development of quality standards which might reflect the contribution of disabled people's organisations. In particular, the study seeks to develop a quality measure of service user participation.

The study in China is being undertaken at a time of rapid transition in the Chinese social and economic structure. At the same time, and largely as a result of the father-son relationship between Deng Xiaoping and the disabled leader of the Chinese Disabled Persons Federation (CDPF), Deng Pufang, disability has been put on the government agenda to an extent unprecedented within China. The coincidence of government awareness, Open Doors, and the internationalisation of rehabilitation through such concepts as Community-Based Rehabilitation (CBR) has led to the introduction of western-evolved models of rehabilitation within the Chinese socio-cultural context. The study seeks to explore the impact of such outsider intervention and to ascertain the degree to which those interventions incorporate, consolidate or challenge local conceptualisations of impairment and rehabilitation. Has the concept of the CBR been adapted to suit local socio-cultural conditions or has it been imposed, thereby recreating local perceptions of impairment along western lines? Does CBR

represent a way forward for disabled people in China and if so, is it a sustainable route? To seek answers to these questions, permission has been sought to undertake action-oriented evaluation research on existing CBR projects in China.

In deciding to undertake disability research, many of our initial concerns revolved around our status as non-disabled researchers and whether we should undertake disability research at all. Such fears have faded into the background, both as a result of encouragement from disabled people and their organizations, and through the realization that disability status alone does not guarantee emancipatory research. The problems which we address below relate primarily to the practicalities of our research production, to the relevance of our research projects and to our roles as researchers.

### ***The Social Relations of Our Research Production***

The importance attributed to challenging the hierarchies of research production has been highlighted as crucial to the concept of emancipatory research. Less has been said about the constraints within which the researcher operates. Regardless of commitment to the emancipatory paradigm, the researcher is required to bow in several directions: to research councils and to academic peers, to disabled people and their organizations. The researcher both acts and is acted upon within these power relationships.

Academic researchers in every field surrender themselves to the mores and conventions of a particular mode of research production and to the authority of a particular academic community every time they undertake a piece of research. Research proposals which are not easily accommodated within established research paradigms may fail to gain access to limited sources of research funding. In this context, it is interesting to note that one of us was advised by our university department to remove the term 'emancipatory research' from the funding application to a major Research Council on the grounds that it might be regarded as too removed from the 'mainstream'. It is also relevant to note that, since our own research projects are being conducted in the course of submitting for doctoral degrees, we are relatively free from funding constraints.

The issue of research constraints has been taken up by Colin Barnes (forthcoming) in his article on 'Disability and the Myth of the Independent Researcher' in which he presents a strong case against academics who lay claim to independence. Whilst highly critical of the constraints placed on researchers by university regulations and research institutions, Barnes does not problematize the situation of the researcher in the field and the practicalities of putting one's skills at the disposal of disabled people and their organizations - issues which are raised in response to Barnes by Shakespeare (forthcoming) and which we develop below.

In responding to the criticisms levied against parasitical research, it is relatively uncontentious to conclude that disabled people should be more involved in disability research production. It is more problematic to determine exactly what the form and content of this involvement should be. Simply increasing levels of participation does not necessarily challenge or alter the power relations of research production. For this reason, Zarb (1992) finds it necessary to distinguish between 'participatory' and 'emancipatory' research methods.

Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how.  
(1992: 128)

Since participation is not tantamount to emancipation, it is important to consider how participation might best be translated into control. The practicalities of participatory data collection have been sufficiently outlined in feminist and third world research methodologies. However, the 'emancipatory' model requires more. It requires full ownership of the means of research production - ownership by the research participants, not the researcher.

In the Derbyshire study, the local coalition of disabled people were encouraged to issue a formal contract to the researcher to conduct the study (without remuneration). It is relevant to note that, while such a process transfers a level of formal power over the conduct of a project, it might well be incompatible with the contracting criteria of some major research funders. Government research



contracts for example commonly prohibit the researcher from engaging in secondary contracts for the same work.

As regards the China study, control of research production is more problematic. The CHB interventions to be studied involve several parties: inter-national organizations, Chinese governmental agencies, the China Disabled Persons Federation, local level project workers, disabled people and the parents of disabled children. Under whose control should the research and researcher be placed? Advocates of the emancipatory paradigm would immediately respond: 'under the control of disabled people', but the question then becomes: 'under the control of *which* disabled people?' Those who call for emancipatory research have not, it seems, taken on board the inconsistencies which arise when homogeneity of disabled research subjects is assumed.

### ***Assumed Homogeneity and Researcher Integrity***

Implicit in the literature on disability research is the assumption that as long as disabled people and their organizations handle the reins of disability research, then all will be well. However, this assumption is far from unproblematic, since it apparently ignores the diversity of experience amongst disabled people, in this country and world-wide (Priestley 1995). It assumes a level of homogeneity (of opinion if not of experience) and where such homogeneity is absent, the researcher is placed in a difficult position.

If the researcher is to seek out ways of transferring power over the research production process then the question arises, to whom is that power to be transferred? At whose disposal are research skills to be placed and which disabled people or organizations are to exercise control?

In the Derbyshire study it is evident that individual disabled service users may sometimes feel as alienated by the politicized nature of disabled people's organizations as they do by state welfare bureaucracies. Devolving control over the research production to a local coalition of disabled people may seem a straightforward means of achieving accountability but it may do little to directly empower individual research participants in the process.

In China, it would certainly be possible to surrender control of the research process to the Chinese Disabled Persons' Federation but, as a semi-governmental organization, this might compromise both the data and the personal integrity of the researcher. There is a fine line between devolving control as partners in research production and becoming mere pawns. Under such circumstances the emancipatory power of credible and rigorous research can soon become prey to allegations of political propaganda. Alternatively, control could be given to Chinese disabled people at the grassroots but that is to assume that Chinese disabled people want to take on the role of researcher and activist. This is equally problematic (although the possibility should be entertained during fieldwork). Practical problems related to diversity and homogeneity are similarly apparent in the context of data collection and analysis.

### ***Where Collectivizing Experience Contradicts a Collective Analysis***

One approach to the collectivization of research data within a participatory framework is to encourage the subjects of the research to prioritize their own interests and experiences through unstructured or semi-structured interviews. By following up the initial interview, the researcher seeks to collectivize individual experience directly through respondent validation and the sharing of data between respondents. In this approach, the researcher attempts to collectivize findings by drawing together diverse personal experiences in the analysis. However, the collectivization of experience is still ordered within *the researcher's* chosen frame of reference (albeit a framework is informed by the agenda of the disabled people's movement). In addition, the collectivization of data occurs at the writing-up stage and thus remains remote from most of the research participants. Consequently, there is limited scope to alter the social relations of research production and the approach is open to criticisms of reinforcing isolation and individualism.

A second, and arguably more emancipatory approach, would seek to collectivize the entire process of data collection and analysis, either through bringing respondents together in one room, or through feeding back the views of other respondents in a dynamic and democratic way (via post, inter-net communities or disabled people's organizations). The commonality of disablement is

thereby recognized not only in the analysis but also in the research design. The goal is to *create an environment in which disabled people are empowering themselves* through research participation. To this end, the use of focus group discussions can substantially enhance the collective and participatory content of the research. Indeed, the initial use of 'focus groups' and service user seminars in the Derbyshire study already seems promising in this respect.

Such an approach is particularly appealing because it seems to address more directly the need to collectivize personal experiences of disablement whilst simultaneously collectivizing the experience of taking part in research production. It is also more likely to be of immediate significance in the lives of all those involved. However, this alone does not solve the researcher's dilemma of what action to take should the collective analysis be at odds with the theoretical and political standpoint determined by the disabled people's movement. The likelihood of this problem arising is increased where research subjects are distanced from the political hardcore of the disability movement. In such circumstances, can it ever be the researcher's role (as an individual committed to the politics of disability rights) to politicize the 'unpoliticized' or act as advocate for a social model of disablement amongst respondents?

Consider disability research within a Chinese context: to politicize and impose western conceptualizations would be (rightly) criticized as proselytization. It would also be condemned for irrelevance where disabled people's struggles revolve around daily survival rather than political emancipation. Consider also the relative degrees of politicization amongst disabled people in Britain: should a researcher exploring users definitions of service quality proselytize amongst those who do not appear sufficiently aware of the wider political nature of their oppression?

We argue that it is at this point that the researcher defers to her/his *theoretical* and *political* standpoint. This need not run counter to the goals of emancipatory research, since taking the initial decision to adopt a social model of disablement as the theory which drives our research is in itself taking an important step in establishing our political commitment to the disability movement and transferring a degree of control to disabled people (or more accurately, to western disabled activists).

## ***Adopting Agendas - First Steps in Devolving Control***

It has been important for us to consider how we might address the social relations of our research production vis-a-vis the disabled people with whom we seek to work and the wider disability movement. At the same time, we find it necessary to satisfy our academic peers and examiners for, in the final analysis, it is the academy rather than disabled people that passes judgment on submitted theses. It is often hard to conceive how this balancing act might be successfully achieved, to which end we have prioritized an aspect of the emancipatory model which we see as mitigating the potential 'tug-of-war' between academic-self and committed-self: theory.

It is relevant to note that all research is inherently theory driven, although this is rarely made overt. Within disability research, several leading theorists have exposed the oppressive rationales which underlie apparently 'neutral' questionnaires and interviewing schedules (see Oliver 1990 and Abberley 1992). The choice of theory which informs the research question is thereby a political decision. Oliver and Abberley therefore advocate the substitution of traditional theoretical approaches with a social model (as theory) and a political commitment to the disabled people's movement.

In accord with this approach, the decision to adopt the epistemology generated by the disability movement is viewed as taking the first step in devolving control to the disability movement - control of the macro research agenda.

Touraine (1981: 205) points out that the exact hypothesis may be refined during the intervention (through analytic induction) and that theories may be tested in discussion with research participants. This is an approach which we seek to adopt by placing our personal hypotheses 'on the table' for scrutiny and modification by the groups with whom we are working. For example, in the Derbyshire study the original choice of research question was devolved to the disabled people's organizations involved. As the study has progressed, changing priorities within those organizations have contributed to the refinement of that question by dictating a shift of emphasis towards the specific issue of user participation standards.

In the China case, there is less room for flexibility since the researcher expects to find a vast divide between the conceptualizations and agenda of western disability organizations and those of Chinese research subjects at the grassroots. In such circumstances, how should the researcher analyse data within a framework that reflects both the ontological and analytical stance of the research subject, and that of the western disability movement?

A similar conflict has been detailed by Tom Shakespeare, a disabled academic, who finds it useful to distinguish between accountability to research subjects and accountability to the movement or specific organizations (Shakespeare forthcoming), arguing that there is a need (if not a duty) to retain a degree of theoretical and analytical autonomy whilst still remaining politically committed to the movement. Yet surely if the researcher maintains the right to collectivize data within a framework that might be external to research subjects, and possibly even run counter to their conceptualizations, the researcher is guilty of adopting the position of expert in the relationship between researcher and researched? This is an area with which we have also had to wrestle.

### ***Knowers And Experts***

One of the cornerstones of the emancipatory epistemology is that disabled people - and not rehabilitation professionals, social workers or researchers - are the true knowers. In third world research, Chambers (1983) has advocated a reversal of analysis and learning which can only be achieved when the researcher relinquishes claims of knowledge and expertise in the field.

Expertise has indeed become a dirty word in radical research, whether feminist, third world or disability. The association is with the stereotyped, predominantly male, white, able-bodied westerner whose arrogant claims to expertise have 'objectified' (and thereby dehumanized) people, producing recommendations that were neither relevant nor 'objective' because they ignored the knowledge of those researched. Radical researchers on the other hand aim to become 'new professionals', operating within a research process that is devoid of hierarchies and unequal power

relations and where expertise is not the sole domain of the academic.

Criticisms of this approach (often in hot-blooded defence of the academy's traditions) have rained down from outside the radical research core. More recently these have been joined by doubters on the inside. Glucksmann (1994: 151) wonders whether there is a 'danger of attempting to establish an egalitarianism in the research situation as a substitute for establishing it in the "real world"'. Other feminist researchers raise the point that eradicating power dynamics might not be possible (or indeed desirable) where research participants are associated with oppressive structures rather than oppressed groups (Maynard 1994; Kelly et al. 1994). Kelly et al. carry the problematic of expertise beyond self-retribution and pessimism by acknowledging positive elements of the researcher's expertise. Thus: 'It is we who have the time, resources and skills to conduct methodical work, to make sense of experience and locate individuals in historic and social contexts' (1994: 37).

The rigorous and expert application of these analytical skills are of vital importance if disability research is to avoid falling into the trap of mere 'story-telling' (the point where symbolic interactionists and post modernist meet). Academic rigour should never be compromised in establishing the criteria for what constitutes 'good research'. But, and this is the crux of the debate, where the researcher has expertise in research skills, this should not be taken as a green light to assume knowledge of the needs, feelings and conceptualizations of other research participants.

We have problematized the principles of surrendering claims to expertise and to control, we have outlined our own anticipated difficulties in implementing collective analysis and have suggested possible solutions. What remains to be considered is the degree to which we foresee ourselves translating political commitments into practical and political action for change.

### ***Proving Our Political Puddings***

Perhaps the most eloquent and radical analysis of the relevance of research and the role of the researcher has been offered by Chambers (1983), writing in a Third World context. His call is for a

‘new professionalism: putting the last first’. Chambers is uncompromising on the issue of taking action, not just writing words

What counts, though, is action. Values - putting the last first - and imagination to visualise the distant effects of action and non-actions, are points of entry. But concentrating on these can be a postponement. It is often bets to get on with doing whatever can be done, however small. (1983: 197)

These are powerful words which would condemn much research conducted by radical researchers in a variety of fields. In defence, many researchers have begun to admit to the limitations of participatory/feminist research in transforming the lives of research participants. Maynard (1994: 17) refutes the notion that ‘studies which cannot be directly linked to transformational politics are not feminist’, since it ignores the question of ‘how far the researcher is in control of the extent and direction of any change which her research might bring about’. She perceives the worth of worthwhile research to lie in its importance for the wider constituency of those whom the participants are taken to represent.

A similar case might be made for researching disability in both China and Derbyshire. It is anticipated that whilst research with Chinese disabled people has the potential to affect grassroots change, that potential may go unrealized in the immediate future. Similarly, within the confines of the British welfare state, it is unlikely that an isolated doctoral research project will do much to change alter the disablement policy agenda. However, if the transformative potential for research extends beyond individuals, then justification might still be found. Where our research is fully and sensitively disseminated, where it can be used to confront social structures of oppression, to contribute to an understanding of disablement within a global political economy, and to locate disability studies more firmly on the academic agenda, then it may be considered worthwhile.

## **Conclusions**

We have summarized the key principles of emancipatory disability research as we construe it and have problematized our role in

relation to those principles in an attempt to tie abstract ideals to pragmatic research activity. We have highlighted several areas in which we anticipate methodological difficulties in conducting our own empirical research in the specific contexts of China and Derbyshire, namely:

- the contradictions between surrendering control and maintaining personal and academic integrity
- the problem of assumed homogeneity
- the importance of accepting our expertise as *researchers* whilst accepting disabled people's expertise as *knowers*.
- the potential conflict between collectivizing experience within a social model and collectivizing analysis, where the social model is not part of participants' own understanding of disablement
- a recognition that failure to transform individual lives need not be the sole criterion of 'good research' where a real contribution can (and must) be made in a wider context

We maintain that the priorities for disability researchers must be the adoption of a social model of disablement, an overt political commitment to the development of the disabled people's movement, the use of non-exploitative research methods and a commitment to research which is widely disseminated for use against oppression.

Finally, if disablement studies, as well as disability politics, are to be taken seriously then there is a need to satisfy the rigorous demands of academe at the same time as furthering the political campaign for emancipation and equality. That these twin goals have been held as inherently conflictual by many within both the research establishment and the disabled people's movement is perhaps not surprising given the current political and research context. However, this should not dissuade the researcher from seeking to achieve both. Indeed, that must ultimately be the disability researcher's obligation and contract.

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