

Book Reviews

EXTENDED REVIEW

Doing Disability Research

COLIN BARNES, GEOF MERCER (Ed.), 1997

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In her contribution to this book, Linda Ward refers to Mike Oliver's review of progress in obtaining increased funding for emancipatory research and quotes his 'verdict ... that little has changed in reality even if superficially some gains appear to have been made' (Ward, p. 34). On this she is in agreement, saying: 'progress remains frustratingly slow'. Linda then injects a more positive note: 'Nowadays, an avowed commitment to the social model of disability is relatively commonplace (in principle if not in practice) but in 1988 this was far from true'. She continues her line of defence, against this agreed slow progress, by saying she takes a 'pragmatic' view and from this perspective small, but significant steps are taking empowering or emancipatory research forward.

Leaving aside further evidence of progress put forward by Linda, what is significant for me in this exchange, and wonderfully brought to light when the thirteen papers in this landmark publication are read as a whole, is the contrast between the excruciatingly slow progress in 'empowering' or emancipatory research, and the almost wholesale adoption of the social model of disability. Is this an accident? Is this contradiction any different to what we know is happening in other areas of disablement? I think not.

I believe the only way that the social model of disability can be widely adopted for research (or elsewhere) without also addressing the problem of *transforming* the disabling society is by accepting the model in principle while ignoring the problem of translating this into *material* changes to practice. A pragmatic view of the model nicely meets this requirement. In other words, using Tom Shakespeare's word, the model is 'rectified' in order to avoid 'rectifying' the disabling society. The rectified social model can then be incorporated into current academic texts read and interpreted by researchers and service providers precisely because it raises no direct challenge to actual practice. Failure to appreciate the motive power embedded in the social model of disability (that action is required to change the disabling society) is only likely to raise more problems than solutions.

For me, then, research guided by the social model of disability (in this context emancipatory research) must of necessity explore and identify appropriate avenues for change in addition to giving consideration to the processes involved in carrying out the investigation. I have to ask, is the object of the investigation something that can be transformed, has to be transformed, or that we want to transform in the process of confronting the exigencies of the disabling society? The publication of *Doing Disability Research*, it seems to me, highlights the importance of tenaciously holding onto these questions.

On the one hand, its publication is clearly another rung in the ladder towards the emancipation of disabled people; further evidence of the ideological triumph of the social model in guiding practice. In the past 30 years, the social model of disability has underpinned significant organisational development of disabled people, been adopted by

disabled academics in the courses that they have managed to influence, provided a theoretical rationale for setting up services managed by disabled people (e.g. the Centres for Integrated/Independent Living), influenced government policy for direct payments to disabled people and strengthened the campaign for entrenched civil rights. The emergence of *The Disability Press* significantly increases access to the media and, together with the *Disability & Society* journal, the dominance of the administrative, individual and medical models of disability have seriously been challenged within the academic and service spheres of the disabling society. This is no mean achievement in the face of the almost universal original resistance from the established health and welfare industry. These publications will undoubtedly create yet more opportunities for the social model to guide the unceasing progress of emancipation as we address the more difficult task of creating new professions allied to the community (PACs) in contrast to the 'care' professions allied to medicine (PAMs) and the omnipotent 'welfare' professions which maintain our passivity and dependency. The publication of *Doing Disability Research*, then, is a significant and very welcome milestone in the extraordinary transformation of 'disability' in the UK that our generation has been privileged to witness.

On the other hand, the book reveals how easy it is for the social model of disability to be turned into an intellectual abstraction so that it is divorced from its material origins concerned with dismantling real barriers in the disabling physical and social environment. A good test for measuring this is to ask whether removing all reference to the social model would make any difference to a research project or the consequent publication. In other words, while a researcher pays homage to the model, is the investigation actually dependent upon the model for identifying either *how* the research is conducted or *what* is being researched? This raises two clear issues:

On the former, how the research is conducted, emancipatory researchers seem to have translated this into a concern about *control* - who controls the research? Most immediately this has focused on the significance of ensuring that control over a research project is exercised through the involvement of disabled people. More recently this has developed into a concern about who controls the research funding. On the latter, what is being researched, emancipatory researchers seem to have been rather reticent - either considering a focus on disabling barriers as a self-evident target for emancipation requiring little legitimisation or, what seems to be the prevailing disposition, simply feeling that since disabled people are in control this makes what is researched an emancipatory issue. I think *Doing Disability Research* demonstrates that the application of the social model of disability to research cannot be reduced to the single issue of *control* by disabled people in order to characterise a research project as emancipatory.

Involving disabled people in research is not new. What is new is that this involvement is now presented as evidence of compliance with the social model of disability and consistent with the principles of emancipatory research. There is, of course, a long history of involving disabled people in research, but as 'case histories'. Biographical and autobiographical accounts of disabling experiences can be used to highlight the incapacity of individuals due to impairments and just as well to provide examples of exclusion as a result of social barriers. In either case, personal accounts may actually uncover little more than the known debilitating effects of living in a world designed for people with abilities. In this respect it is worth noting that in 1974 the UPIAS Policy Statement contained the following.

We reject also the whole idea of 'experts' and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the 'psychology' of disablement. We already know what it feels like to be poor,

isolated, segregated, done good to, stared at, and talked down to-far better than any able-bodied expert. We as a Union are not interested in, descriptions of how awful it is to be disabled. What we *are* interested in, are ways of *changing our conditions of life*, and thus *overcoming* the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us.

(UPIAS 1974, amended 1976.)

In practice disabled researchers, as well as the disabled individuals who have a controlling interest in a research project, may only become the new 'experts', 'professionals' or 'elite', replacing people with abilities who have traditionally been in this relationship to those being researched. All too often, we can be deluded by contemporary language to regard a project as involving emancipatory research, while in reality the substance of the research is actually traditional and sympathetic to the individual model of disability. In looking at modern research and reviewing research literature, then, I also ask whether the investigation adds to our knowledge about the social structures and processes, which *create* disabling barriers; does the research take us any further than provide additional case material about the impact of, our experiences of, or our reaction to, these disabling barriers? Is the social model of disability a tool for focusing a microscope on the inner workings of the disabling society or merely a frame holding a magnifying glass for exaggerating the social experiences of disabled people living in the disabling society?

Personally, I look to emancipatory research for its ability to help us address the barriers that prevent disabled people from creating a society in our own interests. In this respect, it seems to me *Doing Disability Research* demonstrates that we have an awful long way to go! However, perhaps this is also one of the book's strengths. Because of the diverse approaches presented in the papers it is possible to see more clearly the contrast between, what I will call (after Linda Ward), 'pragmatic research', relying on support from a 'rectified' social model of disability, and the challenging difficulty of translating the social model of disability into doing 'emancipatory research' to rectify the disabling society.

It will come as no surprise, then, that when I turn to specific papers in the book I am firstly drawn to what Mike Oliver has had to say. In his paper, Mike takes a global look at disability related research and specifically at the project on disability politics that he completed jointly with Jane Campbell (Campbell & Oliver, 1996). As always I find his carefully constructed opinion very provocative. As one of the initial advocates of emancipatory research Mike's critical question about who benefits from conducting research based on the social model should be taken very seriously. It reminds us not to be fooled into thinking that because disabled people are involved in a project then it must be beneficial in its own right: a challenging reconsideration of the old slogan 'disabled people are the experts'! This, you might think, would encourage us to question whether disabled people's control over a research project is a sufficient indicator of its adherence to the social model of disability. Although Mike says that 'the question of doing emancipatory research is a false one, rather the issue is the role of research in the process of emancipation' (p.25) he never seems to disentangle his argument from its focus on the necessity to involve disabled people: 'The two central issues so far discussed can be summarised in political terms as control over process and control over resources' (p.24). In my view if the issue really is 'the role of research in the process of emancipation' then, alongside who controls the research, we have also to give equal emphasis to *what* are legitimate targets for emancipatory research. To leave this issue void can only leave us in a permanent state of dependency, reacting to the agenda set for us by society, policy makers, Government or others - 'this means that research can only be judged emancipatory after the event.'

What the research should focus on was a critical decision made by disabled people for the investigation carried out by Mark Priestly. This project also had the added attraction, for those concerned with clarifying the dimensions of emancipatory research, of involving disabled people at a high level of decision making as well as being carried out by a non-disabled researcher. Mark's paper, however, highlights the need to be careful about distinguishing between the *real* and *apparent* commanders of an agenda for research.

Working with disabled people he notes that 'Our agreed agenda for research focused attention on the definition and measurement of service quality' (p.99) provided by the Derbyshire Centre for Integrated Living (DCIL) but, we are told earlier, the context for this had *really* been laid on the table by the Government's reform of community care policies: 'It was clear that the unfolding purchaser-provider reforms required DCDP (Derbyshire Coalition of Disabled People) and DCIL to re-evaluate their historical relationship with the agencies of the local state' (p. 94). Surely this means the research agenda was reactive to the real agenda set by non-disabled people going about their normal business of regulating the disabling society?

Leading disabled people have repeatedly pointed out that we 'do not want or need, *care*' - 'care' is a form of assistance appropriate to children and those who are ill. Is it possible, then, to *do* emancipatory research around an agenda set by reforms of community care? I think not. While Mark does point out that his interest was motivated by 'how the new community care reforms might be exploited ... to promote more participatory modes of welfare production' (p.93), he does not appear to ask whether we can have emancipatory research on an agenda of participatory modes of welfare production. Participatory research, of course, is compatible with the social model of disability but not dependent on it. In practice this means that while participatory research may indicate benefits that can be extracted from community care policies, in this context research is hardly likely to play a role in the process of emancipation (in Mike Oliver's terms).

For example: people living in a residential institution may see benefits in supporting research which highlights ways of improving access within the building and increasing their participation in management, but it would be an illusion to believe that this could promote emancipation. If there was only one contemporary lesson to be learnt from the notorious Miller and Gwynne research into Cheshire Homes (Miller & Gwynne, 1972), it would be the need for clarity between participatory and emancipatory research.

With this worry in mind, I cannot agree with Mark that 'To secure funding from a major government research council for a project defined by representatives of disabled people's organisations was in itself a partial vindication of the emancipatory approach' (p.95). I suspect that this was rather more like evidence of how the social model of disability gets rectified in order to make it respectable for a research programme into community care services. To try and maintain that an emancipatory agenda is still embedded in such research can only, in my view, lead to a string of problems with those implementing the community care services. This is very nicely illustrated by Mark on page 100: '... the opportunities for social services participation in the research design became increasingly limited and it was necessary to re-focus my efforts on the primary research participants.' From here on, in my view, there is a driving logic to the paper's concluding paragraph, containing the sentence which might be called Oliver's gibe: 'It is fair to say that, at the time of writing, the research was more personally empowering to me than to anyone else.' I highly recommend this paper for all those wishing to get to grips with the problems of *doing* emancipatory research. At the very least researchers might like to ponder the 'six core principles' that Mark (and Emma Stone) say characterise emancipatory research (p.91), and then ask how Mark manages to reconcile his use of Oliver's gibe with his very last sentence!

In his paper, Gerry Zarb (1995) takes great care in differentiating participatory from emancipatory research. He casts serious doubt about the ability to carry out emancipatory research within the constraints that regulate current research projects, especially the control exercised by research funders. Focused on the measurement of disabling barriers Gerry emphasises the purpose of his research is to make a start on developing methodologies consistent with the social model of disability: ‘one of the main criticisms levelled against social model research has been that it has lacked fully developed methodologies which would allow some of the primary propositions contained in the model to be subjected to empirical analysis’ (p.55). I think this paper is particularly important reading for **three** reasons:

Firstly, it highlights problems in engaging disabled people in the research process when the social model of disability provides the framework for the project. I will borrow from quantum mechanics to restate this concern in terms of the ‘uncertainty principle’: ‘Within the disabling society it is impossible to conduct social model based research simultaneously on barriers and ensure inclusive participation of disabled people with any degree of certainty.’ From this point of view the principle translates into an expectation of ‘uncertainty’ in completing a project *and at the same time* including disabled people in the programme when the project is conducted within the disabling society. Gerry puts the problem faced by him this way: ‘The project is intended to provide a model for undertaking large-scale participatory research based on the social model of disability. In practice there have been a number of significant problems in meeting this objective’ (p.49). He goes on to outline the effects of the disabled researchers being unable to fulfil their duties, and says: ‘Statistically, the chances of three consecutive post-holders having to leave their jobs in this way must be viewed as pretty remote’ (p.62). While this experience may have been extreme it does, in my view, actually highlight the significance of the ‘uncertainty principle’ in planning and funding social model based research.

In reviewing the research programme Gerry acknowledges this reality, referring to Colin Barnes’ warning: ‘Some disabled workers (particularly if they have “unpredictable” or intermittent impairments) are always likely to experience a need for “a more flexible and less demanding work schedule” from time to time ...’ (p. 63). However, I believe the significance of the ‘uncertainty principle’ goes further than a recognition of the need for flexibility in engaging workers with differing impairments. It seems to me that the research exercise itself is also an enactment of the clash between two lifestyle frameworks. Disabled people are expected to operate within the (research and funding) parameters designed for able-bodied living even when trying to carry out activities based upon their own interpretation of the world (applying research parameters from the social model of disability). This is an impossibility and must lead to uncertainties. Indeed, it can be argued that the research objective ‘to develop methodologies which would enable us to identify and quantify disabling barriers’ (p. 50) is most wonderfully sited in the statistical problems experienced during the unfolding of the research programme itself!

Secondly, in distinguishing between participatory and emancipatory research Gerry emphasises ‘that the former simply involves disabled people in research, while the latter means that the research is actually controlled by them as part of a broader process of empowerment’ (p.51). However, while this is a very significant distinction the focus is the same - on the degree of involvement of disabled people in research. As I have mentioned earlier we also need to take into account the research focus when identifying a project as involving participatory or emancipatory research. From this point of view Gerry’s research objective is located around ‘disabling barriers’ and this suggests a greater emancipatory than participatory goal despite his own characterisation of the project. If this is so then perhaps

the importance of taking into account the uncertainty principle should have been strengthened when the research project was designed.

Thirdly, the objective ‘to develop methodologies ...’ (p.50) in response to criticisms (from non-disabled people?) is a reaction to neither participatory nor emancipatory issues within the process of *doing* social model based research (both in terms of the subjective involvement of disabled people and objective location of the investigation on barriers). From this point of view the research and paper are dealing with ‘assimilation’ problems - that is, how to assimilate disability research (based on the social model) into the academic tradition established within the health and welfare culture of people with abilities. An important objective of the research, then, is almost certainly contradictory. It is in this respect that any evidence of pragmatic gains may make the research seem worthwhile: ‘The fact remains however that the project is still essentially seeking to meet head-on the methodological criticisms of social model research on the grounds that this is the best way to refute them. Only time will tell if this pragmatism has been successful and whether the compromises which have had to be made along the way have been worthwhile’ (p.61).

If this research turns out to be more emancipatory than Gerry thought, while at the same time less participatory than intended (due to problems in retaining the disabled researchers), then perhaps the research is best characterised (after Linda Ward) as pragmatic research? The ‘compromises’ then, turn out to be part of rectifying the social model rather than contributing to rectifying the disabling society. Gerry, however, remains ‘optimistic that at least some of the products of our research will - eventually - pass the test’ (disabled people will find a use for the products of the research) ‘but, as ever, only time will tell.’ (p.65). True, but in the meantime, I rather suspect that Oliver’s gibe is applicable to the researchers involved in this project.

In his review of the sexuality and disability project carried out together with Kath Gillespie-Sells, and Dominic Davies, ‘pragmatic research’ is all but claimed by Tom Shakespeare. On why did the researchers write their book Tom provides a personal interpretation: ‘There are cynical answers to this question, which would be inaccurate, but cannot entirely be discounted. These include: personal ambition; desire for financial gain; voyeurism; academic credibility; opportunism. The altruistic answers might include: political commitment; perceived need; intellectual curiosity; professional development.’ He concludes: ‘The truth lies somewhere between these positions, and includes a considerable degree of pragmatism’ (p. 178). This approach is reinforced when commenting on the way the ‘intention to document the lives and experiences of disabled people’ was put together in the book. He notes the use of personal accounts between chapters in the book ‘to convey the richness of the material we had gathered, and to give participants a chance to speak for themselves, and also, it has to be admitted, to achieve the target length which the publishers had set for us.’ Tom then adds: ‘This last point indicates the pragmatism which underlay our methodology’ (p.182).

Curiously, given the admittedly pragmatic approach, Tom actually wonders whether it might be labelled emancipatory? Not surprisingly his answer is dilettantish: ‘The million dollar question remains: is the *Sexual Politics of Disability* emancipatory research? To be honest, I don’t know and I don’t really care. I am a pluralist, and would rather follow my own intellectual and ethical standards, rather than trying to conform to orthodoxy’ (p.185). Even curioser is why Tom still feels the need to show some allegiance to the social model of disability since the methodology is quite clearly, to my mind, not dependent upon it: to the question ‘Does the research adhere to the social model of disability?’ he responds, ‘Everything I do adheres to the social model of disability, according to my own interpretation

of it' (p.186). With this kind of interpretation any construction of the social model is equally legitimate. This, I fear, is not just rectifying the model, it's turning it onto its head - personal experience is set as a standard for social meaning. Is this an example of *what is personal for me is political for you?*

By contrast, I cannot imagine anyone ascribing either cynical or altruistic interpretations to why Paul Hunt and fellow residents in the Cheshire Home encouraged others to research their experiences. To my mind this is because there were unquestioned long term emancipatory objectives in the personal and collective sacrifices that were made by these disabled people. Inviting Miller and Gwynne into the Home to conduct research may have been a naïve act but Oliver's gibe certainly does not come to mind when commenting on Paul's publications which truly adhere to the ideas and actions of these pioneers of the social interpretation of disability.

Without their acceptance of accountability in their personal and political lives it is difficult to imagine how the foundations may have been laid for the peculiarly British interpretation of the social model of disability, the significance of which even Linda Ward acknowledges. This accountability was embedded in the UPIAS third fundamental principle: 'that professionals, experts and others who seek to help must be committed to promoting such control by disabled people' (UPIAS, 1976, p.3). Perhaps there is no point in asking whether Oliver's gibe applies to Tom's account of his research: 'I'm not sure I'd ever want to be accountable to anyone other than my publisher and my conscience' (p.186). Pursuing research guided by the radical social model of disability while at the same time keeping to the lifestyle rules of the disabling society is like trying to involve prison inmates in emancipatory research without questioning the endurance of the constraining walls that prevent their escape. This should not be confused with researching ways of enhancing the civil rights that regulate improved care and welfare of the inmates. The disabling society has very well established rules for constraining its inmates according to an idealised lifestyle of people with abilities. The unrelenting question facing disabled people is not how to continue enduring care and welfare but how to emancipate ourselves from this endurance. Research which contributes answers to this question will need to go far beyond mere attempts to include the disabling society's inmates in the process, but focus even more determinedly on the nature of the walls that confine us.

It is, of course, far more than Colin Barnes (as the reviews editor) would tolerate if I went on to pick at each of the remaining chapters that I have not yet addressed in *Doing Disability Research*. What I have tried to do is select the chapters which enabled me to highlight what I regard as the challenging dilemmas that researchers face if they are indeed to be motivated by the drive for social transformation that is incorporated in the radical social model of disability. I apologise to the authors whose work I have not tried to unpack, but perhaps some might regard this as just as well!

Whatever else I have said I wanted to illustrate the perplexing issues raised in applying the social model of disability to research and the range of responses provided by some of the outstanding researchers in the field. *Doing Disability Research* is a key text for the next round of debate and development. There are no answers in this book but a lot of very important questions. Every serious researcher should stick their fingers into this sticky pie and then carefully examine what they pull out. Do start with Colin Barnes and Geof Mercer's invaluable overview of the 'state of the art'. After all, with another publication to their names, you might want to ask whether Oliver's gibe also holds for them?

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