Running out of steam? The impact of research on disability policy and the disability rights agenda

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Introduction

This paper revisits some of the ideas about the early development of participatory and emancipatory research explored in my 1992 paper - 'On the Road to Damascus: first steps towards changing the relations of research production'. (Zarb, 1992)

The paper is intended to be both retrospective and forward-looking. It attempts to draw some lessons for the future of disability research by examining how ideas about the role of research in disability studies were initially developed and how they have been applied in practice. Most importantly, the paper examines the impact research has had on the development of disability policy over the past decade, particularly in relation to its influence on promoting rights, equality and inclusion.

One of the key arguments proposed in my earlier paper was that the transformative potential of disability research was, at the time, significantly constrained by the social and material relations of research production. This current paper examines whether the constraints posed by the organisation of research have been either strengthened or weakened, and the extent to which the early promise of the participatory and emancipatory agendas for disability research has been fulfilled.

The paper argues that research that has contributed directly to improving the position of disabled people in society continues to be the exception rather than the rule. In practice the transformative potential of disability research appears to be declining in the face of an increasingly centralised policy setting agenda. The paper also argues that, in addition to the barriers created by traditional relations of research production, the impact of research has, since the mid 1990s, been further constrained by the focus on very particular forms of 'evidence' relating to the economic and managerial efficacy of policy and practice. This has led to a demotion of alternative research outputs influenced by the disability rights agenda which, as a result, have tended to become marginalised in the policy making process.

Finally, the paper considers the potential for reversing these trends and argues that this can only be achieved by an explicit re-alignment of research and political agendas and by reasserting the social model basis for disability research.

Can research based on the social model of disability be called emancipatory?

My particular purpose in writing the original paper on changing the relations of research production was twofold: First, I wanted to be able to critically evaluate my own work, and those of other researchers I worked with. Second, I wanted to try to make sense of how the work we were engaged in fitted in to the broader objectives implied by the social model framework. In particular, I wanted to analyse whether what were doing - or thought that we were doing - was actually consistent with key social model objectives relating to empowerment and social change.

At the outset, this was intended to be primarily a practical exercise. Although at the time the paper was written most of the research we had been engaged in had either involved working with or for organisations of disabled people, it was clear that the extent to which this work could be described as being genuinely participatory was really quite variable. It was even less clear whether or not what we were trying to do could in any way be described as 'emancipatory'.

Critical reflection on our work up to that time pointed towards the observation that although some limited progress had been made in the direction of emancipatory research through a commitment to genuine partnership between researchers, disabled people, and their representative organisations - i.e. through participatory research, this was really only a first step. The conclusion I came to then was that: "Much more fundamental changes in the relations of research production are needed before we can start to talk about emancipatory research as a practical reality, or even know what doing emancipatory research will actually involve". (Zarb, 1992, p.125)

Part of the reason for this uncertainty was that we had not necessarily thought through - in practical terms - a clearly defined modus operandi. At that time, of course, hardly anyone was actually using phrases like 'emancipatory social model research' to describe either their own, or other researchers work. Certainly some of the academic and disability research community had already started on the theoretical and discursive work that now forms the bedrock of disability studies inspired by, and building on, the earlier writings of pioneering activists (some of whom were themselves academics as well). Some had also started doing what we would now call 'participatory research' - although, mistakenly, this and the term emancipatory research are all too often used interchangeably). However, looked at through the lens of history it is sometimes easy to forget that things were not so neatly defined at the time.

Although more than ten years have passed, the observations about the 'teething problems' associated with the new model of research are probably no less valid today: "In reality, we have spent much more time thinking and talking about changing the way we do research than we have on actually going out and starting to change our practice. ……. the learning curve involved has been not so much like a steep mountain, than a big dipper; as soon as one contradiction or oppressive practice seems to have been understood or resolved, another comes along and forces the realisation that, like it or not, the research is still part of the problem and not the solution" (Zarb, 1992, p. 127)

On reflection, I think I would add another reason to this list; that the agenda for disability research in the late 1980s and early 90s was still mostly a reactive one. This is illustrated by the number projects researching various aspects of 'the experience of disability' at that time in response to criticisms that previous research had made some groups of disabled people 'invisible'. (For example, Gerry Zarb and Mike Oliver's work on older disabled peoples experiences of ageing, Jenny Morris's research on the experiences of disabled women, and early work by Ossie Stuart and Nasa Begum on the position of black disabled people).

Of course, a lot of this work also had a more strategic, or even political, element to it. Research based on disabled people's own experiences was seen as a corrective to the vast majority of research output at that time which was more or less exclusively focused - both conceptually and methodologically - on quantifying impairment and the characteristics of impairment. Nevertheless, I think this was still essentially a reaction to existing research agendas. Obviously, responding to existing research in this way was in effect the first step in formulating a new research agenda and, ultimately, a whole new research paradigm but, in practice, the demarcation lines at the point of transition were probably a bit more blurred than we would like to believe.

It soon became clear however that, whatever choices we made about how we conducted our research activities, there were a wide range of external factors influencing not only how we worked, but even what we researched and. Most importantly, how the products of research could be used. While disability researchers are able - if they chose to - change the social relations of research production through their own practice and the relationships they develop with disabled people and their representative organisations, it was clear that they have much less control over the material relations of research production. Funding institutions and policy makers, it seemed, mostly determined what kind of research it was possible to do.

Finally, these reflections led, in turn, suggested that there was an important distinction to be made between 'participatory' and 'emancipatory' research. "Although some of our existing research could occasionally be said to have 'transformative' or 'emancipatory potential', it is clearly not emancipatory in terms of the two primary principles of 'empowerment' and 'reciprocity' which are at the heart of present debates about emancipatory research. The main reason for this is that, while some genuine progress has been made in terms of reciprocity, our research has done little or nothing to contribute to the empowerment of disabled people". (Zarb, 1992, p. 127)

So, how much has changed over the past decade?

Continuing barriers

In many ways, existing barriers to emancipatory research have been strengthened in recent years by a number of developments in the political and policy making arena, most of which have had a negative impact, not only on disability studies, but all research activity with radical intentions or aspirations.

i) Centralised policy making and the use and misuse of 'evidence'

One of the most significant obstacles in recent years is the way that policy making has become increasingly centralised. As a result research has, if anything, become even more peripheral to the process of informed decision-making, unless it happens to support policy goals that have already been established. Closely related to this is the tendency for only very particular forms of 'evidence' to be seen as having any validity. We see this for example in the development and use of performance assessment indicators within the best value framework, league tables in education, and the drive towards 'evidence based practice' in both health and social services.

These developments are particularly limiting for disabled people and other excluded groups for two main reasons. First, they are all primarily driven by concerns about managerial and economic efficiency rather the genuine pursuit of the understanding necessary to bring about real social change. Second, the kind of evidence used is typically restricted to the evaluation and measurement of structures and processes that already exist. Clearly, if those structures and processes are themselves fundamentally disabling, the use of evidence in this way only serves to maintain them.

Probably the most significant barrier of all however has been the way in which research that seeks to examine structural exclusion is almost completely ignored in the context of recent policy making. As illustrated in Alan Roulstone's excellent analysis of Disability, Dependency and the New Deal for Disabled People (Roulstone, 2000), this can be traced to the dominance of political agendas which seek to redefine exclusion as purely an issue for individuals rather than society as a whole. For example, by focusing on providing disabled people with the personal resources to enter work, policy on employment has more or less completely ignored all of the research evidence on structural problems that have excluded so many people from work in the first place.

ii) Institutional constraints on disability researchers

Obviously, changes during the last decade to the way in which universities and other academic institutions are funded have also had a major impact on how research is conducted and, most importantly, the way that the products of research are processed and disseminated. In particular, one of the main criteria for assessing an institutions ratings is the number of publications they have produced in peer-reviewed academic journals. Researchers still have some kind of choice about how much of their time and energy they want to put into this activity compared to pursuing more practical and accessible outlets for the products of their research. However, given the very strong pressure they face from their own institutions there is often a very high cost to be paid if they chose to take a purely principled approach towards ensuring that all of their research is only disseminated in ways that are universally accessible.

This does create a real dilemma, but one that needs to be faced if the emancipatory goals for disability research are to have any chance of being realised. Indeed, as Dan Goodley and Michele Moore have suggested, it is perhaps "disingenuous for researchers to advocate research and empowerment when they also seek scores in research assessment exercises that are, arguably, inversely related to the prospects for empowerment". (Goodley and Moore, 2000, p. 875)

iii) The relationship between disability research and disabled people

In view of the continuing constraints posed by the social and material barriers of research production it is not surprising that there remains a great deal of scepticism about the role of research among disabled people.

Such scepticism is regrettable, not least because it seems to have crystallised into disenchantment with disability research as whole. Those research projects and researchers that have tried (sometimes successfully and sometimes not) to make a genuine contribution have tended to be 'tarred with the same brush' as those which can, quite rightly, be characterised as being, at best, irrelevant and, at worst, completely self-serving.

While accepting that the overall impact of disability research in the last decade has been disappointing, there are examples of research that has been of practical benefit to disabled people. It is important to recognise these successes and to try to replicate them in the future.

Colin Barnes for example argues that: "Over the last decade or so there have been several pieces of research which conform to an emancipatory research model albeit implicitly rather than explicitly. Notable early examples include the BCODP research on institutional discrimination against disabled people, Mike Oliver and

Gerry Zarb's analysis of personal assistance schemes and subsequent BCODP research on direct payments. Colin Barnes also notes that: "although the rhetoric has yet to be matched with meaningful outcomes, there is a growing emphasis on user participation, if not control, within the research programmes of the various research councils. …. Whilst these changes might not go as far as some might wish … they do mark something of a shift in the right direction (Barnes, 2002, p. 6).

There are other recent examples, which, while they might not reach 'perfection' in terms of every single criterion, all demonstrate particular aspects of the 'ideal model' of emancipatory research.

Research such as the Creating Independent Futures project carried by the University of Leeds (Morgan, Barnes and Mercer, 2000) and the Scottish Executive commissioned work on Implementation of Direct Payments in Scotland has had a practical - and, hopefully lasting, impact on extending disabled people's access to direct payments. In the case of the work by Sally Witcher and her colleagues the research has had a direct influence of changes in legislation in Scotland.

There have also been some good examples of practical collaborations between researchers and disabled people at the local level. For example, research on black disabled people in Warwickshire by Martin Banton and Maureen Hirsh (2000), Rowan Jade's report on young people's personal assistance schemes (2003), and the work on self-advocacy carried out by the Norah Fry Centre and Swindon People First (Gramlich, 2002).

Apart from the participatory methodology employed the main significance of all of these projects is that they addressed issues of immediate and practical concern to disabled people. The work at the Norah Fry Centre is also notable for its emphasis on ensuring that nearly all of their research outputs are produced in fully accessible formats. This practical emphasis on the usability of research can also be seen in some recent projects carried out by disabled people and other user-led organisations themselves. Greater Manchester Coalition of Disabled People's evaluation of a young disabled people's peer mentoring/support project (Bethell and Harrison, 2003) and the Shaping Our Lives work on users' definition of quality outcomes (SOLNUN, 2003; Turner et al, 2003) are particularly interesting examples as both focused as much on building networks as they did on the research findings themselves. Indeed, in both cases, the development of these networks was one of the main products of the research process.

All of these examples indicate that, as long as research addresses issues of immediate and practical concern to disabled people, positive outcomes can still be achieved even within the constraints posed by the existing relations of research production. The final part of this paper will examine the future prospects for disability research as a whole and the kind of research that we need to contribute to the creation of a fully inclusive society. Before that, we need to consider what needs to change within disability research itself.

iv) Problems within 'the academy'

While it is undeniable that both the material and social relations of research production continue to limit the emancipatory potential of disability research, there are certain aspects of the problematic status of disability research that are located within the 'disability studies academy' itself.

First, one of the main difficulties with the self-professed radicalism of disability research is, to put it bluntly, an unrealistic level of expectation about what research can actually achieve in practice. Indeed, this is one of the chief reasons for making the original distinction between participatory and emancipatory research in the first place. Research cannot ever lead directly to the empowerment of disabled people (or any other group for that matter). As Mike Oliver points out, empowerment is not something that can be given, but something that people must take for themselves. The key issue - "is not how to empower people but, once people have decided to empower themselves, precisely what research can do to facilitate this process" (Oliver, 1992, p. 111)

Second, another related problem is the tendency among researchers working in the field of disability studies to have become almost too self-conscious about the both the limitations of research as a tool for change and, in particular, the inherent contradictions attached to their own role within this process. It is probably fair to say that initial optimism about the transformative potential of disability research did help to create unrealistic expectations. But that doesn't mean the original aspirations were misguided in themselves.

Despite the hostility towards research that has been expressed by some activists, many disabled people who engage in research are often more pragmatic about these limitations and contradictions than researchers themselves. A good illustration of this can be seen in the collaboration between Mark Priestley and Derbyshire Centre for Integrated Living. In his review of this work in Disability and Society, Dave Gibbs comments that disabled people involved in the research were well aware of the potential risks and contradictions which he characterises by the use of phrases like "tug of war" and "balancing act". He also points out that: "There is no formula to assure a mutually positive research outcome" (Gibbs, 1999, p. 582). The important point however was that, provided there was genuine commitment and accountability, the possibility of achieving real social change clearly justified the risks involved.

Third, there are a whole new set of concerns associated with the increasingly multi-disciplinary approach to disability studies. While there have been some real benefits to the broadening out of disability studies over the past decade, the down side is that the focus for disability studies has become blurred.

Mike Oliver and Len Barton (2000) have suggested that: "The very notion that this veritable ragbag of ideas about oppression, emancipation, representation, struggle, inclusion, independence, discrimination, rights, genocide and so on, and the ratpack of sociologists, educationalists, psychologists, linguists, historians, literary theorists, disabled people and others who have made a contribution to all this could somehow all be codified and encapsulated into a single discipline called disability studies is itself perplexing." (Oliver and Barton, 2000, p1)

Even more important perhaps is the potential impact these developments might have on the relationship between disability studies and the process of social and political change. Mike Oliver and Len Barton continue their analysis by saying that:

"… because such attempts at codification and encapsulation are linked to some of the dominant social institutions of our time, we are not merely perplexed but concerned about whose interests might ultimately be served. …. also ….. given that the academy is not as accessible (in its broadest sense) as it might be to disabled people, how might such links be maintained? Linking these two aspects of the political together, we cannot help but note that the very point at which women 's studies was accepted as a legitimate academic discipline in its own right was precisely the point at which it seemed to lose its radical, cutting edge. If the price to pay for the codification and encapsulation of disability studies is the loss of its cutting edge, then perhaps the price is too high." (Oliver and Barton, 2000, pp 1-2)

This analysis is clearly very challenging. Encouraging new ideas and, most importantly, enabling new researchers and writers to contribute is both desirable and necessary if disability studies and disability research are going to move forward. The key question is to what purpose are researcher's efforts going to be used? As Colin Barnes put it: "disability studies - what's the point?'

Disability studies - or at least that part of it that is commonly associated with the social model of disability - has particular distinguishing features that demand specific criteria for evaluation. However much debate there might be about the precise definition of the social model, there can be no doubt about it's underlying purpose as a tool for creating a non-disabling society (Zarb, 1997).

Consequently, any evaluation of disability studies and disability research based on the social model cannot be based on purely academic criteria. Rather, research has to be critically examined in terms of its impact on materially advancing the position of disabled people in society.

On that basis, I would go even further and suggest that any disability research that is not explicitly intended to contribute in some practical way to the creation of a non-disabling society should not lay claim to being described as social model research.

Disabling barriers and the experience of disability

We also need to consider the as yet unresolved debates about whether, and if so how, research based on the social model can incorporate the lived experience of disability. These debates have particular significance for disability research in terms of not only of the kind of research subjects and methodologies to be prioritised, but also the practical impact of the research outputs that are produced.

For Finkelstein (Coalition, 1996), researchers face a relatively simple choice between an 'outside in' or an 'inside out' approach. As Colin Barnes and Geof Mercer explain in the introduction to Doing Disability Research: "In the former, disability research and political activity concentrates on the barriers 'out there', while the latter adds an emphasis on disabled people's subjective reality - their experience of physical pain, fatigue and depression." (Barnes and Mercer, 1997, p.7)

It seems to me that the key challenge here will be to develop forms of research and analysis that can link disabled people's experience of discrimination and exclusion with the disabling institutions and processes that help to create that experience in the first place. We need to find a way of making visible the process by which subjective experience becomes a material and practical reality. There are already some pointers to achieving this goal, such as the work by Peter Beresford and others on developing a social model of madness and distress but this has yet to be fully integrated into the core activity of disability studies. Beresford et al, 1996; Beresford, 2000)

We also need to see much more creative work on drawing out the commonality of seemingly disparate experiences. One of the positive achievements of disability research has been to make visible experiences that had previously been invisible. However, an unintended consequence of this has been a tendency towards 'colonisation' of different sets of experiences, which has sometimes made it harder, rather than easier, to identify and challenge common barriers. We also need to be aware that sometimes this plays into the hands of institutions with a vested interest in creating 'hierarchies of exclusion', which obviously does little to further the goal of defining and creating a fully inclusive society.

What kind of research do we need?

As Paul Abberley (2002) has pointed out, if we are to develop effective policies to combat social exclusion, the key challenge for disability studies is to show what a non-disabling society will look like. This challenge has not, so far, been addressed very successfully.

Again, examination of the material relations of research production points to one of the most important reasons for this. Institutions that commission and fund research mostly have much shorter-term objectives driven by what they see as the most pressing policy problems. This makes it extremely difficult to put together a viable programme of research that is both broad enough and - most importantly - forward looking enough to monitor real change (or lack of change) in the position of disabled people in society.

This can be contrasted with long-term research on race and gender inequality that has been running since the 1970s, as well as the vast amount of resources that been put into research on poverty and 'public health' issues. It can be seen that much of this research has been driven by concerns about social cohesion and the related political and economic costs. More recently, we have started to see a similar response to concerns about environmental threats.

Clearly, the exclusion of millions of disabled people from social, economic and civic life is not seen as posing the same kind of social or political threats. Instead, policy responses are focused much more on concerns about the cost of managing this exclusion rather than removing it.

So, what can disability research do to help raise the ante - to help make the political costs of continued exclusion become too uncomfortable to ignore?

One of the criticisms often aimed at social model research is that it has lacked methodological rigour. A related criticism has been that it has focused too much on examining discourse and experience at the expense of providing 'hard evidence' on the material realities of inequality and exclusion.

The first of these criticisms - about methodological rigour - is almost exclusively external and, as much as anything else, reflects the academic establishment's resistance to what is seen as political polemic masquerading as intellectual activity (Zarb, 1995). At the same time, it also provides institutions with a vested interest in maintaining the status quo an excuse to play down or even ignore any research findings that highlight the discrimination that disabled people face.

The second criticism - about the lack of emphasis on the material realities of discrimination and exclusion - has been more of an internal debates among disability researchers themselves although, more importantly perhaps, it also reflects the critical questioning of the relevance of disability research by organisations of disabled people.

As Mike Oliver and Len Barton put it: "this tension centres on the need to ensure that disability studies continues to focus on issues that are important to disabled people and not on issues that are intellectually challenging or academically rewarding for disability studies scholars themselves. Currently fashionable issues like postmodernism, representation and embodiment may well turn on disability studies scholars but their immediate relevance to the struggles of disabled people to lead a decent life are hard to justify." (Oliver and Barton, 2000 p 8)

I think that these criticisms - both external and internal - of research based on the social model of disability are very closely related - and what links them so closely is precisely the issue of how the products of research are used.

The idea that simply increasing the methodological rigour of disability research is a tempting one but, ultimately, misguided. Disability studies, just like any other field of enquiry, can point to numerous pieces of work that can be admired for both their intellectual creativity and methodological rigour but which have had absolutely no impact at all on the business of policy formulation and political decision making.

What marks out the exceptions to this rule is that they have - whether by accident or design - tapped into existing agendas that has enabled various institutions or interest groups to make use of the products of research in furthering their own practical objectives. This happens so consistently as to be almost an 'iron rule' of research: if it fits what we want to do we'll use it, if it doesn't, then 'who cares'. Such bald pragmatism - and the cynicism towards research that it encourages - is not always very comforting. But it is a reality that cannot be easily ignored.

Colin Barnes' seminal work on discrimination and disabled people - which was of course commissioned by, and accountable to disabled people themselves - is a perfect example of the iron law of research. Thorough and rigorous as it was, this work would never have had the impact it did if it hadn't dovetailed so neatly into the practical reality of disability politics at that time and the kind of evidence most needed to further practical action on disability rights.

Nevertheless, despite the body of evidence provided both by this study, and the subsequent work it helped to encourage, we are still a long way off achieving comprehensive civil rights for all disabled people, and even further away from the main goal of creating a fully inclusive society. This does not mean the research has been a waste of time - far from it. But it does show very clearly that the political project itself is still a long way from being complete.

Conclusion

The key issue then for disability research is really exactly the same as it was when the debates about emancipatory research started in earnest back in the early 1990s. It is not so much that - as critics of the social model would have it - disability research is too political but rather that it is not political enough. The obstacles to the transformative goals for disability research have not gone away and, in many ways, they have been strengthened. They can be challenged but this can only be achieved by an explicit re-alignment of research and political agendas and by reasserting the social model basis for disability research.

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