

# DISABLED PEOPLE AND THE RESEARCH COMMUNITY

**David Gibbs, Derbyshire Coalition for Inclusive Living**

(Paper for ESRC funded seminars, 'Theorising Social Work Research', seminar 2, 'Who Owns the Research Process?', Belfast, September'99)

*"We have barely begun to understand where the social interpretation of disability is leading us" (Finkelstein & Hunt 1999)*

## **Introduction**

The perspective of this paper is not that of social work research but of what the seminar objectives call a related field of enquiry - the praxis of applying a social understanding of disability. Derbyshire Coalition for Inclusive Living exists to apply disabled people's own ideas and experience to develop peer support systems and to influence public services and policies. The overall goal is one of 'full participation and equality'. The theoretical base is an understanding of disability in terms of social exclusion, and the strategic framework is seven areas of action for removing socially constructed disability. Programmes within the strategy include: a disabled people's information service, peer counselling, a Personal Support Service for people to manage their own personal assistance, community development, training and research. Associated projects are a Young Disabled People's Project and an Education Programme to develop NVQ level IV qualification in peer support work.

DCIL has had varied contacts with the research community during 18 years of these programmes, and I will draw on these experiences and those of fellow organisations to trace the relationship between disabled people and the research community through several stages. Labels of convenience adopted for these are: *abrasion*, *assertion*, and *convergence*. I will then try by reflecting on this experience to anticipate a further stage of the relationship, *co-production*, and relate this to the seminar themes: ownership of research and theorising social work.

## **First stage: abrasion**

The paper by Peter Beresford in the first seminar of the series sets the scene when he says:

"The starting point for many service users' view of research is as part of a structure of discrimination and oppression; an activity which is both intrusive and disempowering in its own right and which serves the damaging and oppressive purposes of a service system over which they can exert little or no influence or control" (Beresford 1999)

As a specific illustrative text I go back to a 1981 paper entitled 'Settling Accounts with the Parasite People' (Hunt 1981). The focus of Paul Hunt's critique was a research study in the late 60s of residential institutions for disabled people (Miller & Gwynne 1972). The study was asked for by residents of a charity-run institution in Hampshire, who hoped that it would provoke critical examination of life in an institutional setting, place it in a wider context of policy on the provision of support to disabled people, and lead to positive outcomes in their lives. Its conclusions indeed drew critical attention to the 'social death' that resulted from policies centred on 'warehousing' disabled people. It became a widely cited reference, and was one of the set books for an Open University course, 'The Handicapped Person in the Community', introduced in 1975.

Hunt's critique, however, was an attempt to examine and fully understand a profound sense of betrayal felt by himself and others who had instigated, participated in and promoted the research. He took the view that the researchers were 'profoundly biased and committed against the residents interests from the start of their research', and that this was 'evident in their whole conception of the issues, and therefore in their chosen research methods, and in all their analyses, conclusions and recommendations'. He noted that preoccupation with preserving objective detachment seemed to have a main purpose of protecting researchers from the emotional strain of engaging with their subjects, whose plight might undermine their scientific balance. Even while fully recognising the 'living death' and 'inherent pathogenic characteristics' of institutional living, the researchers made no reference to community alternatives or recommendations for fundamental change, but concluded that 'the essential task to be carried out is to help the inmates to make the transition from social death to physical death'.

Hunt's conclusion was that 'the fundamental relationship between (the researchers) and the residents was that of exploiters and exploited'. The depth of feeling this research experience generated is undiminished to this day:

"The inescapable, unacknowledged *political* dimension of 'research' was so obvious it had to be exposed and opposed. Researchers could window shop from an established academic array of 'respectable' formulas, select an off the shelf approach trendy enough to catch the eye, command the respect of peers, satisfy funders, give a nod to scientific method, enhance reputations, preserve the prospect of future assignments, and do wonders for careers. And in their make-believe, value-free objective world always end up reinforcing the status quo" (Davis 1999)

In Hunt's view the objective detachment of this 'scientific method' produced only 'a project totally lacking in scientific objectivity'. That is to say, what the researchers detached themselves from was their primary source of evidence – the perceptions and goals of institutional residents. It might be suspected that the cause of such detachment lay less in 'scientific objectivity' than in an

impoverished facility to engage at a personal level. Such inhibitions will be returned to below in discussing 'internalised oppression'.

On the evidence of this example, then, the perceptions of researchers and disabled people in 'stage one' were so far apart that no common ground is discernible. Put another way, their different concepts of what constitutes 'evidence' seemed to be irreconcilable.

## **Second stage: assertion**

In '91 the Rowntree Foundation funded a series of seminars in London on the subject of 'Researching physical disability'. For the first time, a significant minority of the participants were research academics who were also disabled people. The challenges they put were that, for much the greater part, research on disability fundamentally misunderstood the nature of disability, distorted its experience, failed to involve disabled people, and had no record to speak of in producing real improvements in the quality of their lives.

The seminars led in '92 to a national conference on 'Researching Disability', in which disabled people's claim for ownership of the research process was forcefully asserted. To an organisation like DCIL, seeking strategies to achieve social change by applying a social understanding of disability, the papers from that conference provided a benchmark to link our development work with some of the participative and emancipatory paradigms of research production emerging in the academic research community. These applications to disability research owed much, in turn, to research on women's issues in the 70s, and have begun to shift the central focus of disability research away from welfare and towards civil rights and social change.

In a contemporary development, a sister organisation in Canada produced a particularly illuminating critical analysis of issues around disabled people's participation in research (Woodill & Willi 1993). This led up to a 19-step flow-chart for use as a gruelling obstacle course for research proposals, to help organisations decide whether to help researchers find individual participants. Tools like this quickly had real application in helping to redress imbalances of power, because terms of funding for research on disability issues were beginning to include criteria for involvement of 'users' or their representative organisations. These criteria came to be applied not only by important independent funders like the Rowntree Foundation, but also by Government funders of research. For example, the application pack for proposals to the National Health Service R&D Programme for People with Physical and Complex Disabilities in '95 included in its guidance notes a clear recognition that outcome criteria which assume disabled people want to be 'made normal' are likely to be at total variance with their own goals.

Changing attitudes in this guidance contrast with those in a report some years earlier from the Royal College of Physicians (1986). By seeking to extend a medical territory of 'rehabilitation' over people's lives – inevitably leading to added gatekeeping roles outside medical competence – the report played a

large part in provoking the recognition that disabled people themselves must begin to influence and conduct research production on disability issues and define its outcomes.

It would be highly naïve to suggest this change amounts to a shift in underlying power relations of research production, or to overlook the many devices that have been found to make the inclusion of 'users views' tokenistic or derisory. There are at best encouraging signs. Further stages would be to safeguard against selecting the views only of hand-picked amenable individuals, or of exploiting people who might fear critical statements will jeopardise their services. Instead, participation would extend to a broad prospective user constituency with outcomes defined independently. The safeguarding principle would be one of accountability to peers.

In the absence of clear practical models, however, the present organisation of research production presents obstacles to progress along these lines. A 1995 conference at Leeds brought together perspectives on illness and disability from disabled researchers and other mainly academic commentators. A proposal for a follow-up event on ways to increase disabled people's control of disability research was opposed by almost the whole spectrum of researchers present. They saw in such controls only new restraints on academic freedom, added to those already imposed by government policies to create a kind of pincer movement on the fundamental freedom to pursue knowledge (Barnes 1996). In the light of these legitimate concerns, it is necessary to seek examples where objectives of researchers and their subjects converge in ways that preserve freedoms of the one and advance freedoms of the other. Is there a joint enterprise for disabled people and the research community?

### **Third stage: convergence**

From the greatly increased volume of writings on disability issues in recent years, selection of further examples is assisted by the publication this year of two studies in which objectives and practices of my own organisation, DCIL, are examined in relation to developments in public policy and wider social change. Both studies were done in a period preceding merger this year of a parent Coalition of Disabled People, set up to challenge the social causes of disability, and a Centre for Integrated Living set up to develop practical applications of social models.

Barnes et al (1999) included the Coalition in a study of the relative importance of consumerist and citizenship roles of independent organisations in the context of their influence on local governance. Priestley (1999) analysed the fit between goals of 'integrated living', derived from social model thinking in the disabled people's movement, and the implementation by statutory welfare authorities of 'community care' legislation.

Barnes et al concluded that the main focus of the organisations was a collectivist emphasis on citizenship, rather than an individualist emphasis on consumerism. While the Coalition had often described itself in its earlier

years as a 'consumer organisation', it was able from the research study to recognise that this no longer had its original broad terms of reference in an era of 'internal markets' in public services. Further, the Coalition was alerted to a tendency for newer organisations to receive the consumerist label of 'user groups'. By accepting definition of themselves primarily as consumers of the services provided by their funding agencies, organisations were partially assimilated into the existing service system. They risked becoming detached from long-term goals of changing social structures to support disabled people's inclusion as equal citizens.

These were important insights. They might have emerged in the process of managing changing relationships with public agencies, but arguably were illuminated more clearly and in a broader social setting as a result of the research study. They confirmed and strengthened a commitment to collective action and accountability that was being worn down by opposing tendencies underlying the ideology of the time. As the researchers said:

"It is difficult to avoid the conclusion that the user groups in our study had achieved for themselves, and sometimes for those they sought to represent, a degree of influence that could not have been achieved by individuals."

In studying the programmes by which these developed models translate to practical applications, Priestley's project took the insight a stage further. First, his conclusions endorsed those of Barnes et al and also recognised that policy makers themselves have a stake in promoting self-organisation:

"If policy makers are genuinely committed to greater user involvement in the design, planning and delivery of services, then user *self*-organisation needs to be both encouraged and supported materially without being 'captured' by or incorporated into management."

Here, however, the insight extends to a recognition of how far-reaching can be the application of models derived from what are, initially, very simple shared experiences of exclusion:

"to envisage a society that includes disabled people on equal terms with full participation is to envisage a society which has redefined its relationship to welfare, work and citizenship in ways which would benefit all other marginalised and oppressed groups."

The Open University has proposed to adopt Priestley's book as a set work for a revised course on issues in disability. This will maintain a clear change of orientation introduced in the 80s with the consolidation of what are now called 'disability studies', and has come a very long way from the 'handicapped person in the community' course referred to earlier in relation to 'stage one'.

The insights from these studies were of direct strategic importance to the organisation that took part in them. Convergence of a new paradigm of research and goals of the organisation led to purposive co-working and empowering outcomes. It may be questioned, however, whether one or two

examples amount to evidence of significant change in the dominance of reductionist over 'new paradigm' research aimed at effective co-production. Some committed commentators see scant evidence of this. One eminent disabled researcher (Oliver 1997) harshly scrutinised the emancipatory credentials of his own research over a number of years, and reached a conclusion hardly different from that of Hunt (1981) - that the main beneficiary of research was the researcher. He was led by this conclusion to call for any research with oppressed groups to abandon the idea of research as investigation in favour of a commitment to research as production – engaging with people to change their lives and communities. Emancipation is in oppressed people's own hands; with luck and a following wind, a researcher may find a useful technician's role in support.

To consolidate the positive view placed on the above examples, then, Oliver's call makes it incumbent to seek a more secure framework for commitment to research as production.

### **Praxis and the social understanding of disability**

A theoretical framework for a social understanding of disability, the 'social model', soon emerged from early reflections on the experience of disablement. A particularly influential development of its main themes has been in Oliver's own writings (1983, 1990, 1996), but the social model has been expounded in many theoretical, strategic and activist versions. On one hand these have provided a foundation on which to value diversity and celebrate the experience of disabled people; on the other social models of disability have found a place among other 'new social movements'. There also have been sharp critiques, both of shortcomings in the inclusiveness of the model's dominant versions and of tendencies to blur its original hard-edged social focus.

This paper is not the place to enter into those debates, except to take a position. The praxis of social models – that is, developing them in the process of putting them into effect – makes it unavoidable to seek increasingly inclusive frameworks simply because people contribute a wide range of perspectives on the experience of disablement. A continuous and hopefully creative tension arises from practical needs to both widen the framework and keep it strong. In one sense this position side-steps the issue – but only to safeguard an ongoing basis for action while debate proceeds.

For the present purpose, then, it will be helpful to distinguish three strands in the development of thinking around social models. One is primarily individualist, addressing barriers disabled people encounter in their personal lives. One is collectivist, focussing more on barriers structured into the way society is organised. These are distinguished in sub-sets put forward by Priestley (1998) as materialist (social creationist) and idealist (social constructionist) types of social model. The third strand has been a more subtle undercurrent of the social model's development from its earliest days,

and acknowledges the degree to which experience of oppression and exclusion can become internalised.

Campbell & Oliver (1996) quote a number of clear statements on experience of 'internalised oppression', of simultaneous gender and racial oppressions, and of the self-imposed restraints of 'being reasonable' in the challenge offered to these. From these personal narratives the authors conclude that the most significant effect of the disabled people's movement has been to transform the individual and collective consciousness of its members. This is despite the fact that the organisational basis of this third strand has tended to be more evanescent than that of rigorous theorising and focus on campaigns and practical applications. Outcomes of all these endeavours, then, need to be seen as much in terms of opportunity for personal reconstruction as of effective means for deconstructing socially caused disability.

Insights at the level of socially constructed oppressions that have been internalised may further extend application of the social understanding of disability to other oppressed groups and to wider society. The added layers of exclusion experienced by disabled people are then seen to set in particularly sharp relief experience shared with many other marginalised groups. The disabled people's movement becomes one sharply defined illustration of a much greater change in society. Indeed, there may be a sense in which internalised oppression is very nearly universal. That is to say, it is ultimately an experience that the oppressors also share. At this point it may be appropriate to follow the example of the environmental movement and recognise in the third strand a 'deep social model', where the solutions to internalised oppressions can only be fundamental changes of power relations within society. We can now ask what implications this model has for the theoretical basis of social work research.

### **Implications for theorising social work research**

Parallel to the changing relationship followed above, between disabled people and the research community, has gone a quite different development: the rise of what we know as 'evidence based practice'. This was traced by Parton (1999) in the first seminar of this series, and some threads from his paper can be picked up in asking: could the trends of 'convergence' I've recognised ever reconcile evidence based practice with Oliver's call (1997) for a commitment to research as production?

In Parton's view, the 'injection .. from positivistic science' initially prescribed by Sheldon (1978) has tended to dislodge social work from its origins in 'beliefs about the capacity of human beings for personal transformation'. In our own relations with the research community (as well as with policy makers and practitioners), the 'injection' often has seemed to anaesthetise the very faculties needed to link research with the perceptions and values of its subjects. Indeed, it preserves unreconstructed all the oppressive consequences of 'objective detachment' condemned by Hunt (1981).

It seems bizarre that this reductionist tendency is being so doggedly retained in the one discipline, the social sciences, that might reasonably have been expected to favour a holistic and empowering emphasis. After all, it has long been in retreat in the so-called 'hard' sciences. The writings of Capra, for example, have traced in an accessible way the growing recognition that it is impossible to detach either researcher or subject from the 'complex systems' they share (Capra 1975 in relation to physics, 1982 in relation to economics and health, 1996 in relation to ecological systems). Disabled people themselves have focussed particular concern on one of the last reductionist redoubts, genetics (BCODP 1999), where the degree of detachment from human context and consequences has led activists to 'deal with Genetics first of all as an issue of oppression' (DANE 1998).

In the extended interpretation offered here, reductionist thinking is both a cause and a long-term effect of internalised oppression. There is therefore a basis for co-production that will bridge the gulf between objective and experiential evidences. In its widest setting, internalised oppression has been laid down during a long cultural history in which the core dogmas employed for the sequestration of power have been (in a phrase of Roszak 1972) 'hard at work censoring the natural polyphony of consciousness'. Against this background the secular dogma of 'free markets' becomes the latest stage of a tradition that has overlain diversity and abrogated people's own power, layer by layer, over many generations.

In one interpretation, the civil rights movements and new social movements of our own time seek, in greater or lesser degree, to reverse this historical process. In each of these movements the core issues resonate, first, with other oppressed groups, and second, with the established power structures of social organisation. In their experience and goals may be found a fully grounded cultural basis for a theory of social work research. It might be defined as " the praxis of recovery from the layered history of internalised oppression created by progressive imbalances of power".

Essential stages for the development of praxis from a non-reductionist evidence base are:

- oppressed people confront and define their internalised oppression;
- they found peer support structures to share and value their experience;
- a framework for strategic planning is derived from this experience and an understanding of its social context;
- development work defines the further technical support needs of the supported group, and pilots practical solutions;
- job descriptions and competences are defined around the needs and goals identified;
- practical application feeds back further information about development needs.

Such a process would begin to implement Finkelstein & Stuart's (1996) vision of redirecting services as practical and technical programmes for dismantling the present disabling culture. These tasks might even become the basis for new kinds of profession, redefined just as the concept of disability itself has



been redefined. The social understanding of disability, alongside the realignment of research as co-production and the realignment of services to focus on environments rather than individuals, leads to new kinds of useful work with a profound cultural and historical grounding, entered upon in relationships of equality and respect.

## References

Barnes, C. (1996), Disability and the myth of the independent researcher. *Disability & Society* 11: 107-110.

Barnes, M., Harrison, S., Mort, M., & Shardlow, P. (1999), *Unequal partners: user groups and community care*. The Policy Press, Bristol.

BCODP (1999), *The New Genetics and Disabled People: a discussion document*. British Council of Disabled People.

Beresford, P. (1999), *Service users' knowledges and social work theory: conflict or collaboration?* ESRC seminar series: *Theorising Social Work*. Seminar 1: What Kinds of Knowledge?

Campbell, J. & Oliver, M. (1996), *Disability Politics: understanding our past, changing our future*. Routledge, London.

Capra, F. (1975), *The Tao of Physics*. Wildwood House, London.

Capra, F. (1982), *The Turning Point*. Harper Collins, London.

Capra, F. (1996), *The Web of Life*. Harper Collins, London.

DANE (1998), 'Fighting back against eugenics and the new oppressors'. Disability Action North East, Newcastle.

Davis, K.O. (1999), Personal communication 18<sup>th</sup> August.

Finkelstein, V. & Hunt, J. (1999), 'Strangeways!' Paper given to a seminar on Teaching Disability Studies in Higher Education, Leeds 8-9 July.

Finkelstein, V. & Stuart, O. (1996), 'Developing new services'. In Hales, G. (ed.) *Beyond Disability: towards an Enabling Society*. Sage, London.

Hunt, P. (1981), *Settling accounts with the parasite people: a critique of 'A Life Apart'* by E.J Miller and G.V.Gwynne. *Disability Challenge* 1: 37-50.

Oliver, M. (1983), *Social Work with Disabled People*. Macmillan.

Oliver, M. (1990), *The Politics of Disablement*. Macmillan.

Oliver, M. (1996), *Understanding disability: from theory to practice*. Macmillan.

Oliver, M. (1997), *Emancipatory research: realistic goal or impossible dream*. In Barnes, C. & Mercer, G. (eds), *Doing Disability Research*. The Disability Press, Leeds.

Parton, N. (1999), *Some thoughts on the relationship between theory and practice in and for social work*. ESRC seminar series: *Theorising Social Work*. Seminar 1: *What Kinds of Knowledge?*

Priestley, M. (1998), *Constructions and creations: idealism, materialism and disability theory*. *Disability & Society* 13: 75-94.

Priestley, M. (1999), *Disability politics and community care*. Jessica Kingsley, London.

Roszak, T. (1972), *Where the Wasteland Ends*. Faber & Faber, London.

Royal College of Physicians (1986), *Physical Disability in 1986 and beyond*. *J. Royal Coll. of Physicians London*, 20: 160-195.

Sheldon, M.E.P. (1978), *Theory and practice in social work: a re-examination of a tenuous relationship*. *British Journal of Social Work* 8: 1-22.

Woodill, G. & Willi, V. (1993), *Independent Living and participation in research: a critical analysis*. Centre for Independent Living in Toronto.