



## **Re-Examining Relationships Between Experience, Knowledge, Ideas and Research: A Key Role for Recipients of State Welfare and Their Movements**

*Peter Beresford, Brunel University*

### **1 Introduction**

The focus of this paper is the emergence of new understandings and paradigms of care and support and their implications for mainstream policies, services and professions. These have major implications for social work, which is a profession particularly concerned with issues of care and support. What distinguishes these new approaches is that they come from people with direct experience of such care and support. They are associated with the new movements of service users which over the last 20 to 30 years have developed internationally, in both the west and the majority world. These movements and their organisations - of disabled people, older people, mental health service users/survivors, people with learning difficulties and others - have developed in different ways and at varying paces in different countries and settings. However, what they have in common, is that their discourses and critiques are crucially informed by their lived experience on the receiving end of such policies and provision and their shared identities as 'service users'. In some countries, including the UK, they have begun to have an impact on legislation, policy, politics and even popular culture. It is the new ideas from service users, the experiential knowledge which they are based upon and the issues these have raised and the ramifications they have, which this article explores.

The emergence and engagement of these 'service user' perspectives represents a major departure from the development of care and support services historically, where other perspectives and sources of knowledge and 'expertise' have traditionally been prioritised. The discussion here is concerned with the implications of this involvement of service users for the economics, planning, policy, and practice of care and support. But it focuses particularly on the ramifications of the experiential knowledge of service users and service user research for the conceptualisation, theory-building, knowledge base, research and evaluation of care and support. This has particular relevance to social work where work on the involvement of service users – in policy, practice, learning and research is especially advanced and has gained considerable international interest.

### **2 The emergence of 'user' movements**

The modern mobilization of health, welfare and social care service user movements is a relatively recent development. Its emergence can largely be traced to the last quarter of the twentieth century. Yet, as has been said, while it would be wrong to overstate its impact, it has been significant. It has led to major changes in ideas, culture, practice, policy, processes and legislation on a global scale. Groups that had previously often been hidden, have gained a greater individual, as well as political and cultural presence in societies. In countries like the UK, their viewpoints have begun to permeate the mainstream, just as they have made major steps along the long road to inclusion and equal rights (Office for Disability Issues, 2008). It

is also an international development, finding various expression in North America, Europe and the majority world (Aspis, 1997; Campbell and Oliver, 1996, Morris,1996; Oliver, 1996; 1993; Priestley, 1999; Coleridge, 1993; Charlton, 1998).

The earliest instance of such movements is probably the disabled people's movement. In the UK, for example, this had its origins in the 1960s and the efforts of disabled people both to escape their own institutionalization and to highlight the broader possibilities of alternatives for disabled people more generally (Campbell and Oliver, 1996). In due course, other service user movements also emerged, including movements of psychiatric system survivors, people with learning difficulties, older people, young people in state care and people living with HIV/AIDS. All have placed an emphasis on people's right to live on equal terms in mainstream society, to speak for themselves; on challenging discrimination and ensuring appropriate and adequate support over which they are able to exert greater choice and control (Carter and Beresford, 2000; Campbell and Oliver, 1996; Campbell, 1996).

Each of these movements has particular history, character, culture and traditions. However, they also seem to have some important things in common. All highlight the importance they attach to:

- Service users speaking and acting for themselves;
- Working together to achieve change;
- Having more say over their lives and the support that they receive;
- Challenging stigma and discrimination;
- Having access to alternatives to prevailing medicalised interventions and understandings;
- The value of user controlled organisations, support and services;
- A focus on people's human and civil rights and their citizenship. This has emerged later, but is increasingly evident of the survivors' movement;
- Being part of mainstream life and communities, able to take on responsibilities as well as securing entitlements (Beresford and Harding, 1993; Campbell, 1996; Beresford, 1999; Campbell and Oliver, 1996).

Some of those writing from within these movements have seen them as 'new social movements'. (Oliver and Zarb, 1989; Davis, 1993) Others have seen them as liberatory movements. Tom Shakespeare, for example, has distinguished between post-materialist and liberation movements and argued that the disability movement belongs to the latter category. (Oliver, 1996, p158; Shakespeare, 1993) Significantly in day to day discussion, members of these movements, often identify with other new social movements, like the women's, black people's and lesbian, gay, bisexual and transgender movements, while user movement commentators and theoreticians identify relations and links with these earlier movements (Morris, 1996; Campbell and Oliver, 1996)

### **3 The service user challenge to traditional approaches: an historical case study**

The efforts of service users, their organisations and movements to influence thinking and get involved in developing, reconceiving and changing policy and practice, however, have met resistance. They have not only encountered this in specific areas like social work, social care and anti-poverty and regeneration work. It can be seen to operate more generally in social policy. An important instance of this is provided by well documented discussions which took place early in the history of the UK disabled people's movement between a traditional organisation set up *for* disabled people and a founding organisation *of* disabled people, where control lay formally and explicitly with disabled people. An agreed account of these discussions was published (UPIAS/Disability Alliance, 1976). The disability organisation was the Disability Alliance and the disabled people's organisation was UPIAS, the Union of the Physically Impaired Against Segregation. Significantly Disability Alliance was mainly represented by its co-founder, Peter Townsend, a key figure in modern academic social policy and social policy reform and a major writer on both poverty and disability issues. The UPIAS spokespersons include founders of the UK disabled people's movement including Vic Finkelstein and Paul Hunt.

The agreed aim of the meeting between the two organisations, subject to their 'prior agreement' to a set of 'fundamental principles of disability' identified by UPIAS, was to explore how disabled people 'could become more active in the disability field' and consider a 'long-term programme of action' to make that possible (UPIAS/Disability Alliance, 1976, p3) These 'fundamental principles' were that:

disability is a situation, caused by social conditions, which requires for its elimination:

- (a) that no one aspect such as incomes, mobility or institutions is treated in isolation;
- (b) that disabled people should, with the advice and help of others, assume control over their own lives;
- (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people (op cit p3).

Although both organisations said they had signed up to these principles, UPIAS was not convinced that the Disability Alliance and Peter Townsend actually had, instead seeing them as:

- Pursuing the income issue in isolation – 'it is only one aspect of [disabled people's] oppression';
- Maintaining an approach with 'a small number of [non-disabled] experts' having the central role and most disabled people left 'largely passive';
- Seeking to educate the public through 'expert' information, with a 'narrow concentration on parliamentary pressure' (p4) rather than working for the 'mass participation of disabled people' which UPIAS saw as crucial;
- Not making serious efforts to involve disabled people (op cit, p4).

UPIAS interpreted Peter Townsend's and the Disability Alliance's focus on a comprehensive state income for disabled people, as maintaining their social and economic dependence. It regarded the Alliance's reliance on a medically based model of assessing disability – what people 'couldn't do', rather than a social model – providing the support they needed to live independently - as keeping control with social administrators and taking it from disabled people. UPIAS were critical of what they saw as 'the willingness of the incomes 'experts' to use disabled people to give authority to their own social interests' (op cit p16). Peter Townsend, on the other hand genuinely seemed unable to understand why UPIAS held so determinedly to its own processes and values, wondering why they were 'making such heavy weather of them' (op cit, p8) and saying that the failure to ensure large scale involvement of disabled people in the Disability Alliance was no more than 'a problem of time and organisation' (op cit, p6).

Adam Lent, In his examination of British social movements, concluded:

The meeting was supposedly designed to see whether UPIAS could join the Alliance and whether Alliance members would be allowed to affiliate to UPIAS. In effect, however, it simply emphasized the irreconcilability of the old moderate approach and the new, self-organised radicalism' (Lent, 2002, p107-8)

This dialogue also highlighted the distance between traditional Fabian approaches to social policy and new participatory ones. Such Fabian approaches have traditionally been based on outside 'experts' defining issues, offering their own analyses and solutions to them and then leading reform through parliamentary processes and a model of 'public education' (Beresford, 2010). New participatory approaches, where groups on the receiving end of social policy challenged the right of others to speak for them, developed their own collectivities, ideas and theories, rejecting traditional 'expertise' and emphasizing the expertise that came from direct or lived experience. Not only were the process, aims, and the understandings of the two far apart from each other, but this distance was exacerbated by the apparent inability of either party to understand the other.

There are also further insights to be gained from this case study. Peter Townsend, was not only a key figure in mainstream disability developments. He was also a major contributor to anti-poverty discourse in the UK and internationally, as well as being an active and longstanding anti-poverty campaigner. He was central in the development of a relative model of poverty in the 1960s and 1970s (Townsend, 1979). In the UK this was strongly attacked by the prime minister of the emergent new political right, Mrs. Thatcher, who argued that there was no poverty in the UK, that this was a problem of the 'developing' world and that the issue in the UK was one of inequality rather than poverty and that there was nothing wrong with inequality (Alcock, 1997). In the UK, while there have been organisations of unemployed people and some groups of people experiencing poverty, campaigns and organisations concerned with poverty historically have tended not to be controlled by people with direct experience of poverty, but by others campaigning on their behalf – people like Peter Townsend. Traditionally pressure groups and voluntary organisations were not controlled by people who identified as having experience of poverty. People with direct experience of poverty had also been marginal in the UK in discussions about poverty (Lister and Beresford, 1991; Beresford, 1996; Beresford and Croft, 1995). When the first in-depth study of what people with direct experience of poverty had to say about poverty, its analysis and their experience of it was published, major gaps emerged between prevailing anti-poverty critiques and theirs. Thus they were much more likely to understand poverty in terms of a subsistence

model than a relative model (Beresford et al, 1999). What seems likely from that is that the anti-poverty campaigning during the years of Mrs. Thatcher, which led to such resistance from her governments and harsh policies in relation to poverty will have had limited popular support from people living in poverty. Ironically they seemed to be marginalized by campaigning and movements which were meant to be advancing their interests, reflecting and reinforcing the exclusions imposed by public policy. Any efforts they might make to be actively and equally involved in anti-poverty campaigning at this time tended to be limited by the dominance of professional, third sector and academic campaign leaders. In countries like the UK, where this tradition significantly continues, there has been little evidence of effective grassroots movements developing around the issue of poverty, although interest in involving people with direct experience of poverty has significantly increased (Lister, 2004).

#### **4 A service user critique of ‘care’**

A key concept in human services and health, welfare and social care policy has been ‘care’. The service user movements, particularly the disabled people’s movement have tended to be critical of the concept of ‘care’. Some feminists have seen this as devaluing ‘care’, through a narrow preoccupation with individual autonomy. Barnes, for instance, refers to the ‘downplaying’ of care in favour of independence, rights and empowerment’ (Barnes, 2007, p71). Service user movements, however, have developed a coherent critique of care, linked with a much broader set of values, theories, ways of working and goals. While the development of ideas in these movements has been continuous and is not monolithic, there have been some continuing strands in thought. The disabled people’s movement has challenged traditional concepts of care, but in search of a more egalitarian idea and practice. This has been linked with a move to more social understandings and more inclusive forms of collective action which have called into question traditional distinctions between self-help, mutual aid and campaigning.

#### **5 Care and disabled people**

Jenny Morris, the disabled feminist commentator has argued that for many disabled people, the term ‘care’ assumes dependence and has meant other people controlling service users, restricting their autonomy. For her, regardless of whether it refers to people providing paid or unpaid help:

It does not mean to ‘care about’ someone, in the sense of loving them. Rather it means to ‘care for’ someone, in the sense of taking responsibility, taking charge of them... We need to reclaim the words ‘care’ and ‘caring’ to mean ‘love’ to mean ‘caring *about*’ someone rather than ‘caring *for*’, with its custodial overtones (Morris, 1993, p150, 174).

It is not the ideas and values of mutuality, commitment and affection that service users reject in ‘care’, but what in practice they see as the inherent inequality underpinning it. They believe this is true of both paid and informal caring. They are also critical of the way in which historically the views of those looking after them, rather than their views, have been prioritised.

It has often been suggested that disabled people and service user movements have been polarised against informal carers, that is, people who provide ‘care’ as family members and friends. They argue instead that it is the social construction of informal carers of which they are critical, because of the way in which it reframes relationships between parent and child, partners and siblings in unequal terms of carer/cared for. Reliance on family members for support limits the autonomy of both the service user and the carer. It may diminish personal

relationships, rather than be a positive expression of them. Writers like Jenny Morris also make clear the reciprocity that exists within relationships between disabled people and family members and highlight how many disabled people also have caring responsibilities both as parents and with other adults. They make clear the way in which the care system can both reinforce the over-protectiveness of family members and create barriers in the way of them advocating for the independence of service users.

## **6 An alternative framework for understanding**

The disabled people's movement developed two different interrelated ideas, which have gained broader support from service users more generally. These provide the basis for an alternative concept to 'care'. They are first the social model of disability and second, the philosophy of independent living. Both are concerned with humanising social policy (Priestley, 1999; Oliver, 1996). Both seek to make it more responsive to service users and to the role of society in relation to them. They are concerned with equalising the relationship between the service user and the support they receive. This is conceived of as a process of 'co-production', rather than one of dependence.

## **7 Social model approaches**

The social model of disability draws a distinction between an individual's perceived *impairment*; physical, sensory or intellectual and *disability*, meaning the negative societal reaction to such impairment. Developing discussion has explored the interactions between impairment and disability and the barriers disabled people experience from society, including attitudinal, physical and communication barriers. Such 'barrier based' approaches to understanding are now being related to a widening range of social care service users (Thomas, 2007).

## **8 Independent living**

The philosophy of independent living follows from the social model of disability. It is based on:

- Ensuring people the support that they need under their control to be able to live their lives as fully as they can, on as equal terms as possible, with non-disabled people;
- Equalising their access to mainstream policy and services, like housing, health, education, employment.

The philosophy of independent living turns traditional notions of independence on their head. It is not preoccupied with the individual or narrow ideas of personal autonomy. It does not mean 'standing on your own two feet or managing on your own. Instead of seeing the service user as having a defect or deficiency requiring care, it highlights the need to ensure them the support that they need to be autonomous and live their lives as fully as possible, on equal terms and interdependently with others. This support is not expected to come from family members required to be informal carers. It rejects the concept of care and replaces it with the idea of support. In England, a governmental Independent Living Strategy with cross departmental support has signed up to these values (ODI, 2008).

Independent living does not mean living your life 'the same as others'. Rather it means being in a position to have control and choices like others to live as fully as possible. In this it differs from philosophies like 'normalisation' or 'social role valorisation', which have tended to be associated with dominant values (Wolfensberger, 1972; Race 1999). The idea of

independent living takes account of issues of equality and diversity, as part of a broader philosophy based on valuing human and civil rights, citizenship and equality (Morris, 1993 and 1996).

The disabled people's and service user movements thus frame their objectives in terms of rights, not needs, requiring support and change, rather than care and welfare. They are concerned with the achievement of both their civil and human rights, collective as well as individual rights. To achieve these goals and values service user movements have developed new approaches to collective working. These place an emphasis on self-organisation – developing their own 'user controlled' organisations – as well as on participation and people 'speaking for themselves'. But they also take account of people's feelings and needs for support in the process. To make this possible they have increasingly highlighted ideas of inclusion and empowerment (Campbell and Oliver, 1996; Campbell, 1996).

Many service users face significant barriers to participation, for example, they may communicate differently, have learning difficulties, be unable to go out, live in residential services, have pain, limited strength or energy and need personal assistance. Service users have placed an emphasis on ensuring access, which can include physical, communication and cultural access, to enable broadbased involvement in their activities. They have developed imaginative ways of working together to achieve this. (Campbell and Oliver, 1996) Service user organisations make clear that they see working together in their own organisations not only as an effective way of making broader social and political change, but also crucial for increasing service users' confidence, self-esteem, skills and experience. Collective working thus plays a key part in capacity, as well as in making wider change. The idea of empowerment is valued by these movements because it unifies the need for individual and social change; personal and political development (Charlton, 1998). This is reflected in the wide range of groups and organisations developed by service users, which challenge traditional distinctions between self-help, mutual aid and campaigning. There is particular recognition and support for people's emotional needs and feelings.

## **9 Experiential knowledge**

The ideas and developments that have come from service users and their movements has been based on their particular knowledge. As has been said, what distinguishes service user knowledge (or knowledges) and what is unique about it, is that it is based on direct experience. Unlike other stakeholders in the policy process, like, for example, policymakers, managers, practitioners, researchers or educators, what distinguishes their perspective is that it rests on their role as end users of policy and practice. They 'know' through lived experience. This is the basis and starting point for their views, ideas and proposals. Only they can truly be said to 'know' what policy and provision are like, rather than what its aims, intentions and rationale are, since they live it. As Alison Faulkner and Phil Thomas, have suggested, for example, of mental health service users, the voice of experience is breaking through longstanding barriers of enforced silence, incarceration and compulsion (Faulkner and Thomas, 2002). As Diana Rose has asserted:

Increasingly mental health service users and survivors are coming to be called 'experts by experience'. The National Institute for Mental Health England [NIMHE] even has [had] an 'experts by experience' group (Rose, 2009, p38).

Service users are not suggesting that experiential knowledge is the only knowledge that should be valued or that it should be prioritised. What they have repeatedly expressed

concerns about is the way that it has long been systematically excluded from social policy discussions and developments and from social research (Sweeney et al, 2009). In this they do not deviate from views like those expressed by Norbert Elias, that a balance is required and the full spectrum of research approaches should be considered for inclusion (Elias, 1987).

The helpful role that user knowledge can play in both the construction and analysis of social work practice is now also beginning to emerge. A recent empirical study of specialist palliative care social work, for example, highlighted two inter-related issues. First, service users particularly valued this branch of social work practice and second, they felt that it took serious account of and built on their views and experience (Beresford, Adshead and Croft, 2007). A subsequent national study of ‘person-centred support or ‘personalisation’ in social work and social care, which focused on the perspectives of service users and face to face practitioners, also highlighted the significant consensus in their views of what constituted such practice, the barriers it faced and how these might be overcome (Beresford et al, 2011). Such findings have given rise to a growing sense, at least in the UK where these ideas seem to be especially developed, that an alliance between service users and professional social workers is likely to be the most effective way forward for securing the interests of both (Beresford and Croft, 2004).

This has had an impact in the UK on policy and practice, although a big gulf remains between rhetoric and reality; between the adoption of such principles as policy and their meaningful translation into day to day practice for disabled people and other service users. It is becoming clear that it is one thing for policymakers and others to adopt the language of empowerment, involvement and independent living, but it may be another for the practices to be implemented. In the UK, funding limits and narrowing eligibility criteria, rather than criteria of independent living still largely determine what if any social care support people receive. There is still far from adequate or secure funding provided for service users’ organisations, despite increasing government commitments to it. For example, what has been developed as a democratising and liberatory approach to supporting service users through them being in control of their own ‘package of support’ has tended to be reconceived by policymakers in consumerist terms as the equivalent of them being an individual customer simply purchasing a service. This has seriously undermined and limited the gains achieved so far by these radical new ways of thinking (Boxall, et al, 2009).

While service users and their movements have had an international impact on broader thinking, policy and practice, it should also not be assumed that this has gone uncontested. The reality is that their standpoint is not necessarily treated with the same regard as other more traditional viewpoints involved in the political and policy process. This is a key issue and it is important to examine it more closely. For example, in the UK official methods of grading and synthesising evidence used to develop the evidence base for health care interventions, rank the views of service users as the lowest value evidence. (for instance, DH, 1999, p.6). Yet this approach has been criticised (see, for example, Cohen *et al.*, 2004) on three main grounds: Randomised controlled trials (RCTs) and meta-analysis have not been shown to more reliable than other approaches; they can only answer limited questions; and they do not include other non-statistical forms of knowledge.

Figure 1: A hierarchy of evidence

Hierarchy	Type of Evidence
-----------	------------------

Type I	At least one good systemic review, including at least one randomised controlled trial
Type II	At least one good randomised controlled trial
Type III	At least one well designed intervention study without randomisation
Type IV	At least one well designed observational study
Type V	Expert opinion, including the views of service users and carers

### 10 Experiential knowledge and research

This raises major issues about prevailing perceptions of service users' knowledge. As has been discussed, they are seen to 'know what they are talking about' because they have directly experienced it. However, this flies in the face of traditional research values of 'neutrality', 'objectivity' and 'distance'. By these criteria, the 'knowledge' of service users will automatically be seen to have less value, less credibility and legitimacy. Historically, we know this is what has happened. Meanwhile the knowledge 'claims' of researchers, academics and analysts without such direct experience have been attributed higher status. This has some worrying implications, which so far have tended to be overlooked. Where values associated with research and the development of knowledge about people and how they live, prioritise being distant and separate from the subject under consideration, then major concerns are raised for the people who are the subject of such research or about whom knowledge is being sought.

If an individual has direct experience of problems like disability, poverty or using the mental health system; if they have experience of oppression and discrimination, when such research values are accepted, what they say will also be seen as having less legitimacy. This is because as they will be seen as 'close to the problem' – since it directly affects them – then they cannot claim that they are 'neutral', 'objective' or 'distant' from it. So in addition to any discrimination and oppression they may already experience, they face an additional problem. They are likely to be seen as a *less* reliable, less valid source of knowledge. It is possible to see how this worked for a long time against women and children who were subjected to domestic violence and sexual abuse. In male dominated societies, these were not placed high on public, political or indeed research agendas and the knowledge and experience of women and children who experienced such attacks were not listened to or valued. It is only in recent years in western societies that issues like child sexual abuse, domestic violence and rape have begun to be acknowledged publicly and formally as serious problems.

What this means effectively is that if someone has experience of discrimination and oppression they can expect routinely to face further discrimination and be further

marginalised by being seen as having less credibility and being a less reliable source of knowledge. This is likely to have the effect of further invalidating people who are already heavily disadvantaged.

This has led to the development of a service user hypothesis that counters traditional positivist research values and posits that:

the shorter the distance there is between direct experience and its interpretation (as for example can be offered by user involvement in research and particularly user controlled research), then the less distorted, inaccurate and damaging resulting knowledge is likely to be (Beresford, 2005).

Of course a traditional positivist understanding of user knowledge rests, as Diana Rose has said, on a:

certain view of knowledge production. It is held that scientific knowledge is generated in an unbiased and objective way, and the subjectivity of the scientist exerts no influence on the knowledge that is produced (Rose, 2009, p40).

However, as she argues, mainstream research comes from a particular standpoint (that of those who deliver and research services and treatments), no less than do service users. Building on the work of feminist epistemologists like Sandra Harding, she argues for the recognition of different standpoints and the challenging of traditional hierarchies of credibility, validity and legitimacy (Harding, 1993, Rose, 2009, pp41-42).

### **11 User involvement, diversity and inclusion**

A longstanding criticism that has been made of user involvement generally and of user involvement specifically in relation to research is that such involvement is ‘unrepresentative’ and can be exclusionary in nature, privileging some perspectives and leaving out others (Croft and Beresford, 1990). This has repeatedly been called into question. Significantly while issues of inclusion and representativeness have been raised in relation to service users, they have not previously been raised in relation to traditional stakeholders and professionals (Beresford and Campbell, 1994). The level of sophistication that has now been attained in ensuring thoroughgoing and diverse involvement is exemplified by the work of Diana Rose and SURE – Service User Research Enterprise, based at the UK Institute of Psychiatry. They have carried out large scale international systematic reviews and randomised controlled trials (RCTs). While RCTs have been seen as offering a research ‘gold standard’, service users have questioned the assumed ‘neutrality’ of their measures on the basis that their outcome measures are defined by clinicians and particularly researchers. Rose and her colleagues have developed a different approach based primarily on service users’ views and experience. Here the process is to:

- Bring together focus groups of diverse service users with relevant experience with user facilitators
- Tape record and transcribe discussions and check frequency of issues identified for discussion at follow up focus group meetings

- Create a mixed method questionnaire with open and closed questions to be discussed and checked by ‘expert’ panels of services users with relevant experience, facilitated by service users. Check accessibility of language and correct duplication of questions.
- Pilot the questionnaire through a feasibility study with 50 service users completing the questionnaire, to gain their views and modify accordingly.

This process has now been employed in four studies, including one on acute mental health wards and another on continuity of care (Rose et al 2008 and 2009).

## **12 A personal standpoint**

It is also important to acknowledge this article’s own particular standpoint. I write as a service user (a long term user of mental health services) and someone actively involved in the mental health service user/survivor movement, as well as an academic, educator and researcher. As this indicates, standpoints, reflecting our identities, can be plural and complex. Issues have been raised about how far it is possible to represent the standpoint of others. For example, women are diverse and heterogeneous in terms of age, ethnicity, class, culture, sexuality, disability and so on. The same could be said of service users. Can a mental health service user, for example, helpfully comment on, understand or appreciate the experience of those who have been subject to compulsory treatment and constraint, if they themselves have not?

Service user movements have been sensitive to such standpoint issues and have sought to develop their collective as well as individual knowledge. This has significantly followed from collective discussions and collective action. However, they have not only staked a claim to the legitimacy of their own individual and collective knowledge – making their own ‘knowledge claims’. They have also developed their own service user research to advance such knowledge in structured and systematic ways. This has variously come to be called ‘user-controlled’, ‘survivor’ and ‘emancipatory disability research’ (Turner and Beresford, 2005).

## **13 Service user research**

Interest in developing their own research began early among service users and began with disabled people. It has now spread to other service user groups, including people with learning difficulties, mental health service users and older people. (Oliver, 1992 and 1996; Barnes and Mercer, 1997; Mercer, 2002; Lindow, 2001; Wallcraft, 1998; Taylor, et al, 2007) Interest in undertaking their own research began with disabled people in the UK concluding that mainstream research served and reinforced the assumptions and interests of dominant structures of policy and provision, rather than being independent or supporting their rights and needs. This was embodied in a famous case where a group of disabled people in residential services invited researchers to explore their ability to live independently in the community. The researchers concluded, however that this was unrealistic and that they were ‘unproductive parasites’. The researchers, Eric Miller and Geraldine Gwynne discussed at length their efforts to conduct neutral, ‘balanced’, ‘detached’ and ‘scientific’ research. (Miller and Gwynne, 1972) Paul Hunt, one of the leaders of this group of disabled people and a key founder of the UK disabled people’s movement, however, emphasised the study’s bias. He criticised its failure to be ‘neutral’, demonstrating that it was entrenched in an individualistic/medical interpretation of disability. (Hunt, 1999, 1972, 1981) Subsequently research has confirmed the views of Hunt and other disabled people that with appropriate support, disabled people can live independently outside such institutions.

Such emancipatory disability research and other research that has developed since has emphasised three overlapping concerns about research and evaluation. These are:

- What research is for
- The process of research
- Where control of research lies.

The central purpose of research is seen as supporting the empowerment of service users, securing their rights and needs and the making of broader social change. In emancipatory disability research this has also meant that research is based on a social model of disability approach. The process of research is envisaged as one which prioritises the equalizing of relations between researcher and research, changing the social relations of research production. Finally it is seen as important that control of research lies with the constituencies who are the subjects of research, if it is to serve their needs. Such control is related to the whole range of research processes and activities, from the origination of research focus and questions, control of research funding, data collection and analysis, to dissemination and follow-up action.

Such service user research is thus explicitly political. It can be seen as an essentially political activity, rather than a neutral 'fact-finding mission'. It is concerned primarily with improving people's lives rather than solely with generating knowledge. We can expect fundamental questions to be raised about the relation of emancipatory and user controlled research with traditional positivist research values of 'objectivity' and 'neutrality', even though new paradigm research has made its own challenge to these (Reason and Rowan, 1981; Reason and Bradbury, 2006). Findings from such involvement will need to address the challenge that they are partisan. There will be questions about the problems which user controlled research raises because one sectional interest may be seen to be dominant - that of service users. There will be concern to consider it in relation to criteria of 'validity' and 'reliability'. There will be questions to answer about who is a service user. There are also broader issues to be examined around the validity of different knowledge standpoints and knowledge claims; the ownership of knowledge and its interpretation; dominant hierarchies of credibility; the nature of the relationship between knowledge and direct experience; the meaning of 'evidence-based' and what counts as 'evidence'.

Discussion about user controlled research thus focuses attention on a number of underpinning issues for research more generally. However, while these issues tend to be associated with such new paradigm research, they are truly ones which all research must address too. But they must nonetheless be addressed by user research and user researchers. There is clearly a need for the systematic and coherent evaluation of user controlled research to explore its strengths and weaknesses, benefits and disadvantages. This needs to be a process of evaluation in which service users, their organisations and user researchers are also involved in fully and equally.

There is also a further point to be made. While interest in user involvement in research more generally is growing and it is increasingly required by government, research funders and research organisations, so far there have been relatively few user controlled research projects. Such research thus still faces major barriers in relation to funding, credibility, status,

recognition and publication. Only a very small proportion of research funding budgets has as yet gone towards it (Turner and Beresford, 2005). Yet it is important if user knowledge is to be fully and equally included in the evidence base of policy that such user controlled research is supported and also evaluated.

## 14 Conclusion

The development of service user ideas and thinking has been significantly underpinned by a growing body of service users' own research. For example, work on independent living, direct payments, user led services and centres for independent living have all been well researched by disabled people and other service users. All these have been valuable ideas and developments which have improved policy understanding and people's support. Enormous progress has been made in spreading service user ideas about care and support and these now have an unprecedented influence, particularly in countries where these developments are relatively advanced, like the UK,. But they still tend to be outlier developments; discourses which seek to challenge traditional dominant social policy approaches, rather than which have succeeded them, or sit safely alongside them and they are still vulnerable to being subverted by them. If we are to access and make the best use of the new ideas that service users and their movements are developing based on direct experience, then greater equality in supporting their research is likely to be needed. This will be key to advancing the evidence base. This is likely to require both culture change in research and a reappraisal of research funding priorities in order to support:

- The service user controlled organisations that are the most effective homes for taking forward the development and sharing of experiential knowledge
- Service user research which can support the full development of an inclusive evidence base that draws equally on user knowledge

In this way the gains from service user knowledge are likely to be most effectively and speedily identified and most helpfully integrated into public policy and practice.

## References

**Alcock, P.** 1997: *Understanding Poverty*, Second edition, Basingstoke, Macmillan, pp71-2.

**Aspis, S.** 1997: Self-advocacy for People with Learning Difficulties; does it have a future?, *Disability & Society*, Vol. 12, No. 4, pp647-654.

**Barnes, C. and Mercer, G** (ed) 1997: *Doing Disability Research*. The Disability Press: Leeds.

**Barnes, M.** 2007: Participation, Citizenship And A Feminist Ethic Of Care, in Balloch, S. and Hill, M. (editors), *Care, Community And Citizenship: Research and practice in a changing policy context*, Bristol, Policy Press, pp59-74.

**Beresford, P.** 2005: Developing The Theoretical Base For Service User/Survivor-Led Research And Equal Involvement In Research, in, *Epidemiologia e Psichiatria Sociale (EPS)*, Vol 14, Issue 1, January, pp4 -9.

**Beresford, P and Campbell, J.** 1994: Disabled People, Service Users, User Involvement And Representation, *Disability & Society*, Vol 9, No 3, pp 315-325.

**Beresford, P. Green, D. Lister, R. Woodard, K.** 1999: *Poverty First Hand*, London, Child Poverty Action Group.

- Beresford, P.** 1996: Poverty And Disabled People: Challenging dominant debates and policies, *Disability And Society*, Vol 11, No 4, pp 553-567.
- Beresford, P. and Harding, T.** (editors), 1993: *A Challenge To Change: Practical experiences of building user led services*, London, National Institute for Social Work.
- Beresford, P.** 1999: Making Participation Possible: Movements of disabled people and psychiatric system survivors, in T. Jordan, and A. Lent, (editors) *Storming The Millennium: The new politics of change*, London: Lawrence and Wishart, pp34-50.
- Beresford, P. and Croft, S.** 2004: Service Users And Practitioners Reunited: The key component for social work reform, *The Future of Social Work, Special Issue, British Journal of Social Work*, January, Vol 34, pp53-68.
- Beresford, P.** 2010: Peter Townsend, Disability, Fabianism And Self-Organisation – an enduring difficulty, *An Obituary, Disability & Society*, Vol 25, No2, March, pp253-258.
- Beresford, P. and Croft, S.** 1995: Time For A New Approach To Anti-Poverty Campaigning?, *Poverty, Journal of the Child Poverty Action Group*, Spring, No 90, pp 12-14.
- Beresford, P. Adshead, L. and Croft, S.** 2007: *Palliative Care, Social Work And Service Users: Making life possible*, London, Jessica Kingsley.
- Beresford, P. Bewley, C. Branfield, F. Croft, S. Fleming, J. Glynn, M. Postle, K.** 2011, (forthcoming), *Supporting People: Towards a person-centred approach*, Bristol, Policy Press.
- Boxall, K. Dowson, S. and Beresford, P.** 2009: Selling Individual budgets, choice and control: local and global influences on UK social care policy for people with learning difficulties, *Policy & Politics*, Vol 37, No 4, October, pp499-515.
- Campbell, J. and Oliver, M.** 1996: *Disability Politics: Understanding our past, changing our future*, Basingstoke, Macmillan.
- Campbell, P.** 1996: The History Of The User Movement In The United Kingdom, in, Heller, T. Reynolds, J. Gomm, R. Muston, R. and Pattison, S. (editors), *Mental Health Matters: A Reader*, Basingstoke, Macmillan.
- Carter, T. and P. Beresford** 2000: *Age and Change: Models of Involvement for Older People*. York, York Publishing in association with Joseph Rowntree Foundation.
- Charlton, J.I.** 1998: *Nothing About Us Without Us: Disability, oppression and empowerment*, California, University of California Press.
- Cohen, A.M. Stavri, P.Z. and Hersh, W.R.** 2004: A Categorization And Analysis Of The Criticism of Evidence-based Medicine, *International Journal of Medical Informatics*, No 73, pp35-43.
- Coleridge, P.** 1993: *Disability, Liberation And Development*, Oxford, Oxfam in association with Action on Disability and Development.
- Croft, S.** 1990: and Beresford, P. 1990: *From Paternalism To Participation: Involving people in social services*, London, Joseph Rowntree Foundation and Open Services Project.
- Davis, K.** 1993: On The Movement, in, Swain, J. Finkelstein, V. French, S. and Oliver, M. (editors), *Disabling Barriers: Enabling Environments*, London, Sage in association with the Open University.
- DH**, 1999: *National Service Framework For Mental Health: Modern standards and service models*, London, Department of Health.
- Elias, N.** 1987: *Involvement And Detachment: Contributions to the sociology of knowledge*, Oxford, England, Blackwell.
- Faulkner, A. and Thomas, P.** 2002: User-led Research And Evidence Based Medicine, *British Journal of Psychiatry*, No 180, pp1-3.

- Harding, S.** 1993: Rethinking Standpoint Epistemology: What is strong objectivity?, in, Alcoff, L. and Potter, E. (editors), *Feminist Epistemologies*, London and New York, Routledge, pp67-99.
- Lindow, V.** 2001: Survivor Research. In *This Is Madness Too*. (ed C. Newnes, G. Holmes and C. Dunn). pp 135-146. PCCS Books: Ross on Wye.
- Hunt, P.** 1966: A Critical Condition. In *The Disability Reader*. (ed T. Shakespeare). pp 7-19. Cassell: London and New York.
- Hunt, P.** 1972: Parasite people. *Cheshire Smile*, Autumn. 18 (3) 15.
- Hunt, P.** 1981: Settling Accounts With The Parasite People: A critique of 'A Life Apart' by E.J. Miller and G.V. Gwynne. In *Disability Challenge* (ed P. Hunt) 1 37-50.
- Lent, A.** 2002: *British Social Movements Since 1945: Sex, colour, peace and power*, Basingstoke, Palgrave Macmillan.
- Lindow, V.** 2001: Survivor Research. In *This Is Madness Too*. (ed C. Newnes, Lister, R. (2004), *Poverty: Key concepts*, Cambridge, Polity.
- Lister, R. and Beresford, P.** 1991: *Working Together Against Poverty: Involving poor people in action against poverty*, London, Open Services Project/Department of Applied Social Studies, University of Bradford.
- Mercer, G.** 2002: Emancipatory Disability Research. In *Disability Studies Today*. (ed C. Barnes, M. Oliver, L. Barton) pp 228-249. Policy: Cambridge.
- Miller, E.J. and Gwynne, G.V.** 1972: *A Life Apart*. Tavistock Publications and Lippincott: London.
- Morris, J.** 1993: *Independent Lives: Community care and disabled people*, Basingstoke, Macmillan.
- Morris, J.** 1996: *Encounters With Strangers: Feminism and disability*, London, Women's Press.
- ODI**, 2008: *The Independent living strategy: A cross government strategy about independent living for disabled people*, London, Office for Disability Issues.
- Oliver, M.** 1996: *Understanding Disability: From theory to practice*, Basingstoke, Macmillan.
- Oliver, M. and Zarb, G.** 1989: The Politics Of Disability: A new approach, *Disability, Handicap and Society*, Vol 4, No 3, pp221 – 40.
- Oliver, M.** 1992: Changing The Social Relations Of Research Production, *Disability, Handicap & Society*, No 7, pp101-115.
- Oliver, M.** 1996: *Understanding Disability: From Theory to Practice*. Macmillan: Basingstoke.
- Priestley, M.** 1999: *Disability Politics And Community Care*, London, Jessica Kingsley.
- Race, D.** 1999: *Social Role Valorization and The English Experience*, London, Whiting and Birch.
- Reason, P. and Bradbury**, (editors), 2006: *Handbook Of Action Research*, Concise edition, London, Sage.
- Reason, P. and Rowan, J.** (editors), 1981: *Human Inquiry: A sourcebook of new paradigm research*, Chichester, Wiley.
- Rose, D.** 2009: Survivor-produced Knowledge, in, Sweeney, A. Beresford, P. Faulkner, A. Nettle, M. and Rose, D. (editors), *This Is Survivor Research*, Ross-on-Wye, PCCS Books.
- Rose, D. Wykes, T. Farrier, D. Dolan A-M. Sporle, T. Bogner, D.** 2008: What Do Clients Think Of Cognitive Remediation Therapy?: A Consumer-Led Investigation of Satisfaction and Side Effects. *American Journal of Psychiatric Rehabilitation*, Vol 11, No 2, pp181–204.

**Rose, D. Sweeney, A. Leese, M. Clement, S. Burns, T. Catty, J. and Wykes, T.** 2009: Developing A User-generated Measure Of Continuity Of Care: Brief report, Acta Psychiatrica Scandinavica, No 119, pp320–324.

**Shakespeare, T.** 1993: Disabled People’s Self-Organisation: A new social movement?, Disability, Handicap and Society, Vol 8, No 3, pp249-64.

**Sweeney, A. Beresford, P. Faulkner, A. Nettle, M. Rose, D.** (editors), 2009: This Is Survivor Research, Ross-on-Wye, PCSS Books.

**Taylor, J. Williams, V. Johnson, R. Hiscutt, I. Brennan, M.** 2007: We Are Not Stupid, People First Lambeth, London, Shaping Our Lives.

**Thomas, C.** 2007: Sociologies Of Disability And Illness: Contested ideas in disability studies and medical sociology, Basingstoke, Palgrave/Macmillan.

**Townsend, P.** 1979: Poverty In The UK, London, Penguin.

**Turner, M. and Beresford, P.** 2005: User Controlled Research: Its Meanings And Potential, Final report, Shaping Our Lives and the Centre for Citizen Participation, Brunel University, Eastleigh, Involve.

**UPIAS/Disability Alliance,** 1976: Fundamental Principles of Disability: Being a summary of the discussion held on 22nd November, 1975 and containing commentaries from each organization, London, The Union of the Physically Impaired Against Segregation and the Disability Alliance.

**Wallcraft, J.** 1998: Survivor-led Research in Human Services: Challenging the Dominant Medical Paradigm. In Needs Assessment and Community Care: Clinical Practice and Policy Making. (ed Baldwin, S.). pp 186 – 208. Butterworth-Heinemann: Oxford.

**Wolfensberger, W.** 1972: the Principle of Normalization in Human Services, Toronto, National Institute on Mental Retardation.

**Author’s Address:**

Centre for Citizen Participation, Brunel University  
Mary Seacole Building  
Uxbridge  
UB8 3PH  
England, UK  
Tel: +44 (0)1895 268741  
Fax +44 (0)1895 269853  
Email: [peter.beresford@brunel.ac.uk](mailto:peter.beresford@brunel.ac.uk)

