

User Involvement in Research and Evaluation: Liberation or Regulation?

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This article explores the progressive and regressive potential of 'user involvement' in research and evaluation, with particular reference to social policy. There is growing political and research interest in user involvement. This article critically explores key different approaches to user involvement in research and relates them to consumerist and democratic models of involvement in policy and practice, management and development. The article highlights the need to approach user involvement in research critically and systematically, taking account of the diversity of approaches that have developed and to take forward user involvement in research in equal association with service user organisations and movements.

The focus of this discussion is user involvement in research and evaluation. There is now a growing interest in more participatory approaches to research and evaluation, particularly in public and social policy and specifically in health and social care (Kemshall and Littlechild, 2000). So far, what discussion there has been has tended to be uncritical. 'User involvement' in research has generally been presented as a 'good thing' and counter views have so far tended either to be focused on perceived deficiencies in the methods and methodologies employed or not been clearly or publicly articulated. The aim of this discussion is to try and develop this debate by exploring both the liberatory and regressive potential of user involvement in research as well as touching on some of its implications for research methods and methodology, ethics, training and funding.

The origins of the issue

Mainstream discussion about user involvement in research is a very recent development. But interest in participation in public policy and practice has a much longer history. As a specific policy development, it can be traced to community development initiatives and the legal requirements for public participation embodied in land use planning from the late 1960s (Beresford and Croft, 1992).

The last decade of the twentieth century witnessed a massive expansion of interest in participation in public and social policy generally and in social care specifically. In the context of social policy and social care, there was a growing focus on involving service users in the shaping of policy and practice. (Means and Smith, 1998) This was signalled by the development of a new rhetoric and terminology of 'user-involvement', 'partner-

ship', and 'empowerment'. New government policy, legislation, and guidance requiring such involvement were both the cause and effect of this interest.

Renewal of interest in participation towards the end of the twentieth century can be traced to two new powerful pressures. The first of these was the commitment of the political New Right, then on the ascendancy, both in the UK and more generally internationally, to more market-led approaches to public policy and provision and its devaluing of state intervention and provision. It prioritised placing a new emphasis on purchase of service and individualised arrangements and responsibility for health and welfare. The second pressure came from the emerging movements and organisations of welfare and social care service users. Since the 1980s, these have developed on an unprecedented scale, growing in scale, influence, and confidence. These movements include those of disabled people, people, with learning difficulties, older people, mental health service users/survivors, people living with HIV/AIDS, looked-after young people, and so on.

There can be little question that the emergence of these new movements was assisted by the challenge to traditional paternalistic welfare represented by the political New Right and its rhetorical emphasis on the 'active citizen', and individual rights and choice. Intentionally or otherwise doors were opened. But, while both the political New Right and associated governments and the new movements of welfare and social care service users and their supporters highlighted participation and user involvement, it would be a mistake to assume that both placed the same interpretation upon the terms. Indeed it is the differences in understanding between the two which have played an important part in shaping the recent (theoretical and policy) history of participation in public and social policy. More specifically here, these *differences* may also offer a helpful key to improving understanding of current issues and developments relating to user involvement in research and evaluation.

Models of involvement

The history of involvement is littered with classifications and typologies, beginning with Sherry Arnstein's enduring and often cited 'ladder of participation' (Arnstein, 1969). However, two distinct conceptual models or approaches to participation have predominated since the 1990s. These can most simply be characterised as 'consumerist' and 'democratic' approaches to participation. While it can be argued that at points the two approaches to involvement may blur into each other, with overlapping interests and objectives, they can also be seen to be based on distinct and different philosophical and ideological approaches. Each may be seen to have strengths and weaknesses. It will not, for example, be suggested here that the consumerist approach is inherently defective, because in practice this author has seen some participatory initiatives, which have been rooted in this model, having effective outcomes for service users. What is important though, is to be clear about our understandings of involvement and to recognise the significant differences that exist between these two approaches. There has been frequent failure to do this.

The consumerist approach to user involvement has been most closely identified with the political right and the welfare and social care service system. Its progress has continued in the context of New Labour's 'third way' remix of state and market interventions and emphasis on managerialism. It reflects the broader interest associated

with the market in maximising profitability and effectiveness, and the tendency to equate the latter with the former. Framed mainly in market research terms of 'improving the product' through market testing and feedback, the consumerist approach has so far mainly been based on consultative and data collection methods of involvement. Its use has largely been focused on the planning and management of policy and provision. For example, new legislative provisions for such involvement were introduced in the early 1990s in the context of 'community care' and these required local and user involvement in the drawing up of formal community care plans and introduced procedures for comment and complaint about services. As the clear equivalent of the market testing and focus groups associated with mainstream commercial goods and services, its role in improving provision on the basis of 'consumer' or 'customer' intelligence gathering can be readily understood. The perceived customer responsive/friendly approaches of organisations like Marks and Spencers and Kwik-Fit were frequently cited in its early development. During the 1990s, the golden age of such consumerist approaches, user involvement was mainly related to advancing the 'three Es' highlighted for public provision by Conservative administrations: efficiency, economy, and effectiveness.

The second approach to participation, the democratic approach, has been particularly linked with organisations and movements of disabled people and social care service users. It is primarily concerned with people having more say in agencies, organisations, and institutions which impact upon them and being able to exert more control over their own lives. Service users' interest in participation has been part of broader political and social philosophies which prioritise people's inclusion, autonomy, and independence, and the achievement of their human and civil rights. Participation has been one expression of a commitment to 'self-advocacy'; of people being able to speak and act on their own behalf. It has also been framed primarily in terms of involvement through collective action in independent disabled people's and service users' groups and organisations (Oliver, 1996; Campbell, 1996; Campbell and Oliver, 1996; Newnes, Holmes, and Dunn, 2001). The democratic approach to involvement is explicitly political.

A number of differences can be identified between these two approaches to participation. The first approach generally starts with policy and the *service system*; the second is rooted in people's *lives* and in their aspirations to improve the nature and conditions of their lives. Both approaches may be concerned with bringing about change and influencing what happens. However, in the consumerist approach, the search is for external input which the initiating agencies (state, service providers, or policy makers) *themselves* decide what to do with. The democratic approach is concerned with ensuring that participants have the direct capacity and opportunity to make change. This latter approach highlights issues of power and the (re)distribution of power. These are not explicit concerns of the consumerist model of involvement.

These two approaches to participation, the *consumerist* and *democratic* approaches, do not necessarily sit comfortably. One is managerialist and instrumental in purpose, without any commitment to the redistribution of power or control; the other liberatory, with a commitment to personal and political empowerment. The latter's concern is with bringing about direct change in people's lives, through *collective* as well as individual action. The disabled people's movement, for example, bases its approach to participation on the social model of disability, using both parliamentary and direct action to achieve change. It has prioritised the introduction of civil rights and freedom of information

legislation and the provision of adequate support for organisations controlled by disabled people themselves, establishing the 'independent living' movement to ensure that disabled people can maintain control over their personal support through direct payments and self-run personal assistance schemes. While the logic of the democratic approach is for 'user-led' and 'user-controlled' services, a consumerist approach is compatible with the retention of a provider-led approach to policy and services. While the democratic approach is explicitly political (and can expect to come in for criticism for this reason), the consumerist approach tends to be abstracted and treated as if it were unrelated to any broader ideology or philosophy.

User involvement in research and evaluation

Just as parallel discussions about user involvement in policy and practice can be identified from the service system and service users, so they can be discerned about user involvement in research and evaluation. Interest in user involvement in mainstream research agendas has been a very recent development. Nonetheless it is now becoming significant and widespread. While some funding organisations, like the Joseph Rowntree Foundation and National Lottery Charities Board, have highlighted user involvement in research for some time, it is now identified as a requirement for funding bids by a much wider range of both statutory and non-statutory research funders, ranging from the Department of Health and the Wellcome Foundation to the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC). Interest in user involvement in research has extended to government. In 2000, at a major national conference on user involvement in research, Lord Hunt, the Health Minister with responsibility for research and development said that: 'This has not to be a token involvement. It has to be a genuine partnership. The philosophy (of involvement) must extend to user involvement in research.' He argued the importance of patient knowledge as a form of evidence, to help restore the credibility, among the public, of the NHS. At the same event, Sir John Pattison, Head of Research and Development at the NHS said, 'We're going to have to shift resources to this new activity (involving consumers in research). This is something I'm going to think about and try to achieve' (Consumers in NHS Research, 2000). In its Quality Strategy for Social Care, the government highlights the importance of users' views and experience and identifies them as one of four key sources of evidence for 'evidence-based' policy and practice (Department of Health, 2000: 14). In 2001, as part of its commitment to service user involvement in research, the Social Policy and Social Work Panel of the Research Assessment Exercise (RAE), formally supported by the Higher Education Funding Council (HEFCE), met with a group of service users to discuss the interpretation of its criteria from service users' perspectives (Tiller, 2001).

Mainstream interest in user involvement has tended to focus on the problems and practicalities of user involvement in research and evaluation. Concern has been with how to do it; producing practice guides; discussing ways of reaching so-called 'hard to reach groups' and of providing training to facilitate the exercise (for example, Hanley, 1999; Hanley and others, 2000). The establishment in 1996 of Consumers in NHS Research represents a significant development in this area. It can be seen as a ginger group signifying official commitment to user involvement. In 2001 its responsibilities

were extended to include user involvement in social care and public health, as well as health research.

Service users and research

The discussion among service user researchers about user involvement in research has been a much more complex, multi-faceted, and far-reaching one. It also has a longer history (for example, Barton and Oliver, 1997). The lead came from researchers in the disabled people's movement. They saw existing research as 'a greater source of exploitation than liberation' (Barnes and Mercer, 1997: 5). They emphasised the destructive effects of traditional research, arguing that it has formed part of a broader system of oppression, manifest in the subordination of disabled people in western societies and the (discriminatory) responses that are made to their impairments (Oliver, 1991 and 1996). Their approach to research rests on a social rather than the traditional medicalised individual model which:

is based on the assumption that the individual is 'disabled' by their impairment whereas the social model of disability reverses this causal chain to explore how socially constructed barriers . . . have disabled people with a perceived impairment. (Barnes and Mercer, 1997: 1-2)

They have been influenced by the 'critical social research' of feminists, Black writers, and educationalists who have allied themselves with oppressed groups, rejecting traditional research claims to 'objectivity', 'neutrality' and 'distance'. Research is seen as an essentially political activity, rather than a neutral 'fact-finding mission'. The disabled people's movement has highlighted the importance of changing (and equalising) the social relations of research production,

including the role of funding bodies; the relationship between researchers and those being researched; and the links between research and policy initiatives. (Barnes and Mercer, 1997: 5)

Social care service user organisations and movements have emphasised two overlapping concerns in research and evaluation: what research is for and where control of research lies. This is reflected in the emergence of the 'emancipatory research paradigm' and associated interest in 'user-controlled research'.

Emancipatory research

In emancipatory research, the central purpose of research is seen as supporting the empowerment of service users and the making of broader social change. Mike Oliver, the disability activist and academic, identifies three key priorities for the 'emancipatory' research paradigm which the disabled people's movement has pioneered. These are reciprocity, gain, and empowerment (Oliver, 1992: 111). As he says:

disillusion with existing research paradigms has raised the issue of developing an alternative, emancipatory approach in order to make disability research both more relevant to the lives of disabled people and more influential in improving their material circumstances. (Oliver, 1996: 141)

This predicates both a different kind of and purpose for research:

If the category disability is to be produced in ways different from the individualised, pathological way it is currently produced, then what should be researched is not the disabled people of the positivist and interpretative research paradigms but the 'disablism' ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablism society. (Oliver, 1996: 143)

In this research paradigm, user involvement seems to be regarded as a necessary, but not sufficient condition for research to improve the lives of disabled people, individually and collectively. User involvement has generally been treated by disabled researchers much more as a means to undertaking helpful research rather than as an end in itself. There are concerns (similar to those expressed in policy and practice development) that the nature and focus of participatory research encourages the abstraction of participation from its political and ideological relations. This is why the emphasis has been on *emancipatory* rather than participatory research. John Swain, for example, highlights the limits of the participatory approach, arguing that:

Essentially user involvement and participation raise questions about the micro-politics of research processes, rather than the macro-politics of disability and research production . . . In participatory research, researchers define the terms of involvement. (Swain, 2001: 625)

At the same time, it is emphasised that 'emancipation' is the goal, not necessarily the achievement, of such research. The degree to which such research may actually be able to support disabled people to emancipate themselves may often be limited and difficult to estimate (Oliver, 1997).

User-controlled research

If emancipatory research emphasises the equalisation of research relationships, changed social relations of research production, empowerment, and social change, the focus of user-controlled research is with who originates and makes decisions about research and evaluation. Its general contention is that such control rarely lies with the (disadvantaged and oppressed) groups which are most liable to become research subjects. While as yet there are not any agreed definitions of user-controlled research, as the term makes clear, it is committed to service users being in control. Discussion of user-controlled research has developed in parallel with that of emancipatory research. So far, there has been little attempt to connect the two discussions. However, in their discussion of user-controlled research, Clare Evans and Mike Fisher do raise issues about the relation between emancipatory research and user control when they state

A key question with this (emancipatory) model, however, concerns how far research can be emancipatory if it is not originated by service users and conducted under their control. (Evans and Fisher, 1999a: 103)

While the focus of this research paradigm on control clearly overlaps with the interest of emancipatory research in the equalisation of research relationships, user-controlled research and evaluation have tended to be presented in terms of some kind of continuum of involvement and influence. For example, from:

- information provision to control (Evans and Fisher, (1999a :108; see also Evans and Fisher, 1999b);

- service users not involved to service users deciding, controlling, and being fully involved (Beresford and Evans, 1999: 674–6);
- absent (user) research to (user) controlled research (Lindow, 2001: 140).

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.

While generally it is not suggested in such discussions that user-controlled research is the only acceptable kind of research, there is a strong tendency to see it as having particular merits. Limited involvement is not always presented as a negative, but an increase in user control is generally seen as positive. At the same time, the frequent presentation of user-controlled research as part of a continuum, highlights the overlaps and continuities (as well as discontinuities between it and traditional research paradigms), whereas emancipatory research tends to be offered as distinct in its aims and nature.

User research and user involvement in research

There is also now growing interest among service users, user organisations, and user researchers in ‘user research’, as distinct from user involvement in research. Viv Lindow talks about ‘survivor’ research to:

find out what works for people currently badly served by existing medical and social services, we need research from our perspectives. To counter research that judges outcomes of traditional services by criteria acceptable to workers rather than recipients, a new set of questions is being formulated. (Lindow, 2001: 136)

There is the same interest in the disabled people’s movement as in the movement sponsoring its own research. The Centre for Disability Studies at Leeds University is the research arm of the British Council of Disabled People, the umbrella organisation of organisations controlled by disabled people. There is a growing sense of developing ‘our own’ research as service users (Barnes, Mercer, and Morgan, 2000). There is now a well-established (psychiatric system) Survivor Researchers Network, hosted by the Strategies for Living Project at the Mental Health Foundation. There are currently also some flourishing examples of large national emancipatory and user-controlled research projects (Beresford, 2001a; Faulkner and Layzell, 2000; Rose, 2001a). Major, frequently contentious questions are being raised for debate by the proponents of such research. For example, can the researcher ever be truly ‘independent’ (for example, Barnes, 1997; Bury, 1997). In disability research, is the role of the non-disabled researcher inherently problematic (for example, Duckett, 1997; Branfield, 1998).

While there are overlaps and interrelations between the interest in user involvement in research, which comes from service user movements and from mainstream services and research, as can be seen there are also significant differences. These seem to mirror the ideological differences in interest in user involvement which emerged earlier in service policy and development. The disabled people’s and service user movements’ interest in research is explicitly political. While mainstream interest in user involvement in research and evaluation highlights feeding user knowledge and experience into existing research arrangements and paradigms, service users and their organisations emphasise the transformation of research philosophy, production social relations, and

objectives. If the former reflects a consumerist approach to participation, the latter embodies the same concern that service user organisations and movements have generally had with democratisation and democratic approaches to involvement.

Focuses for the future

This raises big questions for user involvement in research and evaluation. We know that consumerist approaches to user involvement in the service system have come to be seen as a very mixed blessing by service users and their organisations. Serious concerns are raised about tokenism and incorporation. Service users and their organisations talk about 'consultation fatigue' and being 'consulted out'. The gains achieved have frequently been seen to be slight for the effort involved. Consumerist approaches to user involvement in research and evaluation are likely to raise similar issues. Crucially, they raise the issue of whether user involvement in research and evaluation can necessarily be assumed to be a progressive and positive development, or whether it has a regressive potential. While service user researchers, organisations, and movements have tended to see user involvement in research and user-controlled research as part of a process of developing their own knowledge and discourses (as a basis for change), for service providers, the focus is essentially service-led, and for mainstream researchers tied in to developing new domains for professional and academic activity. Already tensions are emerging with publications about user involvement in research being produced either without or with only limited user involvement (e.g. Kemshall and Littlechild, 2000; Beresford, 2001b) and serious concerns are increasingly being expressed informally, that where user or 'consumer' involvement is required by research funders, it is frequently treated as a 'box ticking' exercise and seen by some researchers more as a nuisance than of any real importance.

An increasing interest is now emerging in evaluating user involvement in research. Advocates and critics alike both feel that the interest such user involvement has attracted and the progress it has made, mean that it is now time to examine it systematically to explore its strengths and weaknesses, benefits, and disadvantages. If this is to happen, however, it is important that such evaluation addresses the *full range* of approaches to user involvement in research, from the most limited and tokenistic involvement, to user-controlled and emancipatory research – however they are defined – rather than seeing user involvement as monolithic and uniform. So far emancipatory and user-controlled research, while growing in absolute terms, account for only a tiny proportion of funded health and social research. They face the same barriers and inequalities that democratic approaches to participation have faced more generally. These must be challenged and more support given to such research approaches if systematic evaluation is to be possible and meaningful.

Discussion about user involvement in research and user-controlled research has focused attention on a number of underpinning issues for research. While these issues tend to be associated with such new paradigm research, they are truly ones which all research must address too. These include, for example, issues around the validity of different knowledge standpoints and knowledge claims; the ownership of knowledge and its interpretation; dominant hierarchies of credibility (Harding, 1993; Rose, 2001b; Wilson, and Beresford, 2000); the nature of the relationship between knowledge and direct experience (Beresford, 2000); the meaning of 'evidence-based' and what counts as

'evidence' (Lewis, 2001). Any approach to the evaluation of user involvement in research and user-controlled research needs to consider such broader methodological issues as well as narrower ones seen to relate to judgements about the technical merits and demerits of involving service users. So far mainstream discussion has mainly been concentrated on the former.

Conclusion

Social policy as a discipline and research area is so far at an early stage in developing user involvement in its activities and organisations. There are as yet, for instance, a minimal number of examples of user-controlled social policy research. Discussion about user involvement in research and evaluation has been limited and there still seems to be some intellectual and professional caution and suspicion about it – although this is now more likely to be tacit than explicit. However the Social Policy Association has begun to show an interest in user involvement in research (and learning) (Beresford, 1999; Beresford and Lister, 1999; Beresford, 2000b,c,d; Thomas, 2000; Beresford, 2001c,d; Penet, 2001); there is now an institutional link between Consumers in NHS Research and the Social Policy Research Unit at the University of York and there are plans to set up a national service user workshop to explore issues and share information around user involvement in social policy from service user perspectives. The exploration and development of user involvement in research and emancipatory research approaches, in this author's view, needs to be given much greater priority on the social policy agenda and embedded in it. If changed and more equal relationships are to develop in social policy research and analysis, then it is important that this project is taken forward in close and equal partnership with user researchers and user-controlled organisations.

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