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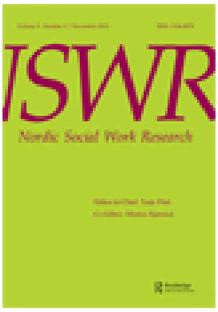

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From 'other' to involved: user involvement in research: an emerging paradigm

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From ‘other’ to involved: user involvement in research: an emerging paradigm

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This article explores the issue of ‘othering’ service users and the role that involving them, particularly in social policy and social work research may play in reducing this. It takes, as its starting point, the concept of ‘social exclusion’, which has developed in Europe and the marginal role that those who have been included in this construct have played in its development and the damaging effects this may have. The article explores service user involvement in research and is itself written from a service user perspective. It pays particular attention to the ideological, practical, theoretical, ethical and methodological issues that such user involvement may raise for research. It examines problems that both research and user involvement may give rise to and also considers developments internationally to involve service users/subjects of research, highlighting some of the possible implications and gains of engaging service user knowledge in research and the need for this to be evaluated.

Keywords: social work; user involvement; ‘othering’; research; evaluation; theory; user knowledge

The original title given to this discussion by the organisers of the conference, ‘Understanding The Other’, for which this article was prepared, ‘Involving the others in social work research’, raises significant and interesting issues, and helps us address some of them. At the heart of this is the part that *not* involving people in research plays in ‘othering’ them or in reinforcing their ‘othered’ status. Thus this discussion is primarily concerned with what has come to be known as ‘user involvement’ in research.

However in addressing this topic, which is commanding increasing international interest our attention is drawn to aspects of the social construction of ‘othering’ which extend into its study, as well as its social construction. The key concerns of this discussion are thus user involvement, research, social work, disempowerment and marginalisation. But as a route into these, this paper begins by considering the ramifications for ‘othering’ people of excluding them from research, analysis and knowledge formation. It starts by offering a case study of their exclusion from the discussion and analysis of a key modern social policy concept – that of social exclusion.

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The othering effects of exclusive discussion of exclusion

The concept of social exclusion, already one of the central significance in Europe, gained major recognition in the UK under New Labour from 1997.

Yet although dominant UK understandings of social exclusion were mainly regressive (Levitas 2005), people included in the category of social exclusion have played little or no part in discussion about its definition and conceptualisation and have had few opportunities to develop their own discourses on the subject (Beresford and Wilson 1998). Their effective exclusion from the discussion about their exclusion can also be seen as an extension of their 'othering', reinforcing negative views of their capacity and highlighting an uncritical tradition in social policy, including social work of:

- Professionals speaking for people rather than supporting them to speak for themselves.
- Models of analysis and policy development based on evidence gathered by outside 'experts' granted credibility and legitimacy, seeking to educate 'the public'.
- Fears about such 'expert' professional roles being undermined by the inclusion of service users or the subjects of social policy.
- Assumptions of people as unable to or uninterested in participating or overburdening by it.
- The ease of excluding them since these groups frequently lack the power to ensure their inclusion (Beresford and Wilson 1998, 89).

The UK social work commentator Chris Jones has thus talked of 'the legacy whereby clients are too often disregarded, not listened to and generally presented as people who don't count' (Jones 1996, 197). Yet a range of important benefits can be identified from including the subjects of social policy, including social work in discussions and developments concerning them. Among these are: better-informed debate; stronger and more effective action; minimisation of the risk of 'objectification'; the signalling of respect for the rights and citizenship of such groups and individuals; encouraging diversity in discussion (Beresford and Wilson 1998, 90–92).

Nonetheless service user involvement in social work and social policy more generally continues to be more or less limited. A recent special issue of the journal *Social Work Education* highlights both the increasing academic and professional interest in user involvement in social work education, as well as the barriers that continue to obstruct and limit it (Beresford and Boxall 2012). This is a time of major change for social work and social policy, where the competing pressures of neo-liberalism, the emancipatory aspirations of new social movements and the desire for professional autonomy and discretion can all be seen to be at work, seeking to exert an influence. All are having a bearing on the situation of service users, variously increasing and challenging the tendency for them to be treated as 'other'. Thus currently in the UK, a major government programme framed in terms of 'welfare reform' is widely seen to be having a stigmatising and destructive effect on disabled people and other people reliant on state welfare benefits, leading to an increasing public hostility against them and their stereotyping in negative terms. This has been developed through a concerted media campaign sparked off by government plans and involving right wing tabloid media (Rutherford and Davison 2012).

At the same time, in the UK, there are increasing government and other requirements and pressures for the involvement of service users in research (Lowes and Hulatt

2005). This is reflected in the setting up of a government advisory body, the National Institute for Health Research, Involve and the recent establishment of an official Director of Public and Patient Participation in Research (in relation to health, public health and social care, including social work). Thus research offers a helpful case study of the development of user involvement in social work as well as the relations this may have with the othering of social work service users, the context of this paper.

A personal insight

But first it may be helpful to introduce myself into this discussion because issues of involvement and 'othering' lead us to include the issue of identity in discussion, rather than taking it as a given. What distinguishes user involvement in research from traditional approaches is the emphasis it places on experiential knowledge; the importance of service users developing and being involved in research because of their direct personal experience of the issues is under study. Thus their knowledge comes not from their role as researchers or some other assumed expertise, but from direct experience of the subject under study. For this reason it becomes pertinent to consider the identity of the researcher and their viewpoint.

I bring three affiliations to this discussion, first, working as an academic researcher in a university, second having long-term experience of using mental health services – being a 'service user' and third being actively involved in service user movements as an activist and service user researcher. This is pertinent because user involvement is a research development that highlights issues and complexities of identity, experience and standpoint.

My academic responsibilities include directing a research centre at Brunel University, the Centre for Citizen Participation. Its work focuses on the involvement of citizens, including people who are health patients and users of long-term care and support services – people who are often seen as 'other'. The Centre seeks to involve people in both how it does its work and in the focus of its work. It has an advisory group made up of a wide range of service users who help shape and guide the work it undertakes. It has carried out research projects concerned with end of life care, disability, understandings of madness, person-centred support and welfare reform. The Centre is particularly interested in developing participatory research methodology.

Like most people, my identity is more complex than just my job and has more strands to it. I have long-term experience of using a wide range of mental health services. I have lived on welfare benefits for a long period and that has had as important and life-affecting consequences as the experience of distress and using mental health services. It's particularly positive as a service user to play a part in the education of social work and other professionals at a university, to bring the insights of being on the receiving end of services and support. This involvement of service users (and carers) is currently a requirement in qualifying and post-qualifying social work education in England.

Equally important is my involvement in service user organisations; that is organisations controlled by service users themselves. Shaping Our Lives, which I chair, is a national independent user-controlled organisation and network. Established for 14 years, it aims to increase service users' say and involvement in their lives and services and improve the quality of the latter. It undertakes research, campaigning, educational and publication work. Shaping Our Lives is managed by service users, works closely with the government and independent organisations and maintains strong links with service users and their organisations at national and local levels. www.shapingourlives.org.uk/ and its networking website SOLNET (http://www.solnetwork.org.uk/index.asp) links up in active networking and partnership more than 400 service user led organisations.

One unusual feature of Shaping Our Lives is that it works across a wide range of service users rather than focusing narrowly on one group. This includes mental health service users, older people, disabled people, people living with HIV/Aids, with chronic conditions, who have had alcohol and drug problems, young people with experience of being looked after in state care, people with learning difficulties and people with life-limiting illnesses and conditions (Branfield et al. 2006). These different groups experience different issues and can face different problems. But they also have many things in common and can learn more about each other and the shared difficulties they face, and gain understanding working together, avoid crude categorisations that don't reflect the reality of people's experience and lives and can gain in strength and solidarity together. Shaping Our Lives also places a particular emphasis on addressing issues of diversity, in relation to gender, ethnicity, belief, culture, class, sexuality, age, impairment and so on (Beresford and Branfield 2011). Thus issues of 'otherness' and of involving 'the others' are aspects of who I am which can and have been seen as 'other', and the work we do in Shaping Our Lives has much to do with challenging ideas and assumptions about 'the other' and othering.

User involvement in research

Once we begin to examine user involvement in research, what becomes apparent is how great the range and extent of such involvement can be. It can extend to include: identifying the focus of research and research questions; commissioning or buying research; seeking, obtaining and controlling research funding; undertaking the research; collating and analysing data; producing findings; writing up and producing publications and other outputs; developing and carrying out dissemination policies; deciding and undertaking follow-up action.

Service users may be involved in all, some or none of these. Their involvement may range from none, some or full involvement (Watson 2012).

Three broad approaches to involvement in research projects are also identified. First is user involvement research, where input from service users is added to existing arrangements; second, collaborative or partnership research, where service users and/or their organisations and researchers and/or their organisations jointly develop and undertake projects and third is the user-controlled research where service users and their organisations initiate and control the research (Sweeney et al. 2009).

Service users may also be involved in the broader processes and structures of research, including identifying and setting research agendas; having a role in research organisations and bodies; purchasing research; developing research methods and methodology; selecting research projects for funding; research training and education; peer reviewing for and membership on editorial boards of journals and other research publications; and speaking on research platforms.

There are now numerous examples of all of these in the UK and increasingly elsewhere in the world. User involvement in research is an international development, but in this article I will focus particularly on the UK experience because I know this is best and in many ways it seems to be the most developed (Sweeney et al. 2009).

Interest among service users and their organisations in user involvement in research now has a history in the UK stretching back about 40 years. It can be seen as part of a broader interest among service users in having more say and involvement in their lives and society. It originated in the disabled people's movement, which saw disability research as a part of broader structures of oppression and discrimination in society (Campbell and Oliver 1996; Barnes and Mercer 1997; Barnes 2003, 2004). One particular event gained special importance in the UK, both in the development of such research and of the disabled people's movement more generally. A group of disabled people living in a residential institution got together and said to the organisation providing the service that they wanted to live like non-disabled people in the community. The organisation rejected their requests. They then thought that if they could obtain independent evidence that they could live in the community, the organisation would have to listen. So they approached researchers and asked them to undertake a research project with them, which they agreed to do.

However, when the research report was published, the researchers concluded that these disabled people could not live alongside non-disabled people and described them as essentially 'parasites' relying on others to look after them. One of these disabled people, Hunt, a founder of the UK disabled people's movement then accused the researchers of being 'parasites' themselves who simply accepted conventional views of disabled people rather than developing independent evidence. The question: 'whose side are you on?' became a key for disabled activists in the UK. Disabled people decided that they would have to undertake their own research if they wanted research that was not biassed against them (Miller and Gwynne 1972; Hunt 1981; Campbell and Oliver 1996).

Disabled researchers were influenced by the 'critical social research' of feminists, black writers and educationalists who allied themselves with oppressed groups. The disabled people's movement highlighted the importance of changing (and equalising) the social relations of research production so that the researched were treated equally with the researchers. Disabled people's and social care service-user organisations and movements emphasised two overlapping concerns in research and evaluation: what research is for and where control of research lies (Oliver 1992; Zarb 1992; Barnes and Mercer 1997). This is reflected in the emergence of the 'emancipatory disability research paradigm' and related interest in 'user controlled research', in which the central purpose of research is seen as supporting the empowerment of service users and the making of broader social change. Since then disabled people and other service users, in the UK and increasingly internationally have developed their own research approach, projects and broader involvement in research and research structures and organisations.

Mainstream research interest in service user involvement in research has developed much more recently, probably over the last 10–15 years and is reflected in a number of developments (Barnes and Cotterell 2011). These include increasing requirements for evidence of involvement in research funding bids and projects; the establishment of Involve by government, which aims to advance user and public involvement in research and evaluation; ministerial and government statements of support for user involvement in research, the production of how to do it practice guides; and a developing discussion of the issue in mainstream research fora and the exploration of such involvement as a criterion in the evaluation of research projects. The focus of interest has been on seeking and including the views of service users in the research process. The underpinning rationale has been that this is a route to better quality research (Hanley 1999; Fisher 2002).

Key questions

Having set the scene by examining the background to user involvement in research, particularly in the UK, it may be helpful to raise some key questions to guide the rest of this discussion. I will seek to address two of these here, but the third is the one that is likely to benefit from wider knowledge of this journal's international readership. The questions are:

- What issues might user involvement and user research raise for research – ideological, practical, ethical and methodological?
- What problems and possibilities do user involvement and user research raise? What strengths and weaknesses might they have?
- How do developments internationally to Involve service users/the subjects of research compare with the developments described here?

Ideological issues for user involvement in research

So far relatively little attempt seems to have been made to consider the ideological basis of user involvement in research or indeed of different approaches to user involvement in research. Such ideological discussion has been neglected in user involvement more generally, as if it can be treated as a mere technical, practical matter. But it is helpful to consider the different philosophical and ideological models that have underpinned modern developments in user involvement.

Two particular ideological approaches have had particular importance generally. First is the managerialist/ consumerist approach, concerned with advancing the information base of services, developed by state and service system, drawing in the views and ideas of the public and service users as consumers or customers. It represents a kind of intelligence gathering/market research activity, with origins in the philosophies of the market and managerialism and their stated interest in cost-effectiveness and effective control and rational decision-making. This has strongly influenced developments in the UK.

The second is the democratic or empowerment model, developed by service users and their organisations and concerned with increasing their say, redistributing power and ensuring them involvement in decision-making. These two are very different approaches and should not be confused. This leads us to consider the relations of the different approaches to participation in research, which have been discussed, to the different ideological models that have underpinned the development of user involvement more generally in policy and practice. Mainstream user involvement research seems often to reflect the managerialist/consumerist model – drawing in the voice of service users, while service users demands for emancipatory/user-controlled research much more reflect the aspirations of a democratic approach to involvement (Beresford 2000).

The disabled people's and service user movements' interest in research is concerned with having more say and making change. While mainstream interest in user involvement in research 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.

Both these approaches to research can be helpful and both raise big questions for research and researchers and service users, although here, I want to focus particularly on the questions for research and researchers, beginning with the broader interest in user involvement in research that seems to relate most closely to a managerialist/consumerist model.

Many UK service users and their organisations have come to feel that dominant managerialist/consumerist approaches to user involvement in the service system can be a very mixed blessing. Serious concerns are raised about tokenism. They talk about 'consultation fatigue' and being 'all consulted out'. The gains achieved from getting involved have frequently been seen to be slight. A managerialist/consumerist approach to user involvement in research and evaluation may raise similar issues. There may indeed be serious problems of tokenism and incorporation here (Beresford 2012).

Possibilities and problems of user involvement in research

Crucially, this raises the issue of whether user involvement in research can necessarily be assumed to be a positive development or whether it has a regressive potential. Will there be gains for service users if they are merely drawn into traditional research methods, methodologies and processes established without their involvement? Why would it help, for example, for mental health service users to be involved in traditionally focused research funded by pharmaceutical companies, narrowly concerned with the efficacy of different drug therapies, when service users highlight many other important and neglected social focuses for research?

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 knowledges and discourses to achieve change; for service providers, the focus is essentially service led while for mainstream researchers, is likely to be tied to all the usual pressures and constraints of the academy/university. Some serious concerns have already been expressed 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. So there are fundamental ethical and philosophical issues about how to ensure that the service users' involvement goes beyond tokenism (Sweeney et al. 2009).

The politics of user involvement in research

Research concerns about involvement based on a democratic approach are more predictable and well developed. Both approaches, managerialist/consumerist and democratic are inherently political, but the former tends to be abstracted and treated as technical, as if it were unrelated to any broader ideology or philosophy. The democratic approach is explicitly political. Research here is 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. So these issues will apply in both cases, but we can expect they will be focused particularly on user involvement based on a democratic model.

Fundamental questions are raised about the relation of emancipatory and user-controlled research with traditional positivist research values of 'objectivity', 'distance' and 'neutrality', even though new paradigm research has made its own challenge to these (Reason and Rowan 1981). Findings from such involvement will need to address questioning of them as partisan or biassed. 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' and questions to answer about who is a service user.

User involvement in research and theory

Next we need to consider the theoretical basis for user involvement and service user/survivor-led research and equal involvement in research. This draws us to consider the inclusion of service user experiential knowledge in research and the development of service user knowledge. These are two overlapping, but different concerns, which again mirror the different concerns of mainstream and service user approaches to involvement in research.

Research is not the only way in which we develop, form or accumulate knowledge, but it is one important and systematic means. It therefore has particular importance. When service users develop their own knowledge, both individual and collective knowledge; find out things for themselves from their perspective, on the basis of what concerns them, then they will be advancing their understanding, their questions and their evidence. It is the development of their own knowledge/s as service users which tends to be service users' primary concern. Why would they be particularly concerned to advance the knowledge of others, like psychiatrists or managers? We know that they want to make things different and better for themselves and people like them – to inform themselves and gain power through knowledge on the basis that knowledge is power.

But such experiential knowledge, whose starting point is that people have lived the issues under examination have long been devalued in research. The 'objectivist' approach to research inherent in a positivist model highlights the need for and possibility of research which is neutral, unbiased and distanced from its subject. The unbiased value-free position of the researcher is seen as a central tenet of such research. By claiming to eliminate the subjectivity of the researcher, the credibility of the research and its findings are ostensibly maximised. Research can therefore be replicated in similar situations and always offer the same results. Research which does not follow these rules and which is not based on this value set is seen as inferior, with less valid and reliable results. This, however, really devalues first hand or experiential knowledge, yet we know that in ordinarily life we place a particular value on such knowledge. Service users' knowledge flies in the face of traditional positivist research values which grant it has less value, credibility and legitimacy. Often it has been ignored or marginalised. Meanwhile the knowledge claims of researchers without such direct experience are seen to be stronger (Beresford 2003). This is what has happened historically.

The discriminatory effects of traditional theory

What this means is that if an individual has direct experience of problems like disability or poverty, or of oppression and discrimination, when such research values are accepted, what they say will be seen as having less legitimacy. Because they will be seen as 'close to the problem', they cannot claim they are 'neutral', 'objective' or 'distant' from it. So, in addition to any discrimination and oppression they already experienced, they are likely to be seen as a less reliable and a less valid source of knowledge.

This means 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 further invalidates people who are already heavily disadvantaged. Thus research plays a part in the othering of people.

It is therefore perhaps time to rethink assumptions about credibility and legitimacy. One assumption, which may particularly need to be re-examined is that:

> the greater the distance there is between direct experience and its interpretation, the more reliable it is.

It is perhaps time instead to explore the evidence and the theoretical framework for testing out whether:

> 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 2003)

Exploring such a hypothesis may offer us intellectual and academic arguments to omplement current moral and ethical arguments for extending service user involvement in research. It may equally lead us to adopt a more critical response and help us to differentiate between different approaches to user involvement in research.

Towards the systematic evaluation of user involvement in research

It is time to examine user involvement in research systematically, to explore its strengths and weaknesses, benefits and disadvantages. This process needs to be one involving service users, their organisations and user researchers fully and equally. The full range of approaches to user involvement in research from the most limited to user-controlled research must be supported and included for evaluation. There is now significant interest in the UK in the 'impact' that user involvement in research has; that is its influence and effects (Staley 2009; Barber et al. 2011). There are many dimensions to explore when considering the impact that user involvement in research may have; on the nature and quality of the research; on researchers and research funders and on the influence that the research has on policy and practice. One area that is likely to benefit from such investigation is the effect on those traditionally seen as 'other'. There may be some grounds for expecting, from what we are already discovering, that the tendency to 'other' may be diminished by such participatory approaches to research, as they seek to be more inclusive, challenge the 'them' and 'us' of the research process and help ensure the equal inclusion of research participants' perspectives, identities and knowledge. This may be one of the promises of user involvement in research, which it is time to be testing.

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