

Engagement and Empowerment, Research and Relevance: Comments on User-Controlled Research

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Abstract

Based on their shared experiences of engagement in research, from the perspective of a disabled person as a commissioner of research and as a researcher, and a non-disabled person as a researcher and service manager, issues of service user engagement and empowerment in and through research, and how this enriches and makes research more relevant, are explored. Examples are given of how user-led research has had an impact on national local policy and practice.

Keywords: user-controlled research, participation, user involvement, disability

One of the strands of argument running through this paper is that biography, one's personal experience, is of significance for research, whether one is the subject of research, the researcher, or the research reader. It shapes how we respond within and to the research process. If we have control, it also shapes the research process itself.

So, how do we come to be writing this paper together? Well, we have been colleagues within a shared enterprise in Wiltshire for 14 years, and indeed have become collaborators and friends. Our shared commitments, albeit from different experiences and expertise, have allowed us to build joint agendas focussed on user participation and user/professional partnerships, and on promoting choice and control for service users and service change shaped by users.

Clare Evans was a founder member (in 1992), former director, then chair and now president of the Wiltshire and Swindon Users Network (WSUN), for which she received the MBE in 2003. The Network (see Evans and Fisher, 1999a) brings together hundreds of disabled people across Wiltshire and Swindon who engage in collective advocacy to reform and reshape life experiences and services (and not just social care and health services, but also, for example, transport, library, employment and rural and urban planning) for disabled people. Clare had a background as a social worker and then in community development in the voluntary sector, and is a disabled person herself. She is now the manager of the Leonard Cheshire Disabled People's Forum (see Evans and Fisher, 1999b), working with Leonard Cheshire service users to generate change within the organisation through the efforts of disabled people who are collectively empowering themselves.

Ray Jones is a former social worker and university

lecturer who in 1992 became director of social services (now director of adult and community services) with Wiltshire County Council. In 2001-2002 he was the first chief executive of the Social Care Institute for Excellence (SCIE). With a background in social care practice and management he has also been a researcher (see, for example, Jones, 1979; Jones, 1982; Jones, 1987; Jones, 1996). He was the founder of the Association of Directors of Social Services (ADSS) Disability Network, in which role he led negotiations with the Disabled Action Network (DAN) in the months after they stormed the ADSS Spring Seminar in Bournemouth in 1999!

So, two different biographies that started to touch each other and intertwine at the time of the reforms following the NHS and Community Care Act 1990.

One of the outcomes of our work together has been the development of our joint understanding about the importance of service users becoming major players in the development and reform of services.

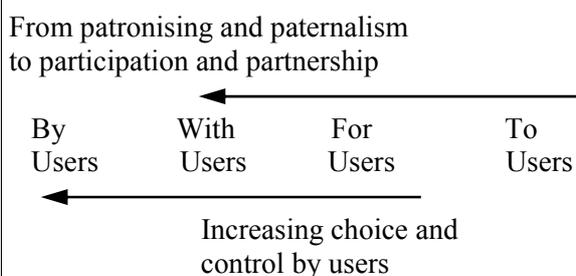
This has included, for example, service user involvement in the training of social care workers (see Evans and Hughes, 1993), in service planning and policy development, in meetings with local politicians to comment on and inform the decisions they take, in promoting user-controlled services and direct payments (Evans, 1995), and in monitoring and evaluating the outputs and outcomes of policies and services and service re-design. It is this latter aspect on which the rest of this paper now concentrates.

Understanding User Engagement and Empowerment

In 1994 we delivered a presentation together at a Policy Studies Institute conference on 'Removing Disabling Barriers'. A part of the presentation noted a continuum of user engagement and empowerment (see Figure 1). This reflected our

understanding that the aspiration was to move from the ‘to users’ end of the continuum to the ‘by users’ end.

Figure 1 - A Continuum of User Engagement and Empowerment



(see Jones, 1995)

Involvement in Social Care’, Braye identifies particular service user mandates for participation growing out of the Disabled People’s Movement and psychiatric survivor movement (Braye, 2002). In the democratic model of participation the focus is upon citizenship and participatory rights.

It is not only, however, disabled people who are identified in such power relationships, as noted by Holman:

Researchers have power. The danger of social work research is that it can reinforce the powerlessness of the most vulnerable members of society. Decisions about the nature of research are made by powerful agencies and rarely by the users of social services. The latter have little control over what is done to them, how it is interpreted and how it is used. They have no more say about most research than they do over the setting of government targets. In short, social work investigations can be a reflection of an unequal society. (Holman, 2001).

This was within a piece by Holman from his perspective and experience of working with families in Easterhouse in Glasgow, making critical comment about the New Labour government setting up the Social Care Institute for Excellence (SCIE) with an initial grant of £2m (one of the current authors was appointed to do just that!).

And, just to add to an uncomfortable feeling, Holman went on to add:

a research group of social services users could study directors of social services departments and large voluntary societies. They could assemble data on where they lived, their lifestyles, what recent experience they had as front line social workers, when they last conversed with delinquent youngsters or had a meal with stressed-out parents. The researcher would then be in a position to make judgements about the directors’ values, their relevant experience, skills and closeness to people in need. They could then comment on their suitability to run social services. Upside-down research would not only contribute to better services, it would also put more power in the hands of the powerless. (Holman, 2001).

The direction of movement in Figure 1 was also within the intentions of the community care reforms of the early 1990s (but at that time with the emphasis on ‘with users’ rather than ‘by users’). But it was really powered by disabled people themselves, the organisations they created and the clarity and conceptualisation they brought through the shaping and promotion of the social model of disability (see Campbell and Oliver, 1996).

The relevance for research is that there was a challenge to the traditional means of production and ownership of research:

The power of the researcher-experts is enshrined in their control over the design, implementation, analysis and dissemination of research findings. As a consequence, the ‘subjects’ of research are treated as ‘objects’ with little positive input to the overall research process. The emancipatory paradigm [see below] rejects this notion of research-experts moving between projects like ‘academic tourists’, and using disability as a commodity to exchange for advancing their own status and interests. The response of disabled people is quite simply: ‘no participation without representation’ (Barnes and Mercer, 1997).

User issues related to user participation in social care research, as in social care more generally, are complex and some participation is contested by service users as ‘tokenism’ with no real influence, power and control being handed over to them. Thus, in her overview of ‘Participation and

In essence, it was no longer seen as good enough to just ask service users, with questions pre-framed by the researchers, what they thought of the services they received. This in its own right had been seen as radical within our professional life-times, with the Mayer and Timms' (1970) study of users' views being seen as a seminal and sea-changing new approach (see also, for example, Rees (1978), Sainsbury (1975), and Jones (1987).

What was now being recognised was that the production and process of research themselves were about power, the power to define issues, how they should be explored, and how they should be evaluated and explained:

... there is no guarantee that the issues under investigation will be those which service users would have chosen, and no guarantee that any power sharing will be maintained if service users decide a course of action which professionals oppose. In many ways, therefore, participation initiated by professionals remains conditional ... what is needed is to go beyond

these models of research and find new frameworks which recognise not just the rights of service users to participate but also their right to determine the research agenda in the first place. (Evans and Fisher, 1999a).

Much of this, and more, was captured in the term 'emancipatory research':

The issue then for the emancipatory research paradigm is not how to empower people but, once they have decided to empower themselves, precisely what research can do to facilitate this process. This does mean that the social relations of research production do have to be fundamentally changed, researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever way they choose. (Oliver, 1992).

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Figure 2 below, taken from Truman and Raine (2001), links Figure 1 above, about a continuum of user engagement and empowerment, with a

Figure 2 - Participation, Involvement and Research		
Mode of Participation	Nature of User Involvement	Relationship between research and users
Co-option	Token: representatives are chosen, but no real action	On
Compliance	Tasks are assigned, with incentives researchers decide agenda and direct the process.	For
Consultation	Users' opinions asked, researchers analyse and decide on a course of action	For/with
Co-operation	Users work together with researchers to determine priorities responsibility remains with researchers for directing the process.	With
Co-learning	Users and researchers share their knowledge to create new understanding and work together to form action plans with researcher facilitation	With/by
Collective action	Users set their own agenda and mobilize to carry it out, in the absence of outside researchers or facilitators.	By
(Truman and Raine 2001)		

particular focus on changing power and relationships within research, reflecting much of the argument above.

The need to value the direct ‘lived experience’ of service users in research and indeed to challenge the rules and values of traditional research and knowledge based upon it which are seen as oppressive, have recently been explored in more depth by Beresford (2003).

User-Led Research

So, what is entailed in user-led research? Essentially it is about service users determining the research focus, the research process, the interpretation of the research findings, and the conclusions to be drawn for policy and practice.

It is about service users becoming ‘research commissioners’ and ‘research producers’ (Beresford and Evans, 1999). It impacts on every stage of the research process as indicated in Figure 3.

Figure 3 - The Research Process

1. Who identifies and defines the issue or topic to be studied?
2. Who identifies and defines the hypothesis to be tested and/or the questions to be asked?
3. Who determines the methodologies to be used?
4. Who undertakes the research?
5. Who applies the methodologies/asks the questions?
6. Who decides what, and how, to record the responses?
7. Who collates and interprets the data?
8. Who decides what conclusions should be drawn?
9. Who decides how to present the conclusions?
10. Who draws the lessons for policy and practice?
11. Who follows through to see action results?

In user-led research, the answer to the ‘who questions’ in Figure 3 will largely, if not always, be ‘service users’. The research process comes under the control of service users and the significance of

such research is not just that it changes power relationships within the research process but that it is likely to lead to a different research product:

We define user-controlled research in the following terms. It must bring service users greater power to define their needs and the outcomes that matter to them. Service users must select the issues for research and acquire control over the funds to conduct it. We think that service users should wherever possible become researchers, so that their influence pervades the research: this includes responsibility for data analysis and for dissemination. (Evans and Fisher, 1999b).

Disabled Parents: A Paradigm-Shift

One topical example (at least at the time of writing this paper, but in a few years’ time it will be seen as ‘old hat’ and ‘obvious’) of user-led research producing a different focus and outcome is the paradigm shift, a change in mind-set, that is being driven forward by disabled adults who are parents.

In the past the service focus has been on the children of disabled adults as potentially ‘children in need’ and as ‘young carers’ needing assistance and respite in their own right. Indeed, only a few years ago, the identification of the issue of ‘young carers’ was seen as innovative and radical, with ‘Young Carers Projects’ (promoted by the then Carers National Association now Carers UK) springing up across the country. ‘Young Carers Strategies’ (as in Wiltshire!) are still being produced with the focus on assessing the needs of the children and young people and providing compensatory opportunities for them as ‘young carers’.

But the focus is now being turned, led by the Disabled Parents Network (DPN), to the assistance disabled adults may need to fulfil their parenting responsibilities, roles and tasks rather than focusing on their children as ‘children in need’ or ‘young carers’. This paradigm-shift (to use a term coined by Kuhn in 1961) draws on the social model of disability, with disability created by the social, physical and attitudinal environment not by a person’s impairment, whereas previously:

Minimising the negative impact of parent impairment becomes the focus, rather than supporting the parent to uphold the welfare of the child. Within this frame of reference, the child comes to be seen as the primary client within the family while the support needs of the disabled adult in relation to parenting remain unaddressed. (Olsen and Wates, 2003).

The Role of the Professional Researcher

None of this means that there is no longer a role for the skills and expertise of the professional researcher, whether user or not. The role here, however, is to be an ally, an advisor, an enabler, and maybe a partner, to users undertaking research (see Barnes and Mercer, 1997; Evans and Fisher, 1999a). They may, for example, advise and assist with sample design, questionnaire construction and data analysis, whilst the control and power remain with the service user commissioners.

In emancipatory research the political standpoint informs the style and methods of the researcher:

Researchers place their knowledge and research skills at the disposal of disabled people and their organisations, acceding to them control over decisions about what should be researched, as well as the means of research production and distribution. (Ellis, 2002; see also Barnes, 1992; Oliver, 1992; Priestly, 1999).

Service users will value meaning not just measurement and accounts of real experience (eg through narrative telling or diary keeping) rather than just aggregated average measurements which lose the focus on difference as well as similarities (see Olsen and Wates, 2003; Sabat, 2003).

However, Olsen and Wates also note:

There is no reason why large-scale quantitative studies involving large, randomised surveys of disabled parents with a control group drawn from the population of non-disabled parents should not be compatible with the social model of disability, increasing understanding of the barriers faced by disabled parents and their families and directed towards improving the

support available. (Olsen and Wates, 2003, see also Truman and Raine, 2003).

However, such quantitative studies should be preceded by disabled parents identifying and scoping the issues to be focused on in the research.

But what is likely to make professional non-user researchers change their understanding and commitment so that they work more inclusively with service users? What may lead them to re-define their role to become allies and partners in the research process with service users?

Firstly, it can be threatening for non-user researchers to have the legitimacy and the process of their research challenged. But no one is saying non-user researchers do not have expertise. Indeed, as above, the expertise and skills of non-user researchers have been explicitly noted. What non-user researchers are being asked to do is to deploy their expertise in new ways and to see their role as assisting service users within a user-led research process. Not a bad mission! It is rewarding in its own right, presents in own challenges and learning opportunities, and yet still recognises the expertise and competence of the non-user researcher.

Secondly, it gives opportunities for the non-user researcher to see the research process enriched. The hypothesis set, the questions asked, and the methodologies employed are all likely to be improved, and made more relevant, through being immediately informed by the experiences and aspirations of service users. For example, capturing and recounting real experiences (e.g. through diary keeping), rather than only collating and recording aggregated responses often tells a more powerful story with enhanced impact.

Thirdly, being beside service users as a partner or collaborator enriches and broadens the personal experiences for the non-user researcher. It gives another window on experience. Personal experiences for us have included standing in the rain on a pavement in London flagging down taxis only to see them slow down and shoot away again as they have spotted Clare in her wheelchair, arriving at a conference venue to find the

presenters have been located on a platform 5 steps above the rest of the hall and having to give our presentation at hall level below the other speakers, or, for Ray, struggling to make sense of a jumble and jigsaw of three wheelchairs, all of which had been dismantled and placed in the boot of his car, and which needed rebuilding when we arrived, with two disabled colleagues, at a conference venue in Maidenhead (again in the rain)!

Finally, in commenting generally on user-led research, it is important to recognise that it does not mean less quality or less rigour. Indeed by focusing on the important issues for service users, and exploring the issues in ways which capture the experience, and expertise based on experience, of service users it is likely that user-led research will have greater validity in tackling important issues.

User-controlled research still, however, needs to be well-designed and well-conducted research:

In summary, emancipatory research in the disability context should be enabling not disabling. It must be 'reflective' and self-critical lest a new orthodoxy is established which turns 'doing disability research' into a technical routine. Disability research must not deteriorate into propaganda: it must be politically committed but rigorous. (Barnes and Mercer, 1997)

And this was the commitment given, and context achieved, in Wiltshire where user-led and controlled, and user-undertaken, research was well designed and well-conducted.

Wiltshire Vignettes

A strong user-controlled organisation (Wiltshire and Swindon Users Network), providing regular forum meeting opportunities for service users, identified service deficits through the informal research process. For example, firstly, a lone under-represented voice identified a lack of day activity services for younger disabled people with physical impairments, which led to a commissioning manager funding a small piece of more formal research into the needs of a wider group of such disabled people.

Secondly, the informal research process of facilitating older people's focus groups to identify deficits in their service, led to them requesting as a priority across the county the home care service to cut toenails for older people. Such a strong voice can provide evidence for the planning and development of services and their need has been met albeit 8 years later! These are examples of users' knowledge being used in the planning and development of services (see Beresford, 2003).

Sometimes service users in Wiltshire have found it appropriate to seek funds to carry out research under their own control. To date there have been few examples of user-controlled research because service users have difficulty finding funding for such work. In 1994 Wiltshire and Swindon Users Network, however, obtained funding of £18,000 from Community Care infrastructure funding to carry out research into service users' views of Wiltshire Independent Living Fund Support Service, which was part of the third party scheme to enable users to receive funding to hire their own personal assistants, which preceded Direct Payments legislation.

The research group of users designed the research questions and methods and some received user-led training to carry out interviews. As described above, a professional researcher ally also put his skills at the disposal of the group at each stage of the research process (Evans and Fisher, 1999a). The most demanding part of the research process to share a group of users was the analysis of results. The resulting publication, 'I am in Control' (Wiltshire Users Network, 1996) was disseminated to those the users wanted to influence in planning the service

A larger piece of user-controlled research was carried out by Wiltshire and Swindon Users Network in 2001 as a Best Value Review of Direct Payments, funded by the Joseph Rowntree Foundation. Again, service users felt most confident about designing research on a service about which they had considerable knowledge and valued themselves. They negotiated the research to be a Best Value Review since this was the framework being established within local authorities to evaluate their services. The Network received assistance from professional researchers

as allies at the Joseph Rowntree Foundation and the University of Bath in setting up the research proposal and carrying it out. Again, a group of direct payment users and prospective users, facilitated by a professional user researcher, designed and carried out the various pieces of investigation, which made up the Review process. The group valued the user researcher's commitment to their access needs and good practice generally, as well as her professional knowledge.

It was noticeable that the disabled people involved were concerned that the effectiveness of the dissemination was judged in terms of its effectiveness in achieving improvements in the service rather than in spreading research knowledge *per se*. Any concerns they feared at the start by having to follow the formal Best Value Review procedures and timetable were dispelled as they learnt how to 'manage' the process and make use of the flexibility of local authority allies (Evans and Carmichael, 2002).

User expertise can be brought to bear to enhance any research into service provision. For example, three service user Network members carried out telephone interviews of those recently discharged from hospital, to gain their views of services through this process. Their independence of the service, 'lived' experience and empathy of the issues discussed enabled them to gain more realistic evidence than the local authority could, to inform the future planning of services (Evans and Fisher, 1999b).

There is also increasing recognition of service users' priorities in evaluating domiciliary home care services. Home care users, for example, designed the questions to enable the Wiltshire home care service to conduct a regular audit of its services. This fits with the National Care Standards Commission requirement of service providers to carry out an annual survey of users of their service. This has also led the Leonard Cheshire Disabled People's Forum to request a user-led design of a similar survey within the Leonard Cheshire organisation. Evidence of users' priority outcomes of domiciliary care researched by the University of York Outcomes into Practice research project (see Nicholas et al, 2003) have

been developed into draft questions. These have then in turn been used to consult Leonard Cheshire users on the wording and subject matter of the survey.

Making a Difference

But has the research led and conducted by service users had any impact? Has anything changed as a consequence of the research in policy and practice?

Well, yes, but sometimes with a time lag! For example, the research which identified the potential benefits of home carers giving more attention to footcare of disabled and older people led eight years later, following continuing campaigning by service users and managing challenges to professional vested interests and fears about health and safety litigation, to home carers in Wiltshire now being trained by podiatrists to file nails rather than service users having to visit chiropodists (who in a large rural county may be 20 miles away).

Secondly, the user-led research on direct payments emphasised the importance of training on direct payments for care managers, the setting up of a central co-ordinating lead officer with Social Services and a user-led group to monitor the ensuring Best Value action plan.

Thirdly, the user-led and undertaken research on the experiences of disabled adults with parenting roles and responsibilities, and the Disabled Persons Network's survey of local authority policies and practice, have led to the requirements for assistance by disabled parents being emphasised in revised Department of Health guidance on community care regulations and care management practice. It is also leading to local authorities, including Wiltshire, reviewing (or creating from new) their own policies on assisting disabled parents rather than focussing on their children as 'children in need'.

Concluding Comments

There are at least two dangers, however, with the current state of play with regard to user-led research. Firstly, it may erroneously be assumed that it is now wide-spread and mainstreamed. There are plenty of Government statements and

initiatives promoting choice and control for service users, and particular initiatives giving attention to service users and research (see, for example, Social Services Inspectorate, 2003).

However, a recent survey of 518 NHS research projects (Telford et al, 2003) found that only 17 per cent (n = 88) of projects involved, other than as research subjects, a consumer in the research process in any way at all. An analysis of how much of even this limited involvement led to real user influence power in the research process is needed.

Secondly, there is a danger that user-controlled research in its own right could be colonised by non-user researchers, turning it into another opportunity for commentary and debate with service users excluded.

So, two dangers, but also lots of opportunities, reflecting not only changes in the proprietors, production and process of research but hopefully also reflecting changing relationships between service users, service commentators and service deliverers.

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Personal footnote from RJ: my biography also intertwines with Bob Holman. He was Professor of Social Work and Social Policy at Bath University when he appointed me as a lecturer. I worked as a volunteer on the Southdown Project (see Holman 1981: Jones 1982) which he established. And we shared an after-dinner conference platform at Surrey University when I argued that it was important as researchers to recognise the partnership nature of research and to seek to give a commitment to feedback to those who had participated in the research the conclusions drawn. This was seen as outrageous in the late 1970s and led to a complaint, which was investigated by the Pro-Vice Chancellor at the University of Bath, with RJ being defended by Bob Holman!

