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Who calls the tune: Participation and partnership in research

Abstract

This paper explores issues of partnership and participation in research and evaluation, drawing on the experiences of evaluating a move from hostel accommodation to independent supported living for people with mental health difficulties or learning disabilities. The service change project involved a partnership between a local authority and a housing association with over 300 people moving into their own tenancies in newly-built flats and bungalows. The accompanying evaluation was designed on a model of service user participation and action research and was specifically concerned to explore the impact of the changes on people's actual or perceived social inclusion into local communities. Ten service user and carer researchers, some of whom were directly involved in the move from hostel to independent living, were recruited and worked with 'professional' researchers to examine both the process and the outcomes of the move.

The work will be viewed through the insights offered by feminist, transformative and participatory approaches to research. The 'positioning' of the researcher in relation to boundaries and the construction of the 'other' will be considered, emphasising an approach grounded in reflexivity and an acknowledgement of the complex ethical issues involved.

A key feature of this study has been the negotiation involved between a complex change project and a participatory evaluation design. Learning points from the work so far will also be considered in terms of their wider application in future evaluations of complex change projects that involve multiple stakeholders.

Introduction

This evaluation based on a model of user involvement and participatory research involved three organisations - a local authority adult social care department, a housing association and a university. An action research component ensured that learning from the evaluation was fed back into practice throughout the life of the study.

The study arose from the closure of local authority hostels for people with mental health difficulties or learning disabilities and their replacement by core and cluster accommodation in private tenancies, funded by a private finance initiative. Continuing support to service users is provided by housing support workers employed by the local authority, many of whom previously worked as residential care staff. Close working relationships between the housing association and the adult social care department were maintained to ensure the smooth handover of the new accommodation. The primary aim of the evaluation was to consider the extent to which changes in accommodation and support improved social inclusion in local communities.

The original intention to evaluate the service transition involved meetings with interested parties including a local university and it was agreed that an external evaluation would be most effective in providing an independent perspective on the project. A successful bid for funding from the Big Lottery was led by the housing association and a management group was created to oversee the evaluation. Staffing for the evaluation included a senior researcher, a research officer and a part-time administrator working with a university researcher involved in the original funding bid for the evaluation.

The decision to adopt a participatory and action research approach was taken to ensure that user and carer concerns and priorities were central to the evaluation and that their knowledge and experience was valued (Metcalfe & Humphries, 2002). This approach recognises the importance of both the *process* and the outcome of the research, offering potential for transformation in the lives of those taking part. The original intention was to involve 24 service user / carer researchers in order to achieve two balanced groups of people from the learning disability services and from mental health services and to allow for drop-out. However it proved difficult to recruit sufficient numbers of people and it was agreed that a smaller group might be more appropriate for reasons that will be discussed later in this paper. An initial group of six researchers were recruited with a further four later joining the group.

The paper will begin by locating the overall project within the broader debate on user participation in research. This will be followed by identifying some of the challenges that have been faced in the evaluation. Finally the lessons learnt from this experience will be highlighted, identifying some of the strategies that have been found to be effective in contributing to a positive outcome. The discussion will explore some of the theoretical and conceptual frameworks that helped to make sense of these experiences, highlighting the frequently messy and challenging nature of participatory action research. In particular attention will be drawn to issues of power and partnership and the multi-faceted relationships that invariably characterise the research process.

The paper will be informed by the underlying question, asked by Mertens and Ginsberg (2008:486) of any researcher striving to work within a transformative paradigm as to 'How can my research….contribute to social justice?' Pease (2010:98) argues that, despite the revival of interest in critical and anti-oppressive approaches to social work practice, there have been only limited attempts to address critical theory in relation to social work research.

Throughout this paper the term 'co-researchers' has been chosen as the preferred term to refer to user and carer researchers involved in the evaluation, with the term 'researchers' referring to the senior researcher and research officer.

Service user involvement and participatory approaches to research and evaluation

Involving service users and carers in research is increasingly accepted as a legitimate strategy, endorsed within UK health research policy as part of the wider patient involvement agenda (Department of Health, 1999; 2000;2001; 2005a; 2005b). However it still may not be seen as a high priority by funders and in some academic and research circles where there is a continuing emphasis on a positivist paradigm and researcher objectivity. Furthermore the considerable time required to develop relationships and trust with disadvantaged groups may also limit the possibilities for research grounded in tight timescales and budgets.

There is also a very broad understanding of what counts as user involvement ranging from consultation and collaboration through to user-led or controlled research (Beresford, 2000; Evans & Fisher, 1999). In addition to risks of tokenism and ambiguity of language, these terms however can conceal more complex questions regarding what exactly defines control and responsibility for the research process. (McLaughlin, 2009; Minogue et al, 2009). Turner and Beresford (2005) suggest that user participation can be categorised as either managerialist / consumerist or democratic. They challenge what they see as the tokenism of much research which claims to be based on a model of user involvement, instead advocating for user-controlled research with a clearly articulated agenda based on emancipatory objectives. These can be demonstrated in a number of successful examples of user-led research (Kotecha et al, 2007; Mental Health Foundation, 2000).

Within the broader context of user involvement in health and social care, there is the recognition that there is only limited evidence to indicate its effectiveness in bringing about different outcomes in service delivery (Carr, 2004). However, there are suggestions (Telford & Faulkner, 2004;Trivedi & Wykes, 2002) that the experience of involvement may influence research outcomes in addition to having the potential to create transformative outcomes in terms of new knowledge and skills for those involved.

Involving users and carers in research, by necessity, needs to pay attention to issues of power, although this may vary across the research cycle where there may be different opportunities for engagement at different stages of the process. For example, in this study some of the co-researchers opted to be involved in devising questionnaires or undertaking analysis, rather than interviewing, although all met together regularly and took part in the training and wider research activities and discussion. This was to ensure that the benefits associated with involving users and carers as interviewers (Bengtsson-Tops & Svensson, 2010), should form part of a wider strategy for involvement including research design, data analysis or dissemination (Rethink, 2009; Staley, 2009; Trivedi & Wykes, 2002).

The experience of this study highlights the conceptual and practical challenge in clarifying what ‘user involvement’ in research entails as this study fails to fit neatly into any one category. Users and carers were represented but did not lead the group that initiated the research design and funding application. The successful bid triggered some lengthy negotiations between the three main organisations involved in order to achieve a tri-partite partnership agreement that would provide clear and transparent systems for managing the evaluation. This was followed by the recruitment of two full–time researchers and a part-time administrator, employed by the Housing Association and based in the University. However neither the partnership agreement nor the recruitment of the researchers involved users and carers. Only with the research team in place could attention turn to the recruitment of the co-researchers. This required time to contact users and carers from the relevant services and provide information about the evaluation to help people make an informed choice regarding their possible involvement. Interested individuals were asked to complete a brief application and to attend an informal interview with the researchers. A second wave of recruitment involved existing co-researchers in designing interview questions and acting as members of the selection panel. Once the initial group of co-researchers was established, regular meetings were held to offer them training and support. Individuals were supported to select those activities that best matched their skills and interests across the range of tasks including devising questionnaires, data collection and analysis.

This somewhat lengthy process highlights both involvement and non-involvement at different points as the research began. Although this study would not meet some criteria for user-controlled research, (Beresford, 2000; Evans and Fisher, 1999) it does demonstrate a dynamic process of increasing levels of involvement and participation over the life of the evaluation.

This study was also informed by participatory and community-based research described as emphasising:

> '... the importance of collaboration, participation and social justice agendas over positivist notions of objectivity ... [rendering] research more understandable, responsive and pertinent to people's lives.... [helping] individuals make lasting personal and social change.'
>
> (Flicker et al,2008:107)

A key aspect of participatory research is the emphasis on the process and its potential in assisting marginalised groups to gain in confidence and contribute to the community. Respect and recognition for local knowledge and experience is paramount and the work needs to be sensitive to the specific conditions and context of the area (de Koning & Martin, 1996). Participatory research emphasises the perspective of the researched as well as the researchers, challenges top-down expertise and acknowledges the fundamental importance of challenging inequalities. A particular feature of this study was the involvement of co-researchers from both learning disability and mental health services. Although there are numerous examples of research involving survivors and users of mental health services, there are, as yet, fewer examples of the involvement of researchers with a learning disability (Ham et al, 2004; Redmond, 2005; Abell et al, 2007). There is also a recognition, influenced by a feminist perspective, of the importance of critically examining difference within research relationship (Ramazanoglu & Holland, 2002) and the need for reflexivity within a framework of ethical practice (Humphreys, 2008).

It is also important to locate participatory evaluation within a range of approaches to evaluation, recognizing the political context within which the activity is taking place and which, in many instances, is a determining factor in the choice of focus, funding and overall purpose. Humphreys (2005) refers to Beresford and Evans (1999) in suggesting that social research is increasingly reactive in evaluating and legitimating policy developments, rather than initiating them. Similarly, Everitt and Hardiker suggest that rational-technical approaches have become 'synonomous' with evaluation as: '… part of the repertoire of those controlling policy and resource allocation mechanisms.' (1996: 83) The challenge to such views rests in the notion that social research is a 'moral and political activity' (Humphries, 2005: 281), supporting an understanding of participatory research and evaluation that is emancipatory and transformative, recognizing issues of power and justice and the need to challenge powerlessness, inequality and oppression.

Whilst user involvement in research might simply appear to function as one sub-set of participatory research, a more rigorous analysis of some of the issues involved requires questioning both the purpose and the process of the research. In terms of purpose, the emphasis on social justice and empowerment that is seen to be fundamental to participatory research would suggest that it is only that research that falls into the democratic category outlined by Turner and Beresford (2005) that has this potential. The involvement of service users within a managerialist or consumerist frame may be related to pre-determined areas of inquiry that may not, in themselves, promote social justice. In relation to this study, one limitation could seen as the fact that the evaluation was intended to meet the needs of a managerialist agenda in reviewing the success of the move to independent living. This may be further understood in the context of a change project designed to meet policy and financial objectives and within which service users had to respond to an imposed agenda with no choice regarding the move from hostels to independent tenancies.

Positionality and Reflexivity

The need for researchers to acknowledge their own position and the way in which this impacts on the research design, question and methods has frequently been highlighted (Pease, 2010; Ramazanoglu, 2002). This requires reflecting on 'how one is inserted in grids of power relations and how that influences methods, interpretation and knowledge production.' (Sultana,nd:13)

In writing this it is important for the authors to acknowledge their own positions, both individually and as a team, including acknowledging issues of privilege in relation to background and education and the fact that all the researchers were white women. These and other experiences inevitably impacted on our work and influenced the relationships involved in the research process in terms of the dynamics of power. The co-researchers included equal numbers of men and women, most of whom had experience of using mental health services, a minority from learning disability services and one carer.

Insights from feminist perspectives on research, in particular Bhavani's (2004) understanding of Haraway's notion of feminist objectivity as meaning 'situated knowledge' (1988:581) are relevant here. The concept of *accountability*, that is avoiding complicity with dominant representations of the researched and not re-inscribing powerlessness was important in terms of avoiding the oppositional thinking that can accompany categories such as 'professional–service user', recognising that these may be shifting rather than static, with potential to obscure rather than illuminate other more nuanced issues. This also requires a critical view of identities as 'service users', frequently described as fixed and all-encompassing. Such categories serve to maintain notions of powerlessness offering only one-dimensional descriptions of complex lives and identities.

P*artiality*, referring to the way in which questions of difference are seen through the research process also highlights the challenges involved in foregrounding the experiences of service users and carers, whilst also sidelining the competing knowledge claims of others. In this study it could be argued that many of the staff, the majority female, whilst in day-to-day positions of power vis-a-vis service users, were also themselves disempowered within the agency structures and systems. Despite their contribution as research participants, their involvement in the research process itself was not explicitly sought.

The need, in this study, to pay attention to the dynamics involved in working with a range of stakeholders required attention to *positioning* involving micropolitical processes and relationships within the research. This included working with a complex web of relationships including members of the partnership management group, users and carers and other community-based groups, local health and social services, as well as the funders. In discussing the importance of critical reflexivity to professional expertise Fook (2000) stresses the need for contextuality, being 'the ability to work in and with the whole context of the situation, as well as the specific and diverse perspectives that are contained within this'. This required continuing attention to dialogue and negotiation of meaning as dynamic and fluid at every stage of the process.

Exploring partnership issues - who calls the tune?

In undertaking this study there has been a continuing dialogue both within the research team and between the team and the partners, concerning relationships and communication. Whilst a traditional paradigm of evaluation would maintain the importance of distance and objectivity, such a stance was neither achievable nor desirable. Additionally, such a position, where the evaluation team presented themselves as the academic 'experts' would not be in keeping with a participatory approach striving to decrease inequalities and respect local knowledge and first hand experiences.

Attention to the sensitivities of the positioning of the evaluation was vital in creating and maintaining appropriate relationships with all the partners. It was important from the start to assert the independence of the study and to avoid being identified with the service providers. Questions of ownership and control of the evaluation were carefully negotiated whilst acknowledging that this study was initiated by the service provider partners, ultimately responsible and accountable to the funders in ensuring the delivery of the original aim of the evaluation. Access to service users and carers, initially to recruit the co-researchers and then services users, staff and carers as participants, could also only be achieved via the service providers. To encourage staff to support users to become involved and to take part themselves, it was emphasised that the evaluation was intended to provide an independent account of the changes taking place. For the researchers this required maintaining a neutral stance to ensure that the entire range of views about the programme could be elicited.

This was particularly relevant as some participants may have been unwilling to participate in an evaluation that might have been seen as tokenistic or risky in terms of their employment or care if it was directly accountable to service providers. Indeed, a minority of staff, sceptical about the changing configuration of services, initially voiced their ambivalence regarding the purpose and worth of the evaluation, seeing this as part of the service rather than separate. Establishing a clear identity for the evaluation and promoting this with newsletters and information helped to convey independence. An independent research advisory group with members from local voluntary sector, health and social care services as well as service user and carer representation was also established quite separately from the management group, although with clear lines of communication between the two groups.

A series of independently facilitated action research seminars were held to feedback the findings of the evaluation and encourage staff and managers to consider ways of responding to the issues that were raised. This provided opportunities to share aspects of evaluation and research, suggesting that an 'outside' evaluation team can assist in capacity building as regards evaluation practice as well as 'engaging in a partnership of investigation at the grass roots, offering facilitation of a jointly owned process' (Dullea & Mullender, 1999:83).

It was also essential to be clear about the purpose of the research with users and carers. The provision of accessible information and clear communication attempted to clarify the role of the researchers and to prevent them being seen as able to respond to day-to-day issues. However it was made clear that any concerns regarding risk that were brought to the attention of the researchers, would need to be passed on appropriately. On one occasion information was received during an interview that raised serious concerns about the quality of care offered in one part of the service. Effective communication with the service providers enabled the exchange of information needed to ensure that issues could be addressed to reduce risk without compromising the anonymity of the participant.

Although it is recognised (Hanley et al 2004) that user involvement in research may benefit those involved in terms of empowerment, Carr (2004) comments on the tendency to emphasise the 'therapeutic' benefits of user participation in social care services, rather than their contribution to making a difference. Within this study, whilst the model of user participation did raise important questions about where to draw the line in terms of the personal benefits of involvement for the co-researchers and the need for support, it was also essential that these did not take precedence over meeting the evaluation outcomes. The involvement of co-researchers requiring varying levels of support meant that the researchers paid close attention to each individual's circumstances so that this could be tailored appropriately. However this was framed within a 'social model of disability', emphasising tackling the barriers that might hinder involvement, rather than taking a 'therapeutic' orientation. When necessary, co-researchers were offered information regarding other sources of assistance. This level of support, tailored to individuals' needs, would also not have been possible with a larger group of co-researchers, providing further justification of the value of a small group. At times it was also evident from discussion at the co-researchers' meetings that the service changes taking place were directly impacting on those co-researchers involved in moving into new accommodation. Whilst this material was relevant for the research it was not appropriate to include this data as the experiences were shared informally outside of formal protocols of consent and interview practice.

Working in partnership also brings its own challenges when having to reconcile the needs of service user and carer researchers with the requirements and systems of large organisations. For example, Read and Maslin Prothero (2011) build on Fox et al's (2007) work to develop a framework with six key 'ingredients' for user and carer involvement. One 'ingredient' concerns financial support to fully support and celebrate user and carer involvement. In this project, the housing association delegated the university to make payments to users and carers, however, despite adequate funds, payments were subject to financial regulations of the university as well as the Inland Revenue and the Benefits Agency and researchers had to be creative to ensure that users and carers received payments in a timely manner.

Place and Space

Questions of power are played out in a spatial context, generating critical messages about who has control. An initial decision was made to hold co-researchers' meetings within the university as this offered an accessible location and appropriate facilities and could be seen to offer an implicit message regarding the value placed upon the research. At the same time there was a concern that this might be experienced as a potentially oppressive environment where co-researchers, with limited experience of higher education, might feel uncomfortable as well as the practicalities of finding their way round a large and unfamiliar buildings. In practice some of the group needed support in the practicalities of attending sessions, ranging from reminders as to the date and time of the next session using phone calls, text messages and written reminders, the provision of taxis to the venue and being met on arrival at the university. Wherever possible meetings were held in the same room each week to promote familiarity with the environment.

On balance the decision to hold meetings at the university was seen to have been appropriate and some of the co-researchers' initial apprehensions were short-lived. Indeed the use of the university as a base for the work as found by others (Palmer et al, 2009) can be seen to have added to the co-researchers' confidence and sense of self worth as it became apparent that attending meetings at the university was itself experienced as a valuable part of the overall experience with an observable increase in skills and confidence.

It is also relevant to consider the physical location of the research team in the university. This was seen to offer support for the researchers within an existing research culture but at times did create challenges in responding to systems and processes. Again it was important to draw a clear boundary around the team in order that they could remain focused on their primary task, assisted by the fact that the research team were not in fact employed by the university, but by another research partner.

Working on the edge

In many respects a study such as this could be understood as working on the edge or boundary of various systems whilst working to maintain a clear set of boundaries around the research itself. This can be seen in relation to mainstream research expectations and systems as well as wider institutional priorities.

In relation to ethical issues, the study received approval from the local authority and the University Ethics Committee. Others (Smith & Bailey, 2010) have found that involving service users and carers can raise a number of questions concerning the role of the co-researchers and the need to assess the capacity of the participants. A joint statement from Involve and the NHS National Patient Safety Agency (2009) emphasises that user and carer involvement in research design, data analysis and dissemination does not usually raise any particular ethical issues for those involved, however direct contact with participants, such as being involved in interviewing requires that attention to the well-being of both interviewers and those being interviewed. In particular it recommends that appropriate training and support is offered to service user researchers and that there are no additional risks for interviewees.

For this study, it was agreed that ethical approval required a clear statement regarding the need to assess the capacity of potential research participants to give consent to be interviewed. In line with the Mental Capacity Act Code of Practice (Department of Constitutional Affairs, 2005) there was an assumption of capacity amongst potential participants who were provided with accessible information, both written and verbal, regarding the evaluation in order for them to make an informed decision, with the option of support from a support worker, family carer or advocate. It was also agreed that any situation requiring an assessment of capacity would be the responsibility of the researchers, rather than the co-researchers.

Following training, it was agreed that those co-researchers who chose to take on the interviewing role would always work in pairs in order to provide support for one another. Interviews were pre-arranged so that the whereabouts of the interviewers was known. Additionally the researchers were available as back up in the event of any unforeseen difficulties or to discuss any concerns that the interview might have raised. For those being interviewed, there was the opportunity to invite a friend or support worker to be present. Interviews took place during the day in accommodation where staff were on call and other tenants nearby.

Undertaking Criminal Record Bureau (CRB) checks for service user and carer researchers in order that they could be involved in interviewing participants also presented challenges (Repper et al, 2007). Some co-researchers lacked the required documentation and the suggestion that this could be overcome by going to the police station for finger-printing by the police was not seen as acceptable by the group, limiting the involvement of one potential interviewer to other activities.

It is also relevant to consider the risks involved for the co-researchers in taking part. Several were anxious that their benefits might be stopped, despite the information and checks that had taken place to ensure that their payments fell within the range of what was acceptable in terms of benefits and tax etc. There was also the question of supporting co-researchers to develop skills and confidence during the evaluation , only for them to be left without meaningful activity at the end of the study. This required advance preparation and anticipatory discussion as well as the availability of appropriate advice and guidance well before the end of the study.

For the researchers, a study of this kind is frequently located on the margins of what is seen to be acceptable academic research. Kassam and Tettey (2003) question the way in which traditional research paradigms devalue the importance of community-based research and may disregard the time and resources required to work in collaboration with community partners and organisations. They propose that universities become ‘responsible institutional citizens based on an ethos of social justice’(2003:70). Similarly, Mayo et al (2009:134) advocate the creation of research partnerships based on reflexivity, commitment, trust, respect, flexibility, patience and the recognition of processes.

Lessons

It may be helpful here to summarise some of the key areas of learning from this work that may be relevant for others embarking on participatory partnership research.

One of the most important considerations, often in short supply, is simply that of *time*. It is relevant to note that the time involved between the successful award of funding and the first appointment of the co-researchers was well over a year. This included time to make contact and build trust with users and carers before the recruitment process began. The success of this strategy is demonstrated by the successful retention of eight out of the ten co-researchers and the recognition that of the other two, there were reasons outside of the research that caused their withdrawal.

Time is also evident in the relationships built up with the staff of the services. This did offer challenges initially as some staff groups appeared unwilling to engage although this shifted with persistence and patience and the provision of information about the evaluation. On occasions it was necessary to hold back the pace of the work in order that important relationships could be built, despite the temptation to succumb to the pressure for quick results to meet others’ priorities.

The establishment of *clear contractual relationships* between the partners also provided a robust framework within which the evaluation could take place. This helped to manage any unforeseen problems and forestall any potential difficulties between the partners which could have had serious consequences, for example in terms of the employment of the staff, the sharing and ownership of findings or reporting mechanisms back to the funders.

Creating *an independent position* for the work involved delineating an identity that was unique to the research team and the co-researchers. Without this there was a risk that the work would be overly identified with one or another of the service provider partners, to the detriment of the outcomes. This was also facilitated by partnership framework and the researchers and co-researchers spending time to give the project its own name and identity. This was used on promotional material and helped in recruiting and maintaining the involvement of participants.

Conclusion

In conclusion, it is reasonable to ask the question, ‘who calls the tune?’ in a study of this nature. In examining some of the issues involved in this evaluation this paper has drawn attention to some aspects of the complex web of relationships within which this work was embedded. Participation and partnership in research takes time, there are no quick fixes.

With respect to social justice, this evaluation has attempted to maximise the potential for participation and in so doing, has created new possibilities for the co-researchers. In turn their involvement has helped to ensure that the voices of those involved in this service change have been heard and that their experiences are taken into account.

On balance, evidence from the study suggests that many of those involved do indeed feel empowered. For the co-researchers, value has been placed on the development of research skills as well as wider 'employment' skills such as time-keeping and handling confidential information. Additionally, there has been the benefit of financial gain and a wider circle of support and social activities. More broadly the service user participants, are generally positive about their new accommodation and the opportunities for increased social inclusion, whilst also welcoming the chance to feedback concerns where these are present. Whilst these may be small scale and seemingly insignificant changes, it is important not to underestimate their impact on the lives of those involved.

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