

CONSUMER PARTICIPATION IN MENTAL HEALTH RESEARCH

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Abstract

This paper explores the movement of consumer participation in mental health research, and presents the argument that active consumer participation can produce better and more ethical research. The implications of this for social research and possible models of consumer participation in research are discussed. The paper then highlights the impacts of this type of research on policy: that policymakers need to build the requirement for inclusive research practices into new policy, and that policy development needs to be informed by research that is conducted with a substantial degree of consumer participation.

INTRODUCTION

The field of mental health research has a chequered history in which people with a mental illness have been the unsuspecting victims of morally and ethically corrupt practices (Frese 2002). As late as the 1990s research practices have been documented where intentional substantial harm occurred to unwitting participants (Frese 2002). Fortunately, there is a growing emphasis on more inclusive and participatory approaches to research (Beresford 2002).

The catch cry “Nothing about us without us” reflects the growing expectation – both from within the disabled peoples movement and from many other marginalised groups within societies – for service-user involvement at all levels of social service delivery. The pressure for involvement and participation also applies to the practice of social research.

This paper will explore the implementation of consumer¹ participation and involvement within mental health social research. It will do this by briefly examining the principles of consumer participation and by analysing the reasons for its promotion as a necessary aspect of social research. These reasons are very much founded on ethical issues, which this paper will subsequently explore. The movement of consumer participation within social service delivery is challenging and reshaping social research, and the ways in

1 The term “consumer”, often used to mean service user or tangata whaiora, will be used in this paper to describe people who have previously experienced or currently experience mental ill health and who are recipients of mental health services. The term “user” will be applied synonymously.

which this is happening will be evaluated by reviewing a number of different models of consumer participation within research. Finally, the implications of these shifts for policymakers will also be discussed.

CONSUMER PARTICIPATION – THE ONSET AND THE IMPLICATIONS

Consumer participation has become one of the formal principles of social services (Beresford 2000). Over the past few decades a shift in focus has occurred within mental health service delivery away from a paternalist “profession knows best” approach.

Personal narratives and individualised experiences of people with a mental illness have become validated as a result of both changes in political ideology (i.e. policies of de-institutionalisation and community care) and a growing sense of self-identification among consumers. Opposition to the pre-eminence of psychiatric thought and treatment developed as evidence began to emerge of some of the harm and negative influence that this thought and treatment conferred (Frese 2002). This growing awareness and “owned knowledge” is paralleled in post-modernist thought that highlights concepts of difference, subjective realities and a redress of rationalist assumptions about knowledge and universal truths (Croft and Beresford 1998). In addressing and dismantling the meta-narrative that held that persons experiencing mental illness lack the ability to control their lives and require “professional service delivery” (in its myriad forms), service users began to describe and own their knowledge and discourse.

Interestingly, the documentation of this knowledge often escapes the domain of recognised academic literature within the field (Epstein 2002). This knowledge, referred to by Beresford (2000:493) as “hidden users knowledge”, comes in the form of user wisdom, advice and learning. While Beresford (2000) states that this knowledge is becoming ever more available in different forums, it is still essentially devalued by dominant professional discourses as lacking in professional integrity and authority.

The implications of the emergence of consumer participation for consumers, healthcare professionals and policymakers have been far reaching. Mental health services cannot (contractually) design or deliver services without transparent and clear processes that indicate consumers are involved in the planning, implementation and evaluation at every level of the service (Ministry of Health 1997). Thus, services have a new sense of moral obligation (not to mention a legal and contractual framework) to ensure that the person being served is central to the purpose of interventions.

The same implication exists for social research, although some commentators maintain that advances in consumer participation in research have been slower and more laboured compared to service delivery (Champ 2002). Parallel discussions are occurring about the similarities between the pressures that shaped and gave rise to consumer participation

in service delivery and those that are shaping social research (Beresford 2002). Those pressures can be described as reactions to exclusionary practices (and policies), marginalisation, stigmatisation and oppression. A lack of authoritative “voice” for consumers in setting research agendas, or in any aspect of research processes, directly contributes to these aspects of their experience.

A SHARED EXPERIENCE

Many people with experience of mental illness have also experienced social exclusion, marginalisation and a loss of their dignity, freedom, control and civil and human rights (Healy 1996). Other groups in society – such as women, indigenous and minority ethnicities, and people with disabilities – have had similar experiences. In this respect, many of the themes that emerge as requiring ethical redress for mental health consumers are also relevant for other marginalised groups.

The common experience of research for these identified groups parallels their experiences within society. That is, they have not been collaborative partners at any stage of the research process. They have not always experienced control and ownership over the direction of research. Indeed, the disabled peoples movement (on which many of the principles of the mental health consumer participation movement are modelled) is said to have been influenced by the critical social research of the feminist, Black and educationalist writers who have all rejected the traditional research requirements of objectivity, neutrality, distance and an empirical definitive (Beresford 2002).

A consistent argument made among these groups concerns the dilemma of who owns the knowledge from research and what benefit the research offers for those being researched (Beresford 2000, 2002, Cram 2001, Kirkman 2001). Champ (2002) describes this process (the subjugation of knowledge) as the colonisation of the experience of consumers by researchers and states:

Sometimes research amplifies the concern of consumers by giving statistical weight or an edited focus to our concerns ... However, many forms of research often in effect sanitise the message from consumers’ experiences by interpreting or failing to reflect the subtleties of our meanings through the language we use or by failing to capture the power of our stories. This restating of the lived experience of consumers by researchers often recontextualises our experience. (Champ 2002:23)

The immediate implication of this concerns the (more often unintended) continued oppression and stigmatisation of consumers through the reinterpretation of lived experience. Research that neglects to consider this possibility has a high likelihood of perpetuating it.

THE ETHICS OF CONSUMER PARTICIPATION IN MENTAL HEALTH RESEARCH

Ethics in research is initially concerned with ensuring that research is conducted in a manner that both protects and enhances the participants' lives (O'Brien 2001). However, while this is a marked improvement on the previous approaches to mental health research, even this notion is being usurped as a result of challenges to traditional research approaches. That is, due to the gaining of some political power (and research can be viewed as a political activity), consumers are demanding – through advocacy groups, political lobbying, informal networks and holding positions of authority within organisations – that research actively seeks to promote the interests and wellbeing of participants. Research increasingly needs to be accountable to those being researched as being of value to the participants either directly, via increased health or wellbeing, or indirectly, by adding to the knowledge base and understanding of intervention methods.

Research processes and outcomes also need to be relevant to the lives of consumers (White 2002). Consumer participation in research can act as a safeguard to this by promoting research that has a higher likelihood of achieving relevance. Indeed, with consumer participation at the very beginning of research discussions, the subject matter may well have a more beneficial focus. A person with experience of mental illness brings insight and understanding to research decisions. Their lived experience can offer nuance and subtle understanding that enhances the research and that would otherwise be missed. Within my own research initiative, I established a Consumer Advisory Panel, the members of which contributed to decision making about research methods, process and data collection. The members of the panel made decisions about the research methods to be used based on their understanding of the methods that would likely bring about greater companionship and shared learning between participants.

Ethical research ensures that research processes and outcomes are accessible to consumers. Research results are not always disseminated to the people from whom they have arisen (Champ 2002). Findings are published in journals not easily accessible to consumers and written in language that is equally inaccessible. If we consider O'Brien's (2001) view that ethics in research is primarily concerned with enhancing and protecting participants, then excluding participants from the research findings will deny an opportunity of promoting enhancement. Consumer participation provides a means of communicating the outcomes of research and ensuring they are disseminated to the people who are their focus. Consumer strategy or advocacy groups would be made aware of research results via participation in research by various group members, and their networks and connections can spread the findings.

A further challenge to ethical research practice occurs when the definition or understanding of what is "ethical" is questioned. The interpretation of what constitutes

morally right and ethical research is a matter of agreement among members of a particular group at a given time; unsurprisingly, different groups will interpret this in different ways (Babbie 2004). As consumers require a role in defining knowledge and intervention methods, so surely should they be party to defining the parameters of ethical research.

An interesting view prevails, reinforced by the research efforts of Lapsley et al. (2002), that the consumer movement and, more specifically, the collectively voiced “stories” of consumers, have addressed the historical imbalance between consumers and mental health services. Moreover, the collectively voiced stories of consumers have recast the “heroic” role to the consumer rather than to the professional. This thought resonates strongly with me; research that is true to this spirit strikes me as having a strong ethical starting point.

Reactions to past unethical research practices have resulted in the requirement for a competent, voluntary, informed and genuine consent process. This requirement is complicated in the domain of mental health research. Historically, the predominant psychiatric and political discourse within mental health has been concerned with the disability of illness and taken a deficit approach (Rodgers and Pilgrim 1996). Inherent concepts of “incompetence” and “incapacity” were antithetical to developing ethical practices emphasising genuinely informed consent. It is argued by Lapsley et al. (2002:4) that traditionally consumers have been:

... stigmatised, regarded as unreliable sources, and denied a voice in the literature of mental health. Linking mental illness (madness or lunacy) with unreason, excess, incapacity and unreliability are historically entrenched attitudes in Western societies. These attitudes sit alongside the growth of power and expertise in the medical and helping professions which have led to the denial of a voice for clients/consumers in treatments for both physical illness and mental illness.

Although this statement concerns the lack of voice for consumers in respect of treatment, it could directly translate to a lack of voice for consumers in research. While there is a sense of the need for the situation described above by Lapsley et al. (2002) to be redressed (particularly within a research context), others (e.g. Griffiths et al. 2004, Epstein 2002) suggest that this is yet to fully occur.

Coinciding with the consumer participation movement is a strong adoption of the recovery approach² to mental health service delivery, whereby the experience of mental illness becomes highly personalised and focused not on the disabling consequences of mental illness but on the hope of recovery (Carpenter 2002). Indeed, the recovery

2 Recovery is described by the Mental Health Commission (1998:1) as “living well in the presence or absence of mental illness”. Therefore recovery can be viewed as regaining life rather than surviving illness.

approach currently represents a paradigm shift within mental health service delivery (Lapsley et al. 2002) and has a strong ethic of person-centredness and consumer involvement. Moreover, commentators maintain that recovery principles are more compatible with Māori mental health models, as a result of the holistic and balanced view recovery holds of all the factors of an individual's life and environment (Kingi 2002, Lapsley et al. 2002). If we believe that research should be of benefit to participants and emancipatory in its application, then the principles and ethics of recovery incorporated in research methodologies will help to achieve this because of its focus on hope, wellbeing, recovery and validation of the experience of the consumer.

MODELS OF PARTICIPATION

Although consumer involvement in conventional research agendas is in its infancy, evidence suggests that it is fast becoming a widespread and significant development (Beresford 2002). A number of different models have emerged, but no single approach has dominated the literature. An important consideration requiring attention is the role that academic researchers have played in supporting the disability movement and, more specifically, the consumer participation movement. This paper has suggested that more ethical and inclusive approaches to research in mental health have occurred as a result of the increased power of participatory efforts and movements. These movements have a history of advocacy from the academic field – more so within the social sciences than the medical sciences. An important role that academic supporters of the consumer participation movement have had is in publishing positions and views that helped induce change by challenging traditional methods of intervening and theorising, and challenging consumers themselves to be more politically and civically active.

Emancipatory Research

The first model of research participation reinforced by the consumer participation movement that will be explored, emancipatory research, reflects concerns about what research is for. The central purpose to this type of research methodology is to support empowerment of service users and to influence broader social change (Beresford 2002). The three key priorities for emancipatory research concern reciprocity, gain and empowerment. If we cast back to White's (2002) claim that research needs to be relevant to its participants, then emancipatory research achieves this. Within this approach, however, consumer involvement is not viewed as an absolute necessity, but rather as a principle of good research (Beresford 2002). This research paradigm grew originally from the disability field and was strongly advocated and supported by Oliver (1996), who is also a disabled activist and academic. So, while the ambitions of emancipatory research (reciprocity, gain and empowerment) are relevant to the participation movement, the focus on this model is primarily emancipatory and not necessarily participatory.

User-Controlled Research

Whereas emancipatory research emphasises the equalisation of research relationships, the focus of user-controlled research is consumer ownership of all aspects of the research. This includes where it originates, and who makes research and evaluation decisions, carries out the research, disseminates findings, and actions any follow-up from the research (Beresford 2000, 2002). Beresford (2002) explains that user-controlled research is primarily concerned with user participation as active and predominant partners throughout the research process. Consumer participation can be measured on a continuum ranging from user-absent to user-controlled research.

White (2002:443), while discussing a model of user participation in research, presents a challenge to user-controlled research when he says:

Although it is important to seek input from consumers as collaborators in the research process, one should recognise that there is a tension between maintaining research rigor and relevance.

White's claim that attempts at user-controlled research will subjugate rigour is a highly contestable notion, because it makes the assumption that consumers involved in research could not be suitably trained, supported and resourced within a framework that ensures research relevance. As previously argued, consumer participation can increase research relevance and, furthermore, user-controlled research would not risk rigour because there remains an expectation of experienced and knowledgeable researcher involvement. Although elements of control over the research remain with consumers, the tensions highlighted by White could be appropriately addressed with careful consideration of the role and function of the researcher and the role and function of the consumer participants. These roles will obviously vary depending on the research methodology and methods of inquiry.

User or Academic Consumer Research

The final research model concerning consumer participation to be explored here has variously been described as "user research" (Beresford 2002) or "academic consumer research" (Griffiths et al. 2004). So far, the discussions in this paper about consumer involvement in research design and process have concerned the role of non-academic consumers. Griffiths et al. (2004:192) hold that researchers have been "artificially dichotomised" as either "professional researchers" (i.e. individuals with research and/or health qualifications and experience in the field of health research) or "consumer researchers" (i.e. people with little or no formal training and experience in doing research). The possibility of a consumer with an academic background as the researcher is not considered.

There has been little or no evidence in the literature on the benefits of consumers as experienced, professional researchers (Griffiths et al. 2004), although interest within this area is growing and the phenomenon is increasingly occurring (Beresford 2002, Champ 2002). However, not all of the interest is viewing consumer researchers in a positive manner. Indeed, Peter Beresford, Professor of Social Policy at Brunel University, an extremely active social researcher and self-described “long-term user of mental health services”, while promoting the benefits of user research, contends that there are still accusations of a lack of objectivity and independence (Beresford 2002).

An immediate advantage of the academic consumer-researcher is apparent in its ready application to well-entrenched research practices. Researchers have not universally welcomed consumer participation and evidence suggests that some of the same problems facing consumer participation in service delivery also confront consumer participation in research (Griffiths et al. 2004, Champ 2002), such as less than equitable relationships, tokenism and no real authority or power. When research is conducted by consumers with a solid research background, they are a full partner in the research process, they have access to funding mechanisms and dissemination methods, they are in positions to influence research policy and funding, and, perhaps most importantly, they are in a position to increase participation from other consumers as participants or co-researchers. The “insider” consumer researcher is not subject to many of the challenges facing “outsider” researchers.

EVIDENCE-BASED PRACTICE, RESEARCH AND POLICY FORMULATION

Within the domain of health service delivery there is an increasing emphasis placed on evidence-based practice and policy, both locally and nationally (Lunt and Davison 2002), although it has been a concept that has existed for some time (Nutley et al. 2003). Commentators are beginning to question not simply which evidence is stronger, but also question the epistemological status of the evidence (Thorncroft and Rose 2005). This has direct application to consumer participation in research, because the source of evidence will have greater integrity if it has had significant contribution from those whom the evidence concerns.

Well-designed social policies intending to improve the social, economic and civil wellbeing of consumers require solid evidence based on the experiences of consumers, and this paper argues that consumer involvement in research is particularly effective in eliciting the true and lived experiences of consumers. Thus increased consumer input into research practices and methods, and consumer participation at all levels in social research, should be seen as essential to effective evidence-based practice.

A further benefit of consumer activism and participation in research (not touched on previously in this paper) occurs via the collaborations of researchers and consumers

creating a substantially stronger polity lobbying for research funds and grants (Champ 2002). In the ever-increasingly competitive domain of funded research, this edge could prove significant for research entities.

SOCIAL POLICY IMPLICATIONS

Consumer participation has a number of implications for policymakers, primarily for their role in directing and determining “best practice”. Policymakers have prescribed policies and standards that enhance consumer participation in service delivery; for example, in the *National Mental Health Standards* (Ministry of Health 1997). The standards did not apply these policies to the domain of research within mental health, but they did make passing reference to consumers “endorsing” all research involving consumers, albeit without explaining how endorsement could occur. Nevertheless, the policies and standards prescribed for consumer participation in service delivery can be applied to the field of research.

In 1999 the Mental Health Commission produced a discussion document concerning ethical research with mental health consumers (Peterson 1999). This document called for consumer involvement in different stages of research and highlighted the potential benefits of such involvement, particularly from a quality perspective. The purpose of the paper was “to promote discussion about and to encourage non-discriminatory, ethical research in mental health” (Peterson 1999:3), and for this it performs an admirable job. What is needed now is for policymakers to quickly rectify the absence of consumer participation requirements for research within mental health.

Policymakers can lend influence in other ways also. They should, for instance, lead by example. Research conducted by social policy agencies (central and local government and non-government alike) should enhance consumer participation in all aspects of research activity. Effective policies are based on effective research and, as discussed earlier, research is made more effective by the inclusion of consumers in its design, implementation and reporting. Thus, policymakers should pursue policies based on research conducted with consumer participation.

Current policy promotes initiatives that augment and enhance social inclusion. Immediate examples include *The Social Development Approach* (Ministry of Social Policy 2001) and *The Draft 2nd National Mental Health and Addictions Plan* (Ministry of Health 2005). Influenced by communitarianism and third-way political ideology, policymakers are promoting movements towards community enhancement with the goal of a fully inclusive society. Communitarian thought is concerned with developing more socially and politically inclusive forms of community while also protecting citizens from authoritarian and intrusive rule (Tam 1998). Third-way political thought draws on the

idea of the emergence of a new social democracy characterised by socially responsible and active citizens, confidently acting in their best interests and participating within the community (Kemshall 2002). Consumer participation in research, in its principles and its benefits, is congruent with both of these traditions and would fit comfortably as prescribed policy.

PRACTICAL IMPLICATIONS

Consumer participation in research has a number of practical benefits and implications, as discussed throughout this paper. In summary, these are as follows.

- Research relevancy and benefits to participants is increased by adopting an approach to consumer participation.
- With training, consumers can be researchers and valuable contributors to the research process.
- Dissemination of research outcomes is made more accessible to participants thereby increasing the ethical value of the research.
- Mental health policies are better informed by evidenced-based research as a result of consumer participation in the research.
- Policy can encourage the use of consumer participation in research and can safeguard against tokenistic participation by establishing ethical standards and approaches.

CONCLUSION

This paper has presented a number of approaches to consumer participation in the practice of social research. The argument is made that traditional research approaches are enhanced by consumer participation and that the wellbeing of research participants (and indeed non-participant consumers) can be similarly enhanced.

Social research practices within the field of mental health, for all of the variation in the means by which it is constructed, completed and shared, is increasingly being influenced by the movement and theory of consumer participation. This influence has a direct positive impact on the quality of policymaking. It also indicates the need for policymakers to be more vigilant in prescribing means to enable consumer participation in research conducted by both policymakers themselves and other research entities.

While consumer participation in research is still a relatively new practice, this paper has presented the positive impact that it could have on policy, and in so doing has identified the writer's beliefs in the value of active and inclusive consumer participation to ethical research. The value resides in the empowerment of a marginalised populace as it gains self-determination over a critical aspect of its identity – knowledge.

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