Article

Participatory Action Research, Mental Health Service User Research, and the Hearing (our) Voices Projects

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Abstract

In this article I discuss participatory action research as a framework for enabling people diagnosed with mental health problems to carry out research and in doing so to promote health equity, citizenship, and social justice for people with a mental health diagnosis. The participatory approach to research aims to involve ordinary community members in generating practical knowledge about issues and problems of concern to them and through this promoting personal and social change. The article traces the development of participatory action research and describes its application in the mental health service user research movement. The Hearing (our) Voices projects, participatory research projects carried out in Calgary, Alberta by a group of people diagnosed with schizophrenia, are described to illustrate this approach to mental health research. Participation in research to promote health equity is about inclusion and about how marginalized people can claim full and equal citizenship as participants in and contributors to society.

Keywords: Participatory action research; mental health service user research; Hearing (our) Voices; citizenship, schizophrenia.

Introduction

In this article I discuss participatory action research (PAR) as a framework for enabling people diagnosed with mental health problems to take part in carrying out research and in doing so to promote health equity, citizenship, and social justice for people with a mental health diagnosis. In my discussion I refer to an eight-year study carried out by a group of people diagnosed with schizophrenia in which they became co-researchers involved in every aspect of carrying out the research and disseminating the results.

The essence of the participatory approach to research is that it aims to involve ordinary community members in generating practical knowledge about issues and problems of concern to them and through this promoting personal and social change. It has been described as "a democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes" (Reason & Bradbury, 2006, p. 1). This definition embeds several key principles of PAR including a commitment to the participation of ordinary people as co-researchers involved in every aspect of the research; respect for the knowledge of all participants; mutual learning among participants; attention to the needs of marginalized or disempowered groups and people; and action to promote social justice for those marginalized people and others like them. Each account of PAR provides a slightly different take on the history and current state of the practice, something that is probably not surprising given its long and somewhat incoherent history. In addition, each PAR project must find its own way to achieve the goal of finding solutions and promoting social justice for the people involved in that particular project. The subtitle of Greenwood and Levin's (2007) book, *Introduction to Action Research,* offers a succinct summary: PAR is *social research for social change*.

As will become apparent, PAR is a philosophy of engagement in the research process rather than a research method. It does not direct researchers to particular research sites or data gathering strategies. Its proponents work in a range of organizational and community settings and use both quantitative and qualitative approaches. Most important is that projects accomplish the three primary goals of PAR: to produce practical knowledge, to take action to make that knowledge available, and to be transformative both socially and for the individuals who take part. In this article I focus particularly on a small but growing corner of PAR work known as the mental health service user research movement in which people with experience of using services in the mental health system take part as active partners in the research process rather than simply as research subjects. Through this involvement, through actively working to generate knowledge that will improve mental health services and change public perceptions of people with mental health diagnoses, service users can achieve a sense of personal empowerment, promote positive change in mental health treatment and in their own lives, and take their place in society as people with the right and ability to speak about issues that concern them.

Origins of PAR

In this section, I sketch some of the threads and currents that have informed the philosophy and practice of PAR. The history of participatory action research is one of independent and overlapping origins with practitioners in many different disciplines and countries. Current versions of PAR typically draw something from all these origins. The first problem is of course the name: what to call it. Many key works in this area use the term *action research* (e.g., Reason & Bradbury, 2001, 2006, 2008; Greenwood & Levin, 2007). This puts the focus squarely on what these writers consider the most important aspect of this approach, namely taking action through

doing collaborative research and using the results to promote social change. Minkler and Wallerstein (2001) use the term *community based participatory research* to signal the collaboration of community members and researchers working together to solve problems, particularly in the health field. I prefer the term *participatory action research*, because it brings into focus the personal transformation experienced by the people who participate. For me, this approach to knowledge generation is concerned both with changing the lives of individuals and changing the cultures and institutions within which they must live. As Reason and Bradbury (2006) suggest, the primary purpose of participatory action research is to "liberate the human body, mind and spirit in the search for a better, freer world" (p. 2).

Many accounts refer to "northern" and "southern" origins of PAR. The northern thread identifies Kurt Lewin as a founding voice for his work in what came to be known as the industrial democracy tradition. He is generally credited with coining the term *action research* (e.g., Greenwood & Levin, 2007; Wallerstein & Duran, 2001) as a way to describe a practical approach to problem solving through a cycle of planning, action, and reflection. Researchers in this tradition have addressed problems primarily in work place and educational settings on the assumption that managers and workers can work together to create more democratic work places. In fact, this tradition embodies much of what we now take for granted in the organization of work, such as teamwork and collaborative improvement processes.

The southern tradition originates in the work of scholars such as Paulo Freire (1970) and Fals Borda and Rahman (1991). This version of PAR emerged from a Marxist tradition in which the "the important thing is not to understand the world but to change it" (Reason & Bradbury, 2006, p. 3). This openly emancipatory approach sought to empower oppressed peoples to challenge both traditional academic knowledge-making practices and their own political domination. As Reason and Bradbury (2006) state, "Knowledge-making cannot be neutral and disinterested but is a political process in the service of particular purposes" (p. 6). Central to this tradition is Freire's concept of conscientization, in which popular education enables socially dispossessed peoples to come to critical consciousness and challenge the oppressive status quo (1970, p.47).

Reason and Bradbury (2006) identify still other contributors to PAR practice. These include psychotherapy, with its T-group and encounter group training, and experiments in England with experiential learning communities based in humanistic education. These led to the development of a thread of PAR known as cooperative inquiry (Heron & Reason, 2001). Minkler and Wallerstein's (2001) community based participatory research is similar to cooperative inquiry, in that it promotes a two way flow of information within the research group: Researchers provide information and tools to enable community members to carry out research and take action, and community members share their expert knowledge and local meanings with researchers to achieve mutual knowledge and solutions to practical problems. In recent years cross-fertilization has taken place and these traditions have begun to share ideas while still retaining distinctive elements. Wallerstein and Duran (2001) suggest that this work can be seen on a continuum, with the problem-solving action research approach of the Lewinian model on one end, the emancipatory tradition the other, and cooperative, mutual inquiry somewhere in the middle. They also claim that the terms *action research* and *participatory action research* have begun to be used interchangeably, signaling a convergence of values and practices.

PAR and the Mental Health Service User/Survivor Research Movement

In this section I describe how participatory approaches to research have been mobilized in the mental health service user/survivor research movement. Before I do this, I want to interject a note about language used in this field. Although the experiences associated with schizophrenia and

other psychiatric diagnostic categories are now well established as illnesses, there exist a significant academic literature and an activist psychiatric survivor social movement that dispute the existence of the coherent medical entities that mental health diagnoses claim to identify (for an excellent overview of this debate see Pilgrim, 2005). I therefore use the term *people diagnosed with schizophrenia* to acknowledge this perspective but also to acknowledge the reality that this medical diagnostic category dramatically shapes the lives of the people to whom it is applied. I also use the term mental health *service user* rather than *consumer*, as that is the term that predominates in the literature in this area. The term *service user* is still somewhat problematic as it identifies people in terms of their use of mental health services, something they may not regard as their primary identity. Many members of the service user movement prefer to call themselves *survivors*, drawing attention to what they regard as the traumatizing effects of the mental health treatments they have experienced.

The use of PAR to carry out mental health research grows out of the mental health service user/survivor movement that developed in the 1970's, a loose connection of individuals and groups working to achieve choice and self-determination for people with psychiatric diagnoses. It also has links to the disability rights movement of the same period. This movement worked to politicize disability, arguing for a social model of disability that rejects the traditional medical model of individual bodily deficiency and instead asserts that disability is produced by societal attitudes towards impairments, rather than by the impairments themselves. Researchers began to focus on the experiences of social discrimination associated with disability, and influential scholars in the field (e.g., Oliver, 1992; Zarb, 1991) advocated a version of PAR described as emancipatory disability research as a way to change the social relations of disability research, from research carried out "on" people with disabilities to research carried out "with" people with disabilities. Building on the disability rights movement slogan, "Nothing about us without us," researchers strove to carry out research that would promote the rights of disabled people, challenge the oppression they face, and change their lives by changing attitudes, services, policies, and legislation.

The mental health service user/survivor research movement has clear links to emancipatory disability research (Sweeney, 2009) and service user research has grown into an active field, particularly in England. Two recent anthologies (Sweeney et. al., 2009; Wallcraft et al., 2009) have established the legitimacy and value of this kind of research. The social model of disability, however, does not translate easily to the field of mental health. The service user/survivor movement has not been able to successfully challenge the strength and dominance of the medical model of mental "illness," which pathologizes the behaviours and experiences of mental distress as individual deficit and illness (Beresford, 2009). People who come to the attention of the mental health system are assigned to medicalized diagnostic categories, leading to treatments based primarily on drugs. And with the current surge of fear about the "dangerousness" of people with mental health problems, legislation is increasingly focused on restricting rather than extending such people's rights. Despite these challenges, the movement is "committed to empowerment through research participation and output" (Sweeney, 2009, p. 28).

Service user research has established a record going back about 20 years. In England, early initiatives include User Focused Monitoring (UFM) at the Sainsbury Centre for Mental Health in London (Rose, 2003) and Strategies for Living (Faulkner & Layzell, 2001) at the Mental Health Foundation. The goals of these efforts were to represent service users' stories, improve services, and produce high quality research that would challenge traditional knowledge about mental health issues. More recently the Service User Research Enterprise (SURE) (http://www.iop.kcl.ac.uk/departments/?locator=300) at the Institute of Psychiatry at King's College London and Suresearch (http://www.suresearch.org.uk/) at the University of Birmingham

are further developing the service user research enterprise. In the US, service user organizations doing research that will give service users a greater voice and larger role in their treatment include the California Network of Mental Health Clients (Campbell & Schraiber, 1989) and Consumer Quality Initiatives (http://www.cqi-mass.org/) (Delman, 2007). Also in the US is a group at Yale University (Davidson et al., 2010) in which service users led a project on how mental health care can be more effective in helping them to rebuild their lives. In Canada, the Bridge to Discharge project (Forchuk, 1998) and the Centre for Community Based Research in Waterloo, ON (http://www.communitybasedresearch.ca) have carried out community based participatory research involving mental health service users (e.g., Nelson, 2010; Ochocka, et al., 2002).

A key area of discussion in mental health service user research is the way in which people with mental health diagnoses are included in research. One of the tenets of the community based participatory research approach as outlined by Minkler and Wallerstein (2001) is the participation of representatives of all interested groups in the community being studied. In a mental health setting this might mean mental health care workers (e.g., psychiatrists and psychiatric nurses), hospital or clinic administrators, mental health service recipients, and professional researchers (e.g., Harris, 2005). In the mental health service user research community, this kind of collaboration is common (e.g., Lowes & Hulatt, 2005), but academic service user researchers, those who have PhD's and now work in academic or clinical settings, also advocate for research carried out without the involvement of professionals or others who do not have a mental health diagnosis. Sweeney (2009) for example, makes a clear distinction between service user research and service user involvement in research. In the former, service users control every aspect of the research; in the latter, they are involved in research in which non-service users retain much of the control.

Writers in this area (e.g., Faulkner, 2004; Happell & Roper, 2007; Rose, 2003; Sweeney & Morgan, 2009) identify a continuum of service user roles in research: consultation, contribution, collaboration, and control. In the consultation role, service users may be invited to be part of an advisory board in which their role is to represent the "stakeholder group" of service users. They are usually outnumbered by health professionals and other interest groups and have minimal involvement in the design and conduct of the research. They may also be regarded as having knowledge or skills that are of value to the research project—they might be asked to help with designing a survey, for example—but control of all aspects of the research is retained by the professional researchers. Contribution describes situations in which service users make significant contributions to the research, such as being employed as part of a larger research team, but decision making about the project still rests with professional researchers. Collaboration describes a situation in which service users collaborate with professional researchers on all aspects of the research, including topic selection, identification of the research question, design of the study, gathering and analysis of data, and dissemination of the findings. The final category, service user controlled research, is research that is initiated, directed, and led by service users. Professional non-service user researchers may be involved, but at the request of the service user researchers rather than as directors of the research. Even with the best of intentions, issues of power loom large when both service users and non-service users are involved (and likely also when only service users are involved). Turner and Beresford (2005) found that service users themselves were cautious about collaboration, as it can be a challenge for ordinary service users to establish a real working partnership of equals when mental health professionals, people who typically have power over them, are involved. Service users were wary of tokenism or being used to give the appearance of service user involvement.

The Hearing (our) Voices Projects

To illustrate how participatory research can be successfully carried out by mental health service users, I now describe the Hearing (our) Voices projects (Schneider, 2010; Schneider et al., 2004). These consisted of two projects carried out in Calgary, Alberta, Canada by a group of people diagnosed with schizophrenia. The first project investigated the interactions of people diagnosed with schizophrenia with their medical professionals, and the second, housing for people diagnosed with schizophrenia. Our projects took place over an eight-year period from 2001-2009. Because of my involvement, it was collaborative rather than user-controlled research. In both projects, however, the co-researchers had a significant degree of control over every aspect of the research. They chose the topics, designed the research, carried out the data gathering, took part in data analysis, and were involved in dissemination. Although we are no longer actively engaged in research, activities from the projects are still ongoing, as members from the research group regularly present their results when requested to by groups in the community.

In the first project, I initiated the research. I had seen a call for grant proposals for participatory projects involving people with disabilities. I had no experience of participatory research, but nevertheless approached the local Schizophrenia Society to see if any of their members would be interested in taking part in a participatory project that would investigate a topic of interest to them. I met with members of the Unsung Heroes, a support group for people diagnosed with schizophrenia. We worked together to write a proposal, and we received a small grant from the Canadian Centre on Disability Studies. We began work in the fall of 2001. None of us really had an understanding of what participatory research would require of us or of what it would bring us in return. But as we worked together for a year on the research itself, and then for another year doing presentations about the research, we became a cohesive and supportive group of co-researchers engaged in something we all thought was important and worth doing.

After this experience the group members no longer thought of themselves as people upon whom others carried out research, but as people who could themselves carry out research. They saw that they could make a significant contribution to changing not only how people diagnosed with schizophrenia are treated in the medical system but also to changing larger societal attitudes about schizophrenia. They wanted to do another project, this time on housing for people diagnosed with schizophrenia, something that was of great concern to them because of their own experiences and the experiences of their friends and colleagues. This project was funded by a series of grants from the Social Sciences and Humanities Research Council of Canada and Human Resources and Social Development Canada, and lasted five years. With this generous support, we accomplished things we could never have imagined when we started the first project.

Seven people took part in the first project. We met for an hour twice a month right before the Unsung Heroes support group meetings on Thursday evenings. We began by brainstorming a number of topics for the research and finally settled on one that everyone could get excited about: their interactions with medical professionals. They had a strong sense that they were treated differently than patients with other illnesses and wanted to do something to change this. We then discussed how to do the research. They had experience only with survey research, but when presented with the idea of open-ended interviews in which they could talk directly to their colleagues about their experiences, they decided to take this approach. We generated a list of interview questions and began interviewing within the group. We used the first interviews not only to generate data but also to train ourselves in how to conduct good interviews. Group members then invited some of their colleagues from the Unsung Heroes to be interviewed. In all we conducted eleven interviews. All were transcribed by a professional transcriber.

Group members found the data analysis stage to be very challenging. At this point I hired a graduate student to help with coding and analyzing the data, based on the categories generated by the group members in our discussions: good experiences, bad experiences, medication, support, and diagnosis. Her analysis resonated with the group members, and after much discussion and a few suggested changes we adopted the scheme she had come up with as a good way to represent the interviewees' experiences. The group then developed recommendations for their medical service providers.

The second project was much more ambitious. Eight people were involved, four of whom had been involved in the first project. As these four had the experience of the first project under their belts, they were much more confident and wanted to do focus groups as well as interviews with people in the community. We again had training sessions for interviewing and this time for focus groups as well. We interviewed twelve people and conducted focus groups with another sixteen people. Group members considered the focus groups to be the highlight of this part of the project, because they felt they were talking to people who cared deeply about the same issues as they did.

I again hired a graduate student to help with coding, and we developed a model of housing stability based on her work and our group discussions. In our discussions, we also developed the main theme of this project: the tension between care and control in all their interactions with their housing and medical service providers. People diagnosed with schizophrenia are caught between their dependence on care and their longing for independent lives. Professionals and family members who help and care for them have a desire to help them, but also have authority and power over them. A relationship intended to be positive, enabling, and empowering is at the same time controlling and disempowering. People diagnosed with schizophrenia want and need care and support from mental health professionals, family members, government agencies, and housing and other social service providers to maintain stability in their lives. But they also want freedom from the paternalistic control that accompanies care, with the ability to make their own choices about medical treatments and how they will live. Involvement in decision making about all aspects of their treatment and housing, achieved through good communication between people diagnosed with schizophrenia and their medical and housing service providers, is essential to achieving a balance between care and control.

In our dissemination activities, we used a range of communication strategies that do not fit neatly into traditional modes for disseminating academic research. Many service user projects create reports that can be found on agency websites such as those mentioned above, and some produce articles that find their way into scholarly journals. These are typically written by the most able service user researchers or by the professionals involved with them (e.g., Davidson, 2010). We did not want our work to disappear into reports and journals never to be seen by any but a scholarly audience. We had two goals in choosing our dissemination activities: involving in dissemination every member of our group who wanted to be involved, and reaching as wide an audience as possible. We started with readers' theatre performances. Readers' theatre is a minimalist style of theatre with no sets, staging, or costumes, in which scripts are used openly in performance. We then made a documentary film about the projects, created a graphic novel version of the material, and turned the graphic novel into an exhibit that travelled across Canada. (See our website to access all these materials: http://callhome.ucalgary.ca). We also travelled the traditional academic route and wrote a scholarly article about our first project (Schneider et al., 2004), a book about both projects (Schneider, 2010), as well as this article. These last were written by me, with input and feedback from group members at several stages of the writing.

In both projects, we used our interview data as a basis for creating the readers' theatre performances. Group members chose excerpts from the interviews that they felt conveyed the

most important aspects of interviewee's experiences. We organized these excerpts around the analytic scheme the group had developed for each project. In the second project, we also made a DVD based on interviews with the group members and excerpts from the readers' theatre performance. We presented our performances and our DVD numerous times in Calgary, across Canada, and internationally. These occasions were challenging for the group members, but also extremely rewarding as they had the opportunity to speak in health centres in which they themselves had been or were being treated, and to feel that their work could make a difference in how others like themselves will be treated in the future. At one performance, a doctor who had seen us at a previous performance told us that he interacts with his patients differently as a result of hearing group members speak. At another, a doctor told the group that he never sees his patients when they are well, only when they are in distress. It was something of a revelation to him to hear group members speak so eloquently and poignantly about their experiences.

Perhaps the most important aspect of our dissemination activities is that they gave the group members the opportunity to say things that as individuals they would likely never have the opportunity to say. People with a diagnosis of schizophrenia are typically constrained from saying anything negative by their need for services and by the expectation that they will be grateful for services. Presenting in a group setting enabled them to speak much more freely about all aspects of their treatment experiences. In fact, it was these opportunities to speak publicly that offered the group members the most transformative moments in the projects. While the research activities were rewarding for everyone, having the opportunity to speak directly to service providers as well as to a more general audience allowed even the most shy group members to become public speakers, well able to come to the microphone to answer audience questions, elaborate on their perspectives, and to feel themselves full participants in public discourse about mental health issues.

Here is a brief excerpt from the journal of one of the group members that illustrates what taking part in dissemination activities meant to them. This was written after our very first presentation at the Edmonton Schizophrenia Conference in 2002.

> This was quite an experience for our group. We were all very nervous. We did our presentation twice in one day. The conference was large; the audience was all people interested in schizophrenia. There were medical professionals, representatives from drug companies, family members, researchers, and on and on. We presented in the latter half of the day in workshop type format. After we did our presentation and recommendations, we broke the audience up into smaller groups. We then went into the audience and talked with them. For me the whole experience was very empowering, as it put me on a level playing field with persons who oftentimes had power over me. I felt heard where it might make a difference some day in the treatment of people suffering from schizophrenia. To top it all off the experience was fun, with the group all traveling together in a rented van with Dr. Barbara Schneider driving. We stayed the night in a very classy hotel and met people from all walks of life.

Discussion

I turn now to a discussion of two central issues in service user research, ethical concerns and the question of validity. As researchers are reminded every time we apply to a research ethics board for permission to conduct research, ethical issues have to do with the engagement of the professional researcher with what are usually called the subjects of the research. In the case of

participatory research, in addition to the standard issues of anonymity, confidentiality, and informed consent, a pressing ethical issue is the management of power relations within the research group. This issue plays a role in the conduct of the research—the choice of topic, research method, and dissemination strategies—and perhaps even more importantly in the long-term engagement of the co-researchers in the project. Certainly I have found power relations to be the most challenging aspect of my involvement in service user research. I am a professional university researcher and do not identify myself as a mental health service user. The people I worked with were ordinary mental health service users with no experience of doing research, although much experience of being subjects of research. I strove throughout our projects to establish an environment for meaningful participation for the members of the research group and to relinquish power in appropriate ways. But this was a delicate balancing act, as one cannot simply "give" people power; they must also be ready and willing to take it up. As we worked together over many years, group members became confident in their abilities as researchers able to make decisions about all aspects of the research, and I in turn was able to let go of control and follow their lead. This was a process that evolved over many years, demonstrating that power is a constantly shifting resource requiring attention not just at the beginning of projects but throughout, as relationships develop and change.

Additional ethical issues include the management of grant money (if the project is lucky enough to have some) and ownership of the data. Ownership of data can be somewhat tricky, as research ethics boards typically want assurances about how data will be stored and used. This is fairly straightforward in projects in which the professional researcher controls all aspects of the research. In such projects it is taken for granted that the researcher is the owner of the data with all rights to its use and responsibility for its appropriate storage. In PAR projects, community co-researchers and the agencies they represent, if any, are also legitimate owners of the data, with equal rights to its use and dissemination. This may require careful negotiation with both research ethics boards and community agencies to assure that data will indeed be stored and used appropriately. In addition, there are questions about whether the professional researcher should be able to use the data for his or her own purposes, for example, in articles or presentations for which the community members do not participate in the analysis and writing, particularly if they express a point of view not shared by the community group members. As with power relations, these are issues that must be negotiated in an ongoing way within each research group even after the project officially ends.

Granting agencies typically award research money to researchers with academic credentials and positions. In our case, the grants were awarded to me, the professional researcher, both because of the kind of research we were proposing, but perhaps more importantly because of my track record of previous grants and publications. If our projects had been truly user-controlled, the agencies would have awarded the money to the group, and group members would have had control over how the money was spent. Instead the money remained under my control, and although we discussed on frequent occasions how money would be spent, I also made decisions without consulting the group. If agencies see the value of including service recipients in research, they may want to reconsider how some grants are awarded, perhaps including service users on adjudication committees and awarding grants to groups that do not have academic institutional affiliations.

Validity is also a key issue in participatory research. Participatory research stands in sharp contrast to traditional social research approaches, whether quantitative or qualitative, in which the professional researcher gathers information from research subjects and turns that information into knowledge. The involvement of non-expert researchers in PAR therefore raises questions about whether knowledge produced by ordinary people can be regarded as valid. The central question is

"whose knowledge counts?" A traditional quantitative approach to research, which dominates in the field of mental health research, prescribes in detail the procedures that must be followed to produce knowledge that will be regarded as reliable and valid, free of contamination and bias. Participatory researchers on the other hand believe that all researchers, quantitative or otherwise, come to their research with values and perspectives and that these inevitably shape the research. They believe that involving people with direct experience of the problem being studied offers a way to improve the quality and relevance of research (e.g., Davidson, et al., 2009) and that individual experience is a valid and important source of knowledge. They promote the use of the terms "values based" (Fulford & Wallcraft, 2009) and "knowledge based" (Beresford, 2006) rather than "evidence based" policy and practice.

Just as qualitative researchers (e.g., Lincoln, 1995; Richardson, 2000) have responded to challenges about validity from traditional quantitative researchers with criteria for assessing quality and validity in qualitative research, PAR researchers (e.g., Anderson & Hall, 1999; Bradbury & Reason, 2001) have responded with criteria for assessing quality and validity in participatory research. Bradbury and Reason (2001) propose a series of six questions to guide assessment of PAR projects: Is there relational participation? Is it practically useful? Is it conceptually, theoretically, and methodologically coherent? Does it extend our ways of knowing? Is it significant? Does it lead to new or changed social practices?

I claim no privileged access to truth for our projects, as all knowledge must be regarded as perspectival. But I believe that we produced valid knowledge that likely could not have been produced in any other way. We met all of Bradbury and Reason's criteria, involving service users in meaningful ways and using a coherent theoretical and methodological approach in the generation of significant new practical knowledge that has already led to changes in practice. Involving people with experience of the problem being studied ensured that the focus remained on the issues that were relevant to them, not just issues thought relevant by service providers or professional researchers. The involvement of service user interviewers likely improved the quality of our data as the service users we were talking to may have felt more comfortable revealing their experiences to others with similar experiences. And the involvement of group members in the data analysis ensured that the analysis remained true to the perspectives of those being studied. All these criteria may not be relevant in the assessment of every PAR project, but they offer a ground on which to claim validity for participatory research.

Conclusion

The Hearing (our) Voices projects demonstrate the potential of participatory research to draw on the strengths and abilities of people diagnosed with schizophrenia. The projects enabled them to offer significant insights into their own situations and experiences, to identify the kinds of treatment and support that will enable them to rebuild their lives, to contribute to the production of knowledge about schizophrenia, and to advocate for change in how people diagnosed with schizophrenia are treated. Participatory research contests the exclusive right of expert researchers to determine how research problems are defined and studied. It asserts ordinary people as a legitimate and important source of expertise and allows people who have historically had little power to articulate their experiences and determine how they are represented. In taking part in participatory projects, marginalized people have the opportunity to generate knowledge that contributes to promoting health equity and social justice for others like themselves. In the end, participation in research to promote health equity is really about inclusion and about how marginalized people can claim full and equal citizenship as participants and contributors to society. Marginalized people, such as those diagnosed with schizophrenia, may need support to achieve full participation, but it is in providing this support that society holds a mirror to itself

and shows that it values the essential humanity of every member, including marginalized members.

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