Reflection/Commentary on a Past Article: “Participatory Action Research, Mental Health Service User Research, and the Hearing (our) Voices Projects”

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How Did It Fit Into My Career Path?

My article, Participatory Action Research, Mental Health Service User Research, and the Hearing (our) Voices Projects, was the last piece I wrote in a research project that lasted almost 10 years and, during that time, occupied my research life almost to the exclusion of everything else. I started doing research in this area because my older son was diagnosed with schizophrenia in early 2000, at just about the same time as I was offered a tenure track position at my university. As a communication studies scholar, I began researching various aspects of how ideas about mental health circulate in society and are taken up by individuals and groups. Shortly after, I saw a call for proposals for a small grant to carry out participatory research with people having disabilities. This was a completely unknown area for me, but I approached the Unsung Heroes Peer Support Group at the Schizophrenia Society in Calgary, and together we created a winning proposal. Overnight, I became an activist (something that had never been part of my life before that time) supporting the research group members (all of whom had a diagnosis of schizophrenia) to take action to advocate for change in how people diagnosed with schizophrenia are regarded and treated in the mental health system.

As we worked together, we came up against many challenges as we learned how to do participatory research (and I unlearned how to do traditional research), but we also reaped many rewards. We all became activists and published our work in various forms, particularly forms that would be accessible to other people with a diagnosis of schizophrenia, their mental health-care providers, and a wider general audience. These included many readers theater performances all across Canada, a documentary film, an illustrated poster book, a traveling exhibit that was shown across Canada, and finally at the end a book. The aim of the book was to share the findings from our work and to provide a roadmap and guidance to others wanting to do participatory mental health service user research. But colleagues kept asking me whether there was an article-length version of the project, and when I saw the call from the International Journal of Qualitative Methods for a special issue on health equity, it seemed the perfect venue. I wrote something that was more focused on the methodological aspects of the projects, appropriate for *IJQM*, which allowed me to think more in depth about various aspects of participatory research. This update has again given me a moment to reflect on this approach to research and I am grateful to the journal for both of these opportunities.

How Did It Impact My Work?

The article came, as I said, at the very end of the Hearing (our) Voices projects and closed off a section of my career. However, I can say that the work I did leading to this article is undoubtedly the most important work I did in my academic career, the work that had the most direct impact on individuals, particularly the people who were involved. During the time they worked on the projects, the participants felt they were doing important work for themselves and others like them, especially when they had opportunities to present and talk directly to mental health professionals and caregivers. This is something that they would have had almost no possibility to do as individuals, but as members of a group, framed by a research context, they all became public speakers and advocates able to clearly articulate their concerns and ideas for change.

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It also had a wonderful side benefit to me of making my career as an academic in a way that was not likely to have happened with my previous more traditional topics and methods. I received invitations for keynote speeches, gained an international reputation, and was promoted to full professor. I worked with my participants for about 10 years when all was said and done, but then I needed a life that was not focused so directly on schizophrenia, and although they were keen to do another project on workplace experiences, I could no longer sustain the intensity. I had met with them every 2 weeks (with short breaks) for 8 years, had devoted much of my research life and some of my social life to the projects, and had come to terms with schizophrenia in my own life. I gradually withdrew from the realm of participatory research.

How Did It Impact the Field?

Participatory research approaches, in all their many guises, are now well accepted across many disciplines. My article has been cited by people doing research with exited sex workers, graduate students, people with dementia, impoverished asylum seekers, people with a diagnosis of bipolar disorder, young people with mental health issues, and people transitioning to supported housing settings, among others. Perhaps most gratifyingly, some of these citations come from scholars I met at conferences who were not yet doing participatory work and were inspired by my projects. Nevertheless, it remains a comparatively marginal approach to research, and, as these articles demonstrate, the struggle for health equity and social justice more generally is ongoing.

When I began research in the area of mental health service user research, there were not many others doing this work. Now, more and more people are engaged in projects of this kind, particularly projects led by or involving service users themselves as equal partners. There is now more awareness among professional researchers that the research should attend to the questions and concerns of the participants and not to the concerns of the professional researchers. This can be very challenging for professional researchers, as we typically have ideas about what we want to study and use these ideas to sell projects to funders. In addition, there is more awareness that participants should be involved in every aspect of the research, not just, for example, in designing questions for a survey or in gathering interview data. These are very common strategies in participatory research, but without participant involvement in project conceptualization and data analysis, it is very easy for the concerns of the participants to move into the background.

Were There Any Surprises That Came From This Publication?

A surprise for me is that although we were extremely engaged in the projects, I am not sure that was there any long-term impact from our work, on the individuals involved, on mental health service provision, or on larger structural issues in society. As I said in the article, I believe that participatory research has (or should have) three goals: “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” (p. 153). Without a doubt, we accomplished the first two goals. We produced knowledge related to the experiences of the participants and took many kinds of action to make the knowledge available. And during the time we worked on the projects, the lives of the people who took part were changed in positive ways. But as soon as the projects stopped, their lives went back to being pretty much as they had been before. It is a source of enduring sadness for me that they were unable to transfer a level of engagement and commitment to other aspects of their lives once they were on their own. As soon as the structure and supports of the projects disappeared so did the benefits of taking part. On the rare occasions that I see participants, it seems to me that although they have fond memories of the projects, any personal transformation that might have taken place during the time we were together has disappeared from their lives. Over a 10-year period, they were deeply engaged in a meaningful endeavor, they developed public-speaking skills, and they were members of a supportive and stimulating research community that may well have contributed to change in how their mental health professionals (at least the ones who saw our presentations) interact with them.

What Is the One Thing That You Think Has Changed the Most in This Area Since You Published This Manuscript?

I would like to be able to report that as a result of our research, changes occurred in mental health service provision and more widely in attitudes toward people with a diagnosis of schizophrenia in the society. But I am doubtful, and I think this is related to the fact that without me, the participants were unable to continue to be advocates and activists. Recently, I had an opportunity to talk about the projects as a guest lecturer in a communication and health course taught by one of my colleagues. The students came into the class with all the old stereotypes about people with a diagnosis of schizophrenia as dangerous, cognitively challenged, and deserving of their marginalization in the society. After they heard about the accomplishments of the participants and saw them speaking in the documentary film, their attitudes changed dramatically, demonstrating that it is possible to produce change, one person at a time, even if it is slow, earthwork work, to paraphrase Ursula Franklin. The message for me was that those who want change cannot let up on their advocacy work for a moment. One-off projects that are completed in a short time (e.g., photo voice projects) or even, it turns out, those like mine that last a relatively long time have an impact at the time they are carried out, but without continuing follow-up work will likely not have lasting impact.

Perhaps I am asking too much of participatory research. Perhaps it is hopelessly optimistic to think that the small inroads that any one effort can make will have truly deep systemic impacts. Participatory research begins with an explicitly political agenda to promote social change to improve the
lives of marginalized peoples. As is the case with my partici-
pants, this advocacy must come from within marginalized com-
munities. But members of these communities are dealing with
many life challenges, such as poverty and mental health issues,
which impede their ability to sustain activist activities, leaving
structures that promote inequity unchanged. Meanwhile, the
professional researchers return to their comfortable academic
lives, much as I did, engaged with schizophrenia now only as
the parent of someone with this diagnosis. Nevertheless, it
seems to me that because of these explicitly political intentions,
participatory approaches, done carefully and with the fullest
possible participation of community members, still offer
researchers better possibilities than traditional approaches for
addressing health and other social inequalities.

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