

PARTICIPATORY ACTION RESEARCH WITH PEOPLE WITH DISABILITIES:
EXPLORING EXPERIENCES OF PARTICIPATION

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If you come here to help me, you're wasting your time. If you come because your liberation is bound up with mine, then let us work together.

Lilla Watson,
Australian Aborigine Organiser

When we realize our shared oppression is our common ground, we suddenly become something much bigger.
Same struggle, different difference.

Dan Wilkins,
The Nth Degree

ABSTRACT

The social model of disability requires that research about disability should be controlled and managed by people with disabilities themselves. Traditional research has tended to marginalise people with disabilities, and the outcomes have been meaningless and irrelevant to them. Three years ago I approached a small disability advocacy organisation, and through six months of collaboration with Disability Justice Advocacy (DJA), the need for a strategic plan was identified.

Developing a strategic plan for DJA became a vehicle for exploring the primary aim of my research, which was to conduct participatory action research with people with disabilities, and to examine its value as an empowering research practice. The literature indicates that while participation, and participatory action research in particular, has the potential to empower people with disabilities, it can also serve to disempower them. This study draws on the experiences of participation in this process, both from the perspective of the participants (six board and six staff members) and myself, as the researcher.

Thematic analysis of the interview data identified barriers to participation at different levels of intervention. At an intrapersonal level, competence of people with disabilities emerged as a critical issue for DJA. This issue resonated with my own experience of the process and, through ongoing critical reflexivity, revealed that underlying ableist attitudes (i.e. attitudes based on non-disabled standards) reinforce the ongoing victimisation and oppression experienced by people with disabilities. This study builds on current knowledge regarding the role and tensions of a community psychologist working with a social justice agenda with people with disabilities.

STUDENT DECLARATION

I, Harriet Radermacher, declare that the Doctorate of Applied Psychology (Community and Health) thesis entitled *Participatory action research with people with disabilities: Exploring experiences of participation* is no more than 40,000 words in length, exclusive of tables, figures, appendices, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signature: _____ Date: _____

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PREAMBLE: A JOURNEY

I sat in Fitzroy Library early in 2003, scanning the disability section in the local service directory. The directory provides a listing of all the disability services across Melbourne, their contact details, and a brief summary of their main activities. I hadn't yet started my Masters in Applied Psychology (which I later converted to a Doctorate), but in anticipation of the requirement to carry out my own research, I had decided to do some preliminary investigations. Disability Justice Advocacy (DJA) caught my eye like a neon sign. For as well as being local and disability-focused most importantly, it also claimed to be 'consumer-led'. DJA appeared to imbue practices and values inherent in a social model approach to disability, and hence, in my view, hope for a better life for people with disabilities. I wrote an email to DJA explaining that I was interested in the work of their organisation and that I had an opportunity to do some research. This thesis tells my story of the journey from that very first email through to the completion of this thesis, three years later.

A NOTE ABOUT TERMINOLOGY

For the purpose of this thesis, when I refer to ‘disability’, I am talking about the ways in which the social world does not accommodate for people with impairments, and hence, the environment disables them. It is also appropriate to clarify my use of the term ‘people with disabilities’. The reason given for using the term ‘people with disabilities’, particularly in Australia and the United States is that it places the person first, before the disability. However, advocates of the social model of disability in the United Kingdom, for example, prefer to differentiate and separate the terms disability and impairment. The term ‘disabled people’ is used due to the belief that the disabling experience of living with an impairment is very much a part of an individual’s identity and it cannot be removed from the experience of that person.

A closer look at the semantics offers further insight. The term ‘people with disabilities’ presents disability as a noun, suggesting that it is tangible, while the term ‘disabled people’ presents it as a verb, emphasising that it is a process that occurs. While I agree with the justification for using the term ‘disabled people’, I have chosen to conform to convention in Australia. This is despite the personal tensions, arising from the nature of semantics, which I experienced in doing so.