

The Perspectives of People with Dementia: Research Methods and Motivations
Wilkinson, H. (ed.) (2002) Jessica Kingsley, £15.95, paperback, 256pp.

This book breaks new ground in bringing together a range of well respected researchers, who have experience in research with people with dementia. It is long overdue and challenges the fundamental myths that continue to prevail - that is, the misguided beliefs that people with dementia are unable to participate in research and, furthermore, that they are incapable of contributing in a meaningful way.

The book is broken down into three sections: Ethical and Practical Issues of Involvement, The Views of People with Dementia, and finally Methods and Motivations. Each chapter within these sections describes the authors' experience in carrying out and evaluating research they have completed or participated in. As such it is a valuable resource for both seasoned and new researchers in health and social care. In Chapter 1, Heather Wilkinson provides a detailed and powerful argument for ensuring that people with dementia are central to any research process which seeks to understand more about this difficult and disabling condition. She presents a clear analysis of the need to shift the power inequalities present in relationships between people with dementia and others and, in addition, to develop understanding of the experience of people with dementia themselves. Finally, she discusses the means through which people with dementia can be involved in research. This forms the basis for subsequent chapters, which provide both a theoretical and practical exposition of the factors that should be considered if we are to effectively engage people with dementia. As Clarke and Keady (p.41) state, 'the challenge is with us as researchers to find effective and meaningful ways of engaging with people with dementia in the research situation... an inability to achieve this is to continue to deny ourselves access to the knowledge of people with dementia that might usefully be deployed in developing care.'

A detailed review of the chapters is not possible in the space provided, however each of the chapters is stimulating and thought provoking, providing key pointers to address in order to move toward emancipatory research with people with dementia. Section one of the book includes contributions from Clarke and Keady on data collection in social research, Bartlett and Martin on ethical issues, Hubbard, Downs and Tester on including the perspectives of older people in institutional care during the consent process, and finally Corner on including people with dementia in advisory networks and user panels. The authors address such issues as: learning that can be obtained from other, equally sensitive areas of research; practical suggestions for assisting with service evaluation; assessment of competency; gaining and monitoring consent; and establishing and evaluating the effectiveness of a user panel. Some of the chapters include narratives from the research carried out, and facilitate a real engagement with the issues being raised and discussed. This was particularly the case in chapter 4, where the accounts gave an extra and real dimension to the author's discussion.

The second section of the book includes contributions from Robinson and McKillop. Both write about their experience of dementia, but within the context of their capacity and desire to be recognised as people first and foremost, with a valid contribution to

make. They give a powerful and honest account, which does not fail to give the clear message that people with dementia are able and willing to engage, and to tell their story. 'I will continue to speak up for myself as long as I possibly can. I urge you to do the same if, like me, you have been diagnosed with Alzheimer's disease, to do the same. No one but us knows what it is really like. I would feel terribly annoyed if we were denied the opportunity to take part in any kind of research into a disease which is gradually tearing apart my life and my husband's too' (p.107).

The final section of the book has contributions from Allen, who discusses working with staff, Bamford and Bruce on using focus groups, Pratt on interviewing people with dementia, Mason and Wilkinson on telephone interviews, Cook on using video observation and finally Bowes and Wilkinson on South Asian people with dementia. As the title of this section implies, the emphasis is on the practical application of research processes. The authors use an honest and critical approach to their work, and as such, encourage the researcher to consider many of the issues they will have to grapple with in order to work with people with dementia through a research process.

In summary, this is a potent and thought provoking book which should be essential reading for any person contemplating health or social care research with people with dementia. It is accessible and easy to read and provides us with many of the clues we need if we are to make emancipatory research a reality.

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