

Book reviews

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Speaking For Patients and Carers: Health Consumer Groups and the Policy Process

Baggott, R. Allsop, J. and Jones, K. (2004) Palgrave Macmillan, £ 55 hardback, 349pp.

Consumer health groups, by their number and influence, have become since the 1960's increasingly significant within the political economy of health. Over the last decade, this has been fuelled by the dissemination of information through, and the networking potential of, the world wide web. This volume explores, at a national level, the ramifications of their influence.

The book stems from an ESRC-funded study based at de Montfort University between 1999 and 2003. The three authors adopt the 'grounded theory' approach, to link their empirical data with intermediate-level social theory. The challenge they present to themselves is to shed light on the activities and roles of such voluntary groups; in the health policy process, and in the implications for government policy concerning patient and public involvement in health.

How did the writers set about this? A postal questionnaire survey went to groups in the five "condition areas" that cause most morbidity and mortality (interestingly, this left out stalwarts like the Parkinson's Disease Society and MS Society). This survey was followed by semi-structured interviews with 39 groups,

then interviews with a group of 'key policy actors' including ex-government ministers. There is an excellent summary of the policy context over the last decade and a thorough bibliography. The research findings are located within two streams of policy making: the drive to strengthen patient and public involvement, and extension of the voluntary sector's role in policy making and provision.

The social structure is essentially a complex network of relationships and this research shifts its focus across all networks involving health groups: health professionals, pharmaceutical industry, government, parliament, and the media. However, as this is a national study, local authorities and local health agencies are of course excluded. The book also examines the resourcing and influence of groups and teases out some useful general findings.

For example, the extent to which some medical conditions are of higher status than others comes across clearly, alongside the greater ease with which groups linked to these achieve influence. Resourcing, size, perceived professionalism and good networking are aids to public and governmental credibility. Clearly, it is very difficult for groups receiving public funds to be both poacher and gamekeeper, and the price of influence emerges occasionally in the research. A question mark is also left over the extent to which the groups studied represented excluded, marginalized, poor or minority groups.

Although the de Montfort study aimed, through a process of induction, to develop “grounded” theories, the findings are exploratory rather than theoretical or probabilistic. This reflects both the interpretive methodology (correctly) chosen, the size of the sample, and the diversity found within the field of investigation. The magic leap from data to theory, whatever sort of classificatory or comparative methodology is used, is rarely as straightforward as the methodological textbooks sometimes appear to suggest. It is a tribute to this group of authors that the results are so clear and organized.

And yes, as so often with this particular methodology, it is in the illustrative detail, the “raw” data collected, rather than the “conclusions”, that the book becomes an interesting read. In the highlighted quotations, the book’s skeleton, we find the feel for what life is like in the world we are exploring with its authors. The groups’ common values emerge: a belief in the NHS, empowerment of users, consultation, involvement, the value of lay (user) knowledge and experience. So, the politics of “influence” simply (and reassuringly) overlay some very human needs, the authors suggesting that a commonly understood ethic of caring binds the groups together.

This book highlights diversity amongst health consumer groups, and demonstrates some of the social capital, or resources, which help them to secure influence on the national stage. In this reviewer’s view, a sharper taste of the passion which motivates many group members, or even the odd chord of humour, would strengthen the book’s integrity to the world it is opening up. A slightly more anthropological approach could have humanized what is a thorough, highly competent but measured and slightly dry

report. Cultural messiness does not seem quite to have been picked up. But perhaps that is for a different study. Although the work’s focus is national, readers active in local health networks will know how this type of research in their localities could help with many challenges. None the less, many of the findings we have outlined here have obvious local relevance. In particular, those involved in the Patient and Public Involvement initiatives, or who are wallowing in the mercurial seas succeeding the demise of the Community Health Councils, should find that this book offers insight and stimulus.

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Reference

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