

Taking Consumer Participation Seriously

This issue of the *Australian Journal of Primary Health* has a strong consumer participation theme. Hegney et al. discuss the extent to which consumers are comfortable with the advance practice role for registered nurses. Johnson et al. tackle the broader role issue of consumer representation and participation in health service planning, management and review. Meehan-Andrews et al. explore the issues involved in getting rural consumer perspectives for health care planning and quality assurance. Pettigrew explores the expectations of older patients and the “senior friendly” hospital.

Increasingly, health services are being required to consider the consumer expectations in planning and to ensure that consumer experience is taken into account in evaluating the quality of services that are provided. Taking consumer perspectives seriously introduces a whole range of new challenges for policy-makers, service providers, professionals, consumer advocacy organisations, and, of course, researchers and educators.

Long ago Alford (1975) pointed out that interests across professionals, government, managers and consumers sometimes coincide but often compete. By and large the voice of professionals has been stronger than that of consumers. Unfortunately, professional dominance can lead to health issues, services, practice and outcomes being defined and delivered without much reference to the lived experience of the consumers involved. At its worst, consumer views are then discounted and marginalised to the realm of uninformed, subjective experience—to be managed as part of the treatment.

The very significant expansion of social rights over the past 30 years has seen the development of rights for a range of disadvantaged and disenfranchised groups across society. Consumer rights have followed this trend. From basic notions about consumer protection and fair dealing we have moved to give consumers an informed voice and meaningful choice in the services provided. Rights to confidentiality, privacy and informed consent have been introduced. The power of individual professionals over the lives of consumers has been constrained.

A raft of regulatory mechanisms now governs the relationships between individual consumers and professionals in the process of service delivery. These range from the codification of appropriate professional behaviour by registration bodies through to complaints’ mechanisms and disciplinary procedures, quality assurance processes and agency accreditation.

More broadly, consumers have been brought into the planning, regulation and review processes for health services. It is now commonplace for agencies to include consumer representatives on planning and review bodies. Consumer views are regularly sought in planning services and in reviewing and evaluating their quality, efficiency and effectiveness.

Yet, even cursory experience with health services is enough to know there are enormous tensions about consumers’ ability to have a say in both their own treatment and the broader operation of health services. Consumers are still often poorly informed and only marginally included in decision-making relating to their own care and treatment. When they participate in service planning and evaluation, consumers are often a lone, relatively unsupported and marginalised voice. There remains little, if any, direct involvement of consumers in setting priorities and evaluating health research.

Despite our best intentions and some significant progress, the impediments of “entrenched medical dominance, antagonistic bureaucratic cultures, a centralist supremacy, an intractable political economy of health, (and) inhibitory professional paradigms”, which Brownlea (1987) noted 20 years ago, remain alive and well.

More needs to be done to strengthen the voice of consumers in health care—not least because we are all current or potential consumers. Research and scholarly debate are vehicles in this project.

It is interesting to speculate on the impact that greater consumer, or, more broadly, community participation would have on the quality and outcomes of our health system. The evidence suggests that active consumer participation leads to improvements in health outcomes and more accessible and effective services (Consumer Focus Collaboration, 2001).

But overall the field of consumer participation research remains relatively under-developed and under-funded. There is relatively little programmatic research on consumer participation in health. There are few professorial positions or dedicated research centres. Generally, data on consumer aspirations, attitudes, experience and satisfaction is gathered for managerial rather than research purposes. Compared with the enormous resources of government, health services and the professions, there is little capacity for consumers to participate in setting research agendas,

particularly in relation to the development of health policy.

Primary care services often have the greatest capacity to engage with consumers and the community. They are the first point of contact and work more closely with local community organisations. The *Australian Journal of Primary Health* encourages research on consumer participation.

Hal Swerissen
Co-Editor

References

- Alford, R. R. (1975). *Health Care Politics: Ideological and Interest Group Barriers to Reform*. Chicago: University of Chicago Press.
- Brownlea, A. (1987). Participation: myths, realities and prognosis. *Social Science and Medicine*, 25(6), 605-14.
- Consumer Focus Collaboration (2001). *The evidence supporting consumer participation in health*. National Resource Centre for Consumer Participation in Health, La Trobe University, Victoria.