

Health Activism to Health 'Consumers'

Hans Löfgren, Michael Leahy and Evelyne de Leeuw

New Public Management, neo-liberalism and the capture of health activism

Many community groups concerned with health issues—women's organisations, disease-oriented patient support groups and older-citizens organisations—were formed long before their designation as 'consumer' groups. Members of health groups founded in the 1960s and 1970s understood themselves as activists for social change, not 'consumers'. They challenged established models of health care and mobilised to redress inequities of access to care and inequalities of power between the medical profession and the 'lay' population. The major campaign in this period was for the establishment of universal health insurance.

The policy influence of the organised consumer movement peaked in the decade from the mid-1980s, when access to the policy table was provided for the first time under Labor governments federally and in several states. In that period both peak and disease-oriented health consumer groups received increased funding from governments and were integrated into mainstream policy processes. These gains, however, came at a price: in exchange for recognition as legitimate policy actors they came under mounting pressure to moderate their activist role and to exclude systemic critique. One of the major sources of pressure on health policy actors was the New Public Management (NPM) reform program, based on neo-liberal ideology. By defining health care provision as a market exchange, with 'choice' as the central value, neo-liberal ideology limited the role of health consumer groups to protecting consumer interests in that exchange.

Assured access to the policy table, we believe, weakened the ability of such groups to autonomously mobilise critical patient, carer and community opinion. While 'mainstreaming' purported to enhance consumer engagement among service providers and policy makers, it reduced such engagement to ascertaining the views and experiences of services users, with users conceived of as individual

consumers with, as Judith Gregory puts it, 'rights to information, access, choice, and redress'.

John Alford's influential model explains the health care policy contest in terms of competing 'structural interests'—the professional monopolists, the corporate rationalisers and the community interest—where typically the community interest comes to be suppressed. John Dryzek, observing relationships between governments and social movements, sees that actors based in civil society 'sometimes face a choice between action in the public sphere and action within the state'. Where the state seeks to exclude social interests, groups have no choice but to mobilise autonomously outside the state. But where the state takes an inclusive approach and permeates civil society, as in Australia, they have a choice to act inside or outside the state. But acting inside the state does not necessarily ensure advancement of the aims of a social movement, or indeed broader democratic objectives. 'Benign inclusion' through co-operative policy-making mechanisms furthers these aims only if two conditions hold: 'a group's defining concern must be capable of assimilation to an established or emerging state imperative [and] civil society's discursive capacities must not be unduly depleted by the group's entry into the state'. Where a social movement cannot link in with a state imperative, its inclusion into the state is likely to be largely symbolic and ultimately detrimental to the vitality of civil society.

Health Activism of the 1960s and 1970s

The struggle for universal health insurance provided a central focus for health activist groups in the 1960s and 1970s. Medibank was introduced by the Whitlam government in 1975 following ferocious conflicts with the conservative Opposition, supported by the Australian Medical Association (AMA). Medibank marked a watershed in Australian health policy. Universality and equity in health care became explicit policy objectives for the first time. As Dick Scotton and Christine Macdonald note, this program enhanced the power of the Commonwealth relative to the states over health policy and weakened 'the veto power of organised medicine in general, and the AMA in particular, over the structure of the health system'. However, the hope that breaking the monopoly power of the medical profession through Medibank would mark an increase in community influence was soon shown to be ill founded. The Fraser government dismantled Medibank through a series of incremental changes, culminating in the removal of the universal right to free hospital care. The power had shifted significantly to the state.

Medibank's successor, Medicare, was introduced by the Hawke Labor government in 1984. On the face of it the re-introduction of universal health insurance appeared to be an expression of social democratic ideology premised on a conception of consumers as citizens. But this was also the

←←←

Health Activism to
Health 'Consumers'

Hans Löfgren,
Michael Leahy and
Evelyne de Leeuw

Hans Löfgren and
Michael Leahy are
in the School of
International and
Political Studies,
and Evelyne de
Leeuw in
Community Health
Systems and Policy,
Deakin University.

This is an edited
and abbreviated
version of a chapter
in Löfgren, de
Leeuw and Leahy
(eds), **Democratising
Health: Consumer
Groups in the Policy
Process** (Edward
Elgar, forthcoming
2011). This book
examines the role
of consumer
organisations in
health policy across
a number of
countries in
Europe, North
America and Asia.
For more
information,
contact
<hans.lofgren
@deakin.edu.au>



12 2010-01 2011
No 109

period in which the NPM was making powerful inroads into Australian public administration, driving Labor governments to compromise commitments to democratic participation implicit in health and other social policy measures. Indeed Labor governments at federal and state levels were the principal drivers of a wave of public sector changes in the 1980s and 1990s underpinned by neo-liberal ideology. The NPM focus on rationality, outcomes, performance measures and customer satisfaction was consistent with a conception of the consumer as a market actor exercising individual choice. As described by Meredith Carter and Debra O'Connor, the opening up of the health services system to consumer representatives from the mid-1980s was 'predicated on the view that a level of consumer participation is necessary to ensure appropriate services and products are available in the marketplace ... and to ensure informed consumer choice as to which services and products best suit the treatment needs experienced by individuals'.

In Australia, as elsewhere, health consumer groups first formed around particular illnesses, with a focus on assisting patients and their families. A broader consumer organisation, the Australian Consumers' Association (today named CHOICE), which also contributed to the organisation of health consumers, was formed in 1959. As Rob Irvine notes, self-help activism and critiques of traditional medical authority gained momentum in the 1970s at the same time as the 'health consumer' emerged as 'a central organising principle and figure of speech'. In this period, reform groups and activists for the rights of women and the physically and mentally disabled campaigned vigorously to change norms, practices and power relationships. The rise of the new, more radical forms of health activism was intertwined with Labor's democratic reform aspirations and, as emphasised, the ongoing mobilisation for universal health insurance.

Active community participation was advanced by the Whitlam government through the creation of the Hospitals and Health Services Commission. The adoption of the recommendations of the Commission resulted in the extension of Commonwealth primary care funding to community-managed health centres, community nurses, regional geriatric and rehabilitation teams, day hospitals, community mental health services, women's health centres and Aboriginal medical services. Perhaps peripheral when measured against mainstream health services, one significant result of these reforms was the emergence of a new sector of local and regional institutions supported by politicised health professionals and activists wedded to the ideas and practices of community health.

Until the mid-1980s at least there was a close relationship between the community health movement and incipient health consumer organisations. In Victoria, health and consumer activists from organisations such as the People's Health Collective, the Health Left and Health Feedback Study Groups, Community Health Action and Information Network, the Medibank Action Coalition, the Workers Health Action Group, Women in Industry, Contraception and Health, Women's Repetition Injury Support Team, the Women's Health Resource Collective and Workers Health Action came together in the early 1980s in defence of the community health program and Medibank. In 1984 the Health Issues Centre, which today still operates as the de facto Victorian peak body for health consumer research and advocacy, emerged from this network of activists.

In the central conflict over universal health insurance, consumer groups were the natural allies of reform advocates like the Australian Consumers' Association, the Australian Council of Social Services and the Doctors' Reform Society. In turn, the Whitlam government made the health policy system increasingly

accessible to such groups. The Fraser government held back their entry into the mainstream but the process recommenced with Labor's return to federal office in 1983 and around the same time in several of the states. The culmination of this development was the establishment in 1987 of a peak organisation, the Consumers Health Forum of Australia (CHF).

Consumer Health Forum

The government's intention, as set down in a 1985 Department of Health document, was for a consumers' health forum to be established as 'a coalition of community and consumer groups' to provide 'a "community voice" on health issues', with the aim of balancing the influence of well-organised professional and industry groups. It was to be funded by the department but to operate as an independent, separate, incorporated body. Today the CHF's membership encompasses most health consumer groups of significance, including peak organisations in each state. With around fifteen full-time staff, it is engaged in submission writing, workshops and educational initiatives, policy advocacy, and the publication of newsletters and other publications. Importantly, it nominates consumer representatives to more than 150 government, industry, research and professional committees.

The historically blurred lines between the Australian Labor Party and community activism for universal health insurance, social equity and a more participatory democracy made the 1980s, when Labor formed government federally and in several of the states, a period favorable to the inclusion of consumer groups in health policy. The CHF was established as the voice of the *community*, with a particular commitment to preventative and public health, and was seen as an influence that could to some extent counter the power of the medical profession. Yet, as a government funded entity, it was from the very outset absorbed into mainstream policy processes and its independence and critical role was muted.

As noted, the policy influence of the CHF peaked in its first decade, a period of Labor governments committed to NPM reforms. As Stephanie Short points out, the CHF's channelling of government funding to consumer and community organisations for autonomous research formed the 'high water mark in terms of community participation in the health policy process'. This program ceased in 1992 when conditions were tightened for peak health and community organisations. The government funding the CHF continued to receive was increasingly targeted to closely audited consultative projects directed towards government ends rather than autonomous community development.

The health consumer movement today presents a relatively cohesive structure through peak bodies at the state level and the national leadership exercised by the CHF. We have only fragmentary knowledge of the dynamics of the several hundred local and state-based groups, which make up the greater part of health consumer activities, and the extent to which they exercise influence in health policy. But the

formal consumer presence within the policy system through organisations such as the CHF does not seem to be sustained by vigorous or resourceful mobilisation of large numbers of patients and carers, nor is there a sense of a new generation of activists following on strongly from those of the 1970s and 1980s. There is no sense of consumer organisations contributing a strong and distinct voice in the public debate on health reform. Disease-oriented groups provide much needed services and support for their particular constituencies, but typically officials and volunteers are preoccupied with issues of funding and organisational survival through government project grants and pharmaceutical industry funding.

By defining health care provision as a market exchange, with 'choice' as the central value, neo-liberal ideology limited the role of health consumer groups to protecting consumer interests in that exchange.

Yet, while the capacity to mobilise autonomously appears to have been largely drained from the sector, the notion of 'consumer engagement' has evolved into a principal objective in health policy at all levels. But most initiatives that come under this heading are oriented towards individual service users or citizens, and the role of consumer organisations tends to be peripheral at best. Typically their contribution is to provide representatives for committees and working groups and to advise on government activities, such as the trials of deliberative democracy in health policy planning implemented in Western Australia between 2001 and 2005.

Over more than twenty years the CHF and other consumer groups have issued a stream of reports, proposals, policy papers and submissions on matters relating to medicines. These include advertising codes and standards; pharmacy practices and product information for consumers; quality use of medicines; and regulatory, access and affordability issues associated with the Pharmaceutical Benefits Scheme (PBS), Australia's tax-financed medicines insurance program.

Medicines Policy

Consumers are represented on most regulatory committees and working groups in the medicines sector. The Pharmaceutical Benefits Advisory Committee (PBAC), which recommends to

the Minister for Health which medicines should be included on the PBS and the conditions for their listing, is the central node of the regulatory system. Membership of this committee would seem to suggest a degree of real influence. Yet, constrained by confidentiality requirements, consumer representatives on this and other committees are to all intents and purposes co-opted as marginal players into a highly complex regulatory system. Positively, the knowledge gained from participation in regulatory and advisory committees ensures the availability of expertise within the consumer movement, but only a small number of activists are engaged with medicines regulation in an ongoing basis. Consumer organisations are excluded from the quasi-secret meetings between government and the pharmaceutical industry where deliberation occurs on major policy issues.

When health consumer activists first made medicines policy a key focus of their activities in the 1980s, they encountered a great deal of suspicion on the part of the medical profession, pharmacy retailers and the pharmaceutical industry. But aversion gradually gave way to acceptance of a legitimate role for consumer groups in this policy sector. The dominant actors each recognised that participation by consumer groups in the policy process provided opportunities for new alliances. The formation of the CHF brought forth a credible voice in support of the government on critical aspects of the reform agenda. In John Alford's terms, incorporation of the previously excluded community interest strengthened the position of the corporate rationalisers. In particular, the pursuit of PBS efficiencies, notably the introduction of cost effectiveness as a condition for the government subsidy, was compatible with the social equity and 'rational medicines policy' program of the consumer movement. Similarly, there was the beginning of more co-operative relations between consumer groups and the pharmaceutical industry. This relationship was subsequently deepened through, for example, consumer representation on the industry committee that oversees adherence to a code of conduct for the ethical marketing and promotion of prescription pharmaceuticals. Today several pharmaceutical companies, including Pfizer and GlaxoSmithKline, are 'corporate members' of the CHF.

The inclusion of the CHF into a set of 'partnerships', within constraints laid down by the pharmaceutical industry and the government, is most evident in the development of Australia's 'national medicines policy'. The notion of a national medicines policy derives from the World Health Assembly and the World Health Organization, in particular its Action Programme on Essential Drugs established in 1981. It was envisaged that health policy in all countries would aim to provide the population with access to appropriately prescribed, safe, effective and affordable medicines.

Australia's health ministers in 1988 adopted a series of general health policy targets in the document *Health for all Australians*. This was followed by the Health Ministers' establishment of the Health Targets and Implementation (Health for All) Committee. The CHF became a co-opted member of this committee and was central in ensuring the committee recommendation that a comprehensive medicinal drugs policy be adopted. The inclusion of the consumer movement in this process was partly in recognition of the intellectual and

←←←

Health Activism to
Health 'Consumers'

Hans Löfgren,
Michael Leahy and
Evelyne de Leeuw

a ←

12 2010-01 2011
Nº 109

advocacy work for a national medicines policy undertaken by the CHF. A model had been presented in a 1988 CHF discussion paper, co-authored by academic John Braithwaite. Circulated to all relevant interest groups and obtaining support from many sources, the discussions triggered by the CHF initiatives paved the way for the de facto adoption around 1994–1995 of a national medicines policy.

The concept of a national medicines policy has since proven a durable de facto policy framework and a reference point for lobbying by all stakeholders. It encompasses four 'arms': timely access to the medicines that Australians need, at a cost that individuals and the community can afford (provided through the PBS); medicines that meet appropriate standards of quality, safety and efficacy; quality use of medicines; and maintenance of a responsible and viable medicines industry. The consumer sector has been a particularly prominent driver of initiatives to meet the third of these objectives, quality use of medicines (QUM).

The limits on the influence of the consumer movement are also discernible in this analysis. Participation in a wide range of co-operative arrangements has not strengthened the capacity and inclination of health consumer groups to mobilise autonomously for democratisation of health services and policy. The national medicines policy was not achieved principally as a result of CHF lobbying, and much less through the mobilisation of its member organisations and supporters. For the pharmaceutical industry the national medicines policy process, as noted, provided the opportunity to gain acceptance for the objective of a 'viable pharmaceutical industry', with implications for the operation of PBS pricing arrangements. That the initial misgivings of industry about the national medicines policy could be overcome is due to the convergence of industry and government interests. In short, although the consumer movement has won an established place in this policy arena, the limited influence it has gained does not pose a challenge to the power of the dominant actors.

State Imperatives and Structural Interests

While no theory provides a full explanation of the metamorphoses of the role of health consumer groups, we believe Alford's 'structural interest' analysis and Dryzek's concept of 'state imperatives' shed light on them. The influence of community and consumer groups in health policy has varied with the objectives pursued, at different times, by the 'corporate rationalisers', but

also with the broader 'state imperatives' of the government of the day. As activist groups born of the wider social movements of the 1960s and 1970s, these organisations have continued to lend vital support to the Labor party in the perennial political contest over universal health insurance. The establishment of Medibank, which weakened the monopoly power of the medical profession, was a limited measure of their success in mitigating the medical dominance of health policy and practice and in opening the door, to some extent, to democratic participation in health policy. Their accessing of the power of the state, however, exposed consumer groups to the forces driving and constraining that power.

When corporate rationalisers in periods of Labor government were concerned with the state's legitimation imperative of popular support for health services reform, the democratising efforts of activist groups were encouraged and their policy role embraced. But when governments shifted to a focus on efficiency and economic and managerial objectives rather than democracy, community activist groups came under pressure to redefine their role more narrowly in accordance with neo-liberal and managerialist paradigms. Having long accepted their designation as 'consumer groups', they tempered their commitment to radical reform of the health system in favour of participation in the mainstream policy process.

Consumer groups have continued to play a role in preserving an important democratic achievement: universal health insurance. They can also boast significant achievements in representing consumer interests on many other issues, including in relation to the national medicines policy. But we cannot fail to observe the negative effects on the autonomy and vitality of such groups of having gained entry into the state and a degree of influence, albeit severely constrained, on government policy. Co-option, while assuring entry to the policy mainstream, marginalises their capacity for mobilising health services users, and citizens more broadly. **□**

Bibliography

- Alford, R. R., *Health Care Politics: Ideological and Interest Group Barriers to Reform*, University of Chicago Press, Chicago, 1975.
- Baldry, E., *The Development of the Health Consumer Movement and its Effect on Value Changes and Health Policy in Australia*, PhD thesis, School of Health Services Management, University of New South Wales, Sydney, 1992.
- Carter, M. and D. O'Connor, 'Consumers and Health Policy Reform', in P. Liamputtong and H. Gardner (eds), *Health, Social Change and Communities*, Oxford University Press, Melbourne, 2003, pp. 22–37.
- Department of Health, *The Review of Community Participation in the Commonwealth Department of Health: Final Report*, Department of Health, Canberra, 1985.
- Dryzek, J. S., *Deliberative Democracy and Beyond: Liberals, Critics, Contestations*, Oxford University Press, Oxford, 2000.
- Gregory, J., *Conceptualising Consumer Engagement: A Review of the Literature*, Working Paper 1 (Revised), Australian Institute of Health Policy Studies, Melbourne, 2007.
- Harvey, K. and M. Murray Hodge, 'Australian Medicinal Drug Policy', in H. Gardner (ed.), *The Politics of Health: The Australian Experience*, C. Livingstone, Melbourne, 1995, pp. 238–283.
- Irvine, R. 'Fabricating "Health Consumers" in Health Care Politics', in S. Henderson and A. Peterson (eds), *Consuming Health: The Commodification of Health Care*, Routledge, London, 2001, pp. 31–46.
- Murray, M., 'Australian National Drug Policies: Facilitating or Fragmenting Health?', *Development Dialogue*, no. 1, 1995, pp. 148–192.
- Scotton, R. B. and C. R. Macdonald, *The Making of Medibank*, School of Health Services Management, University of New South Wales, Kensington, 1993.
- Short, S., 'Community Activism in the Health Policy Process: The Case of the Consumers Health Forum of Australia 1987–96', in A. Yeatman (ed.), *Activism and the Policy Process*, Allen & Unwin, St Leonards, 1998, pp. 122–145.