Partnering with consumers: national standards and lessons from other countries

Effective partnership requires professionals and consumers to redefine their roles and responsibilities

Partnering with consumers is a national priority and central driver of global health care reform.[1,2] The National Safety and Quality Health Service Standards stipulate that partnering with consumers is a central component of safe, high-quality care, and a performance indicator against which health care organisations will be assessed and accredited.[2]

Consumer participation is a complex and dynamic concept.[3] Australian health services are currently undergoing the challenging task of understanding what consumer participation means and how it can be used to improve health and health care. Opportunities for consumer participation are diverse: education and training,[4] research,[5] accreditation,[6] service design and evaluation, policy, patient care and treatment.[7] Empirical evidence describing the best methods to involve consumers and the effects of that involvement is limited,[1,5,7] leaving health services to rely on practical experience and common sense.[7] Although the importance of partnering is widely recognised, in the absence of proven approaches, it is not surprising that efforts to partner with consumers can be tokenistic and ineffective,[7] leaving the goals of consumer participation unrealised, and health providers and consumers disappointed or cynical.

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The National Standards have stimulated widespread interest in consumer participation. Australian examples of community participation are often from rural and Indigenous communities,[8] and published studies with high levels of community participation and long-term evaluation are relatively small in number.[9] Australian health services seeking to discover the characteristics of effective consumer participation can find examples of success from other parts of the world. The examples suggest that effective consumer participation requires a fundamental shift in how both consumers and health care providers define their roles and responsibilities. Successful projects and services go beyond asking select individuals for feedback and advice, but approach and engage entire communities to understand current challenges, design and prioritise services, and implement solutions. Involved, egalitarian relationships based on trust, mutual respect and careful listening appear fundamental to successful engagement and partnership. Professionals must relinquish control as consumers accept greater responsibility. Partnerships are multisectoral and move beyond biomedical models to recognise the social determinants of health.

Lessons from other countries

The Nuka System of Care provides health services for 60 000 Alaska Native and American Indian people and is a leading example of successful health care redesign, receiving a Malcolm Baldrige National Quality Award in 2011.[10] Since 1996, the health service has experienced a 36% reduction in hospital days, a 42% reduction in emergency department and urgent care usage, and a 58% reduction in specialty clinic visits; results have been sustained for at least 10 years.[10] The key to the Nuka system's success is the radical way in which professional–consumer relationships have been redefined, and how roles and responsibilities have changed.[10] Before the Nuka system, Alaska Native people were beneficiaries who received services from a centrally controlled government system. Now, Alaska Native people are customer-owners who share responsibility and ownership with service providers. The new role comes with increased control and responsibility, not just

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regarding personal health choices, but over the entire health system that is managed and owned by the people — a process supported by federal law. Understanding the community's current priorities requires careful listening "with an open mind".[10] The Nuka system goes to great lengths to harness the community's views through opportunities such as comment cards, surveys, a telephone hotline and online form, focus groups and advisory committees. Because reform is based on the needs and values of Alaska Natives, results indicate that it is better positioned to meet the needs and preferences of Alaska Natives.

Beyond Alaska, initiatives in developing nations provide examples of how appropriate and effective consumer partnership can be the difference between successful or failed projects. Many development initiatives have not created sustainable change;[11] between 1973 and 1985 the World Bank lent $19 billion for 498 projects but few succeeded.[12] Failure to engage with communities has been suggested as a major reason for lack of sustainable and scalable change in many poor countries.[11,12]

The Comprehensive Rural Health Project in Jamkhed, India (the Jamkhed project) and the Kakamega Orphan Project in Kenya (the Kakamega project) are examples of successful community-based health care programs that realised great improvements in infant mortality, infectious diseases, malnutrition and sanitation.[11,13,14] The projects demonstrate how partnering with communities can drive successful change and, conversely, how abandoning community participation can lead to project failure. The projects show that partnering with consumers is first about developing trusting, respectful and involved relationships, which takes time, effort and proximity. Project workers went beyond their institutional walls and immersed themselves in the community, avoiding a common mistake made by development projects where workers are geographically and socially distant from the communities they are trying to help. In the Jamkhed project, partnership started with volleyball matches that engaged diverse sections of the community.[14] Project workers subsequently assisted community representatives to identify their own problems, collect their own data and implement their own solutions.

The Jamkhed and Kakamega projects highlight that one of the most important yet difficult activities in partnering with consumers is the attitudinal and behavioural change required to shift control away from professionals and give it to communities.[12] Reflecting on 60 years of development work, Taylor-Ide and Taylor indicated that professionals can be the greatest barrier to change because they can be more interested in protecting their positions and priorities, see balanced partnership as unnecessary, and consider themselves in the senior position.[12] Professionals relinquishing control is vital for successful partnership; it creates a more egalitarian relationship that shares power and responsibility, and sees the community as a partner and colleague rather than employee or subordinate.

The Jamkhed and Kakamega projects underscore the importance of taking a broad view of partnership and the determinants of health. Partnership involves multiple stakeholders including those outside the health sector.[12] In the Kakamega project, women in obstructed labour were unable to access hospitals due to inadequate roads and bridges.[13] The district road engineer became a third partner and, by building bridges and improving roads, was pivotal in improving maternal and obstetric health outcomes. Three-way partnerships created potential for top-down, bottom-up and outside-in perspectives.[12]

Partnership must also recognise that the community's priorities might not be the same as those of health services and that non-health-related priorities might initially take precedence. In the Jamkhed project, community members were more interested in the health of their farm animals than in their own health. Once the animals' needs were met, people became interested in their own health. If health services had prioritised human health at the outset, then locals would have resisted interventions, perhaps passively, and health workers would have been frustrated that the community was not responding to their efforts to help.

Eight years after commencing, the Kakamega project disbanded.[13] Two years before that, following international acclaim for its successes, the Kenyan Ministry of Health took direct control and international donor agencies contributed large amounts of money. As a result, the intimacy of locally built projects was lost in the distance between the community and displaced officials. According to the Kakamega project's founder, bureaucratic rules and top-down directives replaced local ownership and joint decision making, which "killed" the project.[13] Performance targets and less inclusive time frames replaced the unhurried process necessary for community engagement. The Kakamega project exemplifies the difficulty of taking local successes, packaging them and transplanting or upscaling them to other settings.

Consumer participation in Australia

More than 35 years ago, the Declaration of Alma-Ata affirmed that people have the right and duty to participate not only in receiving health care but

also in planning, organising and implementing health care.[15] In Australia, the National Standards have stimulated resurgent interest in consumer participation which creates a unique opportunity to accelerate our understanding of successful consumer participation. Health service accreditation enables collection and collation of consumer participation activities from across the country. Disseminating national data would enable health services to efficiently learn about successful and unsuccessful consumer participation methods; the Australian Commission on Safety and Quality in Health Care could oversee collecting, collating and disseminating consumer participation activities from around Australia. Concurrently, health services can look to other industries, such as retail, for methods to successfully engage consumers in a way that develops products and services that meet consumers' needs and preferences.[16] When replicating or expanding successful initiatives, the process and context of the initiative must be recognised, understanding what worked and why. Bureaucratic processes in the form of rules, regulations and one-size-fits-all programs are likely to suffer the same fate as many development initiates.

Successful partnership requires health services and consumers to redefine their roles and responsibilities. The National Standards have captured health services' attention. Now, the broader community must be engaged, so that consumers understand and participate in health care not just as an individual right but as a shared, corporate responsibility.

Beyond the belief that consumer participation is good (Arnstein famously noted 46 years ago that community participation is like eating spinach — it's obviously good for you),[17] rigorous evaluation of consumer participation is required to identify and fill current knowledge gaps. Research is required to determine if and how consumers and professionals want to partner. Evaluation methods must be incorporated into consumer participation initiatives to demonstrate the effects of partnership on service- and consumer-related outcomes. Concurrently, the potential downsides of partnering with consumers — such as tokenism, slower progress, increased costs and conflict between consumers and professionals — should be evaluated.[7] Research requires time, skill and effort. Unless health services support staff with time, funding and research expertise, high-quality consumer participation research is unlikely to happen.

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References are available online at www.mja.com.au.