# Feedback, Participation and Consumer Diversity

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*There is an increasing recognition of the potential role of consumers in developing effective and appropriate health care services. There is also emerging evidence supporting the wisdom of this participation. However, despite the increasing amount of work being done to enhance consumer participation in the health system, many consumer groups are excluded from involvement in mainstream processes for seeking such input. Consequently, this project was undertaken as part of the establishment phase of the National Resource Centre for Consumer Participation in Health (NRCCPH) to draw together existing information from the literature about participation of previously excluded consumer groups and to highlight existing barriers to the participation of these 'marginalised' groups of consumers. As this article is an overview it does not refer to specific references, however, an annotated bibliography of the references can be viewed by visiting the web site of the NRCCPH cited at the end of this article.*

Much has been written about the diversity of the Australian population and the importance of developing service systems that respond appropriately to this diversity. Despite this, it has been noted that consumers from marginalised groups who may have the poorest health status and potentially the greatest need for services, often have the poorest access to services and access to the least favoured models of care.

It has been argued that developing service systems that respond appropriately to the diversity of consumers in communities requires that organisations and service providers develop the capacity to both examine their own beliefs, attitudes and practices, and to listen to and act on consumer input. This requires the development of organisations that enable consumers to teach the system about themselves and their needs.

However, many groups of consumers are often excluded from participating in feedback and participation processes, such as patient satisfaction surveys and complaints processes, implemented by mainstream health services. Some consumer groups, such as people from culturally and linguistically diverse backgrounds are frequently included only if they are the focus of a particular strategy or program.

## Some Definitions

*Consumer diversity* can be influenced by a range of factors such as ethnicity, race, ability, class, socio-economic background, education, gender, sexuality, religion and health status or health condition. It is often the intersections of a range of factors that contributes to each person's sense of their identity or *culture*.

Health system structures and processes which are not developed to include diverse groups of people can be seen to marginalise those groups of consumers. In this article the term *marginalised groups* is used in recognition that it is health systems and services that marginalise or exclude people through failing to develop appropriate structures and processes for inclusion. This is a shift away from seeing the characteristics of consumers as the reason for exclusion. This puts the emphasis back on services to incorporate, respond to and be accountable to the diversity of the communities in which they exist.

Mainstream health services are those services which aim to provide health care to the general community, as distinct from those services which are established to meet the needs of a specific consumer group.

**Project Process**

The project was greatly assisted by a reference group representing a broad base of consumer and service provider groups. The method included a systematic search of the literature through existing data bases, hand searches of specialist collections and phone calls to peak organisations and individuals known to be doing relevant work. Limitations of the review include:

- relevant literature was dispersed throughout a wide range of publication types; many of the reports do not appear on data bases;

- there is a large body of work that is not yet written up or evaluated;

- time limitations meant that not all literature could be reviewed; and

- some highly relevant work was published as the project was being concluded.

**Key Findings**

**Consumer Participation and Access**

There were many reports in the literature of health services seeking information from consumers from marginalised groups, including people from culturally and linguistically diverse groups, Indigenous people, homeless people, people with mental health issues, people with disabilities, young people, older people, people living in rural areas and people living on low incomes. Most of these reports focused on seeking input from one group of consumers, rather than looking across populations to identify ways a range of groups could be involved.

In the majority of reports, participation of people from marginalised groups was sought because service providers identified that they had poor access to services. This type of work sought to find out about the barriers and issues limiting access and sometimes to ask consumers how services could be improved. Other reasons service providers sought input from marginalised groups of consumers included: recognition that consumers had been excluded from previous feedback or participation processes; to develop and test tools for seeking feedback from specific groups; evaluation of services, programs, resources or participation processes; and a commitment to involving consumers from diverse backgrounds in the development of services. In addition, there were a range of consumer-led activities to address issues for specific groups.

Examination of the reasons service providers sought input from marginalised groups of consumers indicated there is an increasing recognition of the relationship between the development of appropriate and accessible services and consumer participation.

**Structural Issues**

The literature clearly showed that many common issues need to be addressed to promote effective consumer participation by people from different marginalised groups. This highlights that these barriers are systems issues, rather than issues about particular types of consumers. Some of the major issues are:

- Many mainstream organisations had not developed systematic and appropriate strategies for seeking input from consumers from diverse groups and for seeking input from a range of consumers within each group;

- Unless inclusion of diverse groups is specifically addressed in the design of feedback and participation processes these consumers are generally under-represented in resultant activities;

- Traditionally services have located the reasons for marginalisation with groups of consumers, rather than focusing on organisational structure and culture;

- Service providers may have discriminatory attitudes towards consumers from marginalised groups;

- Work done with consumers from marginalised groups is often undertaken as a once-off project, outside of any integrated approach to service development; and

- While much work has been done to find out from consumers about barriers and issues, services are often unable to act on this information.

These structural barriers can result in a circular process in which services identify that they do not have appropriate and accessible services, seek feedback from marginalised groups as part of a strategy with a specific focus and then are unable to implement change based on the information they have gathered.

## Quality of the Information Collected

There are two main consequences of poor processes for collecting feedback from consumers, or for involving consumers more actively. These are firstly the information gathered from consumers may not be the type of information that is useful to inform service development. Secondly, the information gathered may only reflect the needs of those who already have the best access to services, and it is thus not useful for developing services that are appropriate to diverse communities.

Factors that will impact on the quality of information from feedback and participation processes include:

- consumers from marginalised groups are often excluded from having input (for example, surveys written in English will exclude those who speak and write in languages other than English);

- consultation and feedback processes may not respect community processes and may not be culturally appropriate;

- the questions asked may not be relevant to consumers; and

- the time frame for seeking feedback may be too short.

In addition, processes that simply collect information from consumers, and do not involve them in developing strategies to improve services can be experienced as disempowering by consumers. Many consumer reports identify that participating in these types of processes feels tokenistic and can result in consumers being reticent to participate in the future, thus reinforcing marginalisation.

## Consumer Issues

Consumer reports identify a range of issues that impact on their participation. Sometimes consumers may not want to give feedback, particular negative feedback, to health services. Consequently, consumers may express positive views even when they have received poor service. Some of the reasons consumers may not want to give feedback include fear of

discrimination in the future or fear that funding to the service will be withdrawn (and any service may be better than none).

A second critical issue for consumers is that there is very little infrastructure and few resources to support the development of their capacity to participate. Many consumers have little access to ways of learning about participation, or to the information to develop an understanding about health services and their decision making structures. Consumers may also be expected to bear the material costs of participation. In addition, those consumers who are the most marginalised from accessing services may also be the most marginalised from participating in service development and also have the least resources to support and enable their involvement.

**Developing Strategies**

A range of issues about developing the kinds of organisations that respond to, and seek input from, a diverse range of consumer groups, in particular those who have been marginalised, were identified in the literature. In particular, this requires that organisations: affirm their commitment to utilising information provided by consumers to inform service development; develop partnerships with consumers and communities to facilitate the conduct of mutually beneficial work; and develop appropriate strategies for linking with consumers and community groups. It is also important that services develop mechanisms for being accountable to consumers and to funders. This can include developing systems for documenting and evaluating the changes made as a result of consumer participation and communicating this information to consumers.

Development of feedback and participation processes that enable specific consumer groups to participate includes thinking through a number of issues about how to make those processes most appropriate for consumers who have been marginalised. Some of the solutions discussed in the literature include:

- making long term commitments to involving consumers;

- employment of community members;

- consultation with consumers about appropriate strategies; payment for consumers;

- developing effective translation processes;

- ensuring confidentiality and anonymity;

- involving both consumers and service providers in developing questions and in problem solving;

- building feedback into other activities; and

- building consumer feedback and participation into quality improvement processes.

Another key issue was that the methodology should be appropriate to the purpose for undertaking the work. For example, if organisations are wanting to involve consumers as active partners, then patient satisfaction surveys may not be a relevant process. The methodology should also enable consumer views to be properly represented and, if possible, enable the understanding of complex experiences and reflections. It was suggested that poorly designed processes and questions could in fact act as a means of censoring consumers.

The literature includes descriptions of the use of both quantitative and qualitative methods to seek feedback from consumers from marginalised groups. Qualitative methods were found to be useful when little was known about the area, when quantitative data was ambiguous, when measures utilised to seek quantitative information were inappropriate to the group and when more active consumer participation was the goal. The usefulness of combinations of quantitative and qualitative methods was highlighted. For example, qualitative methods, such as interviews with consumers, were often used to inform the development of quantitative tools such as questionnaires or surveys. Sometimes, both types of methods were used to develop more in-depth understanding of issues.

There are no magic solutions to services working with consumers from groups who have previously been excluded from participation. Methods such as questionnaires, focus groups, interviews, forums, meetings, researcher observation, project advisory groups, outreach strategies, community development and action research processes were often adapted to be appropriate for specific consumer groups. These adaptations were often informed by consulting with and involving consumers, relevant workers and community organisations in establishing appropriate feedback processes and in designing the questions to be asked.

The critical finding is that it is essential to ensure that information provided by consumers is used to inform service development. This appears to be most effective when organisations have a leadership commitment to involving consumers from diverse groups and when they are prepared to inquire *with,* plan *with,* act *with* and evaluate *with* consumers.

**Conclusion**

The literature review identified that an enormous amount of work had been done to seek feedback from and involve consumers who had previously been marginalised from participation in health service development. While these initiatives have been important in the establishment of appropriate and accessible localised services, it seems that many of the lessons learnt from this type of work are not incorporated into mainstream strategies for service improvement.

Two critical issues emerge from this review. The first is that organisations seeking feedback and involvement of consumers should ensure their method for engaging with consumers results in the creation of the types of knowledge that produces organisational change and improvement. The second is that all processes used by mainstream health organisations to seek feedback from consumers should be developed so that they enable consumers from diverse backgrounds to participate.

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*For more information about the NRCCPH or the Feedback, Participation and Consumer Diversity Project (including an annotated bibliography of all of the references used in writing this review) contact the NRCCPH's website at http://nrccph.latrobe.edu.au) or Margaret Wohlers, Information Manager at the NRCCPH. Ph: (03) 9479 3529 Email: m.wohlers@latrobe.edu.*