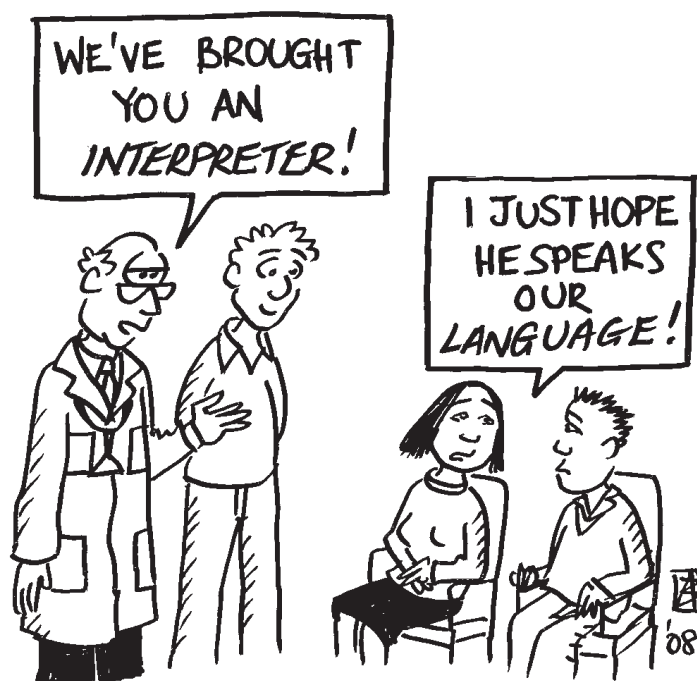




# Participation with Culturally and Linguistically Diverse Communities in Health Services— What Helps and What Hinders?

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In early 2007, Health Issues Centre prepared a discussion paper for acute and primary health services and the Victorian Department of Human Services. The discussion paper sought to identify generalised barriers and enablers for Culturally And Linguistically Diverse (CALD) consumer and community participation in health services and proposed a framework including clear and additional strategies and resources for meaningful CALD consumer participation. This excerpt identifies the key factors that help and hinder CALD consumer participation.



## Reminding Ourselves of the Diversity

People coming to live and settle in Victoria continue to be diverse in many complex ways and experiences. They comprise migrants, refugees and asylum seekers, and stem from an extraordinary range of countries and ethnic backgrounds. The health status of migrants varies according to a series of factors, including birthplace, fluency in English, process of migration, stage of life, whether the individual is part of an established, emerging or refugee community, and each individual's balance of protective and risk factors (National Health and Medical Research Council [NHMRC] 2005, p.17).

It is essential to acknowledge that while migrants arrive in Australia with good health, some refugees, asylum seekers, and people in detention centres present with more health problems than other communities. A recent study by the Victorian Foundation for Survivors of Torture (2004, pp. 23–24) argued

that health issues of concern for refugees include mental health, psychosocial issues and nutrition deficiencies, as well as a variety of other health issues such as intestinal parasitic disease, infectious diseases, chronic disease and women's health concerns.

Participation of CALD consumers, carers and communities in the Victorian health system is essential. They constitute a significant part of the Victorian population. Health services will need to develop specific and deliberate participation interventions to involve CALD consumers and carers in service planning, development, delivery and evaluation from the beginning. This will assist health agencies to meet the needs of all their service users. The involvement of CALD consumers, carers and communities makes an especially valuable contribution because of its capacity to define generalised as well as more CALD-community-specific barriers of access and use of services. It will also guide health policy and program decision makers on the

advantages and shortcomings of different approaches, including generating more culturally appropriate information.

What helps and hinders meaningful CALD consumer participation in health services? The following barriers and enablers for CALD consumer participation emerged from a literature review carried out in the preparation for *Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper*.

## Barriers for CALD Consumer Participation

### Lack of Understanding of Socio-cultural Factors

Insensitivity to the needs of CALD consumers, carers and communities has been pointed out as a barrier for participation. The NHMRC (2005, p. 24) argued that service providers need to: “understand the concept of culture and its impact on human behaviour, and recognise how specific problems are experienced, expressed and defined by consumers and carers of diverse cultural backgrounds (Procter cited in NHMRC 2005, p. 24).

Culture and belief systems are also important considerations to services working with CALD consumers (Rice et al. 1994; Dawson & Gifford 2001; O'Regan 2005). Conceptualising what it means to be ‘sick’ and what it means to be ‘healed’ or ‘cured’ is also culturally constructed and can affect an individual's health beliefs and behaviours (Helman 1985; Dawson et al. 2000).

### Lack of Effective Communication

Effective communication is critical for effective health care. There are a number of aspects of communication that can create problems when working with CALD consumers, carers and communities. Communication and decision making styles, interactions and information sharing, privacy and confidentiality, responsibility and accountability, perceived benefits and health care needs are all culturally mediated.

At the individual level, inability to communicate with health care providers clearly creates a barrier to accessing health care. Further, understanding the English language and/or having an interpreter is a necessary pre-condition but does not always ensure that CALD consumers receive appropriate care. There are a number of other factors—such as cultural misunderstandings, lack of reciprocal communication with service providers, and not understanding how the health system works—that are barriers to receiving appropriate care.

At the organisational level, consumer, carer and community participation may also be affected by socio-cultural factors. The Centre for Cultural Ethnicity and Health (CEH) argued that: “health systems in other countries may be vastly different, so the concept of consumer participation itself may be very unfamiliar” (CEH 2005, pp. 10–11). For example, membership of committees, answering feedback questionnaires or responding to patient satisfaction surveys may be quite unknown to some communities. A cultural practice such as providing feedback to

service providers, or speaking up in a public situation, may not be shared by some CALD communities. The CEH report referred to the difficulty that some CALD consumers and carers may have in speaking up at meetings or the issue that surveys may only elicit positive feedback, in spite of people having negative experiences (CEH 2005, p. 10).

## Systemic and Organisational Barriers

Systemic barriers, which include lack of cultural competency on the part of health service providers, lack of data reflecting CALD health issues, lack of language services and lack of awareness and access to multilingual health information all affect the capacity of CALD consumers, carers and communities to effectively participate at the individual, program, organisational and departmental levels. Among the most clearly identified barriers to consumer and carer participation are:

- Lack of language services—the inability of a health care provider to communicate with CALD consumers clearly impacts on the quality of care received, and decreases the likelihood of follow-up.
- Lack of data—the absence of accurate information about health status and health care needs of CALD communities and subgroups in these communities can prevent effective planning for service provision.
- Lack of awareness of and access to health information—the absence of culturally and linguistically appropriate health education materials about health care options, services available and health issues means that CALD consumers, carers and communities are disadvantaged and lack access to the choices available to them.

## Ongoing Issues for CALD Participation

After their analysis of case studies on CALD consumer participation practice, CEH (2005) concluded that there are a series of interrelated factors acting as barriers to CALD consumers', carers' and community participation. It is important to note that most of the issues identified by CEH as barriers to CALD community participation also affect the broader community's capacity to participate. However, these acquire relevance for CALD communities when combined with the broader socio-cultural barriers referred to above:

- Issue of representation—giving some members of a community a ‘voice’ and/or inviting them to participate in a mentoring scheme may create a hierarchy within a community, where some other members may feel marginalised and powerless; in fact, community ‘leaders’ may not lead all in the community.
- Unequal partnership—most commonly, the health service has more resources and professional expertise, benefits from and instigates consumer participation activities and sets the agenda in terms of community needs, thus creating a barrier to a partnership approach to consumer, carer and community participation.
- Funding for consumer participation—frequently, organisations focus mainly on the demands that consumer

participation impose on the organisation and not on the benefits it offers. Organisations perceive they have inadequate resources to implement CALD consumer participation in a meaningful way. This argument is related to the priority-setting of the organisation; if organisations acknowledge its benefits of consumer participation may become a priority and funding would be allocated appropriately.

- Reimbursement for participation—some organisations experience difficulties when deciding to reimburse community members for participation on committees. This decision may mean supporting only a few members of the community, to the disadvantage of others who may not be able to dedicate time to participation because their priorities may be elsewhere; for example, housing and employment needs.

## Enablers for CALD Consumer Participation

### Cultural Competency

The implementation of appropriate cultural competency 'training' is critical.

This training needs to integrate reflection, which allows health service providers and managers at all levels of the service to consider their own personal, professional and organisational cultures and values. Often, when cultural diversity is discussed, it is done so in reference to 'the other'. Yet this level of reflection and training acknowledges that diversity is inherent and generalised. It is an important beginning point to cultural competency.

This does not deny the importance of learning about the beliefs and behaviours of different cultural and linguistic communities as they affect their health and wellbeing. However, this needs to be augmented by learning that includes recognition of the health inequities experienced by people from CALD communities and the complex barriers they face as migrants (both longer term and/or newly arrived) and/or refugees in the Australian context.

Further, it is important that such training does not stereotype people. There is great diversity of both individual and collective experience within any specific CALD community. There exists a dynamic tension and development of people's cultures, even as a 'minority culture' within a dominant social context.

A culturally competent health system has the potential to overcome cultural and linguistic disparities and inequities. This is integral to the quality of health care received because the objective of culturally competent care is to secure the provision of appropriate services, reduce the incidence of error and improve the efficiency of care.

### Who is and isn't Using the Services

It is important to collate and analyse demographic data and health service utilisation information. A match between health service utilisation of CALD people and their representation in the catchment area of the health service is an important indicator

of an accessible service. A mismatch suggests barriers to access and the need for strategies that effectively encourage reaching out and working with relevant CALD communities and organisations to identify and address these barriers.

### Accessible and Appropriate Language Services

Access to appropriate language services does have an impact on health outcomes for CALD consumers and carers not able to communicate in English.

A common view is that organisations delivering treatment and care to CALD communities should strive to provide interpreting and translating services to patients and their families, and that this would mean a reduction in the cost of service provision to these patients (Department of Victorian Communities 2002, p. 10; Action on Disability with Ethnic Communities 2001, p. 30). For example, patients with access to interpreters are less likely to be re-admitted to emergency departments and more likely to keep follow-up appointments; patients who do not have access to language services may stay longer in emergency departments and have a higher number of diagnostic tests administered; lack of explanation of side effects means negative compliance with medications (Bahro 2002, p. 5).

### Developing Equal Partnerships

Building relationships based on mutual trust with a long-term commitment to the partnership is critical. Effective outreach to initiate dialogue and partnerships with organisations and community groups becomes the responsibility of the health service. Health services need to make efforts to understand communities and identify appropriate and ongoing channels, modes and means of communication.

Outreach to CALD communities may include the provision of health care in identifiable cultural settings and neighbourhoods and in partnership with ethno-specific agencies. This approach focuses on reducing barriers to care by offering services within geographical locations regularly visited by targeted CALD communities, including those that have flexible hours of service. Outreach may also be necessary on particular health issues that cut across geographical boundaries. Strong links with ethno-specific agencies and community leadership across multiple community groups become even more relevant.

Several studies have argued that developing questionnaires, surveys and interviews in collaboration with partner organisations, including bilingual workers, consumer consultants or training bilingual participants to become researchers themselves, have proven to be effective for consumer participation (Karantzas-Sawa & Kirwan 2004; Brisbane Inner South Division of General Practice 2001; Var 2004; Royle et al. 2001; Steel 2004).

Equality in the partnership means that the same value is placed on the expertise of consumers in their organisations and groups as on the health service's organisational and

professional expertise. It is important that partner organisations, community groups and their members are able to define the priorities and agenda in terms of their needs and experience. Equal partnerships need to be of benefit to community group members, their organisations and the health service.

### **Availability of Accessible Health Information**

The availability of culturally and linguistically appropriate health education materials about services and health issues are important to ensure differences in language and sensitivity to cultural beliefs and behaviours are addressed. For example, reporting quality and safety data to ethnic communities needs to be instigated in collaboration with ethno-specific organisations to ensure understanding and appropriateness of the messages and the means of dissemination.

### **Workforce Diversity**

It is important that health services reflect the consumers, carers and communities they work with as well as their broader catchment. The presence of bilingual and bicultural staff in health services increases access by health consumers and also builds on organisational cultural competency.

A key issue for bicultural workers, whether in their direct service provision and especially in their role of access and liaison with CALD communities, is that they can feel and be easily marginalised. Such workers are often having to respond to the barriers and inequities that CALD consumers have faced. Bicultural health workers need to be appropriately supported.

It is also necessary to acknowledge that the work with CALD communities is the responsibility of the whole-of-health service and staff and integrated into the provision of mainstream services.

### **Whole-of-community Approach**

Acknowledging diversity within a particular CALD community, even if they speak the same language or dialect, is essential for successful consumer participation.

Historical background, past conflicts, gender roles, political and socio-economic differences, generational barriers and settlement experience may determine the way in which different members of the 'same' community responds to a health service's invitations to participate.

People can be marginalised even within their own culturally specific groups and it is important that the multiple voices and experiences of members are heard and acknowledged.

For health services working with CALD community leadership and representatives every effort should be made to get to know the nature of the representation; for example, where is the consumer positioned in that community, and how will the

person seek feedback from the community when needed? (Var 2004; Brisbane Inner South Division of General Practice 2001; Karantzas-Savva & Kirwan 2004).

### **Organisational Commitment with Adequate Resources**

Most literature on consumer participation affirms that participation should be included in a whole-of-organisation policy and that written policies are needed for its meaningful implementation (DHS 2006; Government of South Australia 2005).

Having a clear understanding of the rationale for consumer participation in general, and CALD consumer, carer and community participation specifically—and why it is important for a health service—would establish the foundations for a commitment to invest human and financial resources in participation.

### **Conclusion**

The literature review identified and explored important factors that help and hinder CALD consumer participation in health services. Health Issue Centre believes that health services alert to these multiple and interconnected factors can more readily address them and work towards a more inclusive and equitable health service.

*Consumer Participation and Culturally and Linguistically Diverse Communities: A Discussion Paper* develops a framework and strategies that can further enhance the work of health services in promoting participation at all levels of their practice. It is available from our website: [www.healthissuescentre.org.au/documents/items/2008/04/203594-upload-00001.pdf](http://www.healthissuescentre.org.au/documents/items/2008/04/203594-upload-00001.pdf) or by contacting Souzi Markos, Ph: (03) 9479 5827.

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