



CENTRE FOR *culture*
ethnicity & health

Consumer Participation and Culturally and Linguistically Diverse Communities





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Abbreviations

CEH Centre for Culture Ethnicity & Health
 CALD Culturally and Linguistically Diverse/Cultural and Linguistic Diversity
 DHS Department of Human Services

To create services that are truly focussed on the needs of the communities, it is essential that organisations engage the broad spectrum of local consumers.

Foreword

The *Multicultural Victoria Act 2004* states that all Victorians are equally entitled to access opportunities and participate in the social, cultural, economic and political life of the state. The ways in which health and community service providers encourage the participation of culturally and linguistically diverse (CALD) communities has an important bearing on the quality of their services.

The diversity of consumers from non-English speaking backgrounds is a great challenge to service providers. It also brings the possibility of rich and valuable contributions to health and community organisations. To create services that are truly focussed on the needs of the communities, it is essential that organisations engage the broad spectrum of local consumers.

This report encourages critical reflection of the effectiveness of current consumer participation strategies to engage culturally and linguistically diverse consumers. Identifying some of the critical success factors and challenges in working with CALD communities, the report presents a model for good practice as well as case-study examples of work undertaken in the health and community sector.

We hope that this report will assist organisations to reflect on their current practice and build their capacity to implement culturally and linguistically inclusive consumer participation strategies.



George Lekakis
Chairperson
Victorian Multicultural Commission

CALD consumers make up approximately 25% of the Victorian population. Accordingly CALD consumers need to be actively engaged by health and community organisations to ensure that service and program models meet the needs of a quarter of the population.

Introduction



Introduction

Consumer participation in health care encompasses both current and potential consumers of health services, carers and the wider community participating in decision making about health care. For the health and community sector, the parameters of what constitutes consumer participation are very broad and can include anything from individual decisions about care to participating in policy, workforce and service development.

The evidence supporting consumer participation in health demonstrates that participation:

- Can lead to more accessible and effective health services¹
- Is a mechanism to ensure accountability
- Can improve health outcomes and the quality of services²

CALD consumers make up approximately 25% of the Victorian population³. Accordingly, CALD consumers need to be actively engaged by health and community organisations to ensure that service and program models meet the needs of a quarter of the population.

The participation of individuals and communities can be influenced by a variety of factors from personal preference to socioeconomic circumstances. For CALD consumers, their ability to participate may be limited by such things as language proficiency, migration experience, social isolation, other personal priorities such as housing and employment and lack of familiarity with meeting structures and the Australian health system. These factors must be considered in order to determine the relevance of a particular participation strategy to CALD consumers and communities.

'Consumer participation' is used in this report to broadly describe processes of community participation, carer participation, patient-centred care or client participation. CEH has chosen the term consumer participation as it is most commonly used in academic literature on participation in health.

Purpose of the Report

The purpose of this report is to present findings from a conference that CEH held in September 2005 which was called *Consumer Participation and Culturally and Linguistically Diverse Communities: Working Together Towards Good Practice*. The aim of the conference was to explore ways in which health and community organisations facilitate and support the participation of CALD consumers in the planning, implementation and evaluation of services, programs and projects.

The report discusses some of the areas of CALD consumer participation that could be reflected upon when designing and implementing effective strategies. The themes in this report are supported by a series of case studies which demonstrate how a health or community organisation has worked with CALD communities and consumers. These case studies were drawn from presentations at the conference.

¹ National Resource Centre for Consumer Participation in Health *The Evidence Supporting Consumer Participation in Health*, Bundoora, Latrobe University, 2001

² Metropolitan Health and Aged Care Services *Division Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services*, Melbourne: State of Victoria, Department of Human Services, 2005

³ Victorian Office of Multicultural Affairs Website www.voma.vic.gov.au

Introduction

The report also highlights that many key tensions and gaps exist in participatory practice. A variety of challenging ethical concerns have been noted by the practitioners and consumers that contributed to this report. The gap between organisational rhetoric and what is actually happening on the ground has also been pointed to as an area of concern. This is consistent with the policy context of consumer participation, which was described in a discussion paper written by the Department of Human Services (DHS) early in 2005⁴. The paper indicated that current policy directions on consumer participation are somewhat fragmented, occurring in a variety of different policy documents, but with no overarching policy to draw these together. DHS is currently developing a whole of department policy for consumer participation which will hopefully support a more comprehensive and structured approach to consumer participation in the health and community sectors.

The report is written from an organisational point of view, as most of the information gathered was from workers who had developed and implemented participation strategies. The CALD consumer perspective of participation still needs to be explored more fully as the current agenda for CALD consumer participation tends to be service driven. CEH is hoping to develop a complementary resource to this report in the future which reflects CALD consumer perspectives of consumer participation.

For some readers, this report may offer more questions than it answers. It is not an exhaustive account of all the issues that need to be addressed in working with CALD consumers. Rather, it is designed to guide organisations along a path of reflection about the opportunities, benefits and challenges of CALD consumer participation.

Methodology

Each year, CEH conducts a Good Practice Project to explore and promote good practice that aims to enhance the health and well-being of Victoria's CALD communities. Consumer participation (along with language services) was one of the areas that CEH identified for 2004-05 after emerging as a key issue for services in the *Community Health Service Needs Analysis* conducted by CEH in 2004.

In conducting a literature review on this subject, CEH found a lack of documented practice examples. A conference was identified by CEH as a way for workers to share their experiences, identify gaps and work together towards good practice. The rationale was that, in turn, this would provide an opportunity for practice examples to be documented and disseminated more widely.

A steering committee was set up to guide the overall direction of the conference and provide expertise on key areas of CALD consumer participation. Representatives were invited from community health, an ethnic community organisation, a migrant settlement service, a key consumer participation organisation, local government and from within CEH in order to elicit a range of perspectives. The committee discussed how best to gather examples of practice which could demonstrate critical success factors, challenges and key learnings in CALD consumer participation.

Following the first meeting of the committee, a *Call for Submissions* was developed and sent out to health and community organisations, contacts in government and consumer organisations so that they could nominate their work with CALD consumers as an example of good practice.

⁴ Metropolitan Health and Aged Care Services Division *Participation in your health service system: Victorian consumers, carers and the community working together with their health service and the Department of Human Services*, Melbourne: State of Victoria, Department of Human Services, 2005, <http://www.health.vic.gov.au/consumer/participate.pdf>

A conference was identified by CEH as a way for workers to share their experiences, identify gaps and work together towards good practice.

This yielded a small number of submissions, of which ten were selected by the committee to be presented at the conference. Again, there seemed to be a lack of practice examples which could be assessed to determine what good practice might be.

Selection of submissions was based on the range and complexity of different strategies described, with the understanding that a variety of approaches could encompass good practice. Keynote speakers and panel members were also invited to share their experiences of CALD consumer participation to broaden the strategies and viewpoints being presented.

The conference took place in September 2005 and was attended by around 140 people. Information from presentations, discussions at the conference and consultations with presenters and experts in the field has been synthesised to produce this report. Both consumers and workers have contributed to the drafting of the report.

Structure of the Report

Based on information gathered through the conference, CEH has identified a thematic way for organisations to reflect on culturally and linguistically appropriate consumer participation. The 'Themes' section of the report consists of six major considerations for health and community service providers wanting to effectively engage with CALD consumers.

The themes of the report are as follows:

1. Organisational Commitment
2. Cultural and Linguistic Appropriateness
3. Support and Mentoring for Consumers
4. Representative Consumers
5. Ethics, Power, Equality and Reciprocity
6. Levels and Degrees of Participation

The organisational commitment theme provides a context for the rest of the report by demonstrating how consumer participation needs to be co-ordinated, resourced and supported in an organisation in order for it to be successful.

Case Studies

The themes listed above are followed by a selection of case studies which highlight how particular organisations have approached working with CALD consumers. While the case studies do touch on particular themes, they address a variety of considerations which are discussed throughout the report. They are intended to demonstrate that there are diverse ways in which organisations can facilitate the involvement of CALD consumers and each has individual challenges and benefits.

For reasons of space and clarity, not all case studies which were presented at the conference have been included here. Those that have been selected represent a range of organisations, projects and programs, different stages of implementation and with different degrees of participation.

For more information about any of the case studies described, please contact CEH or refer to the contact details on particular case studies where these are provided.

A key consideration in developing a CALD consumer participation strategy is how well placed the organisation is to respond to the needs identified by communities and what capacity the organisation has to support consumer-driven initiatives.

Themes



Themes

Organisational Commitment

CEH's research has demonstrated that there is a gap between organisational rhetoric about commitment to CALD consumer engagement and participation, and the dedication of resources or the organisational know-how to make it happen effectively.

Workers consistently grapple with the notions of ethics, power, equality and reciprocity as they try to determine what constitutes genuine participation, and how true partnership can occur when the agenda is determined by the service provider.

A key consideration in developing a CALD consumer participation strategy is how well placed the organisation is to respond to the needs identified by communities and what capacity the organisation has to support consumer-driven initiatives. How will the organisation manage where its own priorities are different to those of particular CALD communities? Negotiating the gaps with sensitivity, respect and a clear understanding of the organisational limitations will be crucial to the success of participation. Briefing the community clearly on the scope of a project or program will possibly reduce unrealistic expectations and disillusionment and allow them to be practical and solution-focused.

Building organisational capacity to develop and implement effective CALD consumer participation strategies involves exploring a range of key issues. CEH research has shown that an organisation needs to:

- Be clear about why consumer participation is important and what the organisation wants to achieve by including consumers. This bigger picture view needs to be communicated and understood across the entire organisation.
- Know who their CALD consumers are, both current and potential clients.
- Consider what level and degrees of participation will be most appropriate to achieving the goals of the organisation and those of the community.
- Map current CALD consumer participation across the organisation – is there duplication of effort? Are there opportunities? Is the range and scope of consumer participation across the organisation known and coordinated? Are there areas of the organisation implementing effective consumer participation strategies? If so, how are these being captured so that learnings can be shared across the organisation?
- Ensure that staff have appropriate skills, experience and confidence – this might mean an understanding of cultural and linguistic appropriateness, considerations for mentoring and supporting CALD consumers and knowledge of methods of participation.
- Build and maintain ongoing links with ethno-specific organisations and community and cultural associations to facilitate meaningful partnerships.
- Determine what organisational supports are needed to create an environment that enables effective consumer participation – for example, language services, policies, procedures, coordination, evaluation and quality improvement mechanisms, and resource allocation.

Themes

Cultural and Linguistic Appropriateness

Developing a strategy that is appropriate to the cultural background and language preferences and skills of consumers is an important first step.

Language

In order to engage consumers with low English proficiency, communication must occur in the preferred language of the consumer. This can be done through interpreters or bilingual workers, or translations may be utilised if the literacy of the consumers in their first language is sufficient. There may also be a range of languages or dialects that could be spoken by consumers from a particular country of origin and organisations might have to cater accordingly when planning to meet language needs. Prior research or consultation will help to determine which languages are appropriate.

Culture

Some participation methodologies will not be appropriate for all groups due to cultural differences. Asking for individual opinions or feedback may not be a good fit with the collective orientation of some cultures. Satisfaction surveys may only elicit positive feedback from some CALD consumers, regardless of negative experiences. What might be considered traditional practices may not be appropriate for all CALD consumers in a particular community. Replicating practices from the country of origin may not take into account that these are considered unjust by some members of the community, who may feel marginalised in their own community. Examples of this might include how the status of women can differ in other cultures. The key is to check what is preferred and appropriate with the consumer and, if possible, let them shape how their participation might occur.

Targeting Strategies

The target group of a participation strategy could be based on country of origin, language spoken, ethnicity, gender, age, illness/condition or any other relevant variable. Selecting people from a particular language group to be targeted will not necessarily mean that they are a defined community who have links with one another and the same view of their culture. While it is easy for organisations to target, for example, the 'Vietnamese Community', in reality this so-called community may be very dispersed. Individuals may not want to identify themselves as belonging to that community and 'community members' may be ethnically diverse. There may well be considerable gaps in a sense of community belonging between different generations. Acknowledging the diversity and complexity that exists within all groups will be important for determining how to target a particular strategy.

The political and historical background of CALD communities can also be researched to determine whether any past conflicts or events might influence the targeting of a particular group. Recent arrivals from the former Yugoslavia, for example, may need to be targeted in different and separate ways to encourage their participation, given the political context of their migration and their ethnicity. People from migration streams such as humanitarian entrants and skilled migrants may also need to be targeted in different ways as their needs may vary given the context of their migration.

A Variety of Strategies

The diversity of CALD consumers can sometimes be obscured by the use of the banner term 'CALD', which seems to imply one strategy for all people from non-English speaking backgrounds. Offering consumers a range of ways that they could become involved in the development of services and programs has a greater chance of meeting their needs and enabling their participation. This could mean offering options such as focus groups, surveys, community meetings, committee membership and informal interviews.

Acknowledging the diversity and complexity that exists within all groups will be important for determining how to target a particular strategy.

Support and Mentoring for Consumers

Providing support to consumers which assists them to participate, as well as acting as a mentor so that consumers can develop skills and knowledge, provides consumers with a greater opportunity to participate in a sustained and meaningful way.

Types of Support

Support for CALD consumers may be different than that needed by other consumers due to their individual language needs, migration history, knowledge of the health system or cultural values and beliefs. What level and type of support is required will need to be established by working with the individual consumer.

Mentoring a consumer to develop their knowledge of committee structures or the nature of the health system or service provider may mean the difference between meaningful participation and the consumer not being able to contribute at all. Health systems in other countries may be vastly different, so the concept of consumer participation itself may be very unfamiliar.

Briefing consumers prior to meetings and providing an environment where the consumer feels supported to speak up will be extremely important. Many CALD consumers may not want to speak up for fear of retribution or having services withdrawn, particularly where they have come from countries where government corruption is common. This fear can be countered by working with the consumer to develop their understanding of how participation processes operate and what the outcomes might look like. The benefits of support are widespread and can include building the skills of consumers so that they have greater opportunities for employment and higher confidence and self-esteem.

Support such as reimbursement and opportunities for training are not CALD-specific, but are integral to effectively engaging CALD consumers. Reimbursement may be particularly important in smaller communities where there may be ongoing opportunities for participation and input, but only a few in the community who are able to commit their time due to other issues being a priority, such as housing and employment.

Communication

The use of terminology, acronyms and jargon may discourage CALD consumers from fully participating. Support in either making the definitions of different terminology clear or refraining from using jargon at all will help enable CALD consumers to participate more effectively.

Professional Consumers

Organisations often look for an 'authentic' consumer who speaks as a member of a community on particular topics. Over time, through a process of participation, support and mentoring, organisations may find that consumers become more 'professional'. As their knowledge and skills in participation grow, this doesn't necessarily correspond with a decrease in their ability to provide a consumer viewpoint. The apparent professionalisation of consumers is not negative. Rather, they will have a wider range of skills and abilities which could be employed in participation processes.

Themes

Representative Consumers

Representation means being able to speak on behalf of a particular group of people and provide their views on particular issues. While representation can be an important part of consumer participation, as it is not possible to obtain and include the views of every consumer or community member, how it occurs and for what purpose requires consideration.

Community Links

When using a representative of a specific CALD community, or CALD communities in general, organisations need to have an understanding of the links between the representative and the community being represented. How well connected is the consumer to their community? How will feedback and consultation occur? How often will it occur? Is the representative being supported by the organisation to consult with communities on an ongoing basis? Answers to these questions will provide a context for the nature of the representation that is occurring.

Diverse Views

The diversity within CALD communities is high, so the views of all community members cannot be represented by a small number of people. Furthermore, community views may be conflicting and diverse. Asking one consumer to represent others entails providing them with an understanding of whether to present the most dominant view in a community, to talk about the spectrum of viewpoints or think about which views might be marginalised. When asking a representative to provide a cultural perspective, it must also be understood that there are diverse perspectives on particular cultures. Culture itself is dynamic and changes with migration experiences, time spent in different countries, generations and interaction with other cultures.

Over-Representation, Marginalisation and Fatigue

Organisations may find that the same representatives are continually participating. This may happen due to their knowledge of participatory structures, their English proficiency or their status in their community. While they may be a vibrant and dedicated representative, it must also be established whether the views of others are being heard. The specific target group being represented (e.g. women, the elderly, youth, people with a particular illness, etc) needs to be made clear both by the organisation and the representative. Representation may give the illusion of inclusion.

Individual representatives may also lose enthusiasm for their role over time, but feel they must to continue due to community or agency demands. Over-representation by the same individuals or groups may lead to what is referred to as 'consumer fatigue', so having a variety of people that can represent community views may assist in sustaining input over time. Fatigue may need to be recognised and managed by organisations due to the obligations felt by consumers to the community they are representing. This could happen through regulating the amount of time a representative sits on a particular committee or group or rotating different representatives through different functions, or through a co-ordinated approach to consumer participation at the whole of organisation level.

The community needs to benefit equally and tangibly to maintain a good relationship with the organisation and not become disillusioned by providing their time and resources to support organisational practices.

Ethics, Power, Equality and Reciprocity

Ethical considerations are integral to determining how participation is facilitated and sustained. These might include thinking about where power lies, how resources can be shared and whether benefits and contributions are reciprocal.

Community Hierarchies

Giving some consumers the opportunity to provide their opinion, perhaps due to their English proficiency or 'leader' status, and not others, can create a hierarchy within communities that can disturb or compound community structures. This can particularly be the case where mentoring and support is provided to individual consumers. This doesn't mean that mentoring and support shouldn't be provided, just that the organisation needs to understand what effect participation could have on a CALD community as a whole.

The organisation's understanding of a CALD community will influence which channels they approach the community through and whether they call on 'leaders' to participate. Community leaders may not 'lead' all those in what appears to be a designated community. Selection of participants needs to take account of the relationships within a community, possible conflicts and community members who may feel marginalised and powerless within their 'own' CALD communities.

Equal Partners

In order to counter any possible negative consequences of organisations driving participation strategies, where power lies in the participation relationship could be assessed. If communities are equal partners in a particular participation strategy, they have more power to shape how participation occurs and what its outcomes are. Generally, most power sits with the organisation as they have more resources and professional expertise. However, if CALD consumers or communities identify their own needs, rather than respond to a need identified by an organisation, this can spread power more evenly across the organisation and community. This could happen through facilitating open discussion, rather than focused questions which lead consumers down a particular track.

The benefits of consumer participation can often be skewed in favour of the service provider, as it is their requirement that participation is facilitated and under their direction that it occurs. The community needs to benefit equally and tangibly to maintain a good relationship with the organisation and not become disillusioned by providing their time and resources to support organisational practices. Providing feedback on the outcomes of participation, or referral to appropriate alternative services where the organisation recognises that it can't meet particular needs, might prevent this.

Different Contributions

In order to create true community ownership of the services which exist to meet community needs, communities must share decision-making, expertise and resources so that benefits are mutual and sustainable. Communities and organisations have different and complementary expertise and knowledge. Different kinds of contributions need to be understood, encouraged and valued accordingly. This could lead to a higher degree of reciprocity, which will contribute to the sustainability of consumer involvement.

Themes

Levels and Degrees of Participation

A ladder or continuum of participation, which indicates levels of participation, is often referred to in discussions of consumer participation. These scales rate the degree of control that consumers have in decision-making and tend to favour higher levels of control as being more beneficial to consumers.⁵

Levels of Engagement

When it comes to CALD communities, organisations need not just aim for the highest level strategy or the most participatory. Strategies need to be both appropriate to the organisation's capacity and priorities and community needs. The capacity of communities and individuals to participate and their desire for participation will vary widely. Refugee and asylum-seeker communities, for example, may not see health as a high priority as they may be more concerned with employment and housing, so an approach where they control an initiative may not meet their needs.

A range of strategies which traverse the apparent levels of participation are more likely to work as they would address the diversity within and between communities. Options such as focus groups with bilingual facilitators, peer education, one-off forums, in-language surveys and community committees are but a few examples of the range of strategies that could be employed. Community members are likely to have differing levels of comfort in and commitment to each one given both their cultural context and personal situation.

Meaningful Strategies

When selecting a particular strategy, however, organisations need to be aware of fitting the strategy to community needs to ensure that it best meets the needs of the community and doesn't appear tokenistic. Selecting a strategy such as a survey, which gives the community a fairly low level of control, may be viewed as tokenistic if the community has expressed that it wants to be closely involved in shaping a service or program so that it is culturally relevant. Similarly, having places on a Board of Management for CALD consumers as the only strategy available may appear to demonstrate a lack of commitment to genuine and meaningful participation. This strategy relies on the representation of one or two people in one kind of forum for the entire community.

Having the knowledge to determine what kind of participation is going to be appropriate to which community relies on having ongoing and open dialogue with communities and building relationships over time which can elicit community preferences and needs. This is the kind of environment which will support a successful CALD consumer participation approach.

⁵ Examples include:

- Brager and Sprecht, *Ladder of Participation*, 1973.
- Arnstein, Sherry R. "A Ladder of Citizen Participation," *Journal of the American Planning Association*, Vol. 35, No. 4, July 1969.

The focus of the group activities is support, education and skill development, so that group members can feel comfortable with the role of consumer advocate.

Case Studies



flexibility

community-identified needs

The Family Understandings Project: Mental Health and Horn of Africa Communities

Western Region Health Centre (WRHC) is a community health service located in Melbourne's inner west. The catchment area for the service is incredibly diverse, with 35.2% of the population coming from a non-English speaking country, and 7.1% having arrived since 1996. Horn of Africa communities in the catchment have a diverse range of backgrounds, with many having suffered torture and trauma through their migration experiences.

The Health Promotion program at WRHC was having trouble reaching these communities. We identified that there were gaps in the way we were working with Horn of Africa communities around mental health issues, indicated by our lack of understanding of the mental health needs of the communities, and their lack of utilisation of mental health services. Our research failed to find mental health information available in the majority of Horn of African community languages or many culturally appropriate mental health services. We found that communities also had a reluctance to use our services due to language and cultural differences and a lack of knowledge.

“If someone has a mental problem they don't want to admit/accept it for fear of being isolated, therefore people don't receive help and therefore people need education and to hear about solutions”

We invited leaders from over forty community organisations to participate in two forums to talk about the communities' mental health needs, and how WRHC could assist in meeting those needs. Twenty-three leaders attended. At the first forum, the communities identified that lack of family support was a key aspect in dealing with mental health issues, and that this was lacking due to separation and misunderstandings within families and loss, grief and stress experienced from their country of origin, during migration and settlement. Furthermore, the communities also noted that traditional approaches to mental illness were very different to those within the Western model of health care.

“This is very important information for our people” Peer Educator

At the second forum, the community leaders identified a peer education model as the most appropriate way to work with the communities. We called the model 'Family Understandings' to recognise the key link between supportive family structures and addressing mental health issues. The peer education model was designed to offer education sessions about mental health symptoms, strategies and ways to help yourself and others, and how to access appropriate services.

As a result, we recruited peer educators from the communities based on those who were well respected and well networked. We provided training on mental health, mental illness and giving health promotion talks within a community/family support framework. We found the benefits of this approach to be that we have developed a dedicated, enthusiastic and self-motivated group of peer educators who continue to give us feedback on our best way of delivering health promotion messages. The program has continued to evolve as issues continue to be raised. An ongoing challenge has been how the educators can discuss personally challenging topics and motivate their community to take positive action, while continuing to support their families here and those still suffering overseas. We believe that the success of the program so far has happened through having exceptionally committed educators and culturally sensitive, skilled and well networked staff who have had the time and flexibility to respond to what the community identified in a respectful manner.

cultural and linguistic appropriateness

flexibility

Mismatched Caring: The Multicultural Challenge

*The Royal Hospital for Women is a leading teaching and tertiary referral hospital for women and babies in New South Wales. The Professor of Nursing, dually appointed to the **University of Sydney**, leads nursing and midwifery research within the Centre for Women's Health Nursing in the hospital. From 2000 there was a yearly increase in the number of Bangladeshi women accessing the hospital's maternity services. This was a first generation immigrant group about which little was known. There were several challenges dealing with Bangladeshi women and their families who came to the hospital for maternity care.*

With a Diversity Health Grant through the Multicultural Health Unit, we developed a project that would assist us to gain an understanding of the cultural aspects of childbearing that are important to Bangladeshi women and their families. We hoped that this would be the basis for developing culturally competent staff and culturally appropriate services.

We employed a community based Bangladeshi woman, fluent in both English and Bengali, as project coordinator. We began the project with a meeting with key community leaders who were invited to provide advice about the proposed study. They were enthusiastic about the study and two used their community newspaper and SBS program to publicise it.

We then conducted four focus groups with a total of 38 women and two focus groups with a total of 5 men. These were also tape-recorded with consent from each group member. Each group was led through a structured discussion about beliefs, practices, rituals, taboos and appropriate interaction throughout childbearing. Having a bilingual group leader facilitated discussion in both a culturally and personally sensitive manner and in a language the participants found most comfortable for the topic. This was evident during discussion in Bengali, which sometimes reflected a diversity of views between families, regions, religions and generations. We asked each sequential focus group to review information received from previous groups for validation and clarification.

We searched notes and transcripts from the focus groups for cultural aspects of childbearing, and then categorised these into various areas of service delivery such as health education, antenatal, labour and delivery, and postpartum. The project coordinator was both language interpreter and cultural interpreter during this phase. The clinical units and community members provided validation and discussed implications of an action plan for integrating these cultural aspects for both service providers and members of the Bangladeshi community. We then developed clinical guidelines for maternity care service providers and the Bengali press printed a series of articles providing information about the Australian health care system and childbearing services.

We found that our use of community participation provided a bridge between our practices at the Royal Hospital for Women and the beliefs and behaviours in child bearing of Bangladeshi women. This has resulted in space for daily prayers, Halal meat available and the possibility of space for family gatherings if required. Clinicians and Bangladeshi childbearing families have a clearer understanding of areas that can be negotiated within safe practice and cultural needs.

A video entitled *Having a Baby in Australia* is available in Bengali and English. It provides information about pregnancy, labour and delivery and postpartum and is available through the Centre by calling Shamim on (02) 9382 6741 or by emailing Shamim.Islam@SESIHNS.health.nsw.gov.au

The Spectrum of Cultures Group: Giving Mental Health Consumers Voice, Visibility and Respect in Society

The Consumer Advocate at the Victorian Transcultural Psychiatry Unit (VTPU) has created a group for culturally diverse mental health consumers. The group provides mentoring and support for CALD consumers to speak out about their own needs and advocate for changes to the mental health system at relevant forums and networks.

I am a mental health consumer from a CALD background and I lead the Spectrum of Cultures Group. We meet on a monthly basis and follow a guiding agenda set by the group members. I employ a community development approach to skill consumers to become advocates in formal settings. The group has started only recently and already fourteen consumers are participating from five different nationalities! We have begun by sharing stories of our mental health experiences and cultural backgrounds with one another.

I formed the group to address the limited nature of opportunities for CALD mental health consumers to speak out about the interaction between their mental illness or condition and cultural issues. We are also facing the added difficulty of the stigma attached to mental illness in some CALD communities. The group addresses both the structural issues and the stigmatisation through allowing members to first share their personal histories with one another, then I provide mentoring and support for the consumers to communicate their issues to mental health services.

“It is fantastic to meet other people in the same predicament as myself and share some of the happy and sad journeys together. It’s a start of a process to cater for the ethnic mental health consumers in a better light and with a clear vision of positive hope and innovative inspiration.”

The focus of the group activities is support, education and skill development, so that group members can feel comfortable with the role of consumer advocate and be able to adapt to different settings. Peer support will be a key focus of the group so that long lasting, valuable connections can be formed between group members as we begin our journey of participation in the development of mental health services.

I hope that the nature of the group will also encourage mental health services to offer participatory opportunities in a more structured and continuous way, rather than some of the fragmented arrangements that currently exist. I also hope that the group will develop a pool of consumer advocates who will be able and available for mental health services to call upon for consultations.

“It’s therapeutic, it’s fun and it’s empowering us consumers from different backgrounds to share experiences, struggles and ways to cope with our misfortunate illness. More of these groups should develop!”

For more information, please contact Evan Bichara, Consumer Advocate on **0411 054 882** or evan.bichara@svhm.org.au

support and mentoring

representative consumers

Diversity and Disability: Be The Changes You Want

Migrant Resource Centre North West is auspicing a program which was formerly called Multicultural Self-Advocacy Victoria. Based on consumer input, the name of the program is now "Diversity and Disability: Be The Changes You Want". The program will assist people from CALD backgrounds with disabilities to understand their needs and better advocate for them as a result. The program has a steering committee made up of CALD consumers with disabilities.

This program has been driven by consumers, both as workers and members of the steering committee. We, the workers, are CALD consumers with a disability, and have worked extensively in the disability sector to support those with disabilities to speak out and be independent as much as possible. The aim in much of our work, and in this program particularly, has been to enable CALD consumers with a disability to achieve their full potential and be true citizens of their communities.

"I am satisfied with my level (of participation) because I got every opportunity from staff to contribute"

We have set up a steering committee for the program which is entirely comprised of representatives of CALD communities who have a disability. The role of the committee has been to drive the direction of the program through establishing a purpose and aims, services for members, a mission and vision, policies and membership. The committee have also written a three year strategic plan to guide the implementation of the program.

We support members of the steering committee to participate through provision of notes and documents in plain English and coloured folders divided into sections which make it easy to find and store papers in the right section. We provide briefings prior to meetings and create an environment where members feel comfortable to speak up for themselves and respect the opinions of others.

The aim of the program by the end of next year is to build a membership of fifty CALD consumers with a disability, whose skills in self-advocacy and representation can be developed through their involvement. We are planning to grow the membership to five hundred in the future. As a result of this program, connections with the wider community can be created to promote attitudinal change. The group will offer opportunities to workers and carers to consult on the needs of people from CALD backgrounds with disabilities, and enhance wider participation and representation by these consumers in the multi-cultural and disability sector and at local, regional and national forums.

"(The happiest moment for me is that I can) work in a team, develop friendships and be considered equal as part of the community"

Healthy Ageing through Exercises and Healthy Eating

*The Polish Senior Citizens' Club in Ardeer, in western Melbourne, decided that they wanted to get involved in some activities that would improve their physical wellbeing. 80% of the club members are in their 80s or older. They approached **Australian Polish Community Services (APCS)** to ask for some assistance in organising activities and sourcing funds to support the process.*

At an initial meeting with club members and our staff, it was established that the seniors wanted to undertake some gentle exercise and learn more about healthy eating through information sessions with a dietician. We encouraged the group to apply for a Positive Ageing Community Sponsorship Grant and to go ahead with the project.

The seniors were awarded the grant and needed to begin the process of organising the exercise and healthy eating sessions. At this point, however, the seniors started to feel overwhelmed by the process and considered declining the grant. Not only did they need to organise the group in its entirety, they were unfamiliar with the administrative tasks required to manage the grant. They approached us again and asked for some further assistance. A joint decision was made between our organisation and the seniors that we would aid them to seek Polish speaking instructors for the exercise and healthy eating group and would explain the administration aspect of the project.

As a result, the group went ahead with a high level of participation from the seniors. An indicator of the success of this initiative is that the seniors continued to conduct their own exercise sessions for a brief period after the grant had run out. However, some members were no longer able to attend as time went on due to age-related illnesses. Nevertheless, the community was able to build its capacity to drive activities and we were able to offer support in a way that was directed by the community and responded to a need that the community identified for themselves. We were able to work together in a full partnership.

appropriate levels and degrees

meaningful strategies

Ageing, Participation and Wellbeing: The Village Glee Club Intergenerational Choir

Jewish Care operates a high level residential care facility called Munzer Community Residence in Melbourne's inner south-east. This facility has 36 residents who come from Australian, English, Polish, German, Latvian, Russian and Hungarian backgrounds. Most residents are Holocaust survivors. Approximately half of the residents attend the Intergenerational Choir, though this attendance is limited by a lack of physical space as the residence is currently located in temporary premises.

The Village Glee Club Intergenerational Choir came about through an environment that encourages the participation of our residents and their families in decisions about care. Monthly meetings and regular surveys provide information to us about what residents and their families identify as needs. One of the needs identified by these methods was for lifestyle and leisure programs which are culturally and linguistically appropriate and maintain and strengthen links with the community. We thought that a singing group could meet the needs identified by the residents and their families.

“She was even reluctant to join... because she couldn't sing as well as she would like (due to a stroke) but just that involvement has overcome the fact that she thought she would never be able to enjoy that sort of participation again” RESIDENT'S SON

The idea of a singing group was one that had proved successful in other care facilities. At the Munzer Residence, however, we found that there were a variety of challenges. Many residents have hearing and vision loss, others have limited mobility due to strokes and some are experiencing mental health issues such as high levels of anxiety. Most residents are in wheelchairs. This has meant that many residents have difficulty holding song sheets and turning pages or singing with the group. However, we also found that some have been happy to participate simply to tap their feet along to the music and this has broadened our understanding of what 'participation' actually means – that it is inclusive of and reflects the benefits for each individual.

Rather than being a sing-along, the group is actually a choir that practices to perform on significant days. The group is intergenerational because it regularly practices with students from local schools so that students sing *with* rather than *for* the residents. This is an important distinction which residents have expressed to us, as some have felt that their self-esteem and well-being have been enhanced through their participation in the program as they are able to give and teach, despite being considerably incapacitated.

“In spite of my disabilities, I can actively participate”

Throughout the program, we have facilitated and encouraged the participation of residents in the overall planning of the program. We have invited suggestions from the residents for which songs to sing and which schools to invite. Residents have taken the opportunity to select culturally and personally significant songs. Singing these songs with local school children has their enhanced links with the wider community, enabled the residents to share their cultural heritage and take part in additional recreation opportunities. We have experienced a greater degree of contribution to planning as residents have become more enthusiastic about the group.

The most effective participation approach will involve a range of different purposes and different outcomes which can contribute to a variety of aspects of an organisation.

Resources



How to: A PRACTICAL GUIDE TO CALD CONSUMER PARTICIPATION

Culturally and linguistically diverse (CALD) consumer participation encompasses a vast array of different strategies which can be used to engage CALD consumers in the planning, implementation and evaluation of health programs, projects and services. The most effective participation approach will involve a range of different strategies with different purposes and different outcomes which can contribute to a variety of aspects of an organisation. The more that CALD consumers are able to participate in diverse ways, the more likely an organisation is to be responsive to their needs. Below are a number of examples of different strategies that might be employed with some suggestions about how to make them successful.

CALD Consumers on Boards of Management

Description	<ul style="list-style-type: none"> Organisations seek representation on Boards of Management that is reflective of CALD communities within their catchment
Benefits	<ul style="list-style-type: none"> Input is at the top level of decision making Opportunities for skill enhancement and social participation for consumer representatives Consumer can provide input on particular cultural sensitivities in program/service planning
Issues to consider	<ul style="list-style-type: none"> Consumer can't represent all ethnic communities in the catchment Consumer can't be the 'cultural expert' for their community or other ethnic communities
Actions for success	<ul style="list-style-type: none"> Engage with the community to select the most appropriate representative from that community Have a commitment to training, supporting and mentoring the consumer about the health sector and meeting processes Meet the language needs of the consumer

Consumer Planning Days

Description	<ul style="list-style-type: none"> An issue relevant to a particular CALD community is identified and presented to that community to make decisions which are incorporated into planning processes
Benefits	<ul style="list-style-type: none"> Community is given ownership to plan for a particular issue, which will encourage cultural appropriateness, especially if they are also involved at the needs identification stage Community will have closer involvement with mainstream services, therefore greater awareness of services available Agency has greater links with community which may also help to address access issues
Issues to consider	<ul style="list-style-type: none"> Community may not be involved in needs identification, problem definition, implementation or evaluation Community may have lack of knowledge of planning and systemic parameters
Actions for success	<ul style="list-style-type: none"> Provide a clear rationale for the issue Use interpreters and translated materials Work from a community based venue and facilitate the days through community representatives and organisations Develop content and procedures for Planning Days based on community input to ensure cultural appropriateness Be flexible and allow time for information and issues to be fully considered by community

Consumers on Project Reference and Steering Groups

Description	<ul style="list-style-type: none"> Ongoing participation by CALD community members in planning processes and contribution to implementation and evaluation is sought by organisation
Benefits	<ul style="list-style-type: none"> Ongoing engagement and commitment to CALD issues If communities are aware of representation by their own community members they may be more likely to use the services/programs Valuable participation in steering groups may encourage higher levels of participation in the future
Issues to consider	<ul style="list-style-type: none"> Formal meeting structures may be unfamiliar and intimidating Difficulty of recruiting representatives for ongoing time commitment Whether the issue being discussed is one that affects the community in question
Actions for success	<ul style="list-style-type: none"> Using ethno-specific agencies as a contact point for recruiting consumer representatives Reimbursement for attendance Finding a consumer who has good links with their community Support and mentoring in committee structures Ensure that project aims have a clear benefit for the community

Consumer Advisory Groups

Description	<ul style="list-style-type: none"> CALD consumers are engaged to provide input to groups that are separate from Boards of Management to elicit responses to particular questions
Benefits	<ul style="list-style-type: none"> Able to engage with and target particular communities on particular issues Allows for dialogue between consumers of different ethnic backgrounds Facilitators can experience a variety of views within a particular community
Issues to consider	<ul style="list-style-type: none"> Consumers not necessarily learning a lot about health services Benefits are skewed towards agencies As consumers are not involved in decision making, programs may not end up being culturally sensitive
Actions for success	<ul style="list-style-type: none"> Select representatives that have knowledge, experience and interest in the issues Use interpreters when required Pilot test questions to ensure cultural appropriateness and relevance Brief other consumers in the group on how to work with interpreters

Focus Groups

Description	<ul style="list-style-type: none"> An organised discussion where CALD consumers are invited to share their views and experiences on a particular topic
Benefits	<ul style="list-style-type: none"> Allows for specific cultural and linguistic requirements to be met Can provide an opportunity to target smaller or marginalised communities or sub-groups Can discuss a topic that is sensitive in depth and explore cultural understandings
Issues to consider	<ul style="list-style-type: none"> Group may need to be briefed on how to work with interpreters in a group setting Focus group format may not be a culturally appropriate method of consultation
Actions for success	<ul style="list-style-type: none"> Reimbursement for attendance and other supports such as childcare Hold more than one group to cater for different age, gender, language and ethnicity mixes Liaise with specialist services to ensure that subjects for discussion are culturally appropriate Ensure findings and actions are fed back to focus group participants

Information Sessions and Printed Materials

Description	<ul style="list-style-type: none"> Sessions are held to provide information to CALD communities about relevant health issues and services and associated printed materials are also distributed
Benefits	<ul style="list-style-type: none"> Can reach a large number of people in a small amount of time Community leaders can 'spread the word' through distributing printed materials
Issues to consider	<ul style="list-style-type: none"> Consumers are not involved in the development of the information Some information may be irrelevant to a particular community Information or education sessions may not be a familiar mode of learning There may be literacy issues
Actions for success	<ul style="list-style-type: none"> Provide sessions and materials in relevant community languages Do not use straight translations and utilise culturally appropriate visual diagrams Pilot test all materials prior to use Use culturally appropriate venues and disseminate and promote through community representatives Consider different modes of delivery such as peer educators or 'experts' where communities have different expectations of the education process

How to: MAKING FOCUS GROUPS CULTURALLY AND LINGUISTICALLY APPROPRIATE

Focus groups are a useful research strategy to elicit knowledge, experiences and feedback from consumers and communities from culturally and linguistically diverse (CALD) backgrounds. Factoring relevant cultural and linguistic considerations into focus group planning and implementation is critical for success. This resource outlines an approach to focus groups which involves using bilingual facilitators with a group of participants with a common language and cultural background.

Before You Begin

- Use preferred language or dialect, ethnicity and cultural background to identify the participants you want to target. These characteristics will also need to be shared with the facilitator that you select.
- Identify what resources you can access to assist you. These might include bilingual workers in your organisation, demographic data on CALD communities, partnerships with ethno-specific and community organisations, community leaders, networks, existing research and funding opportunities.
- Plan for how you will incorporate diversity variables such as gender, age, English language proficiency, participants' literacy in their preferred language and English, education, migration history, refugee and settlement experiences and acculturation issues into the group composition. These may have an impact on group dynamics, participation levels and research outcomes.
- Be familiar with the levels of community infrastructure and existing networks in your selected target group. This could influence how you approach the community and how you recruit facilitators and participants.
- Establish how much funding is available to support the participation of both facilitators and participants. Reimbursement for the contribution of the community is important.

Recruiting and Supporting Facilitators

- Locate the most appropriate bilingual facilitator. They could be sourced from your organisation, from ethno-specific or community organisations or from the community.
- Where no experienced facilitators are available, be prepared to provide professional development, mentoring and support. This could include facilitation training, briefings, relevant literature or resources.
- Facilitators need good interpersonal skills to support interaction between participants.

Recruiting Participants

- Work with the facilitator to recruit participants for the focus group that meet the purposes of the research. It is important to establish rapport and trust in order to elicit participants' understanding of the purpose of the focus group and to gain their consent and full participation.
- Ensure participants receive oral and written information in their preferred language indicating the purpose, size of the group, how it will work, permission to record the discussions, potential outcomes, uses and ownership of information, a confidentiality clause, a consent form which includes the withdrawal of consent, the feedback process and how reimbursement will occur.

How to: MAKING FOCUS GROUPS CULTURALLY AND LINGUISTICALLY APPROPRIATE *continued ...*

Interpreting and Translations

- Interpreters can be utilised to interpret the proceedings of the group for workers who do not speak the language it is being conducted in. Bilingual facilitators should not undertake this role in addition to facilitation.
- Identify actual costs for professional interpreting and translations including total hours for the following:
 - Translation of forms, letters and transcripts
 - Interpreting for other workers

Focus Group Facilitation

- Give facilitators the opportunity to test questions and rework them for cultural appropriateness prior to conducting focus groups.
- It is important for the facilitator to explain the group process to participants at the outset, including any information that has been communicated previously.
- Consider how cultural differences are expressed through different communication styles such as attitudes towards conflict, approaches to completing tasks, decision making styles, attitudes towards disclosure and confidentiality and issues of individual or group rights. These may affect the group process and outcomes.
- It may be culturally relevant to take time to establish a rapport or it could be more appropriate to get straight down to business.
- Ensure culturally appropriate food and refreshments are available.
- The facilitator also needs to:
 - Brief other workers on specific cultural protocols.
 - Exercise empathy for pre-migration and or refugee experiences.
 - Understand that participants may have little or no previous experience in consumer participation processes.
 - Avoid acronyms and jargon.
 - Allow extra time for interpreting and scribing.

Verifying and Disseminating Information to Participants

- Re-convene the focus group to verify the documented information and to check the areas of recommendation. This is particularly important to ensure the integrity of the participants' input.
- Communicate how recommendations will be actioned in the community.
- Make the recommendations, results or the executive summary available to the participants in the relevant community language(s) and in a timely manner to enhance relationship building with the community.
- Identify a range of ways of disseminating the focus group outcomes such as through ethnic media, ethno-specific or community organisations and community venues.
- If you are launching the findings ensure participants are invited and interpreters are available.



CENTRE FOR *culture*
ethnicity & health

Other resources available from the Centre for Culture Ethnicity & Health include:

Reports

- Language Services: Good Practice in the Victorian Health and Community Sector
- Language Services in Victoria's Health System: Perspectives of Established and Emerging Culturally and Linguistically Diverse Communities (available early 2006)

Resources

- Assessing the Need for an Interpreter
- Bilingual Staff Roles and Organisational Supports
- Communicating with Clients with Low English Proficiency
- Culturally Inclusive Health Assessment
- Recruiting Bilingual Staff
- Reviewing Existing Translated Materials - Checklist
- Translating Health Promotion Materials into Community Languages

Training Workshops

We also offer organisational training workshops in the following areas:

- Consumer Participation and Culturally and Linguistically Diverse Communities
- Cross Cultural Communication
- Culturally Inclusive Health Promotion
- Inclusive Health Assessment
- Palliative Care and Cultural Diversity
- Valuing Cultural Diversity

For further information on our training program, including our annual calendar of training, please visit www.ceh.org.au/education

Notes



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