

A MODEL FOR CALD CONSUMER PARTICIPATION IN MENTAL HEALTH

A Report on the Multicultural Consumer and Community Participation in Mental Health Project



Queensland Transcultural Mental Health Centre
&
Multicultural Centre for Mental Health and Wellbeing

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A MODEL FOR CALD CONSUMER AND COMMUNITY PARTICIPATION IN MENTAL HEALTH

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ABOUT THIS REPORT

This report presents work undertaken during a three year project by the Queensland Transcultural Mental Health Centre in partnership with the Multicultural Centre for Mental Health and Wellbeing Inc. to develop meaningful and sustainable consumer and community participation in mental health. The project took place within culturally and linguistically diverse (CALD) communities and it is anticipated that the model of participation developed by the project will continue to evolve and contribute valuable information and experience to the field.

The concept of consumer participation is not a new one. However, the various approaches to genuine consumer participation are ever changing and evolving. In section one of this report, background issues and concepts about consumer participation are discussed. Key issues are presented that should be considered when embarking on the journey of CALD consumer participation in mental health.

Section two presents an overview of the work undertaken by the project. Since three distinct project stages were completed, these will each be presented with the major highlights of each stage. When perusing section two, it should be borne in mind that the strategies employed were relevant to and consistent with the needs of the communities involved in this project. It is most likely that different needs and issues would arise within CALD communities located in different parts of Australia.

Section three presents a model for CALD consumer and community participation. This section of the report is the most conceptual part, even though we have interspersed reflections throughout to give the reader a flavour of the real-life issues and dilemmas that can be encountered with this work. The model is presented in different sections, each representing a component of a house – the schematic model that was developed by the project.

It is hoped that the information presented in this report will inform further development of CALD consumer participation in a range of settings and locations with consumers from culturally and linguistically diverse backgrounds around Australia, thus improving mental health service delivery to consumers from CALD backgrounds.

SECTION ONE

CALD CONSUMER PARTICIPATION – THE ISSUES

In Section One a number of issues relating to CALD consumer participation are presented. Consumer participation is examined from historic, social and cultural perspectives. A brief overview of relevant government documents that provide the current policy framework for consumer participation in mental health is presented. And finally, a set of key issues that services should consider before embarking on their journey of CALD consumer participation is presented.

What is consumer participation?

'Consumer participation' has a range of meanings and complex conceptual understandings attached to it. Firstly, the term 'consumer' implies an active role of a person who consumes a service, rather than a passive connotation such as that of 'patient' or 'client'. This notion of a consumer has cultural roots in Western society¹ Bevan says that these cultural links are related to notions of the 'customer' and the rise of consumerism in Western capitalist democracies – all specific cultural phenomena with relationships to other issues such as the importance of the individual and the use of medical solutions (e.g. drug therapy) for mental health problems.

Sozomenou et al.² provides a historic account of the term 'consumer' and the 'consumer participation' movement. They also note that the term 'consumer' has its roots in Western countries whose health care systems are influenced by a market model of care. They also observe that in the mental health sector in particular, the connotations of the 'consumer' are often inconsistent with the power that mental health professionals have over the individual in the form of making a diagnosis, the power to make involuntary admissions, and the individual's frequent lack of power to challenge medical authority. "*The patient is often restricted by a lack of knowledge and a lack of options as to where to go for treatment. The consumer has little bargaining power or freedom of choice.*"³

Bevan also notes that the mental health consumer movement (also known as the ex-patients movement, the mental patients liberation movement, and the psychiatric survivor's movement) has been in existence for many years, in many different forms throughout the world⁴, often comprising of organized, fragmented and individual protest.

However, the 'consumer' as a concept is one that is dominant in Western consumer-driven societies and implies some degree of power and choice on the part of the consumer. Thus the concept of 'consumer' is fraught with conceptual contradictions, particularly when the concept is used within CALD communities that may not share ideas around the role of the consumer, the bio-medical mental health system nor the concept of choice and power.

Sozomenou et al.⁵ provides a historic and philosophical account of 'participation' or the participation movement in health services. They note that the consumer movement had an important historic antecedent in the human rights, women's, peace, environment and gay rights movements, which can all be seen as part of

¹ Bevan, K, (1997) Reflections on one year of consumer participation at the Transcultural Mental Health Centre. In Ferguson, B. and Barnes, D, *Perspectives on Transcultural Mental Health*. Transcultural Mental Health Centre: Sydney. 3:22-31.

² Sozomenou, A, Mitchell, P, Fitzgerald, M, Malak, A and Silove, D. (1999) *Mental Health Consumer Participation in a Culturally Diverse Society*. Transcultural Mental Health Centre. p 29.

³ Ibid, p21

⁴ Bevan, Op. cit., p22

⁵ Sozomenou et. al. Op. cit., p29-34

the same tradition. The mental health consumer movement in Australia is however a comparatively young movement compared to that in the United States⁶.

"While commentators on the public health and welfare systems in Australia began to actively discuss and promote the idea of consumer participation in health and welfare in the mid 1970s, levels of activity and discussion have remained relatively low in the area of mental health...Much of the activity in the area of consumer participation in mental health has taken place in very recent times."

Bevan notes that a core expectation of consumer participation is that consumers will wish to participate in the transformation of mental health services from one state-sanctioned style of service to another⁷ Other expectations are that consumers will generally be in agreement with the mental health system on what the transformation of the mental health services should be and the parameters of service provision itself. This is particularly pertinent to CALD communities who often have other strategies (i.e. not drug or talking therapies) to deal with mental illness.

As pointed out by Bevan, notions of consumer participation can be seen as acculturated in a Western biomedical model of health, developed primarily in industrialized, capitalist democracies⁸.

"Some of the other culturally-bound concepts that inform consumer participation are: individual rights, self-advocacy, mental health and mental illness, family rights, charity/benevolence, tolerance of dissent and State involvement in care".

In the context of CALD consumer participation, there are clearly some complex issues and barriers at play. Firstly, people may not share the cultural knowledge that informs consumer participation or an understanding of the mental health system. Many people come from cultures where the concept of the 'consumer' or even 'consumer rights' is totally alien. The following table from Bevan outlines the key areas where culture may impact on consumer participation⁹:

HOW CULTURE IMPACTS ON CONSUMER PARTICIPATION:
* Levels of familiarity with the concept of consumer participation (e.g. understanding of roles), not only limited to participation in service development
* Familiarity with and acceptance of concepts of advocacy
* Unrealistic expectations of the outcomes of consumer participation
* Styles of consumer participation (e.g. committees, boards, voluntary advocates, paid representatives – all of which are linked to cultural values about appropriate behaviour)
* Models of understanding of illness and health
* Frameworks for understanding mental health or mental illness (e.g. spiritual, holistic)

⁶ Sozomenou et. al. Op. cit., p 38

⁷ Bevan, Op. cit. p24

⁸ Bevan, Op. cit., p27

⁹ Bevan, Op. cit., p27

The Centre for Culture, Ethnicity and Health¹⁰ considers CALD consumer participation to encompass a vast array of different strategies to engage CALD consumers in the planning, implementation and evaluation of health programs, projects and services. Here it is thought that the more CALD consumers are able to participate in diverse ways, the more likely an organization will be responsive to their needs and achieve better health outcomes. The strategies put forward by the Centre for Culture, Ethnicity and Health all involve engagement with both CALD consumers and their respective communities.

Community participation is especially important when engaging with CALD consumers. The current project has contributed much valuable information about the necessity to engage with the broader CALD community before any process of individual engagement can be instigated. It was recognized that effective CALD community participation requires adequate support, knowledge, skills and resources for both community members and mental health workers to engage in a constructive dialogue. Multicultural Mental Health Australia states that¹¹:

"Meaningful consumer participation cannot take place without the basic tools of empowerment such as knowledge and support. The failure to understand this creates false expectations in terms of consumer participation and to some extent can set people up for failure."

Stigma and shame associated with mental illness is high in many communities, which has posed a significant barrier to accessing a mental health service voluntarily, and participating as a consumer or carer even more unlikely¹². These barriers, along with other obstacles related to mistrust, differing explanatory models of mental illness, low levels of mental health literacy, inappropriate or unfamiliar engagement strategies and language barriers must be addressed before real participation can be achieved. The special role of community leaders should also be considered. A comprehensive account of community participation can be found in both Parts Two and Three of this report.

It should be noted that consumer participation is not the same as carer participation, or community participation. Carers bring with them a unique perspective and experience of the mental health service system. They are able to present issues impacting upon consumers and the family members of consumers. Involvement of carers and families plays a special significance for many CALD communities who have collective explanatory models and ways of dealing with mental illness. Due to resource constraints the current project focused exclusively on consumer participation and recognized that there were limitations because carers were not involved.

Policy background

Consumer participation in health service planning, development and delivery is a standard that many health services strive for, and in mental health there are set benchmarks for consumer participation as outlined in the *National Standards for Mental Health Services*¹³. Furthermore, mental health service accreditation also sets out requirements for consumer and carer participation as stated in the *ACHS Evaluation and Quality Improvement Program 3rd Edition* (particularly Standard 2.4)¹⁴.

¹⁰ Centre for Culture Ethnicity and Health (2005) *How to: A Practical Guide to CALD Consumer Participation*. Melbourne. www.ceh.org.au

¹¹ Multicultural Mental Health Australia (2004) *Reality Check: Culturally diverse mental health consumers speak out*. NSW. p.8.

¹² Queensland Health (2003) Towards Consumer Centre Services In *Queensland Health Action Plan for Consumer and Carer Participation in Queensland Mental Health Services*. p. 19.

¹³ Commonwealth Dept of Health & Family Services (1996) See Standard 3, Consumer and Carer participation. In *National Standards for Mental Health Services*.

¹⁴ The Australian Council on Healthcare Standards, The EQUiP Guide: A framework to improve quality and safety of health care, 3rd Edition, The Australian Council on Healthcare Standards: Ultimo, NSW, 2002 cited in Queensland Health 2003 op. cit. p. 4

The following diagram outlines a conceptual framework for consumer participation presented in the Queensland Health Action Plan¹⁵:



The Queensland Health Action Plan notes that consumer participation benefits not only the individual consumers (and carers) who become involved, but also all the other consumers and carers who use the service currently and in the future. *'The evidence base supporting consumer and carer participation across all service levels demonstrates this.'*¹⁶

In Queensland, the *Action Plan for Consumer and Carer Participation in Queensland Mental Health Services* provides key action areas where proactive strategies are highly recommended to facilitate effective consumer and carer participation. This action plan was developed in response to issues raised during statewide consultations with consumers, carers, service providers and community organisations in 2001-2002. The Action Plan identifies five 'special consideration areas', with the 'strengthening participation of consumers and carers from culturally and linguistically diverse backgrounds' being one such area¹⁷.

The Action Plan holds that it is important that consumers and carers are involved in culturally appropriate ways:

"Methods of participation developed by the dominant culture will very likely not be appropriate for other cultural groups, particularly those that are quite different from Australian culture. There is a diversity of views across cultures on the causation and treatment of 'mental illness'".

This has certainly been the experience of the Queensland Transcultural Mental Health Centre which has had several attempts at consumer participation through adaptations of the Consumer Advisory Group (CAG) model which were difficult to sustain for a variety of reasons. Due to the diverse cultural beliefs about mental illness amongst the consumers involved, diverse languages, different levels of English language proficiency, different levels of acculturation and lack of work undertaken at the community level in regard to mental health literacy, these groups were difficult to manage and sustain, and were not able to facilitate meaningful participation for the consumers involved.

Essentially the processes previously utilized were a top down approach and by reversing the approach with a focus on building consumer participation from the bottom up, the project was able to achieve a sustainable and meaningful process of CALD consumer participation.

¹⁵ Queensland Health, Op. Cit.

¹⁶ Consumer Focus Collaboration, 2001, cited in Queensland Health, *Towards Consumer Centred Services*, Queensland Health Action Plan for Consumer and Carer Participation in Queensland Mental Health Services, 2003, p. 2.

¹⁷ Queensland Health 2003, op. cit., p. 5

The *National Framework for the implementation of the National Mental Health Plan 2003-2008 in Multicultural Australia* has identified that CALD consumer participation varies across jurisdictions, and lags behind mainstream achievements in participation. It identifies the need for resources, support and training to participate at all levels of the mental health system and the development of appropriate strategies to enhance the capacity of CALD communities, as well as individuals to participate at all levels of the mental health system.

CALD consumer participation – the key issues

In this final part of Section One a number of key issues are presented that are integral to effective CALD consumer participation, based on the experiences of the current project. These issues are so important, that they are worthy of a special mention since they underpin all aspects of the current project and the model that has been developed.

Key issue	Comment
Commitment	To engage with consumers in a meaningful way, an organization must be committed to 'doing its business' differently and be open to hearing things that may be difficult. Commitment must be demonstrated at the highest level of the organization as it will not be meaningful unless there is a total organizational commitment and that all staff understand that it is part of <i>their</i> job, not through an individual project officer.
Integration into 'core business'	Consumer participation cannot be successfully undertaken as an "add-on" activity – the way a lot of projects are done within organizations. It should not be seen as a project, but rather as an integrated process of organizational change. Ideally it should be integrated into the business of the organization as an ongoing and sustainable process such as employing a CALD consumer worker to participate in the planning, development and monitoring processes of an organization.
Resource intensive	Facilitating the process of disadvantaged communities to reach the level where they have knowledge, skills and the capacity to participate requires significant resources, particularly during the initial stages. CALD consumer participation is resource intensive as it requires outreach into many CALD communities to ensure a broad range of cultural perspectives of mental health and illness are presented. The investment of resources into bilingual workers is the driving force of this outreach. Time is another resource often overlooked. The time required for CALD consumer participation is that of consistent time, not intensive time and the ability to be opportunistic.
Community development approach	The approach will be most successful if it is driven and built from the bottom up. Community engagement can only occur at the grass-roots level, from where the momentum for the issues can build.
Reciprocity	Relationships and information flow between professional workers and community members must be reciprocal. Information obtained from communities about their cultural belief systems of mental illness must be reciprocated with information about the Australian mental health system. This process will facilitate an integration of both.

Trust and respect	There is, most likely, a high level of mistrust of mental health services for various reasons. Building trust with CALD communities and consumers is extremely important. Engaging with community leaders is one important strategy for building mutual trust and respect. It is also important that organizations and community leaders work together and support and reinforce each other's role.
Cultural competency of mental health services	Achieving higher levels of cultural competency in mental health services is extremely important to ensure that consumers are responded to in a culturally appropriate manner. Understanding and respecting each others' belief systems is an important component of this.
Ongoing community mental health literacy	Due to the high levels of CALD community stigma around mental illness, ongoing strategies are required to achieve greater mental health literacy. The need for ongoing information through community networks and the ethnic media is a necessary component of this work. The participation of consumers 'talking' to other consumers from their own community has been proven to be a powerful educational tool.

SECTION TWO

PROJECT OVERVIEW

Section Two outlines the fundamental components of the CALD Consumer and Community Participation Project. Since the project was implemented in three distinct stages, Section Two is presented in three parts, each setting out the key components of each project stage. To make the information as usable as possible, there is an emphasis on key issues and lessons learned from the project.

The overall goal of the project was to design an effective model of culturally and linguistically diverse consumer participation in mental health services.

Project management and structure

The project was a partnership between the Queensland Transcultural Mental Health Centre (QTMHC) and the Multicultural Centre for Mental Health and Wellbeing (MCMHW). The project management team was formed from these two organizations:

- Manager, Queensland Transcultural Mental Health Centre
- Coordinator, Multicultural Centre for Mental Health and Wellbeing
- Education and Development Coordinator, Queensland Transcultural Mental Health Centre
- Mental Health Promotion Coordinator, Queensland Transcultural Mental Health Centre
- CALD consumer workers (who joined in Stage 3 when the project focused on direct consumer participation)

A Reference Group comprising key community contacts, community workers from the nine communities targeted and consumer consultants from mainstream mental health services was also formed to advise the project staff. The project staff comprised of a Project Coordinator, Bilingual Sessional Community Development Workers and Consumer Workers.

A National Advisory Group was formed to provide expert advice in regard to consumer participation with people from CALD backgrounds. Members of this group included consumers and mental health professionals from across Australia with considerable experience in the area of CALD consumer participation.

Funding was received from the Mental Health Unit, Queensland Health, and also from Multicultural Affairs Queensland. In addition, the QTMHC has over the past three years contributed five per cent of its non-labour budget to consumer participation and significant project management time through the Mental Health Promotion Coordinator position in order to develop a sustainable mechanism for consumer participation.

Stage One – Community engagement and understanding diverse cultural perspectives of mental health

Stage One of the project commenced in June 2002 and ran until February 2003¹⁸. Previous approaches to consumer participation tried to implement the common model of Consumer Advisory Groups (CAGs) in mainstream mental health, but these were largely unsuccessful. The major reason identified for this failure was that the CAG model did not address the cultural context of mental health issues in different CALD communities. It was found that a group process with people from diverse ethnic backgrounds, with varying degrees of English language proficiency, with different understanding and beliefs about mental illness, was unworkable.

In response to this previous experience, a different approach was instigated. In this approach, fundamental community development principles were embraced and implemented to open a process of dialogue and engagement. Community development was identified as a key strategy to achieve consumer participation as the approach itself relies entirely on community participation. With community development, the organization participates in the community, rather than the other way around (e.g. as in the CAG model).

Stage One involved the engagement of a project coordinator and bilingual community development workers who were trained and supported to hold a series of workshops/discussion groups within their own community on the perceptions, beliefs and understanding of mental health issues. The following communities were involved:

- Arabic-speaking
- Bosnian
- Farsi-speaking
- Filipino
- Samoan
- Spanish-speaking
- Vietnamese
- Sudanese
- Somali

The following were the key objectives of Stage One:

1. To increase the capacity of the project's bilingual workforce to:
 - a. Attract people from their own communities to mental health group discussions
 - b. Facilitate focus group discussions
 - c. Organise a response to mental health needs if required.
2. To consult, through reference and advisory groups, with community organizations and mental health consumer advocacy representatives regarding CALD consumer/community participation in the planning, implementation and evaluation of mental health services.
3. To consult with mental health services regarding CALD consumer/community participation in the planning, implementation and evaluation of mental health services (This objective was dropped from Stage One and was taken up again in Stage Two).
4. To identify the perceptions of the selected communities, including consumers, about mental health, mental health problems, mental illness, their determinants and the manner in which they prefer to see these issues addressed.
5. To plan the next stage of the project.

¹⁸ For a full account of Stage One, please refer to the project report: Queensland Transcultural Mental Health Centre and Multicultural Centre for Mental Health and Wellbeing, Multicultural Community Development in Mental Health Project Stage One Report, 2003. See QTMHC website.

The key strategies/components, issues and lessons learned from Stage One were:

STRATEGY/COMPONENT	ISSUES	LESSONS LEARNED
<p>Recruitment of Bilingual Community Development Workers (BCDWs) – A BCDW was recruited for each participating community. Workers were employed on a sessional basis for 100 hours each.</p>	<ul style="list-style-type: none"> - Important selection criteria for BCDWs included professional skills, strong networking skills, strong links with own community. - Wide dissemination of job information was required by using multicultural sector networks. 	<ul style="list-style-type: none"> - BCDWs who were very closely aligned with a particular sub-group within their community were very successful in engaging those from the same sub-group, but were less successful in engaging those from the wider ethnic community.
<p>Recruitment of Project Coordinator – A Project Coordinator was employed for 12 hours per week for 12 months.</p>	<ul style="list-style-type: none"> - The project was constrained with available resources to 12hrs per week project coordination, which was unrealistic for a project of this complexity. Project management of this project was therefore taken over by the mental health promotion coordinator of the QTMHC. - Project coordination was essential to ensure consistency, without it the project was at risk of becoming nine “mini projects”. 	<ul style="list-style-type: none"> - Substantial additional project management support was provided by the QTMHC mental health promotion coordinator which was vital to supporting a worker in this pivotal role. - The dimensions of the project were too large for a 12 hour per week position and therefore posed many challenges.
<p>Training program for project staff – the BCDWs and the project coordinator undertook 18 hours of initial training as well as ongoing training through the project involving:</p> <ul style="list-style-type: none"> - project overview - project rationale and conceptual framework - Old mental health system - Mental health issues for migrants and refugees - Community development tools - Mental health promotion - Working with consumers 	<ul style="list-style-type: none"> - Ongoing training throughout the project was essential to build the skills and confidence of the BCDWs. 	<ul style="list-style-type: none"> - Training needed to address the important issue of mental health itself. For example, for some communities, there was no verbal translation for ‘mental health’ or ‘mental illness’, posing the risk of individuals misinterpreting key concepts and misunderstanding health information. This misunderstanding could undermine future efforts.

<p>Community sessions – 42 sessions were held involving 299 community members.</p>	<ul style="list-style-type: none"> - It was found that there was a mismatch between the culture of the health system and the needs of community members. - It was found that a Western definition of mental illness was not always applicable to different communities. - Stigma was a key barrier. The extent of stigma varied according to the level of acculturation of individuals in a community. - Mistrust was identified as a major barrier for consumers. - Knowledge of mental health services was low in all communities. 	<ul style="list-style-type: none"> - Close contact with the BCDWs was required to provide support and maintain energy levels for the work and to collect feedback from sessions. - Mental health literacy strategies did produce positive changes in negative attitudes towards mental illness. This however, took time. - Language was a major barrier in accessing mental health services. For example, for some communities, there was no verbal translation for 'mental health' or 'mental illness'. - Through the BCDWs, trust in the mental health system started to develop. They played a crucial and pivotal role.
<p>Documentation – the problems, needs and perceptions expressed in the community sessions were documented into a project report.</p>	<ul style="list-style-type: none"> - Following each community session, an individual meeting with the BCDW took place to ensure important data was documented. 	<ul style="list-style-type: none"> - The validation of the data collated by the BCDWs was empowering.

Stage One yielded valuable information and experience that informed the next stage of the project. It identified the cultural context of how mental health and mental illness are perceived and understood by the participating ethnic communities. Each community identified potential barriers and obstacles to effective mental health promotion and community participation. The themes of Stage One that carried forward into Stage Two of the project were that building trust must underpin all activities; community engagement takes time – do not rush this process; and, Bilingual Community Development Workers are the key instruments in achieving a reciprocal dialogue about mental health issues. For a more detailed discussion of Stage One a separate report is available from the Queensland Transcultural Mental Health Centre or from its website (www.health.qld.gov.au/pahospital/qtmhc/default.asp).

Stage Two – Increase mental health literacy and destigmatise mental illness, and increase cultural competency within mental health services

Stage Two took place between June 2003 and December 2004. At the outset of Stage Two, important information about the nine communities had already been obtained during Stage One and an ongoing process of dialogue and engagement had already been instigated. Given that Stage One had documented the cultural context of how mental health and mental illness were perceived and understood by these communities, Stage Two was able to confidently embark on health promotion activities to increase mental health literacy and therefore destigmatise mental illness in the participating communities. As mentioned in the previous section, the project objective involving the engagement of mental health services to increase cultural competency, was picked up in this stage of the project.

The following were the key objectives of Stage Two:

1. To destigmatise mental illness in the participating CALD communities.
2. To increase the mental health literacy of the selected nine CALD communities.
3. To increase cultural competency of the mental health services attending 'cultural perspective' seminars.
4. To engage with CALD community leaders to obtain support and endorsement for the project.

The key strategies/components, issues and lessons learned from Stage Two were:

STRATEGY/COMPONENT	ISSUES	LESSONS LEARNED
<p>Ethnic media campaigns in nine communities – ethnic radio and newspapers were used to deliver mental health messages.</p>	<ul style="list-style-type: none"> - Some communities did not have any media outlets. - Newly emerging communities still dealing with resettlement and community leadership issues were more difficult to engage in media campaigns. - Core information disseminated needed to be applicable across all cultures with BCDWs illustrating the topics with culturally relevant examples. - BCDWs needed strong connections with those managing media outlets to be able to obtain free use of them as well as obtaining their support. 	<ul style="list-style-type: none"> - Team building strategies were required to support BCDWs who undertook work that was isolating. Being part of a team can support and encourage greatly. - Monthly group supervision meetings were also important to provide support, information and resources. - Not all communities had media networks which required alternative strategies, e.g. the project tried to develop a newsletter for a number of communities but was unable to pursue this due to lack of resources and therefore relied on information dissemination through community networks. - Emerging communities required an outreach small group approach, rather than a media campaign. - Campaigns in the radio and printed media received positive feedback from media outlets and members of the communities. - Topics selected for media

		campaigns were a combination of expressed needs by the community (parenting between two cultures, depression) as well as identified needs by services (stigma associated with mental illness and strategies to keep mentally healthy).
Engage community leaders in community and consumer participation.	<ul style="list-style-type: none"> - Community leaders were vital to engage in any outreach strategy within a CALD community for permission to enter the community; for support to engage; and to provide leadership within the community to reinforce messages delivered by the project. - A very personalised approach, both via the BCDW and the project coordinator, was required to successfully get the attention of community leaders. - In some communities it was important to be aware of the different (sometimes conflicting) groups within a community and try to build on the commonalities if at all possible. 	<ul style="list-style-type: none"> - Leaders were defined as those in a position where they influence the community, e.g. religious figures, heads of community associations and media outlets, health and community workers. - The most successful meetings were when all leaders from a community were brought together in one meeting to ensure a community wide approach. - Other success factors included meeting leaders in their own territory (most often on the weekends or in the evening), highlighting the principle of the organisation fitting in with the community rather than the other way around, and providing refreshments. - For those leaders meeting regularly it was effective to meet them where and when they met. For those from fragmented communities it was more effective to meet them in a neutral place.
Take opportunities for mental health literacy workshops.	<ul style="list-style-type: none"> - As this is a resource intensive undertaking across a large number of communities it is important to be opportunistic, e.g. when resources became available for parenting work it was decided to reframe it to a mental health literacy activity focusing on the impact of acculturation and intergenerational issues on mental wellbeing in families. 	<ul style="list-style-type: none"> - Intensive training and supervision was essential to ensure consistent messages were delivered across the different cultural groups through bilingual workers.

<p>Community events, e.g. Mental Health Week.</p>	<ul style="list-style-type: none"> - Large community events were useful in engaging a large number of people across communities, providing opportunities for cross cultural awareness and reinforcing common issues across communities e.g. through the promotion of the event through the ethnic media. 	<ul style="list-style-type: none"> - Participation in discussions and showcasing of traditional activities that keep people mentally healthy was easy to obtain as it validated and acknowledged community wisdom and capacity in a respectful manner. - The Mental Health Week event that included showcasing traditional practices was an effective strategy to attract a wide range of members of CALD communities. - Allow sufficient time for lead up in terms of planning and engaging people from the communities involved in the delivery of various aspects of the program.
<p>Community Cultural Perspectives Seminars.</p>	<ul style="list-style-type: none"> - Information gathered from the community about the different cultural perspectives of mental health needed to be integrated into training for the mental health workforce to increase their cultural competency. - Care needed to be taken with the design of cultural perspective seminars to avoid cultural stereotyping. 	<ul style="list-style-type: none"> - A significant amount of time was invested into the preparation of the presenters to ensure consistent approaches to information delivery relevant for mental health practitioners. - It was important to have a range of presenters presenting cultural information from diverse perspectives, e.g. cultural informants and mental health clinicians.
<p>Evaluate readiness for direct consumer participation in CALD communities.</p>	<ul style="list-style-type: none"> - Agree on indicators, e.g. level of community leader engagement/support, impact of mental health literacy initiatives within the community, available networks for consumers to engage with or be supported by, participation rates of the community in mental health activities. - The level of mental health literacy of each of the nine CALD communities was different from the beginning of the project and at the end of Stage Two of the project. Those communities with 	<ul style="list-style-type: none"> - At the end of Stage 2, based on agreed indicators and meetings with the BCDWs from each community, it was decided to proceed to Stage 3 with six out of the nine communities. It was determined that it was too early for direct consumer engagement in the other communities where mental health literacy activities needed to be continued to decrease stigma. - Key requirements for consumer participation included support from community leaders, sufficient levels of community mental health literacy and skilful bilingual community workers

	<p>higher levels, at least of a section of the community, were identified as being more ready to engage mental health consumers.</p> <ul style="list-style-type: none"> - It was difficult to objectively assess levels of community readiness for consumer participation. The assessment was based on project outcomes at the time, and interviews with each BCDW plus input from the project management team. 	<p>facilitating the participation processes.</p>
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Stage Two was underpinned by a conceptual framework of community and consumer participation strategies, a community development approach, the notion of expert communities and an approach of reciprocity in education, which aimed to increase community expertise in mental health while acknowledging the diversity of perceptions, values and beliefs held by the communities.

In line with the reciprocity in education principle, the participating communities presented ‘cultural perspectives’ seminars – with each community showcasing their own cultural perspectives of mental health and mental illness. The seminars had a wide target audience, however, there was a particular emphasis on attracting mental health workers. During the life of the project well over 1000 workers participated in the seminars through direct attendance and video conferencing throughout Queensland. Another example of reciprocity during Stage 2 was the nine communities showcasing to mental health services, CALD communities and the wider community, their traditional practices to maintain and enhance their mental health and wellbeing and prevent mental health problems.

In Stage Two, it was once again found that community capacity building for mental health involves a slow but consistent effort to build community networks, destigmatise mental illness and facilitate linkages with mainstream mental health services. Mental health promotion with CALD communities requires a reciprocal relationship with communities that allows for the exploration of various explanatory models of ‘wellbeing’. A Western-based model of mental health can further alienate CALD communities. Enhancing the cultural capacity of mental health services is necessary to facilitate equitable access to mainstream mental health services. Cultural capacity involves the provision of effective and respectful care that is compatible with the cultural health and mental health beliefs, practices and languages of the people receiving services.

Stage Three – Trial CALD consumer participation and develop a CALD consumer and community participation model

Stage Three took place between January and July 2005. This stage was able to build on the good working relationships developed during Stages One and Two with CALD communities participating in the project, and the efforts to decrease stigma and increase mental health literacy. There had been a lot of close contact with the participating communities via the ethnic media campaigns, dialogue with community leaders and other mental health promotion activities. A good appreciation of each community's explanatory model for mental health had also been developed during Stage Two. It was therefore appropriate to move into a trialling or piloting phase during Stage Three. The key activities of Stage Three were to employ two CALD consumer workers and to establish six groups of consumers to provide input into the development of a model of CALD consumer and community participation in mental health. These groups piloted the participation strategies in two different settings, QTMHC and MCMHW.

The following were the key objectives of Stage Three:

1. To continue engaging with the leaders of the nine CALD communities.
2. To continue with mental health promotion activities instigated during Stage Two of the project.
3. To continue with 'cultural perspectives' seminars instigated during Stage Two of the project.
4. To employ two CALD consumer workers within QTMHC to ensure consumer appropriate strategies.
5. To trial consumer participation, including participation in consultative processes.
6. To document a CALD participation model and to reach a common agreement on this model from the participating CALD communities.

The key strategies/components, issues and lessons learned from Stage Three were:

STRATEGY/COMPONENT	ISSUES	LESSONS LEARNED
Continue the Community Cultural Perspectives Seminars	<ul style="list-style-type: none"> - It was important to continue the momentum that the cultural perspectives seminars created. They continued to be presented in addition to regular training provided by the QTMHC. By the end of the bi-monthly seminars, more than 1000 workers and service providers had participated in the seminars. 	<ul style="list-style-type: none"> - These seminars were the spring-board to establish a dialogue between CALD communities and mental health services. - It was useful to hold the seminars at a range of mental health service venues based on the particular ethnic community being more represented locally e.g. Samoan and Spanish-speaking at the Park Centre for Mental Health in West Moreton, Arabic-speaking and Bosnian in Logan City and Sudanese and Somali at the Princess Alexandra Hospital. - Video-conferencing and video tapes of the seminars made the material more accessible to those working outside the metropolitan area, e.g. the Filipino Seminar had a large videoconference audience due to the community being widespread throughout Queensland.

<p>Continue employing a project coordinator and a team of bilingual/bicultural community participation workers.</p>	<ul style="list-style-type: none"> - Having a project coordinator to support the pool of bilingual workers was essential as it enabled the project to develop culturally appropriate strategies with individual communities. 	<ul style="list-style-type: none"> - Well networked and respected bilingual workers were irreplaceable in identifying, linking, outreaching and attracting consumers and community leaders to participate in mental health. - Considerable time had to be invested in team meetings to ensure consistency of practice and message by the bilingual workers.
<p>Employ two CALD consumer workers.</p>	<ul style="list-style-type: none"> - When the project commenced direct work with consumers it was essential to employ two CALD consumer workers to work as part of the project management team to ensure consumer appropriate strategies. - Consumer workers required a significant amount of support. 	<ul style="list-style-type: none"> - Two consumer workers facilitated mutual support for one another in a model of peer support. - When working with CALD consumers through bilingual workers it was essential to have consumer workers involved to providing advice on consumer appropriate strategies. - Consumer workers increased the credibility of the project with other CALD consumers.
<p>Trial participation of consumers in community networks.</p>	<ul style="list-style-type: none"> - Consumers were engaged to provide input into the development of the model. The focus was not on the content but on the process of engagement and participation in order to learn how to facilitate meaningful participation. 	<ul style="list-style-type: none"> - Consumers identified the need for support and education as vital to their ongoing participation. - Consumers identified that the support of community leaders was essential to their role within the community in terms of support and respect and breaking down stigma.
<p>Establish consumer groups to provide input into participation strategies.</p>	<ul style="list-style-type: none"> - Attracting consumers was a labour-intensive job. - Each community had different strategies to attract consumers, e.g. posting letters, phone calls, personal contact. 	<ul style="list-style-type: none"> - A positive response from consumers was largely based on trust established through assistance previously provided to the consumer by the worker/leader. - Consumers reported feeling valued as never before by being invited to share their views. Those who received payment reported feeling further recognized. - Payments to attend consumer groups made it more accessible for most.

<p>Provide options for consumer participation.</p>	<ul style="list-style-type: none"> - A wide range of options were presented to potential consumer participants to increase accessibility. 	<ul style="list-style-type: none"> - Providing options was effective as some preferred participating in a phone interview with a bilingual worker or completing a questionnaire, instead of attending a group.
<p>Trial participation of consumers in mental health services planning, development and implementation.</p>	<ul style="list-style-type: none"> - Six groups of consumers were involved in the trial – two groups at MCMHW and four at QTMHC. Each group was facilitated by a bilingual worker. - Various levels of participation took place: participation in own development successfully attracted consumers who attended in their own time and means; participation strategies at a community level were implemented with leaders and members of the community; participation in service planning and development through providing feedback on QTMHC/MCMHW programs and services. - The testing of generic participation strategies in a culturally specific manner resulted in the development of a model that allowed for both culturally specific participation as well as multicultural participation. 	<ul style="list-style-type: none"> - Community readiness determined whether consumers were engaged for participation activities. - The trialling of participation on specific mental health programs was a very involved process – experts on the program briefed bilingual workers; the project coordinator prepared a simplified presentation; bilingual workers modified the presentation further for cultural appropriateness; consumer workers were then briefed and finally; common consultation questions were developed.
<p>Document and validate the process to develop the CALD consumer participation model.</p>	<ul style="list-style-type: none"> - Each participation trial was carefully documented. - It was important to validate the information gathered from consumers and leaders. 	<ul style="list-style-type: none"> - Establishing clear objectives for each activity greatly assisted the process. - Developing templates to collate feedback from consumer groups can assist greatly. - Visual illustrations were helpful to communicate concepts to consumers.

Stage Three brought to life the principles and strategies that the previous stages had worked towards. The actual trialling process of consumer participation in service development was a potent and crucial part of Stage Three. At the end of this stage the consumers who participated, effectively took over the role of the BCDWs by providing input and linking with their respective CALD community.

However, since it was decided to proceed with six out of the nine communities who started the project to engage consumers in direct consumer participation, a number of reflections have been made about the factors that may have impacted on the readiness of consumers of a CALD community to participate in mental health services. Community readiness may be a key determinant. The project management team pondered whether it was the capacity of the BCDWs that was the crucial determinant, but after detailed analysis and discussion it was concluded that the BCDWs reflected the level of mental health literacy and acculturation of the community. The six communities that proceeded to Stage Three were: Arabic-speaking; Filipino, Spanish-speaking; Samoan; Farsi-speaking and Bosnian. The last two communities managed to conduct consumer sessions but were unable to interest consumers in becoming Consumer Facilitators. In order for the other communities to be ready to engage consumers in consumer participation, more resources were needed to increase mental health literacy in the community and also of the leaders. Unfortunately this was beyond the scope of the project's resources.

SECTION THREE

A MODEL OF CALD CONSUMER AND COMMUNITY PARTICIPATION IN MENTAL HEALTH

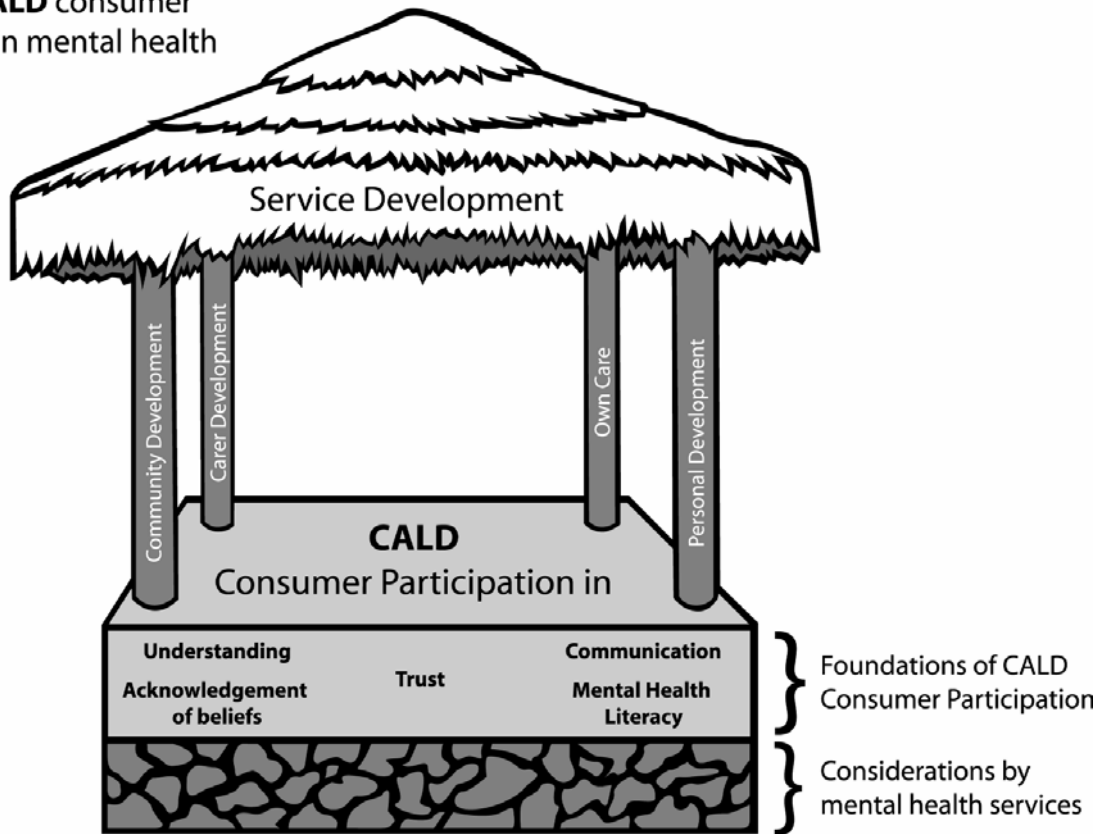
Section Three outlines the model of CALD consumer and community participation developed by this project. The model is not a simple 'how-to' style model that most organizations would cherish for its simplicity. Consumer and community participation is extremely complex and multi-layered and therefore a model for this important work must reflect this complexity. This section outlines the key areas of the model, as shown on the next page.

The first component of the model is titled 'primary foundations – considerations by mental health services'. This first component of the model focuses on the key pre-requisites that must be considered before genuine CALD consumer participation mechanisms can be developed. In many ways, it represents the foundation of successful consumer participation. In short, if these issues are not dealt with at the outset, mechanisms for genuine participation by consumers of CALD background will not be able to be sustained over time.

The second component of the model, 'secondary foundations – underpinning strategies for CALD consumer participation', contains five important strategies that challenge the barriers that CALD communities and consumers experience in the mental health system and in the community in general. These five strategies must be addressed in all activities, or, they can be addressed as stand-alone objectives of your participation project. A number of key indicators are provided to assist in judging whether the strategies are working.

Practical examples are then provided across the various levels of consumer participation. These include participation at the individual level whereby the CALD consumer is able to participate in the development and evaluation of their own care plans, as well as participation in activities that assist in the development of personal skills which aid recovery. Also included are examples for participation at the service level, whereby carers and members of the consumers' ethnic community are enabled to be involved in the development and delivery of mental health services. Finally, practice examples are included that demonstrate participation at the broader community level whereby various ethnic communities are enabled to promote and lobby for the mental health needs of their communities.

A model of **CALD** consumer participation in mental health



Primary foundations – considerations by mental health services

This area of the model is represented by the foundation of the house. Without a sound foundation, the house will not be strong. It is also from the foundation that the rest of the house is built.

The foundations represent important factors or considerations that should be considered before embarking on CALD consumer participation. The underlying context of successful consumer participation is outlined here. Each key pre-requisite will be followed by a series of questions that all intending organizations should ask themselves before embarking on the journey of genuine consumer participation. The questions are designed to generate thought about motivations, knowledge bases, values, resources and commitment. It is, after all, these factors that can seriously undermine or impact on the success of participation efforts. It may be prudent to pay special attention to this section to prevent obstacles and difficulties later!

Community participation involves the building of community capacity, reciprocal relationships and requires the support of community leaders.

- Does your organization know the CALD demographics of its catchment area?
- Have positive relationships been established between your organization and those who influence CALD communities, namely, the community leaders?
- Does your organization focus on the strengths of CALD communities with the purpose of learning from them and helping them to build their capacity for mental health?
- Are leaders acknowledged and offered support with the services they are already providing to their communities?

Mental health promotion is a key strategy to facilitate community and consumer participation.

- Does the organisation know the level of mental health literacy in the community?
- Does the organization understand the diverse perspectives of mental health and mental illness that each of the CALD communities have?
- Does the organisation know the level of stigma and shame about mental illness in the community?
- Does the organization know the key networks, groupings, leaders and activities of the community?
- Does the organization know what the help- seeking behaviour is in the community?
- What mental health promotion initiatives have, or are being implemented with the local CALD communities?

Consumer participation should be integrated into core business.

- Does management believe consumer participation is important to your organisation?
- What is the level of support for consumer participation across the organization? How about management?
- Do you wish to engage consumers for a specific purpose?
- Do you need/value consumer input in the different programs of your organization?
- What is considered your organisation's 'core business'? What are the opportunities for consumers to engage in these core business areas?
- Is your organization prepared to utilize the feedback received from consumers?
- Does the mental health service recognize the role of consumer participation in the recovery process?

Consumer participation should be supported from the top down but is built from the bottom up.

- Does your organization know how to establish an infrastructure that supports consumer participation?
- Does your organization know how to assess this infrastructure to see if it enables the participation of consumers at different levels of acculturation, mental health literacy and English language abilities?
- Does your organization have staff experienced in community development, health promotion, capacity building and consumer participation?
- Are there any training opportunities in community development or health promotion?
- Does your organization know how to be flexible to accommodate the diverse participation needs of consumers?
- Does your organization know how to build reciprocal relationships with local CALD communities?

Cultural competency building within mental health services is a key component of CALD consumer participation.

- Has the service identified how to measure the level of cultural competency of the staff and organization?
- Does your mental health service know how to increase the level of cultural competency of the staff?
- Has the service identified specific training opportunities?
- Does management support cultural competency building in your mental health service?
- Are local consumers and/or community leaders involved in the training to build cultural competency?

Secondary foundations – underpinning strategies for CALD consumer participation

The second area of the foundation deals with the strategies that are necessary to overcome many of the barriers experienced by CALD communities and consumers. In fact, if these barriers did not exist, we would not need a CALD participation model! Therefore, it cannot be emphasized enough that unless specific strategies are employed to work on these barriers, your participation efforts with CALD consumers may go unrewarded. The model holds that these strategies should flow on through all project activities, or they can shape program/project objectives linked to participation activities:

- **Understanding** - dealing with extremely high stigma and shame linked to mental illness,
- **Communication** - dealing with different language and communication styles,
- **Trust** - dealing with mistrust in the mental health system,
- **Acknowledgment of beliefs** - working with different beliefs regarding mental illness, (its causes and how it should be treated) and consumer participation, and
- **Mental health literacy.**

(1) Understanding - dealing with stigma and shame linked to mental illness

In many CALD communities, issues surrounding mental illness are not openly discussed. Consequently, there may be high levels of stigma attached to mental illness and consumers may be reluctant to openly identify as consumers due to their shame about mental illness.

Strategies to deal with stigma and shame:

- Create safe environments for consumers to discuss their traditional views of mental health, mental illness and treatments.
- Listen actively to their cultural views with respect.
- Take the time to validate the cultural views that have helped in the past and that may still be useful now.
- Facilitate the integration of cultural views at the macro level.
- Facilitate opportunities for consumers to consider the views of mental health and mental illness held by the Australian mental health system.
- Engage in an ongoing dialogue with community leaders to:
 - Increase their mental health literacy so they can be even more effective in playing a key role in helping people with mental illness in their communities.
 - Talk about concerns they might have about mental health issues in their communities, their initiatives, and the support offered by the mental health system to address some of these concerns.

REFLECTIONS...

In our project we held meetings with leaders of each community involved in the project and worked for 2½ years to put mental health on the community agenda. Only then was it possible to engage consumers.

Indicators that stigma and shame are decreasing:

REFLECTIONS ...

In our project, decisions were made after Stage Two based on these indicators to assess the readiness of each community to move on to direct engagement with mental health consumers. It was decided to proceed with six out of the nine communities.

- The number and level of participation by CALD consumers in consumer groups, thus overcoming their shame of being identified as a consumer within that context.
- Participation by consumers in educational seminars, forums and other public activities.
- Participation by consumers in ethnic media and community education opportunities on the topic of mental health or illness and stigma.
- Participation by ethnic leaders in public activities and/or ethnic media on the topic of mental health or illness.
- Participation of community members as presenters in seminars to service providers on the cultural perspectives of mental health and mental illness.
- Participation of community members as presenters in radio education sessions on topics such as stigma associated with mental illness and parenting between two cultures.

(2) Communication - dealing with different language and communication styles

It is stating the obvious that different CALD communities have their own language, but it should also be considered that they have very different communication styles. Issues relating to communication flows within the community and styles of communication with mainstream services are important. Issues relating to religious background, gender, age, sub-group membership etc. are also pertinent factors that may impact on communication styles.

Strategies to deal with different languages and communication styles:

- Employ professionally trained bilingual and bicultural community workers with mental health and/or community development knowledge and skills. For example, the project employed at least one worker for each community.
- Employ a worker from each gender or religious group if gender or religious issues are highly relevant in a community.
- When inviting consumers to participate, follow up the processes that involve a personal approach.
- Prepare the consultation questions for a consumer group session across communities based on clear objectives of the consultation, but run each consumer group in a culturally and linguistically appropriate way.
- Establish a range of mechanisms to capture the wealth of consumer feedback including consumer sessions and completion of surveys (but use the same consultation questions) either over the phone or by post and in the preferred language. In special circumstances a home visit is appropriate.
- Make it easy for the worker, and later consumers, to collate the feedback by using templates.

REFLECTIONS ...

In our project we discovered that the personal approach was one of the most important factors in establishing clear lines of communication. This is extremely resource intensive in terms of time and labour as bilingual workers are required but it is the only way to outreach people in communities who are not only isolated from mainstream services due to cultural and language barriers, but also within their own community due to the stigma of mental illness.

Indicators that communication with consumers and the community is effective:

- The wealth of comments, input and feedback that is collected from consumers.
- The expressions of interest from consumers to continue participating/actual participation.
- The low level of attrition from the consumer sessions.

- The quality of input gathered from employed consumer workers who are members of these communities.
- The quality of input gathered from the bilingual workers employed who are also members of these communities.
- The quality of linkages with community leaders.

(3) Trust - dealing with mistrust in the mental health system

The level and type of mistrust in the Australian health system will be different for each community. Mistrust in the mental health system may be even more pronounced, particularly because it is one of the only areas of health where involuntary hospitalisation or treatment can be ordered. It should be assumed that the community with whom you are working with will have some level of mistrust of the mental health system that your organisation probably represents. Whether you are a community-based organisation or a government health service, CALD communities often do not know the difference and any organisation will represent some kind of officialdom or authority. Paying special attention to this barrier or obstacle to participation is very important.

REFLECTIONS ...

Pitching the content and format of the information and discussion sessions with community leaders at a level where they feel acknowledged and comfortable, e.g. content is relevant, has resulted in their increasing attendance at the sessions and has enabled them to take initiatives to disseminate mental health information through community channels.

Strategies to deal with mistrust of the mental health system:

- Have a multi-strategy community approach. For example, link with community leaders, use the media to keep engaging the community regarding mental health, run community mental health activities (e.g. Mental Health Week, Mental Health Forum), run training for consumers and community educators.
- Have a long-term community engagement approach.
- Establish trust and rapport with the community gate-keepers by actively listening to their concerns and perspectives.
- Engage bilingual workers from CALD communities who are respected by a significant section of the community and who have strong community networks.
- Employ CALD Consumer Consultants to ensure consumers that the project is also consumer sensitive.
- Show consumers that you value and respect them and their comments in a number of ways.
- Place an emphasis on building a relationship between the service and the consumers, e.g. support the establishment of a CALD consumer network.
- Emphasise confidentiality.
- Demonstrate that the service is using the feedback obtained from consumers and community leaders.

Indicators that mistrust is decreasing:

- The level of attendance at consumer sessions.
- The number of expressions of interest to attend further consumer sessions.
- The expressions of interest in becoming involved in other activities offered by your organization.
- Level of participation of members of the communities as an audience of, and presenters in activities such as seminars on their cultural perspectives of mental health, mental illness and attitudes towards treatments.
- Participation of members of the communities in radio education sessions on topics such as the stigma associated with people experiencing a mental illness.
- Number of community leaders responding to invitations to attend mental health discussion sessions.

REFLECTIONS ...

Interested consumers decided to increase their level of responsibilities by becoming consumer facilitators during a consumer consultation where they facilitated consumer groups in their own communities and then conveyed their own and comments gathered, directly to a mental health service.

(4) Acknowledgment of beliefs - working with different beliefs regarding mental illness (its causes and how it should be treated) and consumer participation

When working with consumers from diverse backgrounds, you will be working with many different types of experiences with the mental health system both overseas and within Australia. People from diverse cultural backgrounds can have very different ideas and belief systems about mental illness, its causes, its treatment and about people who have a mental illness. It is important that the bio-medical model of understanding mental illness is not taken for granted as being the explanatory model for CALD communities, and more importantly, that it is not foisted upon these communities. In Sections One and Two, the importance of holding reciprocal dialogue with CALD communities about mental health and illness was highlighted.

Similarly, the concept of consumer participation may also be entirely alien to some consumers and others may have unrealistic expectations about the level of involvement that is possible. It is important that consumers have the opportunity to express their beliefs about consumer participation and that your organization be explicitly upfront about the level and types of opportunities available for participation.

Strategies to deal with different beliefs about mental illness and consumer participation:

- Listen attentively to the consumer's views about mental illness and consumer participation with respectful interest; consumers from some communities want to be more involved than what the system here allows and some others wish to be far less involved.
- Facilitate a reciprocal dialogue about mental illness – listen to different explanatory models respectfully and offer information about the Australian mental health system and explanatory model about mental illness.
- Gently explain the view of the Australian mental health system and the rationale behind it.
- Reach a compromise to achieve the best consumer participation outcomes.

REFLECTIONS...

The diversity in the levels of consumer participation in our project has been broad, from members of a consumer group not ready to engage as consumer facilitators to other groups where members were leading the establishment of an open consumer network and linking with the ethnic media to share their experiences as mental health consumers in order to decrease community stigma.

Indicators that more effective consumer participation is being achieved:

- Your organisation has invested a realistic amount of its resources to enable the participation of consumers on an ongoing basis.
- Your organisation has the participation of consumers from the CALD communities in the organisation's catchment area.
- There are linkages established with mainstream consumer participation structures in order to explore inclusiveness of CALD consumers.

(5) Increasing mental health literacy

If your organisation works in an area where little mental health promotion with CALD communities has taken place, it should not be assumed that there will be a basic level of mental health literacy from which you can work. In fact the opposite should be assumed! Because of the levels of stigma, shame and mistrust surrounding mental health issues and the mental health system, the levels of mental health literacy in CALD communities are likely to be relatively low. Unless mental health promotion strategies are an integral component of your participation project, it will be difficult to engage communities and consumers.

Strategies to increase community mental health literacy:

- Maintain a linkage with the leaders of the communities so they keep updated about other ways they could support people with mental health problems and illness and their families, including how the community could be more understanding and supportive and how and when to refer to mental health services.
- Increase the knowledge and understanding of local bilingual community workers about the Australian mental health system to enable them to communicate these to their communities in a culturally appropriate context.
- Sustain a dialogue with the communities about the traditional and the Australian explanations of mental illness, prevention strategies and treatments.
- Identify, acknowledge, value and support the traditional practices they have to prevent mental health problems and enhance mental health and wellbeing

Indicators that community mental health literacy is increasing:

- An increased number of referrals to relevant mental health organisations, including your own (i.e. self-referrals, family referrals and community referrals).
- The level of knowledge of the bilingual workers, their usage of language to articulate mental health concepts that might not exist in their language.
- The increased knowledge of consumers participating.
- The number of requests from community groups and individuals for multilingual mental health information and group discussions.

REFLECTIONS ...

We sustained a dialogue with CALD communities about mental health issues through (1) talks about the mental health system in Australia conducted by QTMHC staff throughout the project, (2) the radio & print media, (3) discussion sessions held by communities in preparation for showcasing their traditional activities to keep mentally healthy at a large event involving all the communities, (4) consumer group sessions, and (5) meetings with community leaders.

During the life of the project, referrals to the QTMHC clinical program increased by 58% from family, friends and self, an indicator that people in communities were starting to seek professional help from a service.

The pillars - participation opportunities

The next area of the model is represented by the pillars. The pillars provide support for the roof and symbolically the pillars are the pathway between the foundations and the roof – or the pinnacle of the participation model. The pillars represent the participation opportunities for consumers and also, in order to obtain meaningful participation in service development, consumers must have had the opportunity to participate in these four areas. Four areas identified are:

1. Consumer own care
2. Consumer personal development
3. Carer development
4. Community development.

Opportunities for participation will be presented for each of these areas:

OWN CARE	Consumers are encouraged to:	<ul style="list-style-type: none"> - Keep informed about their rights and responsibilities as a mental health consumer. - Have a say in own care. - Use all the existing ways available to provide feedback (positive and negative) about the service received.
PERSONAL DEVELOPMENT	Consumers preparing newsletter articles on mental health topics	Purpose is to present cultural views on mental health issues and the processes that have or are assisting them to deal with the issues.
	Consumers participating in therapeutic programs	Purpose is to gain benefit from therapeutic programs and take time out for self care.
	Consumers participating in CALD consumer networks	Purpose is to network with others and break down isolation. Information exchange. Gain information from relevant services on topics of interest.
CARER DEVELOPMENT	Engage with the carer(s) of the consumers involved.	Purpose is to create a supportive environment for the consumer which can be further supported and reinforced by the consumer's carer(s) if they understand and support the participation activities.
COMMUNITY DEVELOPMENT	Consumers are encouraged to undertake the following pro-active activities if they feel comfortable in doing so. This level of participation requires some level of confidence. The activities listed here are starting points only.	<ul style="list-style-type: none"> - Contribute to breaking down the stigma in their communities by talking to community leaders about how consumers like to feel supported by their community, religious group, media, etc. and by talking to other people in their community about how they think they could best provide support to consumers experiencing mental health problems or illness in the community. - Work with their ethnic community to help build its capacity to become involved in service development, eg. in training, meetings with community leaders, mental health promotion activities, etc.

The roof – service development opportunities

The final part of the model is the roof, or the pinnacle of CALD consumer and community participation work – service development. The model recognizes that if the pillars are in place and strong, then it can lead to the roof, or service development. It is likely that if consumers have been involved in participation opportunities regarding their own care and personal development, they will be able to have meaningful input into service development issues.

SERVICE DEVELOPMENT	CALD consumer consultative forums	The role of the CALD consultative forums is to provide advice on issues, projects, programs and services.
	CALD consumer workers	Their role is to support CALD consumer facilitators in the forums; organise the forums; co-facilitate the forum meetings; collate feedback; brief consumers. These workers can also sit on project reference groups and review committees; and provide comments on draft policy documents.
	CALD consumer facilitators	Their role is to participate in the CALD consumer consultative forums; to link with other consumers in their own community to get comments and views; to represent the views of at least three other consumers. They facilitate linkages with CALD consumers who are isolated by language, culture and within their own communities by being able to communicate in their own language in a culturally appropriate manner. They also participate in delivering training to mental health services and in cultural seminars and in organisational activities to provide a consumer perspective, e.g. in training, meetings with community leaders, mental health promotion activities, etc.
	CALD consumers	Their role is to represent only their own views at the forums, or during telephone interviews, or face-to-face meetings.

Finally, regardless of your participation activities, it will be important to gauge the success of your activities.

Indicators that better consumer participation is being achieved:

- Consumers are participating both in paid and unpaid activities.
- Consumers participating are those from communities where other mental health strategies have been sustained for a long period of time.
- The level of commitment of consumers has increased.
- The feedback from participating consumers about the impact of their participation on their recovery process.
- The capacity of the mental health service to sustain the best practice model of consumer participation. (This is best achieved when partnering with a community-based mental health or multicultural community development agency.)
- Consumers express satisfaction with the participation processes.
- The mental health service actively seeks opportunities to implement the consultation model.

- Other organisations seek advice from the mental health service on how to consult with CALD consumers.
- There are clear pathways to take consumer feedback to the highest level possible.

CONCLUSION

This report has outlined both conceptual and practical issues related to CALD consumer and community participation. It is a testament to three years of solid work in this area and reflects a genuine desire to achieve meaningful participation with consumers from CALD backgrounds. Although much has been achieved during these three years, in many ways this work only represents the beginning - the real work on *sustaining* meaningful participation starts now!

It is also prudent to expand the work by replicating this model to facilitate participation with carers from CALD backgrounds and to proactively network with mainstream mental health services' consumer participation activities to facilitate CALD consumer input. The role of the QTMHC will also include liaising with statewide developments in consumer participation and facilitate input from CALD consumers to ensure culturally inclusive strategies for consumer participation in Queensland.

To conclude, we at QTMHC believe that the hurdles and barriers for meaningful consumer participation with culturally and linguistically diverse consumers can be overcome through the model that has been presented in this report. The secondary benefits of such participation are numerous, particularly in regard to the increased involvement of ethnic communities in discussing the often taboo subjects of mental health and mental illness. We trust that this report will provide inspiration and guidance to other organisations wishing to develop CALD consumer participation mechanisms.

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