

REALITYCHECK



culturally diverse mental
health consumers speak out

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Project Partners

National Ethnic Disability Alliance (NEDA)

Multicultural Mental Health Australia (MMHA)

Australian Mental Health Consumer Network (AMHCN)



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definitions

The following abbreviations are used in *Reality Check*:

- CALD** culturally and linguistically diverse
- This refers to the wide range of cultural groups that make up the Australian population and Australian communities. It includes groups and individuals who differ according to religion, race, language or ethnicity. For ease of expression the abbreviation CALD is used in *Reality Check*.
- NESB** non-English speaking background
- NEDA uses the term NESB in all of its documents. MMHA, which is funded by the Australian Government Department of Health and Ageing, who also funded this project, uses the term CALD.
- Consumer** a person using, who has used or will use a mental health service
- Empowerment** The ‘process through which people become more able to influence those people and organisations that affect their lives’ (Research and Development for Psychiatry; cited by Meagher 1996, p.20).

Participation With regard to development... participation includes people's involvement in decision-making processes, in implementing programs... their sharing in the benefits of developmental programs and their involvement in efforts to evaluate such programs. (Unpublished World Health Organisation (WHO) document, JC24/ UNICEF-WHO)

AMHCN Australian Mental Health Consumer Network
The AMHCN, established in 1996, is a national, representative mental health consumer voice, valuing consumer expertise that enables full participation in Australian society.

MMHA Multicultural Mental Health Australia
MMHA provides national leadership in mental health and suicide prevention for Australians from CALD backgrounds.

NEDA National Ethnic Disability Alliance
NEDA is the national consumer-based peak body for people from a NESB with disability, their families and carers.



introduction

Reality Check presents the findings of a series of national consultations with CALD mental health consumers, conducted by the National Ethnic Disability Alliance, Multicultural Mental Health Australia and the Australian Mental Health Consumer Network.

Known as *Strategic Partnering: CALD Consumer Participation*, the project was funded by the Australian Government Department of Health and Ageing, under the National Mental Health Strategy.

CALD Consumer Participation Project Aims and Objectives

This project aimed to obtain information about the needs, concerns and aspirations of CALD people with mental illness and mental health problems to be used for:

- the development of strategies to deal with barriers to effective consumer participation;
- the development of a CALD consumer action plan for services;
- MMHA and NEDA strategic planning and other operational and policy purposes.

The quality and quantity of personal insights volunteered by participants greatly illuminated the subject of CALD mental health consumer participation. *Reality Check* uses many of these insights in the form of direct quotes to clearly communicate the needs and views of CALD mental health consumers to a broad range of stakeholders.

Using the Project Findings

Reality Check has sought to remain deliberately practical as a resource for mental health services and other agencies working with CALD consumers, therefore, only the most significant survey data generated by the project are presented.

Since this study, a CALD subcommittee of the Australian Mental Health Consumer Network (AMHCN) has been established to look at ways of increasing CALD mental health consumer participation in the Network.

MMHA has used, and will continue to use, the findings of this project in its national policy work, for special projects, and the development and provision of resources for CALD mental health consumers through a range of media.

NEDA will use the findings wherever possible in pursuing its advocacy, policy making and information gathering roles.

Reality Check will also be widely available to other CALD consumers, Commonwealth, state and territory governments, health professionals, service providers and community organisations, to improve CALD consumer participation in service delivery and to generally improve service access and quality for CALD mental health consumers.



checking reality: CALD consumer participation revisited

There have been numerous reports and studies highlighting the large range of inequalities faced by people of CALD backgrounds in gaining access to mental health services, and the quality of care they receive when using these services. More information on where to find these studies is included in 'Want to Know More?' on page 24.

It is well documented that:

- language and cultural barriers present significant obstacles for CALD people in gaining access to mental health services;
- people of CALD backgrounds often miss out on generic and psychiatric support services;
- people of CALD backgrounds are often unaware of the range of services and supports available and lack the knowledge necessary to access appropriate services;
- people of CALD backgrounds often misunderstand how services operate and are often misunderstood by health professionals;
- family members and caregivers of CALD people do not have the opportunity to express their problems, frustrations and views about care-giving within a structured and appropriate environment.

Addressing CALD consumer participation needs

The National Standards for Mental Health Services, *Standard 1, Rights*, outlines the actions required to ensure that all mental health consumers, their families and carers have their rights upheld. In relation to people from culturally and linguistically diverse backgrounds, it specifically includes the provision of information in appropriate languages and access to interpreters. *Standard 3, Consumer, carer, community participation*, further highlights the importance of consumer participation at all levels of service planning, delivery and evaluation.

Government, service providers and community organisations often point to consumer participation as a panacea for the inequities that exist.

It is very difficult to argue against the notion of consumer participation given its obvious benefits, such as:

- ensuring services become more accessible and appropriate;
- increasing the community's level of responsibility for its own health;
- developing positive attributes for consumers such as independence, assertiveness, problem-solving, decision-making and self-esteem;
- facilitating a more equitable distribution of resources.

However, 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.

The Project Process

In 2001 the National Ethnic Disability Alliance, Multicultural Mental Health Australia and the Australian Mental Health Consumer Network conducted a series of national consultations, in the form of facilitated focus groups, to better understand the needs, concerns and aspirations of people from culturally and linguistically diverse backgrounds with mental illness.

More than 60 consumers from New South Wales, the Northern Territory, Queensland, South Australia, Victoria and Western Australia participated. They were from a range of backgrounds which included: Burmese, Chinese, Croatian, Dutch, Greek, Indian, Italian, Khmer, Macedonian, Polish, Rumanian, Serbian, Spanish, Sri Lankan, Timorese and Vietnamese.

People were also given the opportunity to speak directly (either face-to-face or by telephone) with a consultation facilitator if they did not feel comfortable speaking about their mental health in front of other people. In Western Australia, four consumers made use of this option.

The facilitators were primarily workers from the various Transcultural Mental Health Centres and CALD-disability advocacy agencies around Australia who are in day-to-day contact with CALD consumers.

Facilitators were given a detailed briefing including a list of questions, an evaluation form and a consumer network sign-up sheet. They were also provided with a standard format for reporting the results.

The questions put to consumers during focus groups sought to identify the gaps in the mental health service system. Consumers then articulated their needs and concerns in terms of practical and concrete solutions.

Focus group discussions were reported by the facilitators using a standard feedback form. Facilitators reported no identifying information and did not record which participants made particular statements. CALD consumers were not asked to identify themselves in the focus groups unless they chose to leave their contact details in relation to the establishment of a Consumer Network. The information provided by CALD consumers has been treated with the strictest confidence and will remain confidential to NEDA.

Feedback was processed using QSR NVivo, a software program that analyses the commonalities and relationships between ideas expressed by different participants and across groups.

The following section of *Reality Check* presents what CALD consumers identified as their major concerns and what issues they considered important for their friends, families and carers.



key findings

A number of studies have identified that people from CALD backgrounds are under-represented in service usage in the broad areas of health and disability due to:

- a reluctance to use services due to language and cultural differences;
- culturally insensitive attitudes of organisations and service providers;
- pre-migration experience and/or trauma experiences;
- lack of information available in community languages;
- lack of culturally appropriate services;
- lack of interpreter use or misuse of interpreters;
- lack of consultation with CALD people with disability;
- lack of appropriately trained staff to work with CALD people with disability. (Sozomenou 2000)

In the focus groups, CALD consumers were asked three sets of questions: the first concentrated on their personal needs and concerns; the second addressed mental health services and their concerns about these; and the third focused on the possibility of linking into a national network of CALD consumers.

Lack of Information

It was very clear from the data provided that the lack of accessible information available to CALD consumers was a significant barrier to accessing services.

Without adequate information and knowledge, consumers cannot access the options available to them within the community. Information and knowledge are also key factors in the empowerment of individuals, which leads to participation:

“I don’t understand as nothing is explained”

“I only know to see a GP but do not know where else to seek help”

Not knowing where to go for help and not understanding what is happening generates anxiety, fear and disempowerment:

“you feel extremely worried until the situation can be explained”

“I feel confused”

“I don’t know what help is available or how much help I can ask for”

Isolation (Stigma)

Stigma was the most common issue raised. It was also clearly identified that different cultures have different understandings of mental illness and to some extent have a different stigma attached to it:

“mental illness has different meanings in different cultures and this makes it hard for people to understand the problem let alone seek help for it”

Stigma appeared to lead to overwhelming feelings of shame, which produced significant barriers for people to overcome in order to seek support:

“mental illness is a taboo subject, it is very sensitive and people are embarrassed so they don’t go to mental health services”

“there is no place for confidential details to be taken, it is done at the front counter where everyone can hear”

Therefore, it is extremely difficult for CALD people to feel confident walking into a service and asking for help.

It was identified by CALD people that mental illness is an extremely personal issue, which is compounded by a range of cultural beliefs and norms.

“we come from cultures and countries where if you have a mental illness, you end up being locked up and the keys are thrown away”

“(mental illness) is seen as a price for past sins or a family curse and the family has to cop it without outside help”

This only enforces the barriers to support services and compounds the isolation issues identified.

The myth of ‘looking after their own’ (impact of ethnicity)

Consumers spoke generally about their personal needs and concerns, highlighting a range of issues related to living with a mental illness including isolation from their own and the broader community, and uncertainty and frustration with the service system.

Consumers also spoke about the impact that ethnicity has on having a mental illness, particularly language difficulties encountered when seeking information.

One of the strongest themes common among all consumers was isolation and lack of community support:

“I have nobody, only a cat”

“you’re alone and you feel the world has abandoned you”

Whilst this is certainly an issue for consumers from Anglo-Australian backgrounds, for CALD consumers the ability to seek support is compounded by language and cultural barriers.

The common myth that ‘ethnic communities look after their own’ did not appear to come through when consumers were being consulted. CALD mental health consumers are just as isolated and cut-off from their communities as Anglo-Australian consumers.

It was also clear that ethnicity was an issue for consumers. Consumers identified that their ethnicity impacted on their ability to seek information and support and also created problems accessing necessary services. However, consumers were very clear that these obstacles were not a result of their own ethnicity, but a failing of the system to cope with diversity.

Interpreters

Consumers identified concerns about interpreters as a major issue in accessing services. There appeared to be two areas of concern: the first was the general lack of interpreters and bilingual staff available; the second, which featured more prominently, was that interpreters are often not well educated about mental health issues, resulting in consumers receiving inaccurate or confusing information.

“I requested an interpreter and she couldn’t translate it to me so she made it up”

“It is very difficult for the interpreter to understand mental health problems unless training is provided”

Perhaps more alarming is the reported number of misdiagnoses because interpreters are not relaying the appropriate information to mental health staff.

“people can’t explain themselves clearly and carers don’t give the right information - if the information doesn’t meet their criteria they don’t get the right diagnosis”

Consumers also identified that service staff have difficulty using interpreters and require more training and support.

Finally, consumers pointed to the abject lack of translated and appropriate materials for people to access about mental illness and mental health services:

“there needs to be more information about what services are available”

“there isn’t enough multicultural information on mental health issues available within ethnic communities”

Service Response

Consumers provided substantial feedback about their experiences with the inaccessibility of services. Responses could be grouped into two broad areas: problems finding a service and problems when using a service.

Problems finding a service

Consumers pointed to stigma and lack of knowledge, due to inaccessible information, as a key barrier to services and support.

“people avoid services because there is a lot of stigma”

“people still experience stigma when seeking help and it does not feel natural to seek help from doctors or workers”

Problems when using a service

After finding and getting into a service, consumers spoke about the quality of service they received once they were part of the system.

“people are not aware of their rights and need to be told that they shouldn’t accept a situation/service as it is if they are not happy”

Consumers also identified a range of challenges experienced when accessing a mental health service.

Consumers highlighted the attitude of service staff as a problem:

“you are made to feel less than other people”

“I understand how difficult it must be given the different cultures and language barriers but no one is prepared to give me any time or understanding”

It was also raised that service staff do not take the necessary time to explain the mental health needs of the consumer to interpreters or carers.

Consumers also pointed to the resourcing of services as a problem, particularly around the issue of long waiting periods, which can exacerbate mental ill health. Consumers expressed their frustration with this, highlighting the fact that their condition would be deteriorating while waiting:

“you get worse and worse and then you have to spend a longer period in hospital which in turn will take you longer to pick yourself up again”

Consumers also provided extensive feedback around the issues of cultural appropriateness within services.

Consumers did not feel that they were receiving quality services, which can also be a barrier to accessing support. If the experience within a particular service was not a positive one, then the likelihood of accessing other supports was low.

Consumers highlighted a range of factors contributing to culturally inappropriate service provision including inappropriate questioning, lack of accessible information, lack of understanding around various cultural needs and a highly “medicalised” approach to dealing with mental illness.

“it’s a quick fix, they give you tablets instead of addressing the whole issue of you as a person”

“the medical system is very linear and this is limiting for consumers”

“often the questions the mental health services ask are not appropriate to people from different cultures”

“local mental health service providers and agencies have no idea how to work with NESB Australians”

“there are just not enough culturally sensitive mental health services and frontline service providers”

Some consumers reported that they also experienced these issues when dealing with GPs.

National Network

It was interesting to note that very little time was spent discussing the need for a national consumer network.

Facilitators and consumers focused on looking at the issue of services. It became clear from the data that being able to understand one’s own mental health, and having the opportunity to access services and support, was a definite prerequisite to meaningful participation on a local level.



consumer recommendations

CALD consumers are not a homogenous group and different issues and needs were identified in the different states and territories.

Consumers put forward a comprehensive range of ideas to overcome the barriers that they identified. The ideas have been arranged into four categories: information provision; community education; culturally competent service provision; and social/support services.

Information Provision

- Setting up a dedicated 1800 number for CALD consumers to call that provides information and referrals. A centralised point of contact would be very useful and would help with the current confusion around the service system. It would be necessary for bilingual workers and interpreters to be available to talk to consumers.
- Developing a phone card for consumers to carry in their wallets, which lists relevant contact numbers, e.g., the dedicated number mentioned above. The card should also include numbers to call in case of an emergency.
- Setting up a buddy system for consumers – someone they could call to talk to about their mental health. It was suggested that a space be provided on the phone card mentioned above where you could write down your buddy's details.

- Linking consumers to specific consumer workers who have the expertise to deal with the issues around mental health and cultural diversity.
- Developing and distributing easy-to-read written information about mental illness.
- Providing information in different formats such as videos – it was felt that written information was not always the best.
- Using SBS radio to provide information about mental illness. This would assist people with low literacy.
- Developing and distributing a booklet about the various mental health services that CALD people can access.
- Developing a poster and other material about ethnicity and mental health.

Community Education

- Providing community education to ethnic groups about mental health issues to help break down stigma. Consumers suggested a range of ways to do this – face-to-face education, written materials, SBS radio.
- Providing education to CALD consumers about mental health, the services and supports available within the community and most importantly, education about consumer rights.

Culturally Competent Service Provision

- Develop and provide accredited cross-cultural training to GPs, service providers and other health professionals to improve cultural competency.

- Develop and provide training to interpreters about mental health so that they can become better conduits for information.
- Use interpreters as standard practice. Provide training in the use of interpreters that also involves consumers in training sessions.

Social/Support Services

- Consumers felt that more social activities were needed to help overcome the issues associated with isolation.
- Consumers suggested that ethno-specific support groups would also be helpful to allow people from similar cultural backgrounds to discuss the relevant mental health issues.



future directions

From the consultations and discussions conducted with consumers, it became very clear that before national or even state-wide consumer participation can be progressed in a meaningful way, there are some basic steps that the service system needs to take to improve service access and provision.

The project partners recognise that all services and agencies experience frustration with limited resources. However, these resources need to be better targeted towards CALD consumers who make up a significant percentage of the population. In Australia in 2001 one person in three identified as having a culturally and linguistically diverse ancestry. More than 250,000 first generation adult Australians from culturally and linguistically diverse backgrounds are estimated to experience some form of mental disorder in a 12-month period, based on the findings of the *National Survey of Mental Health and Wellbeing* (ABS 1998, 2001)

Both MMHA and NEDA intend to follow up the recommendations and issues from this report. Information about this work can be found by contacting either agency. See page 24 for details.

CALD consumer service provider checklist: 10 things that will make a difference

- Is information available to consumers in a range of formats?
- Do you provide interpreter services? In the reception area, is there an interpreter sign that can be used by people to identify their preferred language?
- In the office, are there posters, pictures and other promotional materials that reflect the diversity of the service's consumers?
- Have all staff and workers received accredited cultural competency training?
- Have interpreters been provided with basic information and training about working with mental health consumers?
- Does your organisation's mission statement, policies, procedures etc. incorporate principles and practices that promote diversity and cultural competency?
- Do evaluation mechanisms include assessing the number of consumers from diverse backgrounds against ethnic population distribution in the local area?
- Does the service work collaboratively with local ethno-specific services to draw on their expertise?
- Does the service provide training to consumers so they can support and work with other consumers?
- Is the service aware of local ethno-specific support groups? Does it refer to these services where appropriate?

want to know more?

If you want to know more about the needs of CALD consumers you can contact:

National Organisations

Australian Mental Health Consumer Network (AMHCN)
(07) 3844 3009

National Ethnic Disability Alliance (NEDA)
(02) 9687 8933

Multicultural Mental Health Australia (MMHA)
(02) 9840 3333

Australian Government Department of Health and Ageing
1800 020 103

ACT

ACT Transcultural Mental Health Network - Secretariat
(02) 6207 6279

ACT Multicultural Council
(02) 6249 8994

NSW

NSW Transcultural Mental Health Centre
(02) 9840 3800

Multicultural Disability Advocacy Association of NSW
(02) 9891 6400

Northern Territory

Multicultural Community Services of Central Australia
(08) 8952 8776

South Australia

Multicultural Advocacy & Liaison Services of SA
(08) 8244 7777

Queensland

Queensland Transcultural Mental Health Centre
(07) 3240 2833

Advocacy for NESB People with a Disability (AMPRO)
(07) 3394 9304

Tasmania

Tasmanian Transcultural Mental Health Network
(03) 6332 2200

Multicultural Council of Tasmania
(03) 6231 5067

Victoria

Victorian Transcultural Psychiatry Unit
(03) 9417 4300

Action on Disability within Ethnic Communities (ADEC)
(03) 9383 5566

Western Australia

West Australian Transcultural Mental Health Centre
(08) 9224 1760

Ethnic Disability Advocacy Centre (EDAC)
(08) 9388 7455

further information

The following publications are referred to in *Reality Check*:

Australian Bureau of Statistics (2001) *Census of Population and Housing*. Commonwealth of Australia, Canberra.

Australian Bureau of Statistics. (1998). *1997 Mental health and wellbeing profile of adults, Australia*. Australian Government Publishing Service, Canberra

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Sozomenou, A., Mitchell, P., Fitzgerald, M.H., Malak A., and Silove D. (2000). *Mental Health Consumer Participation in a Culturally Diverse Society*.

Melbourne, Australian Transcultural Mental Health Network

Unpublished World Health Organisation (WHO) document, JC24/ UNICEF-WHO

Websites

Multicultural Mental Health Australia
www.mmha.org.au

National Ethnic Disability Alliance
www.neda.org.au

Australian Mental Health Consumer Network
www.amhcn.org.au



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