

Meeting Needs: Perceptions of Respite Care

Findings from Respite Service Providers and Chinese, Indian & Sri Lankan Focus Groups June 2006

A joint initiative between the MIC and Yooralla

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1. Introduction

While the main objective of the CALD Respite Information Project was to: 'increase access to and use of respite services by CALD communities in the Eastern Metropolitan Region (EMR)', the project has also incorporated a minor element of research. This has included consultations with key stakeholders including; respite service providers in the EMR and targeted CALD community groups. Through the use of surveys (among service providers) and focus groups (among CALD community groups), information has been gathered and this has helped to shape greater understanding of respite services and community perceptions of respite. The latter has been instrumental in designing two Respite Information Forums and a 'Caring for Carers' Brochure (translated into four languages). This is explained in greater detail below with a summary of findings presented on pages 2 – 6.

Surveys

In March 2006 a questionnaire was sent to all respite service providers in the EMR. This survey looked at the common strategies employed by respite service providers in catering for the needs of CALD clients and any perceived service gaps. Additional information that was collected from this survey included service providers' knowledge of their bilingual workforce and CALD clientele.

Surveys were forwarded to 43 organisations and 24 completed surveys were received (56% response rate). Qualitative and quantitative data were collated. A summary of key findings are presented on pages 2-3: 'Overview of Survey Findings'.

Focus Groups

In addition to this, focus group sessions were held with three targeted CALD communities: Chinese, Indian and Sri Lankan. Each session comprised a small number of community members who participated in a relaxed discussed group. The assistance of an interpreter was required for the Chinese session.

The main aim of these focus group sessions was to:

- Gauge people's level of understanding of respite care services.
- Increase understanding of the perceptions of disability and respite among specific target groups.
- Assess the perceived level of cultural appropriateness of the various respite
 options, including which services people felt most / least comfortable in using
 (see pages 4-6: 'Key findings from Community Focus Groups').

^{*} It is important to note that while the findings provide useful insights into the different cultural perceptions of respite care, these findings cannot be generalised to whole communities.

2. Overview of Survey Findings

24 surveys were received out of 43 organisations (56% response rate)

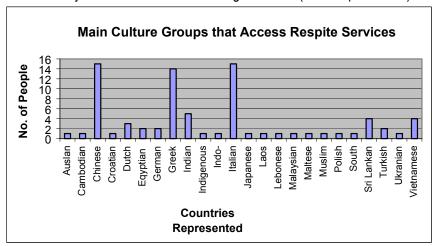


Figure 1. Main culture groups that access respite care services in the EMR

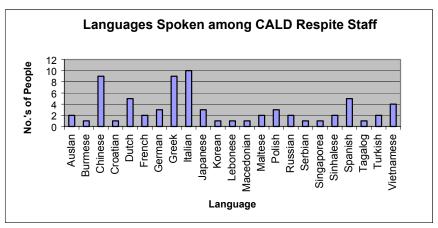


Figure 2. Languages spoken among respite care staff in the EMR

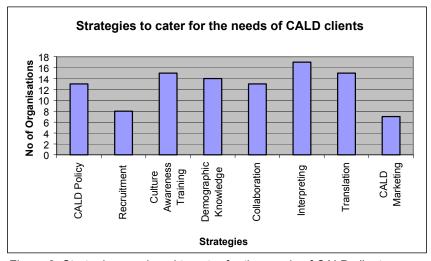


Figure 3. Strategies employed to cater for the needs of CALD clients

2.1 Quantitative Data

- Of the organisations that responded to the survey, an average of 16% of their clients were from CALD backgrounds. The most common languages and cultural backgrounds included Italian, Greek and Chinese-speaking clients. Following this were some smaller communities such as Indian, Vietnamese and Sri Lankan.
- While 71% of organisations were aware of the different languages spoken among their staff, only 33% maintained any formal documentation of this information.
- The most common strategies in place for catering for the needs of CALD clients included: Use of interpreting services (17 Organisations), followed by translating (15) and cultural awareness training (15). The least common strategies included: CALD marketing (7) and CALD recruitment (8).

2.2 Qualitative Data

- Perceived Barriers for CALD Clients
 - Not knowing about services.
 - Respite is not always culturally appropriate.
 - Language barriers.
 - Cultural barriers (special food/religious requirements).
 - o Organisations lack of links with CALD community groups / leaders.
 - Insufficient / lack of bilingual staff.

Use of Interpreters and External Workers

One quarter of respondents utilised external workers including the use of interpreters. Few specified the use of qualified bilingual carers as opposed to the use of interpreters. The most common agencies listed were: Fronditha, Italcare and the Australian Greek Welfare Association. Others included: VITS, Tempstar, Dasi, Diversecare, and the Multicultural Resource Centre in Richmond.

Support

Of the different ways that organisations felt they could be better supported to cater for the needs of CALD clients, the most common response was the desire for affordable and effective service promotion to CALD communities (6 agencies). Following this was increased access to funds, recruitment of bilingual staff, and cultural awareness training (3 respectively). Other factors that were raised include; dealing with cultural barriers, appropriate referral, collaboration with CALD and multicultural agencies and access to CALD resources/information. These included; translated information, regional demographics and a framework for how to write a CALD policy.

Perceived Service Gaps

Service gaps that were highlighted from the survey included insufficient funding and/or budget allocation for language services. Organisations were aware that some CALD groups were simply unaware of their organisation and the services available. Some felt that these barriers were linked to language barriers, lack of targeted CALD marketing and bilingual staff.

3. Key Findings from Community Focus Groups

3.1 Chinese Focus Group

Attendance: 17 people

Experience / Knowledge of Respite Services

- Most members stated that they had never heard of respite prior to the presentation.
- While everyone agreed this was a foreign concept, over the time of the focus
 group members were able to recall past experience or knowledge of some
 form of respite care (through friends or relatives). It seems that some were in
 fact familiar with respite however never knew what this service was called.
- The Chinese translation of respite care is difficult to understand, even though
 we provided 3 different translations of respite care. The term needs further
 explanations to capture the concept of respite services.

Thoughts on Respite

- One person commented that they felt respite was a positive service.
- Another person felt it was a family responsibility to look after each other. Caring
 was considered "A family responsibility not a social responsibility". This person
 felt that the Australian government was interfering in the caring process.
- Most agreed that of the different respite options 'in-home' was the best option for both parties, however, it really depends on the situation.
- Most people agreed that they would recommend this service to a friend or relative.
- People felt that when they used general health services, language was the greatest barrier in accessing services. Waiting time was another barrier.

Respite Information Forum

The following points were suggested in regards to a Disability Respite Forum targeting the Chinese community. It was suggested:

- NOT to use the term 'disability' in the title. This is most likely to attract a negative response and people are less likely to attend.
- Possible titles: 'How to help the carer solve temporary problems in the home'
 - The best suggested title was 'Caring for the Carer' or 'Caring for Carers'.
- People wanted to hear a range of speakers from different service providers, including a speaker from a respite organisation and Centrelink.
- People also wanted to hear personal stories from a carer's perspective what are some of the problems they have faced.
- Day / Time preference weekday in the morning.

3.2 Indian Focus Group

Attendance: 5 people

Cultural Perceptions on Disability

- The group felt that generally there was no stigma attached to disability among the Indian community.
- If there are services offered and the community is aware of them, they will most likely access the services.
- Members felt that they would like to be more informed about what services are available to them.
- Family is very important to the Indian community, but they also recognise that dynamics are changing in Australia. Where both men and women are working and their lives are busy with less time for younger people to care for other family members in their homes.
- Generally it was considered that it was the family's responsibility to care for a family member with a disability or when people become frail due to old age.

Thoughts on Respite

- Of the different respite options, members felt they would be most comfortable
 using recreational or community-based respite. They felt that this was the
 best option for the individual with a disability as they could engage in a fun,
 recreational activity.
- Members felt that residential care was not an option for the Indian community. It would be like "sending them away".

Barriers to Using Respite

- Key barriers to accessing residential respite were concerns around what other people in the community would say or think about them.
- One person felt that people in the Indian community feel that they have to keep up an image of things being OK even if they are not.
- To use a service like residential respite it would appear as though "they can't cope".

Respite Information Forum

- There would be no problem to market the forum using the word 'Disability' in the title
- The issue around financial independence for aged people was raised.
 Participants felt that it would be good to have a speaker from Centrelink talk about what kind of financial support is available to carers e.g. carer support allowance.
- Best time for the forum Saturday morning.

3.3 Sri Lankan Focus Group

Attendance: 4 people

 Most people said that they had heard of respite before but did not know what it meant.

<u>Cultural Perceptions on Disability</u>

- They felt that generally there was no stigma attached to disability but recognised that some people might feel ashamed.
- In the discussion people recognised that society is changing Perhaps there was some shame attached to disability among older people, however this is less so among the younger generation.
- They also felt that people in the community were not very open about issues such as mental illness or depression – if anyone suffered from this no-one would know (as they are concerned about what other people would think).

Respite options that people were most comfortable to use

- Most agreed that it would depend on the situation, but they were most inclined to use recreation/community based respite. They felt this was best for the client because they could enjoy an outing.
- They also suggested that you should ask the person with a disability what they would prefer. A carer would be most happy if they knew that their family member was also happy.
- All members felt that they were least likely to use residential care. Some of key the reasons for this were as follows:
 - Connotations of a hospital being for the mentally ill.
 - Not culturally appropriate (care is a family's responsibility).
 - The community perception would be that you have "dumped them", and that you have no time for your parents/family member.
 - Community perception of being selfish (absorbed in your own interests) and that people would look down on you.

Barriers to using respite

- There was a strong sense of caring about what other people will think.
- In-home care: This is OK only if it was recommended or referred by a professional or a doctor. "If I was to seek it out myself, I'd feel sneaky, like I'm doing something behind their backs" (regarding frail aged parents).