Project Report on the Study into the Needs of Carers from Culturally and Linguistically Diverse Communities in the Nepean Area

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- Western Sydney Community Forum, HACC translation project
## Acronyms and Glossary of Terms

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<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>Com Packs</td>
<td>Joint discharge program between multidisciplinary health teams and non health community care case managers where the patient requires two or more services to remain at home (NSW Health, 2008)</td>
</tr>
<tr>
<td>DADHC</td>
<td>Department of Ageing Disability and Home Care</td>
</tr>
<tr>
<td>EDAC</td>
<td>Ethnic Disability Advocacy Centre, W.A.</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>GREAT</td>
<td>Greater Regions, Essential, Accessible Transport (Penrith and Blue Mountains)</td>
</tr>
<tr>
<td>HACC</td>
<td>Home and Community Care</td>
</tr>
<tr>
<td>ISAF</td>
<td>Interpreting Services Administrative Framework</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>MSO</td>
<td>Multicultural Services Officer</td>
</tr>
<tr>
<td>NEDA</td>
<td>National Ethnic Disability Alliance</td>
</tr>
<tr>
<td>Nepean Multicultural Access Project</td>
<td>Formally known as the Nepean HACC Access Project</td>
</tr>
<tr>
<td>NESB</td>
<td>Non English Speaking Background</td>
</tr>
<tr>
<td>PDRC</td>
<td>Penrith Disabilities Resource Centre</td>
</tr>
<tr>
<td>SDAC</td>
<td>Survey of Disability, Ageing and Carers</td>
</tr>
<tr>
<td>TRI</td>
<td>TRI Community Exchange</td>
</tr>
<tr>
<td>WAT</td>
<td>Wheel chair accessible taxis</td>
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Executive Summary

There is an under-utilisation of community care services by carers from culturally and linguistically diverse (CALD) backgrounds throughout Australia, including the Nepean area. The level of access and usage of HACC services by people from CALD communities in NSW (8.6%), is markedly lower than the National Benchmark of 19.1%. These facts are evidence enough to suggest that barriers to service access and usage exist for this population group. Services in the Nepean area, however, can only develop locally appropriate strategies to overcome these barriers when they are aware of the specific issues for people from CALD communities in the Nepean area.

Consequently, the researchers in this project undertook to study the experiences of service access by carers from CALD backgrounds in the Nepean area, to explore the ways that service access could be enhanced by carers from CALD backgrounds in the Nepean area and also ascertain which aged care and disability services were needed to support carers from CALD backgrounds in the Nepean area.

The project partners, the ‘Nepean Multicultural Access Project’, auspiced by ‘TRI Community Exchange’ and the ‘Strengthening Community Links for People with Disabilities in the Nepean Area Project’, auspiced by ‘Penrith Disabilities Resource Centre’, consulted with sample groups from three different CALD communities and one language group. A total of 92 participants participated across four specific focus groups for people from the Greek, Macedonian and Filipino communities and also the Arabic speaking communities. Existing networks with culturally relevant workers were utilised to assist in the recruitment process. To ensure a transparent and equitable process, a professional facilitator and professional interpreters were engaged for these four focus groups.

Five important recurring themes emerged from this study. Firstly, participants from this study stated that they not only had a need for community care services but that they were willing to use these services, which is contrary to prevailing misbeliefs /misconceptions that “CALD communities do not demand or need services because they will look after their own” (NSW Aged Care Alliance, 2004, p.12).

The second theme to emerge from this study is a general lack of awareness, amongst CALD carers in the Nepean area, of service availability and the method of access to these services. The prevailing message from all four focus groups was that CALD communities who are potential system users are unable to access community services information.

Participants within each of the four focus groups offered strategies aimed at overcoming these barriers to information access. These included the distribution of relevant language, multimodal material distributed through exposure points such as medical officers, pharmacists, churches, guest speakers at social groups, print and electronic media, and Centrelink mail outs. They also included a centralised point for information access and language specific instructions on agency answering machines. In addition,
the Filipino group discussed the need for visually attractive material, including culturally relevant images.

Also evident was a lack of concept/understanding of a community services system. Families declared that they were unaware how to access the ‘system’ and they didn’t know where to start, who to talk to, what to do or how systems such as ‘Com Packs’ operated.

Thirdly, the researchers observed that there was some reliance on the interpreters for effective communication in each of the focus groups, no matter the length of settlement since migration. This level of reliance, however, did appear to be related to the length of time that communities had been settled in Australia and consequently, whether the group included participants who had been born in Australia, and also the possibility of exposure to English language development prior to migration.

The need for interpreters for each particular focus group did not necessarily match the researchers’ beliefs as to the need for an interpreter. The researchers’ beliefs were based on the assumption that some focus groups would not be reliant on the services of an interpreter. Therefore, the researchers became aware of the need for caution when deciding on the need for interpreters for any community group or family. An obvious outcome of this research was that members of CALD communities may be disadvantaged if interpreters are not offered or available, regardless of the level of English language proficiency perceived by the community services worker/s.

The fourth major theme to emerge from this study was in relation to culturally and regionally appropriate referral networks. There was a direct correlation between the success of recruitment for a particular focus group and the strength of the networks between the researchers and relevant ethno specific workers, i.e. the greater the network connection between the worker and the community group, the higher the attendance rate in the focus group.

Finally, a strong underpinning theme emerged from this study in relation to the need for social groups. This was not only discussed within each group as a means to increase social capital and to improve the social health of participants but, more importantly for this study, the participants stressed the importance of social outlets as a means of accessing information relevant to their future and present care needs.

On the basis of the information gathered in this study, the researchers provide the following recommendations:

1. Further work is required to determine appropriate strategies to overcome the barriers experienced by carers from CALD communities in accessing and utilising community care services. Some strategies have already been offered by these groups. The fact that four focus groups have already been engaged in this study indicates the possibility of future access to these groups for the purpose of further strategy development.

The focus group participants have offered a ‘blue print for change’ in the strategies already offered, i.e. that guest speakers provide information sessions on the availability and method of access to community care services through
carer support groups, ethno specific social groups and day care centres. All four groups stressed the importance of an information session occurring within a social context.

2. The researchers experienced the highest access to, and responses from, CALD communities when a strong liaison existed between the researchers and culturally relevant workers who also had strong connections to a particular CALD community. Organisations, therefore, are recommended to implement consultations with CALD communities in association with a culturally relevant worker, preferably one who is also known to that particular community.

3. Other strategies suggested by the participants deserve further exploration, particularly in light of the suggested multimodal approach for raising awareness of service availability and methods of access to these services in the Nepean area, outlined in the discussion section of this paper.

4. The outcomes of this research need to be disseminated through the community services sector and other exposure points such as the Nepean and Blue Mountains Division of General Practitioners to engage them in the process of culturally appropriate service provision.

5. That community services in the Nepean area develop appropriate strategies for CALD clients which take into account that CALD communities may differ in their perceptions of services and understandings of the community services system. These strategies also need to take into account that this difference may be linked to both the length of settlement of particular communities and the level of connectedness between that community and other communities, i.e. the greater the degree of marginalization; the greater the need for specialist strategies.

6. That funds be made available for training programs for generic community care service workers. This training needs to provide an opportunity for workers to acquire the necessary knowledge and skills to:

   a. develop strategies for improved access to CALD communities and
   b. provide culturally appropriate services to marginalised communities such as the Arabic speaking communities.

7. That community care services apply the knowledge and skills referred to in Recommendation 6 to provide services to CALD communities as part of their core business, including the provision of a culturally appropriate assessment process.

8. That the community services sector in the Nepean area develop the practice of offering and/or using interpreters, irrespective of the worker’s beliefs regarding the carers level of English language skills. This is strongly recommended on occasions when assessments are carried out and service agreements are explained, so that opportunities can be provided to achieve optimal understanding of the service provided.
9. That the implementation of social support service models for specific CALD communities be explored / researched.

10. As previously stated in this report, the Nepean area includes in its resident population, people from multiple cultural and language groups. Unlike other Sydney areas there is no predominant CALD group in the Nepean area and consequently, very few specific CALD services. The researchers, therefore, recommend that culturally specific case management services be provided within Nepean community care services with the aim of developing links between service providers and potential service users within CALD communities, in particular new and emerging communities. This may assist in overcoming the barriers to service access for these marginalised communities.

**Conclusion:**

New learning has been achieved through this research and these insights have been discussed in this paper and included as recommendations for the community services sector within the Nepean area. The active participation and generous responses of the group participants within this study highlighted to the researchers the need for carers’ support within CALD communities; a need which is contrary to some beliefs. This research also highlighted that CALD communities are not a homogenous group and accordingly, that the needs between and within these groups may be vastly different.

The outcomes of this research have formed the foundation for understanding why there is an under-utilisation of services by clients from CALD backgrounds; identifying and understanding the barriers to service access in the Nepean area and, most important, what carers need to support them in their caring role. Existing strategies to enhance service access by carers from CALD backgrounds may require urgent review if we are to address what will become a major health problem of under-supported carers. This study can form the basis for further strategy development in the Nepean area in relation to service access by carers from CALD communities.

Simply stated, the focus group participants offer the final comments:

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“We need to accept help but it will need to remain a personal choice”
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and

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“We need to learn to ask”
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In light of these statements, perhaps the community services sector also needs to be mindful of something else, i.e. the need to listen.
Introduction

Many families, from all cultural backgrounds, care for a family member who is either a frail older person or a younger person with a disability. In some cases, a family will simultaneously care for both an older person and a younger person with a disability.

There is evidence, on a National and State wide level, that the level of access and usage of aged and disability community care services by people from culturally and linguistically diverse (CALD) communities is comparatively lower than the service access and usage by people from Anglo Australian communities. Evidence is also available, from a New South Wales perspective, on the impact of cultural issues on the role of a family member who provides care for a frail older person or a younger person with a disability.

The needs of frail older people, people with a disability and their carers from CALD backgrounds are therefore disproportionately under-serviced in comparison to the general population. Levels of demand and type of need are currently under-researched and under-valued. As a result, these demand levels and need types within CALD communities are hidden, leading to inequitable service provision.

The under-representation of CALD clients and carers within Home and Community Care (HACC) and disability services is evidence enough that barriers exist for this population group. The explanations for these barriers, however, are sometimes based on anecdotal evidence, assumptions and stereotypes. Other studies, such as those implemented by EDAC (2005) and Cardona, Chalmers & Neilson (2006) explored the experiences of carers from CALD communities in NSW and provide some insight into these barriers. Issues related specifically to the use of HACC and other disability services by CALD community members in the Nepean area have not been fully explored to date. These and other relevant issues were explored in this project.

The Nepean is an area that encompasses the outer western Sydney basin and mountain areas west of the Nepean / Hawkesbury river system. The area is composed of the three local government areas (LGAs) of Penrith, Blue Mountains & Hawkesbury. The Nepean area is unique because it contains a mixture of rural farmland and villages, bush land and moderately populated urban areas. The area also contains a mixture of older settlement migrant groups and more recently settled migrant groups. Approximately 9.7% of residents in the Nepean area, (2001 Census, cited in Boyde, 2006) were born in a non English speaking country but, unlike other Sydney areas, these residents are from multiple cultural and language groups, i.e. there is no predominant CALD group in the Nepean area.

The authors of this study were not able to locate any local study on carers’ use and attitudes towards aged care and disability services in the Nepean area. However, the Nepean Multicultural Access Project has collected some data that indicates the existence of barriers to service access for carers from CALD communities in the Nepean area. Local research was required so that local services could understand the issues
and begin to address the issue of under-utilisation of services by carers from CALD backgrounds.

The following report describes a qualitative study into the service use needs of carers from CALD communities in the Nepean area in 2007. This research study was implemented as a response to the authors’ concerns that there is a dearth of understanding as to:

1. The reasons for under-utilisation of community care services by carers from CALD backgrounds in the Nepean area and
2. If there are barriers to service access by carers from CALD communities in the Nepean area; the reasons that these barriers exist

The purpose of the research was to gather information and then gain some understanding of the issues which shape the CALD carers' world view in relation to service access. This was aimed at forming an understanding of the reasons for the under-utilisation of services by clients from CALD backgrounds; the barriers to service access in the Nepean area and, most important, what carers need to support them in their caring role.

The authors of this report were also research partners in this study and will hereafter be referred to as 'researchers'.

**Aims of the Project**

As there did not appear to be any locally relevant information regarding CALD carers in the Nepean area to date, the authors considered that a fundamental step in addressing the issue of service under-utilisation was to gain some insight and understanding of the reality of CALD carers in relation to service access. The aims which followed from this were:

1. To determine the experiences of service access by carers from CALD backgrounds in the Nepean area.

2. To explore the ways that service access could be enhanced by carers from CALD backgrounds in the Nepean area.

3. To ascertain which aged care and disability services were needed by carers from CALD backgrounds in the Nepean area to support them in their caring role.
Literature Review

NSW currently has a population of approximately 6,750,000 people. Approximately one quarter of the state’s population comes from a background where they, or one of their parents, were both born overseas and have a CALD background. The proportion of people from CALD backgrounds is steadily increasing in NSW, but their use of aged care and disability services is disproportionately lower than that for other Australians (NSW DADHC, 2005 and Multicultural Mental Health Australia, 2004).

Additionally, the NSW Aged Care Alliance (2004) reveals that approximately 20% of the Australian population group of people who were aged 65 years and over in 2004 emanated from a CALD background (some longer term settled communities have a much higher proportion in this age group). Yet, at 14.7%, the national usage of Home and Community Care (HACC) services by older people who were born overseas in a non English speaking country falls short of the national benchmark of 19.1% (NSW Aged Care Alliance, 2004). The situation is of greater concern in NSW, where only 8.6% of HACC clients are people who do not use English as their primary language at home (Carers NSW, 2006).

![Comparison of Usage of HACC Services against National Benchmark](chart.png)

- % of NESB Clients participating in HACC Services in NSW
- National Benchmark for NESB clients in HACC Services
In the 2003 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), 3,958,300 or 20% of Australia’s population had a reported disability. These figures are the same for NSW (cited in Physical Disability Council of NSW, 2006). People from CALD backgrounds account for one quarter of the people with a disability in NSW, yet they are substantially under-represented in terms of their access to disability services, i.e. “they only account for 6.8% of government provided or funded disability services in NSW”. (NSW DADHC, 2005, p.1). The Ethnic Disability Advocacy Centre (EDAC) in Western Australia also reports that, although 15.4% of people with disabilities in W.A. are from CALD backgrounds, only 4.3% of these people access disability services. EDAC also reports that people from CALD backgrounds, or their families, are less likely to report their unmet needs or seek assistance to meet these needs (EDAC, 2003).
The National Ethnic Disability Alliance (NEDA) (2005) refers to the Disability Support Services 2002 - National Data on services provided under the Commonwealth / State / Territory Disability Agreement which highlights that only 3.6% of service users are from non English speaking countries/backgrounds. Further to this, the data also highlights that only 1.3% of service users are those that utilised interpreters for spoken languages other than English. These figures clearly demonstrate that people with a disability from CALD backgrounds experience a systemic disadvantage when they need to access disability services. NEDA (2005) also suggests that existing racial and disability discrimination manifests in many ways including lack of access to information in community languages, lack of culturally competent service provision, lack of access to interpreters, the “prevalence of myths, misconceptions and negative stereotypes about disability and ethnicity” (p.2), and lack of equity in income support.

In Western Australia, the Ethnic Disability Advocacy Centre (EDAC, 2005) reports that there is widespread misinformation on services available to carers and that carers view the available services with anxiety and confusion. EDAC also reports that there were marked differences in service access between those with English proficiency and those without. The report also referred to the difficulties experienced by newly arrived migrants and those who had arrived as refugees in communicating their service needs. (EDAC, 2005) No explanation for these differences was provided in the EDAC report.

The experience of care giving within CALD communities in Sydney has also been explored by Cardona, Chalmers & Neilson (2006). In their report, Cardona et al conclude that there appears to be a gap between the existence of information strategies, e.g. Commonwealth Carelink Centres, and the dissemination of information about these strategies to carers in CALD communities.

A 2004 survey of Carers NSW members showed that CALD carers were more likely than other carers to report a need for information and, contrary to popular belief, just as likely to report a need for services such as respite. (Carers NSW, 2006) Anecdotal information supports the view that there is a general lack of awareness amongst CALD carers of service availability. The NSW Aged Care Alliance suggests that this may be due to culturally and regionally inappropriate information and referral networks. The NSW Aged Care Alliance also refers to the stereotypical perception that “CALD communities do not demand or need services because they will look after their own” (NSW Aged Care Alliance, 2004, p.12).

In addition to the Carers NSW research, Plunkett and Quine, (1996) in their study of Australian carers from non English speaking backgrounds, report that some of the difficulties experienced in using services were common to many carers, irrespective of background. Other difficulties, however, were specifically related to cultural background and English language difficulties.

The above studies have explored issues such as the experience of ‘caring’ in CALD communities and/or the barriers to service access. Cardona et al, (2006) also comment on issues such as ‘cultural competence’. Cultural competence is usually understood from the perspective of service providers, i.e. what service providers need to do to be culturally sensitive/appropriate to CALD communities. Cardona, Chalmers and Neilson discuss this issue and comment on the presumption by Anglo based services that they
are ‘culture neutral’, which of course implies the absence of an Anglo culture. Because of the notion of cultural neutrality, the presumption could be that a family attempting to negotiate a complex system of disability and aged care services within the dominant Anglo Australian system does not have to deal with a cultural set of social practices and mores. Negotiating an Anglo Australian system, however, requires a high degree of Anglo Australian cultural competence and language; something that may be extremely difficult for people from CALD communities.

EDAC’s (2005) reference to the lower rates of service access for members of CALD communities who are not proficient in English is testament to the difficulties experienced by CALD carers in attempting to negotiate the system in Australia (EDAC, 2005). This was also an important consideration that required further exploration within a local, i.e. Nepean area, context.

In November 2004, Nepean Migrant Access Service, in collaboration with Hawkesbury City Council and (the then titled) Wentworth Area Health Service, surveyed CALD residents in the Hawkesbury LGA. This study explored issues in the general community and consequently did not provide specific information about the needs of carers. The study did, however, demonstrate that lack of access to services by CALD communities in the Hawkesbury area is ‘across the board’. The study indicated that generalist community service providers, i.e. not only HACC type service providers, in the Hawkesbury area report an under-utilisation of their services by people from CALD backgrounds. This 2004 survey of the CALD community also revealed that the majority of generalist services were unknown by over half of the respondents. (Luckhurst-Khan, 2005)

The majority of available information regarding carers appears to be related to carers of frail older people and carers of people with mental health disorders. A literature search revealed a paucity of information related to carers of people with disabilities in NSW. The 2005 survey of three different groups, i.e. people with disabilities, carers of people with disabilities, and service providers in the Nepean area by Penrith Disabilities Resource Centre (Sedger, 2006), revealed that half of the 32 carers surveyed experienced difficulties in accessing information on services and resources. Although this study appears to be one of the few that focuses on issues specific to people with disabilities and their service providers and carers, this study could not be considered as representative of the needs of CALD carers because all but one of the respondents to this survey were from Anglo Australian background. The study, however, does provide some insight into issues that are possibly common to carers, irrespective of background.
Methodology

Project Partners
The project partners in this research project were two, well established community based projects which function within the Nepean area:

The Nepean Multicultural Access Project aims to respond to everyone’s fundamental right to be able to access services and participate in support and help provided to the members of the Australian community. The project is auspiced by TRI Community Exchange Inc. and receives re-current funding from the NSW Department of Aging, Disability & Home Care (DADHC) under the Home & Community Care (HACC) program. The target group is NESB/CALD frail older people, people with disabilities, their families and carers living in the Nepean Area.

The project objectives are to:

- To increase awareness of and access to HACC funded services in the Nepean Area for frail older people and people with disabilities from CALD backgrounds, their families and carers, and
- To assist, support & resource HACC funded services in providing CALD appropriate care/services to meet the needs of their clients.

The Strengthening Community Links project is a four year community development project funded by the Western Sydney Area Assistance Scheme from May 2005 to May 2009. This project is auspiced by Penrith Disabilities Resource Centre. The project objectives are to:

- Develop strategies for improved coordinated service delivery to people with disabilities.
- Explore and develop ways to improve services to communities isolated by culture and geography.
- Provide community support to existing disability services who are seeking to build onto existing services and develop new networks.

As the above projects do not provide a direct ‘service’, e.g. respite or domestic assistance, they could be described as relatively impartial and therefore, were well placed to implement this research. Focus group participants were therefore assured of this impartiality, which enhanced and facilitated the possibility of open, honest discussion within the focus groups and reduced any possible fear of retribution from a service provider.
Research Tasks
The study described in this paper is qualitative research framed within an Interpretive Methodology. This approach focuses on the phenomena of human action and interaction. Qualitative research involves the use of qualitative data, such as interviews, documents, and participant observation data, to understand and explain social phenomena (Packer, 2000). The researchers suggest that this methodology increased the understanding of the experiences of carers from CALD backgrounds in the Nepean area in relation to their use or non use of aged care and/or disability services. Carr and Kemmis (1986) outlined tasks that they considered important within an Interpretive Social Science Framework. These tasks were identified in this research and they helped to provide achievable objectives in terms of researching service access by carers from CALD communities:

Task one - "To discover the meaning ..." that carers from CALD communities assign to aged care and disability service access. (Carr & Kemmis, 1986, p. 88)

Task two - "To uncover the set of social rules, [i.e. the world in which they live which may include cultural and social mores], which give point to ... " their use or non use of aged care and disability services. (Carr & Kemmis, 1986, p. 89).

Project Strategies and Methodology of Data Collection

Ethical Considerations
The researchers consulted Burns and Grove’s 1993 research text as an authoritative source of ethics research.

The core ethical issues identified for this study were those of privacy, confidentiality and informed consent. The researchers were also aware, through their networks with ethno specific workers, of the possibility of some focus group participants perceiving the researchers/facilitator as authority figures, with possible resultant implications of power imbalance. These issues were carefully explained at the beginning of each focus group.

A major consideration in ensuring that ethical standards were met was the fact that participants were from a non English speaking background, and therefore, could be disadvantaged if appropriate procedures were not implemented. Accordingly, the following methods were used to ensure participant privacy, confidentiality and protection from unintended consequences:

1. Verbal, informed consent to participate and for session documentation was sought and gained from the adult participants through the use of an interpreter prior to the commencement of each focus group. This verbal consent was then documented by the researchers prior to the commencement of each focus group. The researchers provided the following information before the commencement of each focus group and before seeking and gaining the participants’ consent to document the participants’ responses:

   • an explanation that a study is being implemented
• a statement explaining why the research is taking place
• possible benefits from this research to carers from CALD communities
• an explanation of the processes involved in this research
• their role in this study and what is expected from them
• an assurance of anonymity and confidentiality
• an assurance that identifying details will not be provided to any service or Government Department
• an assurance that they have the opportunity to speak openly and candidly about their experiences without censure or judgement from the facilitator and / or the researchers
• an assurance that they will not be disadvantaged in relation to service use because of their participation in this study
• an option for participants to withdraw if desired
• the researchers also offered to clarify any issues about the research before proceeding

2. Participants were assured that no release of identifying data would take place without their prior written authorisation and that any documentation would be stored in a secure place. They were also assured that only the researchers would have access to the documented data.

3. The researchers also ensured participants that no member of any group would be identified in the final report of the study.

**Study Sample**

As stated previously, this research aimed to explore the experience of service access, how that service access could be enhanced, and also to ascertain which aged care and disability services were needed by carers from CALD backgrounds in the Nepean area. The recruitment process specifically targeted carers; defined for the purpose of this study as “…usually family members who provide care and assistance to others, including children and adults with a disability and frail, older people” (NSW DADHC, 2007). However, as focus groups self selected for this study, the researchers discovered that, as well as carers, some of the participants in each focus group were either community members or care recipients. In many cases, the whole family attended, i.e. carers, care recipients and other non caring family members. The researchers considered that excluding non carers from the focus groups may be culturally inappropriate, i.e. a ‘cultural bind’ and therefore could be seen as a limiting factor in collecting qualitative data.

The study samples, therefore, consisted of a group of adult carers of frail older people and/or people with disabilities and other adult community members from three different CALD communities and one language group; all of whom lived in the Nepean area. Two
different groups were interviewed during focus group sessions in the Penrith LGA. One group consisted of carers and other members of an older established community, i.e. the Greek community and the other group consisted of carers and other members of comparatively new established community groups, i.e. members of Arabic speaking communities.

The researchers were aware that people from the Arabic speaking population originated from a variety of countries in both the African continent and Middle Eastern region, and therefore, would utilise two different dialects. However, as there was no predominant Arabic dialect or country of origin in the Nepean area, the resource limitations of this project were such that only one language specific focus group was offered for the Arabic speaking population, rather than a focus group for each country of origin.

Carers and other members of the Macedonian community were interviewed in the Hawkesbury LGA, whilst carers and other members of the Filipino community were interviewed in the Blue Mountains LGA.

These specific CALD groups were selected according to the following criteria:

- Information from Centrelink indicated that a reasonable proportion of carers of frail older people and people with disabilities from a particular CALD group existed in the three LGAs,
- The researchers’ access to particular CALD groups and
- Future planning requirements that complied with funding streams within DADHC
- The probability that no previous consultation regarding carers’ issues had been implemented with this particular community or language group
- The lack of published research for these target groups within the Nepean area
Recruitment
Prospective participants were targeted for each focus group in two ways:

1. Directly and

2. Indirectly through relevant worker networks.

A bi-lingual flyer, which had the English version on one side and the relevant translation on the reverse side, was developed for each focus group. Workers from the relevant language groups were consulted on the cultural appropriateness of the English wording prior to translation. The fliers were translated through the professional translation services for HACC funded services offered through Western Sydney Community Forum (See appendices i - viii).

Recruitment methods were as follows:

1. Direct methods, i.e. direct to prospective participants:

   a. A partnership was developed between the researchers and the Penrith Centrelink office’s Multicultural Services Officer (MSO). This resulted in an agreement for Centrelink to provide an information session on carer’s payments at the conclusion of each focus group. Centrelink implemented a ‘hard copy’ mail out of a package which included invitations to the information session and relevant bi-lingual fliers promoting the focus groups to people who were in receipt of some form of carer’s payment within the selected cultural and language groups.

   b. Presentations by the researchers to various CALD groups in the Nepean area. These presentations consisted of verbal information provision through an interpreter and distribution of translated flyers. Group members were also encouraged to seek clarification about the research process at these presentations.

   c. Website at Penrith Disabilities Resource Centre.

2. Indirect methods, i.e. accessing prospective participants through community services:

   a. Website at TRI Community Exchange (through communityNet)

   b. Email networks such as those operated by the Strengthening Community Links Project and the three local Council Aged and Disability Services Officers.

   c. Flier distribution and information sharing through Nepean Community Care Forums, Disability Forums and Generalist Interagencies.
d. Direct requests were also made through formal and informal networks of aged care, disability and multi-cultural service providers. Workers in the latter group were able to use their professional and personal community networks to promote the concept of the focus groups and Centrelink information session.

e. Fliers were distributed to specific language community radio programs.

f. Media articles forwarded to Blue Mountains Gazette, Penrith Press (see appendix ix), and Hawkesbury Gazette.

Participants self selected for each group and attendance was purely voluntary.

Culturally appropriate refreshments and lunch were also offered, thereby creating a social occasion, an encouragement to participate in the carer focus groups, and a means of expressing the researchers' gratitude for their participation. Participants were informed of this prior to the focus groups via the fliers and presentations.

**Communication between the Facilitator and Focus Group Participants**

Language appropriate interpreters for each focus group were booked through the Interpreting Services Administrative Framework (ISAF) pilot project (funded through DADHC) using Health Care Interpreters. The researchers worked on the premise that each focus group would consist of approximately twenty people and that each group would have one facilitator, one interpreter and one scribe. Where registrations exceeded the expected twenty participants, extra interpreters were booked and extra facilitators and scribes were organised to be present.

The researchers were aware of the possibility of the Arabic speaking focus group participants using two different dialects. The plan for this focus group, therefore, included the use of two interpreters, each from a different continent of origin who spoke using a separate dialect. The interpreters were then matched with the relevant sub group.

Transport was offered through Great Community Transport (for Penrith and Blue Mountains LGAs) and Peppercorn Community Transport (for the Hawkesbury LGA) at no cost to participants. This transport option was also stated on the promotional fliers.
**Focus Group Facilitation:** An independent, professional facilitator was contracted to work with each of the four groups. This facilitator was selected on the basis that she had demonstrated culturally competent practice across a variety of settings. The focus group instrument was developed by the research partners in consultation with the facilitator. Each of the focus groups were asked to respond to the same questions which were asked by the facilitator as outlined below:

1. Who do you look after?
2. What help does the person that you care for need? What do you need to do for him/her?
3. What assistance have you received/do you receive in looking after your family member? From whom?
4. What services do you currently use to assist you with your family member? What do you think about the service/s you use?
5. Are there any services that you have used in the past? What did you think about them?
6. How did you find out about services?
7. Have there been any difficulties or obstacles in finding out about or using services? If yes, what would make it easy/easier for you to use a service?
8. Have any of the services organised or offered to organise interpreters?
9. What is your experience of the staff from services that you have used?
10. Are there any staff from your language/culture? How important is that to you?
11. Is there any type of support/assistance that you would find useful now/in the future?
12. What do you think is the best way to let people know about assistance/services that are available? What can workers do to make it easier for people to find out about and use services to assist them with their family member?
13. Any other comments?

**Documentation of the focus group participants’ responses** was implemented by scribes who took notes during the focus groups.
Results

Description of Focus Groups
Each of the four focus groups contained a mixture of community members and adult carers of family members who were either frail older relatives or younger adults and children with a disability. The majority of these carers provided care for a frail older person. A variety of ages and both men and women were represented in each focus group.

The community members included people who were not currently using services and also care recipients. Although the fliers specifically stated carers, the participants clearly communicated to the researchers their desire for care recipients and other interested parties (in some situations whole families) to also be included in the focus groups and Centrelink information sessions which followed these focus groups. Information was collected within an open framework which ensured each participant’s privacy. Detailed information as to each individual was not collected and therefore, is unavailable.

Where the group registrations far exceeded the researchers’ expectations of 20 participants, arrangements were made to engage extra interpreters, facilitators and scribes. The researchers noted that there was a correlation between the availability of ethno specific or culturally relevant workers and the recruitment success rate for each group, i.e. the greater the connection between the worker and the community group, the higher the attendance rate in the focus group.

Initially, the researchers planned for individual follow up on request but found that the need was rather a group intervention follow up, either with existing groups or to facilitate the setting up of new groups.

Throughout all of the focus group sessions, participants frequently sought information and/or clarification of the procedures used by community care services. Wherever possible, this information was provided at the conclusion of the session or participants were referred to future planned information sessions. Participants generally requested information on assessment processes, service agreements and service delivery fees.

Greek Group
The focus group and information session group for the Greek community was held in the St Demetrius Church Hall at St Marys. This focus group also included a representative from the Greek Orthodox Church. There were forty participants in total, who came from three different culturally specific social groups in the Penrith LGA, i.e. the Enosis Greek Seniors Group at St. Marys, the Seniors Greek Group at the Greek Orthodox Church in St Marys and the Olympus Greek Seniors Group at Emu Plains. Fifty seven registrations were originally received for the Greek group and, therefore the original plan was to divide this group into three sub groups, with an interpreter, facilitator and scribe for each sub group. However, although three interpreters were booked, only one
interpreter arrived at the venue. The forty participants who attended the venue were subsequently divided into two sub groups with the bi-lingual Penrith City Council Aged and Disability Services Officer acting in a dual role as both the interpreter and facilitator for one sub group.

This group contained a mixture of language abilities, i.e. some participants were bi-lingual whilst other participants had limited English and were reliant on the interpreters. Some male participants commented on cultural gender issues such as the difficulties encountered when a man was providing personal care for a female relative “who is not your wife”, e.g. their mother in law. Some older male participants also stated that they found it difficult to provide intimate personal care such as showering and toileting for their wives as they were concerned for their wife’s modesty. These men stated that for some older couples within the Greek culture both parties would be uncomfortable providing intimate personal care. One woman lived alone with no carer and discussed the difficulties that she encountered due to the limitations of available community services, e.g. she had no way of washing windows or curtains.

Not all participants had a current need for community services. However, these participants clearly articulated their desire to access services in the future when and if the need arose.

**Arabic Speaking Group**

The Arabic speaking focus group was held in the Arthur Neave Memorial Hall at Werrington. There were twenty eight participants in total, whose origins were countries on the African continent (e.g. Egypt and the Sudan) and Middle Eastern countries. Some were of Islamic faith and others were Coptic Christians. These groups demonstrated limited English speaking skills in general and most were reliant on the interpreters. When invited to separate into two different groups, for very practical reasons the participants selected to join the group with an interpreter that spoke their preferred Arabic dialect.

Prior to the focus group commencement, one participant reminded the research partners that twenty two countries speak Arabic and that the people in these countries have diverse cultures and backgrounds. This participant also commented on the dialectical and pronunciation differences in the Arabic spoken language and the impact that this could have on communication between the interpreters and the focus group participants. That is, different pronunciations created different word meanings. As discussed previously, the researchers were prepared for this contingency and the participant was reassured of this and also of the existence of two interpreters, each from a different continent of origin who spoke using a separate dialect.

The Arabic speaking groups also appeared to have less access to private transport than other groups as nine people accessed the community transport option. Age differences between some participant couples meant that some men were older and frail (and therefore part of the HACC target group and in receipt of an aged pension) while their wives, who in some cases were much younger, were simultaneously caring for their children and their older frail husband.
Macedonian Group
The Macedonian focus group was held in the Neighbourhood Centre at Richmond; a venue well known to many of the participants. There were fifteen participants in total, 12 women and 3 men.

Participants in this group also discussed the unique language situation experienced by Macedonians who have migrated to Australia, i.e. that English language skills and country of origin language depended on the date of migration to Australia. Participants stated that post World War II and pre 1970’s migrants would probably have limited English language skills but may have some knowledge of neighbouring languages such as Serbian, Croatian or Bosnian (because these nations were subsumed into the country of Yugoslavia at that time). Post 1970’s migrants may have some English but no knowledge of neighbouring languages. Participants also stated that this often causes confusion when interpreting services are used, as their language needs are not fully understood, i.e. a post 1970s migrant may be offered an interpreter for a neighbouring language, e.g. Serbia, which they may not understand. Contrary to the researchers’ beliefs, most participants were reliant on the interpreter when responding to the focus group questions.

Filipino Group
The Filipino focus group was held in the Santa Maria Centre at Lawson. This Centre is a venue well known to workers in the Community Care sector and because of its central location in the Blue Mountains and its accessible buildings it was considered an appropriate choice by the researchers. However, some participants commented on the inaccessibility of this location and suggested that Springwood or Katoomba may have been more accessible because of proximity to transport. There were nine participants in total; 7 women and 2 men. Cross cultural relationships were evident within this group. Two female participants were married to older Anglo Australian men; one female participant was married to an older Greek man and another was a widow whose husband had been Spanish.

Two different socio economic sub groups were also evident within this group. This may also reflect the societal environment of the Philippines. Six of the participants lived in the Blue Mountains and three lived in the Penrith LGA.
Responses to Focus Group Instrument Questions
The responses to the focus group questions are documented below for each group under the relevant heading, i.e. the ‘question’.

1. Who do you look after?

Greek Group
The carer participants in the Greek focus group stated that they cared for their spouses, parents (sometimes both spouse and parent by the same carer) and parents in law. Two women discussed the negative impact of caring upon their own health and that this is leading to the carers requiring support for their own needs. This discussion prompted others to express a need for future planning when both partners become frail. Several senior participants (care recipients) stated that they felt they were a burden on their adult children who were caring for them. Some also commented that they were unable to rely on their children because of their children’s own parenting responsibilities and employment commitments, i.e. their children and respective spouses were both employed and therefore unavailable as primary carers. It was very clear from the majority of the participant’s comments that they did not expect to be cared for by their adult children. Alternatively, they expressed a desire to remain independent, rather than be dependent on their children for care.

Arabic Speaking Group
The carer participants in the Arabic speaking group stated that they cared for their husbands, siblings and frail older parents. One female participant, who has five children, stated that she cared for her son, who is an illicit substance user, and her mother in law. One man was cared for by his wife because of a workplace accident. An 87 year old woman’s care was shared between her 55 year old son and his sister.

Macedonian Group
The carer participants in the Macedonian group stated that they cared for a child with a disability, older parents, parents-in-law and husbands. One couple stated that they provided care for each other. Two other participants said that they needed care but did not have a carer and were not receiving any services.

Filipino Group
The carer participants in the Filipino group described the following caring situations:

- One older couple care for the wife’s frail 99 year old mother. This couple, who are in their seventies, also require care and, consequently, are also receiving services for themselves.
• Two female participants cared for their husbands; one of whom was a frail older man while the other man had a back injury. This man’s wife also stated that she had arthritis and visual difficulties due to macular degeneration.

• Another participant described her prior experiences of caring for her husband who had died of cancer.

• A family, consisting of a mother and her aunt and uncle, cared for a young man with intellectual disability.

2. What help does the person that you care for need? What do you do for him / her?

**Greek Group**

Carer participants in the Greek group stated that their caring role included assisting with medication, cooking, meal preparation, cleaning and transport to medical appointments. One female participant has a friend who helps her with washing curtains, while another participant stated that she provides all care for both parents who live separate to her in their own home. This care includes transport to medical appointments, cleaning, meal preparation, shopping and paying bills. This woman also has young children and she stated that she is pressured by Centrelink to find employment.

Another participant was concerned that he was “taking advantage of his daughter” who provides personal care for him. According to this man his daughter is employed and therefore isn’t entitled to carer’s benefits.

**Arabic Speaking Group**

In the Arabic speaking group, carer participants stated that their role included providing transport, window washing and house cleaning. Many participants were non specific, stating that they “do everything”; including a mother of young children who cares for her husband who has a disability (“I do everything for him”). This woman stated that she provides all care and that her husband is unwilling to accept help from services.

One family said that they shared the caring responsibilities for their mother who lives alone and has dementia, whilst another family stated that they did everything except showering. One young male participant provided some care for his mother which is limited because of his full time studies. This woman has severe health problems and is unable to “do anything some days”.

Other participants stated that they relied on their adult children for transport to shopping & medical appointments.
Macedonian Group
Carer participants in the Macedonian group described their roles as providing most care, including personal care.

One family related a story that highlighted their need for respite. The family, who provided all care for their frail older mother, transported their mother from the Hawkesbury area to relatives on the South Coast for an overnight stay while they were attending a family wedding in the Hawkesbury area. This trip was then repeated on the following day when they returned to the South Coast to collect their mother and transport her back to their home in the Hawkesbury. The family was not aware of the existence of respite services.

Filipino Group
In the Filipino group, carers described their experiences as follows:

- One female participant provided care (not specified) for her husband who has hearing difficulties and memory loss.

- One male participant stated that he supports his niece by providing transport for her and her 19 year old son. The young man’s mother stated that she is doing more for her son as his needs increase. She stated that he now needs care all day, every day and that her caring role was negatively impacted because his challenging behaviours were increasing. According to the mother, her son was happier and had less challenging behaviours when he was involved in activities at a Saturday recreational program for children up to 18 years old.

- An older couple discussed their care of the wife’s 99 year old mother. They stated that they also have disabilities, i.e. they access a hydrotherapy service to enhance their mobility and both have hearing impairments, and consequently require significant support for their own needs. They would like to move into a retirement village but are unable to do so because of their caring responsibilities.

- One woman stated that her 69 year old husband was “not much problem at present” but she was concerned about his lack of activity.
3. What assistance or services have you received / do you receive to assist you with your family member?
4. What services do you currently use to assist you with your family member? What do you think about the service/s you use?

Greek Group
The participants in the Greek group stated that they received respite, personal care and domestic assistance, home modification and support equipment, e.g. shower chairs. Five participants stated that they currently received a lawn mowing service. One participant has lawns mowed every 3 weeks at $12.00 per service “through the Church” and that she was happy with this service. [Authors’ note: the service referred to by this participant was possibly organised through a local church based organisation which has HACC funded programs]. One woman stated that she has received domestic assistance and shopping services for 25 years. Some help was also received from the ‘community’, but the type or source of this assistance was not specified.

Arabic Speaking Group
The researchers concluded, because of the nature of the descriptions, that some service experiences may have been those provided through the ‘ComPacks’ model of care, although the participants seemed to have minimal awareness of this system. One participant, a mother of young children, said that she received a lawn mowing service when her husband “first came out of hospital”; while another stated that equipment such as toilet surrounds were provided following discharge from hospital for a short term only. There seemed to be a lack of understanding within this group as to the procedures involved in such systems, e.g. ‘ComPacks’, especially in relation to the commencement and cessation of services and retrieval of equipment at the end of the ComPacks package time frame.

One 74 year old man stated that he received a cleaning service for $36 a fortnight to assist him with his sibling’s care. This man also stated that this service was not effective, although he did not provide specific information on this. Personal care services were also provided for one participant’s husband and the mother of other participants. Another participant stated that their relative had received physiotherapy but only as a hospital inpatient. This carer qualified this comment by stating that the physiotherapy treatment needed to be continued after discharge.

Interestingly, most of the participants stated they had not received any services. The family who provided all care for their mother with dementia stated that their mother would not accept services as she considers it the family’s responsibility to provide all care for her. Because their mother lived alone, this family expressed concerns for their mother’s safety. They also stated that they need help to care for their mother and that
they were torn between their familial responsibilities and the knowledge that their mother’s level of care was beyond their capacity to provide.

In one of the sub groups, only two out of the twelve participants received any services. Others stated that their adult children “helped” but this assistance was limited because their children had their own lives to live.

**Macedonian Group:**
Most participants did not demonstrate any real understanding of services that were available.

Home hair cuts were discussed in this group. The carer commented that the person was initially resistant to this home service because they enjoyed going out into the community for a haircut. One person received personal care, domestic assistance and a respite service. Another participant mentioned that they received a lawn mowing service at $30.00 each week.

Some participants had been offered respite but refused the service, while others had not been offered respite but thought it would be “good to have a break”.

**Filipino Group:**
The participant who provided full care for her husband with hearing difficulties and memory loss stated that she received no current services but will need help in the future. The aged carers of their frail older mother stated that their mother (who lives in her own quarters within their house) receives one and a half hours domestic assistance per week and personal care but they feel that far more help is needed. This couple, because of their own support needs, also receives fortnightly domestic assistance for their own living area.

The young man with an intellectual disability is able to access a community participation program five days per week (9 am to 2.30 pm) and his mother stated that she also receives occasional in house respite.

5. **Are there any services that you have used in the past? What did you think about them? What is your experience of the staff from services that you have used?**

**Greek Group**
Some carer participants in the Greek group commented on respite and issues of trust in relation to a home based service, i.e. having ‘strangers’ caring for a family member for respite.

These carers stated that “when you are comfortable with them (paid workers) in the home you (the carer) can leave the home or they can take the person (client) out.”
One couple felt that weekly cleaning was inadequate and wanted daily services. Another woman was very happy with the services received but would like them to do more. She has been informed that workers cannot clean curtains because it is an occupational health and safety issue.

**Arabic Speaking Group**
Participants in the Arabic speaking group declared their confusion and concern about a service that ceased four years ago. These participants stated they did not understand why the service was ceased when the need was still apparent.

**Macedonian Group**
One participant in the Macedonian group discussed the high cost of services previously used. This participant stated that she paid $40.00 for a three hour cleaning service when she hurt her back.

**Filipino Group**
Another participant in the Filipino group described her previous experience with the Blue Mountains Palliative Care group prior to her husband’s death from cancer. She stated that she had a strong involvement with this group and that they provided “great support and fantastic service”. This service included respite and laundry service as well as patient transport for chemotherapy treatment.

“All the help from community makes your life bearable”.

6. **How did you find out about services?**

**Greek Group**
Responses to this question from the Greek group encompassed sources such as workers in the HACC Home Modification and Maintenance Service, the Hospital Social Worker and “through the hospital” (no specific source identified). Interestingly, participants stated that they found out about this focus group through culturally specific workers.

**Arabic Speaking Group**
Interestingly, there were no responses to this question from the Arabic speaking group, apart from the comment “no one has spoken about services”.

**Macedonian Group**
Participants in the Macedonian group stated that they have received information about services and that most information is received in English. Some received information through a social group at the Neighbourhood Centre or a women’s group at the local Women’s Centre. Other participants stated that they received information about services from informal discussions with other Macedonians while in hospital.
Filipino Group
The Filipino group participants stated that they received information from “Filipino friends”, the hospital social worker and Blue Mountains City Council. One person stated that she had a contact in Centrelink who provided her with information. Participants varied in their experiences of information provision from the local newspaper – some stated information was “limited” while others stated there was “plenty” of information.

7. Have there been any difficulties or obstacles in finding out about or using services?

Greek Group
Participants in the Greek group stated that they didn’t know how to access services:

“No one informs us”.

Language was cited by this group as a barrier to finding out about services. Several participants commented that answering machines with directions in English were an obstacle to using a service, particularly where there are English language difficulties. Some also commented that racist attitudes by government workers such as Centrelink staff impeded information access.

One female participant stated that her parents prefer not to use services and that they are totally dependent on her because she provides all their care. This woman also stated that she will need to find employment and that her parents will use services if necessary.

Service cost was a major point of discussion as a barrier to using services. Some said that they have many expenses, including medical expenses, and expressed concerns regarding their ability to pay for services. Many participants were unaware of what costs were involved in obtaining services and were also concerned that costs would be prohibitive for those on an aged pension. One care recipient stated that she paid fifteen dollars for two hours cleaning & cooking and was concerned that she would not be able to afford services in the future.

Arabic Speaking Group
A general response to this question from the Arabic speaking group was that they were not aware of available services, nor did they know how to access the community care system or where to go to ask for assistance. They also demonstrated a lack of understanding regarding entitlements to services. They therefore felt they had limited ability to answer this question. The previously discussed situation of the children of the woman with dementia highlighted this when the family declared that they were unaware how to access the ‘system’ and they didn’t know where to start, who to talk to or what to do.
Language and language difficulties was also listed as a barrier for this group, as was the lack of Arabic speaking workers, volunteers or respite carers. One carer simply stated that there was “no one to help”. Some knew of services that had Arabic speaking workers but stated that these were too far away and therefore inaccessible. One example provided was of an Arabic speaking speech therapist in Maroubra, which was too far for the family to travel to.

Overall, communication issues seemed to be a general barrier with comments such as:

- There was no follow up after hospital discharge, “they are forgotten”.
- “We [husband of a woman with cancer] were placed on a waiting list after assessment but were never contacted by services.”
- “We did not receive any communication regarding a service waiting list.”
- One family had an understanding that the worker would provide all the personal care required for their father / husband. However, the family carer’s perspective was that the worker was present but didn’t provide any of this care, while she (the family carer) implemented personal care activities such as showering and nail care. Accordingly, the service was cancelled because of the family’s dissatisfaction.
- One woman was told she was the wrong age, i.e. too young to receive services.
- Another family described incidents on two separate hospital admissions when they were asked if they needed assistance at home and indicated they did but “nothing happened” following this question.

One family also commented on the assessment process; they felt that too many questions were asked, with the result that they decided not to accept any services. Some discussed their difficulties in speaking about their problems in front of others.

Waiting lists were mentioned as a barrier by participants in this group. The issues discussed included lengthy waiting lists for ACAT assessments, a twelve month waiting list for Community Options and an 18 month waiting list for services in general.
The cost of service provision and perceived inability to pay was a major issue with this group as well. Some participants also commented on the difficulty of paying for medical specialists when they are on Centrelink benefits.

Lack of transport was cited by some as a barrier to service access, while others stated that services [authors’ note: this was possibly a reference to social / day centre groups] were in another area and they were unable to get there.

One family stated that their mother had to be in hospital before she got help and for one woman, who expressed a great need for services to help care for her husband, the barrier to service access was her husband’s refusal for services to come in to their home. This woman now has soft tissue injuries from providing care.

For others, lack of consistency of workers, i.e. several different paid carers providing the same service at different times, created a barrier to the effective use of a service.

**Macedonian Group**

Lack of knowledge was a major barrier to the use of services for the Macedonian group as well. The family that described their experiences when they attended a wedding (see question 2 – What do you do for him / her?) were disadvantaged because they didn’t know about respite services, rather than any other barrier, i.e. they thought they had no other choice.

Language barriers were also cited by participants in this group. Some stated that they needed their children to translate written material for them. Many do not read English language newspapers or understand English language TV or radio. Some were also not literate in Macedonian and were therefore unable to read translated materials. As previously stated, language barriers vary according to the date of migration, i.e. post 1970s migrants may not, contrary to the expectations of interpreting services, have adequate language skills of the languages of neighbouring countries to Macedonia, e.g. Bosnia, Croatia or Serbia.

Financial issues were mentioned by others. One woman stated that she was unable to receive community care services because she had assets, apart from her family home. However, she also stated that she was in an untenable position because her house had been damaged by recent tenants and she was unable to repair it for rent or sale as she doesn’t have sufficient funds. Service cost was cited as a barrier by one participant – one person stated that she pays $40.00 for a 3 hour cleaning service. [Authors’ note: this may have been a private, rather than a HACC funded service]

**Filipino Group**

Within the Filipino group the major barriers discussed were transport, and lack of knowledge about, and limited availability of, service resources.

Participants stated that getting to medical appointments was difficult. Community transport options were perceived as having inflexible schedules and there was limited or nil public and community transport on weekends.
Waiting lists for services and case management and limited hours for available services were also discussed as barriers to service access. One woman stated that her son had been on a waiting list for case management since finishing school in 2006. This woman had also searched for, but was unable to find any weekend recreational outlets for her son. This woman stated that she had been offered overnight respite for her son but was not comfortable leaving him overnight.

As in other groups, barriers due to lack of knowledge were demonstrated by the question: “What services are there?” Another participant who was in a cross cultural relationship, i.e. her husband was Anglo Australian, also stated that she did not know what services were available. Others stated they did not know what costs were involved. St Vincent de Paul offices were mentioned as an option for support services by one of the participants, although he also stated that “no one comes to them for help”.

Even though this group was not wholly reliant on interpretation for communication within this focus group, they still discussed language difficulties as a barrier to service access because they stated that “some things do not translate well”. They also stated that Filipino people may not know how to ask for help.

8. Have any of the services organised, or offered to organise, interpreters?

**Greek Group**
Nearly all participants in the Greek group responded in the affirmative to this question. However, among those who stated yes, some stated that the interpreters were useful while others cited difficulties with the interpreter services. These difficulties included Interpreters booked, but not arriving, for appointments at Centrelink & Nepean Hospital. Interpreters were not always available at hospitals. One Medical Specialist suggested appointment rescheduling when the interpreter did not arrive but the care recipient refused this offer. Most participants stated that changes to service operations were offered as translated material. However, one service recipient stated that he has never been offered an interpreter.

Overall, the perception seemed to be that interpreters were offered generally for serious matters such as Centrelink interviews, medical appointments and Courts. However, there was very little discussion of interpreters within the context of community care services.

**Arabic Speaking Group**
Responses within this group were varied. Participants stated that on most occasions they would take a relative to interpret. One person stated that she has taken her son out of school to interpret for her. However, they also felt that if they asked for an interpreter, then one would be provided. One person stated that they were always offered an interpreter and found them helpful.
The lack of interpreters for medical appointments outside hospitals was commented on, i.e. they felt that interpreter services were limited or nonexistent at the offices of General Practitioners or Medical Specialists.

Most considered it was helpful to have an interpreter for services in the home, but it was dependent on what the service is, e.g. “if cleaning windows it doesn’t matter”.

**Macedonian Group**
The responses from the Macedonian group indicated that interpreters were offered in the health system and found useful by some. Participants stated that hospitals and doctors had organised interpreters and that their own children had been refused as interpreters. According to the participants, pre-arranged (booked) sessions seemed to work better because in an emergency they may get an interpreter who speaks a similar language such as Serbian, Croatian or Bosnian, which may or may not be appropriate depending on the date of their migration from Macedonia. This issue was discussed in the responses to question 7: “Have there been any difficulties or obstacles in finding out about or using services?” Participants stated that sometimes they were ashamed to ask for an interpreter or didn’t know how to ask for an interpreter and that they were unaware of offers for interpreting services within community care services.

While discussing the possible difficulties, the participants also offered possible strategies to overcome these problems such as:

- Forms offering interpreters were often printed in English, so participants saw minimal advantage in this process and suggested that a single page, containing a variety of translated explanatory phrases in community languages, be forwarded to people with NESB family names. Participants considered that this could be a comparatively easy task to achieve as “After all, they [people with Macedonian last names] are not Mr Smith”.

- Providing a list of emergency contact numbers that could be placed near their home phones for use in an emergency or when they need help. They suggested that this could be especially useful when their circumstances changed.

- Access to a 24 hour interpreting service was needed to enable responses in emergency situations at all times.

**Filipino Group**
The Filipino group made no comments on this issue.
9. What is your experience of the staff from services that you have used?

10. Are there any staff within community services that are from your language / culture? How important is that to you?

Greek Group
Most participants within the Greek group stated that it was “better if they speak Greek”, but that it wasn’t essential. They also stated they were happy with Anglo Australian workers and participants within one sub group resolutely stated that it is “The standard of care that is important, not whether they are Greek or speak the language”.

Arabic Speaking Group
Conversely, the majority of participants in the Arabic speaking group stated that language was very important. Some said that language as well as country of origin was very important for workers who come into their home. On the other hand, others stated it was not important; they just needed someone to help!

Macedonian Group
Participants in the Macedonian group also stated that “it would be easier” to have a Macedonian worker and some stated that they had difficulty accepting ‘strangers’ into their home.

Filipino Group
Within this group, cultural safety seemed to a bigger issue than language. This group stated that culturally appropriate workers in the home are important — don’t have to be Filipino but they need to understand the culture. This group felt that workers need to be empathic; “to give some time to the old people” and that it would be useful if carer, general support and social groups were coordinated by Filipinos. Most considered that communication is more effective when speaking with other Filipinos because of the non verbal content of their communication. The group stated that with Filipino people: “You just need to look at someone to know what they are saying”.

11. Is there any type of support/assistance that you would find useful now/in the future?

Most groups commented on the need for lawn mowing and personal care services.

Greek Group
This was true within the Greek group where the issue of lawn mowing issue was discussed at length and seemed to be an area of high importance to most participants. Personal care was listed as important because hygiene was a top priority. In general,
this group also discussed the need for services which would allow them to stay home for as long as possible, avoid moving into residential care [nursing home] and provide assistance in planning for the future.

This group also commented on the need for culturally and/or linguistically appropriate, and local, aged care services.

Other needs included:

- Culturally appropriate meals, “cooked food delivered to home” [food services] and food cooked in the home.
- House cleaning and social support to prevent isolation were also mentioned. Companionship was also considered to be very important.
- Medical transport.
- Home modifications, i.e. shower modification.
- Carer support was also stated, including culturally specific support groups- “their [the carers] work is needed” and therefore deserves support.

**Arabic Speaking Group**

Not unexpectedly, [because of the previously discussed service access difficulties] the Arabic speaking group stated that they needed support and assistance in many other areas, as well as lawn mowing. These included:

- Transport access and provision. This was a major issue with this group. Many carers were not able to drive a vehicle and their transport needs included transport to medical appointments (“can't do it all”) and access to Maxi cabs [wheel chair accessible taxis]
- Home delivery for pharmaceuticals
- Domestic assistance
- Garden maintenance and tree pruning
- Counselling support for carers as well as other family members
- Needs some “time off” from caring duties
- Social opportunities: One carer stated that she finds it very hard to socialise because of her caring responsibilities and another described her loneliness since her husband died. Some carers also commented on their social isolation within Penrith because of the lack of culturally and spiritually specific venues / areas for them to socialise
- Other carers stated that they now needed care themselves because of their own health issues that they felt were exacerbated because of their caring role
- Carer support for stressed families, which includes “a worker to explain how to do things”
- Case management
- Support to stay at home [the type of support was unspecified]
- Housing NSW assistance with accommodation in the Penrith LGA.
- More information about Centrelink payments for carers

Specific language and cultural issues were also mentioned within this group. English language lessons were a high priority as some had not learned to speak English and suggested home tutoring and teaching of basic English skills. In addition to this, participants also mentioned the need for computer / IT training and access, particularly in Arabic. Specific cultural services listed were the need for a specific aged care hostel for Arabic speaking people and an Arabic Community Centre in St Clair [in the Penrith LGA].

The final point is a poignant comment: “We need to accept help but it will need to remain a personal choice”

**Macedonian Group**

Some participants in the Macedonian group currently drive their own cars but are concerned for the future when they are no longer able to drive. This group was also very keen to have a social outlet, i.e. someplace where they can gather and socialise (talk and share food), but without the burden of venue hiring costs.

One female participant, who was caring for her ageing parents in law and also has three children of her own, stated that she currently wasn’t receiving any assistance and that she also wasn’t aware of available services should she need them.

**Filipino Group**

As well as lawn mowing, the Filipino group also discussed the need for assistance with heavy domestic work, e.g. washing blankets and, for one person who has Parkinson’s disease, personal care assistance when preparing to leave the house for medical appointments.

One female participant within this group stated that she currently needed help for her son with speech therapy, behavioural support, a DADHC case manager, and emergency & weekend respite. This woman also needs recreational / respite options for her son as he is no longer eligible for the Saturday recreational program that he attended until the age of 18 years. She was also concerned about what will happen to her son in the future when she ages.

For the future this group mentioned the need for information on available services and how to access them as well as culturally specific social groups to reduce isolation. Carers’ and general support groups were discussed as a means of providing peer support as well as a means to share information.
12. What do you think is the best way to let people know about assistance or services that are available? What can workers do to make it easier for people to find out about and use services to assist them with their family member?

Greek Group
Within this group, participants suggested translated written material on community services. This material needs to be available at doctors, hospitals, and pharmacies for them to take home. They also stated that there should be instructions on agency answering machines in different languages and that existing and new services need to be promoted specifically to the Greek community.

This group also stated that information on services needs to be available at the time of need, not only for future need, and that a local central phone number needed to be available for emergency contacts, e.g. Council or community organisations.

“I could be at home living on my own and need emergency assistance, or I could be discharged from hospital and need to know about [available] services.”

The 'Council' was also mentioned as an agency which needed to play a bigger role in supporting the establishment of Senior's groups and that Council workers need to be more visible.

This group also suggested that Centrelink and Penrith City Council information needs to be promoted in local newspapers and information in both English and Greek needs to go to all three Greek social groups in the Penrith LGA and Church groups.

Interestingly, two people out of a sub group of twenty had heard of Commonwealth Carelink Centres through the local newspaper and a poster in their Doctor's office.

Arabic Speaking Group
The Arabic speaking group also provided numerous and varied suggestions as to possible exposure points for information provision:

- Information meetings; especially with Centrelink information for pensioners
- SBS radio
- Arabic language newspapers
- Set up mixed gender information groups (mornings mid week) and inform people about the group via radio. This information group could then progress to a social group
- Fliers at Nepean Migrant Access and information at the weekly Arabic speaking group
• Through English speaking classes
• Speakers and information distributed through local churches
• Current community groups
• Mail out of translated material

As well as these points, participants in this particular group also stressed the need to provide contact details such as address and phone number, as well as information on entitlements and to have Arabic speaking workers available when they phoned for information.

Other strategies mentioned were:
• Access to information on services
• The availability of translated information and translated information booklets.
• Items need to be stated in Arabic, as well as English.
• Arabic culture needs to be more visible in Australia.
• It would be useful for someone to speak to an Arabic community group on a regular basis.
• To be able to access someone to talk about their needs

Interestingly, no one had heard of Commonwealth Carelink Centres within this group and some simply stated that they didn’t know [the best way to let people know].

The group also stated that not everyone can afford ‘Foxtel’ so that they can access Arabic TV and that it was important to consider different cultures among Arabic speaking people when providing information sessions and services.

Macedonian Group
The Macedonian group suggested strategies for both increasing knowledge of available services and increasing the uptake of services by Macedonian people as follows:
• Translated written material to be mailed to homes
• Communal gatherings, which could serve a dual purpose of providing a social outlet (“nice to get together”) and information distribution
• Churches
• Radio – this was the majority response
• Council information needs to be translated as well

This group also reminded the researchers that some people in the Hawkesbury area have problems receiving SBS radio.
Filipino Group
Participants in the Filipino group suggested that information about services needs to include a description of what is available, as well as how to access that service. One participant commented that the distribution of information needs to be centralised and organised and that a needs analysis could be implemented through charities working together.

- The information format needs to be visually attractive and to include Filipino images to encourage the reading of this information material by Filipino people.

- Information could also be shared at carers’ support groups. The group also stressed that any carers’ information needs to be targeted at the whole family and not targeted solely at the carer.

- Information provision through the Church was stressed within this group because of the important role that the Church plays in Filipino culture. It was also mentioned that churches currently had no information on carers’ services.

- Specific Filipino social groups were also stressed as a possible exposure point for information distribution; with the suggestion that organisations could provide guest speakers for these groups and that the social groups could develop their own information fliers. The participants became quite passionate about this concept at this stage, stating: “We need more groups like this”; “This is fantastic” (for identifying needs and receiving information). Any such group would need to be social in nature and centrally located and accessible to public transport, e.g. Katoomba.

- Local newspapers, local Council, Seniors Newspaper and Centrelink were all seen as valuable information sources, as well as fliers placed in medical centres, doctor’s offices and hospitals.
13. Other comments
Not all issues discussed during the focus group were in response to the focus group questions or related to community care issues. Some were related to other community/State/Commonwealth services and facilities such as public transport issues and access to Government Departments. The researchers felt that it was important to include discussion about ‘general’ issues in this report so as to present an honest and holistic report and therefore, represent the views of the participants. These issues are documented below:

Greek Group:

- **Discussion on staying at home:** Some older focus group participants commented on the need to sell their property in the future to enable admission to Nursing Home or Retirement “Home” (Village). Many participants stated that Retirement Villages were not seen as a viable option because the sale of houses in their area (St Marys area) would not enable them to purchase a unit in a Retirement Village. The unanimous comment from one sub group was that everyone wants to ‘age at home’ with affordable care.

  "We want to stay forever!"

- **Contact with Penrith City Council** – Some participants were unable to pay their rates. This was complicated because many were unable to read Council correspondence in English and therefore unable to follow up due to language difficulties.

- **Health issues:** Medication costs were difficult for those participants without a pensioner concession; one person stated that she pays $55.00 for 30 tablets twice a month.
  - Extremely lengthy waiting lists for surgery, medical, dental, podiatry and other allied health treatment created health difficulties. Participants considered that the health of their eyes and teeth were extremely important as both of these health issues impacted on their general health, quality of life and ability to remain at home.
  - Participants also commented on centralised intake systems for medical and dental appointments, which were described as complicated, therefore making it difficult to access.
  - Participants also stated that they didn’t know how to make a complaint about the hospital system.
  - Some participants also stated that they were not provided with information about the side effects of medication by their general practitioner (GP). This resulted in the need to revisit their GP and purchase alternative medications
until they found the right medication which in turn resulted in extra costs. This was viewed as an unnecessary process.

- **Isolation/access issue:** Participants discussed the difficult physical access, e.g. lack of lifts, on some rail stations such as Redfern & Newtown stations, which needed to be used to access doctors and friends.

One sub group thanked the organisers and facilitators for implementing the focus group ("being here today") and asking the participants for their input.

As well as responding to the focus group questions, this group also had questions of their own on issues such as determination of community services fees, whether fees were regulated and the possibility of receiving services if they could not pay. They also asked questions on respite and expressed concern around issues of trust regarding the concept of strangers caring for their family member.

**Arabic Speaking Group:**

This group also discussed issues that were either outside the scope of the focus group questions or not related to community care issues. These issues are documented below:

- **English language skills:** Participants expressed the need for more frequent English classes and stated that they felt that weekly sessions were inadequate for developing and acquiring effective English language skills.

- **Legal issues:** One woman was concerned about her son who has “been in trouble with the law” and also been in prison. This woman expressed a great need for counselling for both herself (stated she needs help with her son) and her son.

- **Isolation issues / social outlets:** Some participants belonged to a small Arabic speaking social group for frail older people, which they stated was beneficial in reducing isolation. These participants stated that transport to and from the group venue is available via the organisation’s bus. There was a variety of cultures within this particular social group and members of this social group also attend church and other social outings together.

Some relied heavily on neighbours for many things and stated that they wouldn’t know what to do in an emergency. Participants requested that the focus group organisers collect names and contact details so that information on groups could be distributed to them. One person was very interested in volunteering and a comment was made that the “Arabic community helps all the time”.

- **Financial issues:** Some participants stated that Centrelink payments and aged pensions are insufficient to keep up with the cost of living and cover all expenses.

This group also stressed that there are a large number of Arabic speaking people in the Penrith area, which they felt were not recognized and also not supported by the ‘government’, i.e. through the provision of services.
Macedonian Group:
This group also discussed issues that were either outside the scope of focus group questions or not related to community care issues. These issues are documented below:

- **Financial issues:** One female participant discussed issues related to owning a rental property and being unable to receive Centrelink payments / benefits. She stated that she was in a difficult financial position because the property had been vandalized; she was unable to rent or sell the property and therefore received no income. She also stated that her health problems and medication costs ($40.00 plus per week) exacerbated the problem.

  “Work hard all your life and get nothing, but the bludgers do nothing and get plenty of help”.

- **Isolation issues / social outlets:** This group expressed general interest in the development of a social group which could meet and attend outings. They stated that they previously met in a local Neighbourhood Centre (for a nominal fee of two dollars for tea and coffee) but that this venue is no longer available to them.

- **Comparison of experiences in Australia:** Some commented that things were a lot better for people from CALD communities in Australia today than they were many years ago.

  The participants in this group stated that aged pensions should not be means tested and that their children are busy working full time and unable to provide all the care needed.

  The older participants in this group also discussed the difficulties with literacy levels and one person stated “I only went to school for three months, so I didn’t learn to read”.

  Case example of previous experience from many years ago:

  One woman described her hospital experience when she gave birth to her first child many years ago in a Sydney hospital. She stated that she was not literate in English at that time and that for two subsequent meal times she was not served any food. When she enquired about this, asking: “Where is my food?” she was told that she did not fill out the “form” [menu] and therefore no food had been prepared for her.
Filipino Group:
Once again, this group also discussed issues that were either outside the scope of the focus group questions or not related to community care issues:

- **Language / communication issues:** Participants commented that many Filipino people speak English but have difficulty fully expressing themselves in English because “some things do not translate well”, e.g. there is no word for ‘please’ in Tagalog. They stated that Filipino people may seem rude because they would say “would you”, rather than “please”, within a social context.

  The use of non verbal communication between Filipino / Filipina is evident from the comment “you just have to look at someone (a Filipino person) to know what they are saying”. Participants also commented on the communication limitations in cross cultural situations and that this led to a feeling of being misunderstood.

- **Isolation issues/social needs:** A previous carer of her husband with cancer ceased employment to care for him and now feels isolated because of this. This participant also stated that support from the Filipino community was valuable and that she was in attendance because she wanted to “get to know everybody”.

  Participants who lived in the Blue Mountains expressed a need for a social group to reduce their isolation. They stated that a Filipino specific group was preferable so that they “can open up more and be themselves”.

Participants stated that Church involvement was different in Australia. They attended Church in the Philippines as a normal duty and family expectation. They stated that Church involvement in Australia may be for additional reasons such as the need to find an information source for Australian services.

One female participant (mother) stated that she was very stressed due to her dual caring role of caring for her son with a disability as well as her two other children.

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*A closing comment from this group was “we need to learn to ask”.*
Discussion

Five important recurring themes, related to the experiences of service access by carers from CALD backgrounds in the Nepean area and the methods that service access could be enhanced, have emerged from this study.

Firstly, the majority of CALD carers and other participants in the Nepean area who participated in this study stated that they not only had a need for community care services but that they were willing to use these services. This result is contrary to prevailing misbeliefs / misconceptions that “CALD communities do not demand or need services because they will look after their own” (NSW Aged Care Alliance, 2004, p.12). The participants in this study confirmed the 2006 Carers NSW report that CALD carers were just as likely as Anglo Australian communities to report a need for services such as respite.

The second theme to emerge from this study is that there is a general lack of awareness, amongst CALD carers in the Nepean area, of service availability and service access. The prevailing message from all four focus groups was that CALD communities who are potential system users are unable to access community services information. Very few participants (no participants within the Arabic speaking group) were aware of the role of, nor had ever heard of, Commonwealth Carelink Centres.

Participants within each of the four focus groups offered strategies which they felt could be used to overcome these barriers to information access. These strategies included the distribution of relevant language, multimodal material distributed through exposure points such as medical officers, pharmacists, churches, guest speakers at social groups, print and electronic media, and Centrelink mail outs. They also included a centralised point for information access and language specific instructions on agency answering machines. In addition, the Filipino group discussed the need for visually attractive material, including culturally relevant images. Given that the participants felt that these strategies were not currently implemented by community care agencies, the position of the NSW Aged Care Alliance that a lack of information about service availability and service access may be due to culturally and regionally inappropriate information was supported from this study.

The previously discussed situations of the Arabic speaking family of the woman with dementia and the ‘Macedonian wedding’ story highlighted this issue when the families declared that they were unaware how to access the ‘system’ and they didn’t know where to start, who to talk to or what to do. Also evident was the lack of understanding of the operation of systems such as ‘ComPacks’. These reports indicated a lack of concept and understanding of a community services system. When this is coupled with their stated concerns regarding ability to pay for services; this creates a major barrier to accessing such services.

Thirdly, the researchers observed that there was some reliance on the interpreters for effective communication in each of the focus groups, no matter the length of settlement since migration.
The level of reliance, however, did appear to be related to the length of time that communities had been settled in Australia and consequently, whether the group included participants who had been born in Australia, and also the possibility of exposure to English language development prior to migration. For example, there was an observable difference between the Greek communities (longer settlement term) and the Arabic speaking communities (comparatively shorter settlement term) in relation to their need for interpreters. Within the Filipino and Arabic speaking groups, there was an observable difference according to the socio economic backgrounds of participants, and therefore, the likelihood of their exposure to higher educational levels and English language development prior to migration.

The need for interpreters for each particular focus group did not necessarily match the researcher's beliefs as to the need for an interpreter, e.g. prior networking with members of the Macedonian community indicated that the presence of an interpreter was merely a formality and not completely necessary. The reality, however, was quite different in that several members of this particular focus group were quite reliant on the interpreter for effective responses to the focus group questions. Therefore, the researchers became aware of the need for caution when deciding on the need for interpreters for any community group or family; and that members of CALD communities may be disadvantaged if interpreters are not offered or available, regardless of the level of English language proficiency perceived by the community services worker/s.

As previously highlighted in the literature review of this report, there are lower rates of service access for members of CALD communities who are not proficient in English. English language difficulties, therefore, can be a barrier for members of CALD communities when attempting to negotiate a community care service system in Australia (EDAC, 2005). The community care service industry cannot presume that any carer from a CALD background will not require the services of an interpreter or access to translated material on community care services.

The fourth major theme to emerge from this study was in relation to culturally and regionally appropriate referral networks. As previously discussed, there was a direct correlation between the success of recruitment for a particular focus group and the strength of the networks between the researchers and relevant ethno specific workers, i.e. the greater the network connection between the worker and the community group, the higher the attendance rate in the focus group.

Finally, a strong underpinning theme emerged from this study in relation to the need for social groups. This was not only discussed within each group as a means to increase social capital and to improve the social health of participants but, more importantly for this study, the participants stressed the importance of social outlets as a means of accessing information relevant to their future and present care needs.
Differences and Similarities between the Four Focus Groups

Many similarities between the four focus groups were evident:

1. That participation in these focus groups was perceived to be a whole community concern, because the issue was viewed as a whole community issue.

2. A strong sense of familial obligation was evident within all four focus groups. However, this was not always matched by the carers’ capacity to provide the care required.

3. The type of service that was most in demand, i.e. most participants across the four focus groups stated that their priority was for lawn mowing and personal care services.

4. Most participants also stated that when they received information about community care services, this information was in English.

5. Participants stated that interpreters were generally offered when accessing health services but not generally when accessing community care services. Issues of shame (regarding the need for an interpreter) and not knowing how to ask for an interpreter were also widespread among the focus groups.

Differences between the four focus groups were also evident:

1. Care recipient participants in the Greek group stated that they did not expect to be cared for by their adult children, either because they did not want to be a burden on their adult children or that they were unable to rely on their adult children because of their children’s employment and family commitments. These sentiments, which differed greatly from the other groups in this study, may reflect the length of settlement within Australia for the Greek community and possible subsequent change in cultural expectations.

2. The Arabic speaking group appeared to be less well resourced than other groups. This was evidenced by their statements on awareness of community care services, their level of access to community care services and the number of areas where they required community care support. There were overall differences between the four groups as to the perception of services and understanding of the community services system in the Nepean area.

3. Both the Arabic speaking and Greek groups discussed their concerns regarding the need for certain questions that were asked during the assessment processes. This appears to be a barrier to the acceptance of such services. These concerns were not articulated at all in the Filipino and Macedonian groups.

4. The Arabic speaking group expressed concern about the lack of consistency of workers for the same services, i.e. they were not able to develop relationships of trust with a number of workers, whereas they felt that they could develop this
relationship if only one or a few workers carried out the service. The subsequent barrier to effective service use may imply some trust issues. If issues of trust are evident, these issues may raise barriers for both themselves and workers which may have more far reaching consequences of reduced social and emotional well being.

5. Limited social capital was observed within Filipino group and Arabic speaking groups, whereas a greater sense of community and connectedness was obvious in the Greek and Macedonian groups.

6. Most participants within the Greek group stated that having access to a worker from the Greek community was desirable but certainly not essential. Conversely, the majority of participants in the Arabic speaking group stated that language was very important. Some said that language as well as country of origin was very important for workers who come into their home. On the other hand, others stated it was not important; they just needed someone to help!

7. Sources of information on community care services varied between the four groups. The Greek group mentioned a particular community care service as an information source and both Greek and Filipino groups mentioned hospital sources such as the hospital Social Worker and generally “through the hospital”. Participants in the Macedonian group, however, cited sources such as social groups, the local Women's Centre and informal networks with other Macedonians while in hospital. Social groups and informal networks (through friends) were also common to the Filipino group as an information source, but this group was the only one to mention the local Council and local newspapers as an information source. The Arabic speaking group’s comment was profound in its simplicity: “No one has spoken about services”.

Limitations to This Study

1. It is difficult to pose questions to participants and elicit responses to situations with which they are unfamiliar or have no direct experience or knowledge. On questions such as “How did you find out about services?” the Arabic speaking group were unable to provide information due to their lack of knowledge of such services or how to access them. This posed a dilemma for the facilitator between the need to inform the participants about community care services so that they could respond appropriately, versus the need to ensure that the research wasn’t contaminated, i.e. participants were provided with information which then may have skewed the research.

2. A limitation in this study also occurred because of minimal access to the population group, i.e. a representative sample. As previously stated, focus group participants self selected for this study. A self-selection process alone will not ensure that there is a gender / age mix of carers proportionate to the gender / age groupings within the CALD carer populations.

3. A limitation for this study may have been the fact that only three CALD communities and one language group participated in this research. Other CALD
groups, which may have vastly different needs, were excluded. This study, therefore, should not be definitively viewed as representative of a whole CALD carer population. However, although the findings and interpretations from this study need to be viewed in relation to the needs and attitudes expressed by the participants in these focus groups, the findings could have applicability with other CALD communities.

4. There is limited access to meeting venues within the Nepean area, particularly in the Blue Mountains. This may have limited this research because of the unfamiliar settings of some venues, e.g. Community Halls or the limited access to transport to some venues, e.g. the Santa Maria Centre at Lawson. The Santa Maria Centre, although well known and popular as a meeting venue with community services workers and chosen because it was midway in the Blue Mountains, is not a venue that is well known as a community centre by community members. The Filipino group in the Blue Mountains was smaller than the other three focus groups, and therefore was possibly less representative of this cultural group than the other groups. Participants stated that transport was difficult to access for this venue and therefore, a barrier to participation, even though community transport was offered. The other possibility is that participants felt that this venue was not appropriate as a community centre. Either, or both, of these possibilities may have limited this study in relation to the Filipino communities.
Recommendations

On the basis of the information gathered in this study, the researchers provide the following ten recommendations:

1. Further work is required to determine appropriate strategies to overcome the barriers experienced by carers from CALD communities in accessing and utilising community care services. Some strategies have already been offered by these groups. The fact that four focus groups have already been engaged in this study indicates the possibility of future access to these groups for the purpose of further strategy development.

The focus group participants have offered a ‘blue print for change’ in the strategies already offered, i.e. that guest speakers provide information sessions on the availability and method of access to community care services through carer support groups, ethno specific social groups and day care centres. All four groups stressed the importance of an information session occurring within a social context.

2. The researchers experienced the highest access to, and responses from, CALD communities when a strong liaison existed between the researchers and culturally relevant workers who also had strong connections to a particular CALD community. Organisations, therefore, are recommended to implement consultations with CALD communities in association with a culturally relevant worker, preferably one who is also known to that particular community.

3. Other strategies suggested by the participants deserve further exploration, particularly in light of the suggested multimodal approach for raising awareness of service availability and methods of access to these services in the Nepean area, outlined in the discussion section of this paper.

4. The outcomes of this research need to be disseminated through the community services sector and other exposure points such as the Nepean and Blue Mountains Division of General Practitioners to engage them in the process of culturally appropriate service provision.

5. That community services in the Nepean area develop appropriate strategies for CALD clients which take into account that CALD communities may differ in their perceptions of services and understandings of the community services system, and that this difference may be linked to both the length of settlement of particular communities and the level of connectedness between that community and other communities, i.e. the greater the degree of marginalization; the greater the need for specialist strategies.
6. That funds be made available for training programs for generic community care service workers. This training needs to provide an opportunity for workers to acquire the necessary knowledge and skills to:

   a. develop strategies for improved access to CALD communities and

   b. provide culturally appropriate services to marginalised communities such as the Arabic speaking communities.

7. That community care services apply the knowledge and skills referred to in Recommendation 6 to provide services to CALD communities as part of their core business, including the provision of a culturally appropriate assessment process.

8. That the community services sector in the Nepean area develop the practice of offering and/or using interpreters, irrespective of the worker's beliefs regarding the carers level of English language skills. This is strongly recommended on occasions when assessments are carried out and service agreements are explained, so that opportunities can be provided to achieve optimal understanding of the service provided.

9. That the implementation of social support service models for specific CALD communities be explored / researched.

10. As previously stated in this report, the Nepean area includes in its resident population, people from multiple cultural and language groups. Unlike other Sydney areas there is no predominant CALD group in the Nepean area and consequently, very few specific CALD services. The researchers, therefore, recommend that culturally specific case management services be provided within Nepean community care services with the aim of developing links between service providers and potential service users within CALD communities, in particular new and emerging communities. This may assist in overcoming the barriers to service access for these marginalised communities.
Conclusion

As discussed in this paper, there is an under-utilisation of services by carers from CALD backgrounds throughout Australia, including the Nepean area. The under-representation of CALD clients and carers within HACC and disability services is evidence enough that barriers exist for this population group.

The fact that only 8.6% of HACC clients in NSW are those who do not use English as their primary language at home is a major concern because it is less than half of the national benchmark of 19.1%. Paradoxically, the 2004 Carers NSW survey revealed that CALD carers were more likely than other carers to report a need for information and, contrary to popular belief, just as likely to report a need for services such as respite. (Carers NSW, 2006) The results of this study of CALD carers also support anecdotal information that there is a general lack of awareness of service availability amongst CALD carers as well as the NSW Aged Care Alliance suggestion that this may be due to culturally and regionally inappropriate information and referral networks. The stereotypical perception, also referred to by the NSW Aged Care Alliance, (2004, p.12) that “CALD communities do not demand or need services because they will look after their own” was not supported by this research. In fact, the opposite was revealed, i.e. that the majority of participants from the CALD communities in this research not only demonstrated their need for community care services but also their willingness to accept such services. The needs of CALD carers in the Nepean area have been hidden; a situation which has led to inequitable service provision. The major barrier to service access identified in this research was in relation to the availability of information about available services and the lack of understanding about how to access these same services.

It is clearly evident from the literature search conducted within this study that there was a paucity of specific data which could enlighten service providers in the Nepean area to the needs of the carers of frail older people and people with disabilities in CALD communities. Local research was necessary so that local services could begin to address the issue of under-utilisation of services by carers from CALD backgrounds. This study has built upon existing research and documentation and explored issues related to CALD carers from a local Nepean perspective.

New learning has been achieved through this research and these insights have been discussed in this paper and included as recommendations for the community services sector within the Nepean area. The active participation and generous responses of the group participants within this study highlighted to the researchers the need for carers’ support within CALD communities; a need which is contrary to some beliefs. This research also highlighted that CALD communities are not a homogenous group and accordingly, that the needs between and within these groups may be vastly different.

The outcomes of this research have formed the foundation for understanding why there is an under-utilisation of services by clients from CALD backgrounds; identifying and understanding the barriers to service access in the Nepean area and, most important,
what carers need to support them in their caring role. Existing strategies to enhance service access by carers from CALD backgrounds may require urgent review if we are to address what will become a major health problem of under-supported carers. This study can form the basis for further strategy development in the Nepean area in relation to service access by carers from CALD communities.

Simply stated, the focus group participants offered the final comments:

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"We need to accept help but it will need to remain a personal choice"
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and

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“We need to learn to ask”
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In light of these statements, perhaps the community services sector also needs to be mindful of something else, i.e. the need to listen.


4. Carers Australia NSW, 2006, Carers NSW submission on Statewide issues in NSW for the Home and Community Care (HACC) program 2006 / 07


7. Luckhurst-Khan F, 2005, People from Culturally and Linguistically Diverse backgrounds (CALD) in the Hawkesbury, Nepean Migrant Access


13. NSW Department of Ageing Disability and Home Care, 2007, *Carers*,

14. NSW Health; NSW COPs, downloaded August 2008, *Com Packs Project: Guidelines and Information*,


17. Plunkett A & Quine S, Published online 2008, *Difficulties experienced by carers from non English speaking backgrounds using health and other support services*, Australian and New Zealand Journal of Public Health, Vol 20, Issue 1, pp. 27-32


Appendix i – Greek Flyer

Do you look after someone who is old and frail?  
Do you look after an adult or child who has a disability?

If you are from a Greek background and live in the Penrith, Hawkesbury or Blue Mountains areas we want to hear what you need to help you look after your family member or friend.

Perhaps you have tried to use services before and it has not been what you needed or expected.

We need your help to understand what your situation is. Any information that you provide will remain anonymous.

You are invited to a session where you can tell us about your experiences and difficulties. Centrelink will also be available with some helpful information and to answer any questions about their service.

A Greek interpreter will also be available.

Venue: Greek Orthodox Parish of 'St. Demetrius'  
47 Hobart St  
St Marys

On: Friday 11th May 2007  
To start at 9.30 and finish at 1 pm when lunch will be served.

Free refreshments and lunch will be provided.

If you would like to attend, please phone Diane Boyde by 4th May on 4732 6301 for catering purposes or if you require transport to attend this session.
Appendix ii – Greek Translated

Μήπως φροντίζετε κάποιον ο οποίος είναι ηλικιωμένος και αδύναμος;
Μήπως φροντίζετε κάποιον ενήλικο ή παιδί που έχει κάποια αναπηρία;
Εάν είστε ελληνικής καταγωγής και ζείτε στις περιοχές του Πένριθ, Χόκσμπερν ή στα Μπλου Μάουντενς, θέλουμε να μάθουμε τι χρειάζεστε για να σας βοηθήσει να φροντίσετε το μέλος της οικογένειάς σας ή το φίλο σας.

Τόσοις προσπαθήσατε να χρησιμοποιήσετε υπηρεσίες στο παρελθόν και βλέπετε ότι δεν είναι αυτό που χρειάζοσατον ή περιμένετε.
Χρειάζομαι να μας βοηθήσετε να καταλάβουμε ποια είναι η κατάστασή σας.
Οποιαδήποτε πληροφορία μας παράγετε θα παραμείνει ανώνυμη.

Σας προσκαλούμε σε μια συγκέντρωση όπου θα μπορέσετε να μας πείτε σχετικά με τις εμπειρίες σας και τις δυσκολίες σας. Το Centrelink θα είναι επίσης διαθέσιμο με μερικές χρησιμες πληροφορίες και για να απαντήσει οποιεσδήποτε ερωτήσεις σχετικά με τις υπηρεσίες τους.

Θα υπάρχει επίσης Έλληνας διερμηνεύως.

Τόπος: Ελληνικόδιδαξ Ευαγω Αγίου Δημητρίου
47 Hobart St
St. Mary’s

Της: Παρασκευή 11 Μαΐου 2007

Θα αρχίσει στις 9.30 και θα λήξει στις 1 μ. όταν θα προσφερθεί γεύμα.

Θα προσφέρονται φαγητό και αναψυκτικά δωρεάν

Εάν θέλετε να παραστείτε, προσκαλείστε να τηλεφωνήσετε στην Diane Boyde, μέχρι τις 4 Μαίου στο 4732 6301 για λόγους τροφοδοσίας ή εάν χρειάζεστε μεταφορά για να παραστείτε στη συγκέντρωση.
Appendix iii – Arabic Flyer

Do you look after someone who is old and frail at home?
Do you look after an adult or child who has a disability
and lives at home?

If you are from an Arabic speaking background and live
in the Penrith, Hawkesbury or Blue Mountains areas we
want to hear what you need to help you look after your
family member or friend.

Perhaps you have tried to use services before and it
has not been what you needed or expected.

We need your help to understand what your situation
is. Any information that you provide will remain
anonymous.

You are invited to a session where you can tell us
about your experiences and difficulties. Centrelink
will also be available with some helpful information
and to answer any questions about their service.

An Arabic language interpreter will also be available.

Venue: Arthur Neave Memorial Hall
        Parkes Avenue
        Werrington

On: Tuesday 12 June 2007
    To start at 9.30 and finish at 1 pm when
    lunch will be served.

Free refreshments and lunch will be provided.

If you would like to attend, please phone Diane Boyle
by 5th June on 4732 6301 for catering purposes or if
you require transport to attend this session.
Appendix iv – Arabic Translated

هل تعتنون بشخص كبير في السن أو شخص ضعيف في البيت؟
هل تعتنون بشخص كبير أو ب الطفل معاق يسكن في البيت؟

إن كنت من خلفيات تتكلم اللغة العربية و تسلكون في Hawkesbury أو Penrith و فانتنا ترغب بالسما العائدة لاحتياجاتكم لمساعدكم في Blue Mountains أو النهائية التي تقدمها لأحد اعضاء العائلة أو الإصقاة.

ربما قد حاولت سابقا بالحصول على مثل هذه الخدمات ولكن لم تكن مناسبة أو مماثلة لاحتياجكم.

فانا بحاجة لمساعدكم لفهم احتياجاتكم. كل المعلومات التي تتضمنها ستكون سريعة ندروكم الآن لندولة حيث يمكننا اعلامكم عن احتياجاتكم والمصادر التي تواجهها. سيحضر هذه اللدود ممثلي من Centrelink لتوفير المعلومات والإجابة على استفساراتكم حول الخدمات التي يقدمها.

سيتوفر مترجم باللغة العربية

المكان: Arthur Neave Memorial Hall
Parkes Avenue
Werrington

الزمان: يوم الثلاثاء 12 حزيران/يونيو 2007
وتبدأ الندوة الساعة 9 صبحا و تنتهي الساعة 1 ظهرا حيث ستقدم الغذاء.

سنقدم الغذاء والمرافق أثناء الندوة مجاناً.

إن كنت ترغب بالحضور بالرجاء الاتصال مع Diane Boyde على الرقم 6301 4732 أو تتوفر الغذاء أو إن كنت بحاجة للمساعدة في المواسات لحضور الندوة.
Do you look after someone who is old and frail? Do you look after an adult or child who has a disability?

If you are from a Macedonian background and live in the Penrith, Hawkesbury or Blue Mountains areas we want to hear what you need to help you look after your family member or friend.

Perhaps you have tried to use services before and it has not been what you needed or expected.

We need your help to understand what your situation is. Any information that you provide will remain anonymous.

You are invited to a session where you can tell us about your experiences and difficulties. Centrelink will also be available with some helpful information and to answer any questions about their service.

A Macedonian interpreter will also be available.

Venue: Richmond Neighbourhood Centre
20 West Market St
Richmond

On: Friday 22nd June 2007
To start at 9.30 and finish at 1 pm when lunch will be served.

Free refreshments and lunch will be provided.

If you would like to attend, please phone Diane Boyde by 15th June on 4732 6301 for catering purposes or if you require transport to attend this session.
Дали се грижете за лице во години со нарушенос здравје? 
Дали се грижете за онеспособено возрасно лице или дете?

Ако сте од македонско потекло и живеете во регионот на Penrith, Hawkesbury или Blue Mountains, би сакале да слушните од вас што ви е потребно за да можете да се грижете за член од вашето семејство или пријател.

Можеби веќе сте се обиделе да користите услуги и тие не беа го што ви беше потребно или што го очекувале.

Не треба вашата помош да ја разбереме вашата ситуација. Сите податоци кои ќе ни ги дадете ќе се чуват во доверливост.

Ве покануваме на средба на која ќе можете да ни кажете за вашите искуства и тешкотии. Исто така, на средбата ќе присуствува лице од Centrelink кое ќе може да ви даде некои корисни информации и да одговори на сите прашања во врска со нивните услуги.

На средбата ќе присуствува и македонски преводач.

**Место:** Richmond Neighbourhood Centre  
20 West Market St  
Richmond  

**Датум:** Петок, 22 јуни 2007  
Средбата ќе започне во 9.30 ч. наутро и ќе заврши во 1 ч. попладнев, после што ќе се служи ручек.

Ќе се служат бесплатен ручек и освежителни пијалоци.

Ако сакате да присуствуваате на средбата, ве молиме телефонирајте и на Diane Boyce најакусно до 15 јуни на +61 432 6301 за да може да ги организира набавките за ручекот или ако ви е потребен превоз за да можете да присуствуваате на оваа средба.
Appendix vii – Filipino Flyer

Do you look after someone who is old and frail?
Do you look after an adult or child who has a disability?

If you are from a Filipino background and live in the Penrith, Hawkesbury or Blue Mountains areas we want to hear what you need to help you look after your family member or friend.

Perhaps you have tried to use services before and it has not been what you needed or expected.

We need your help to understand what your situation is. Any information that you provide will remain anonymous.

You are invited to a session where you can tell us about your experiences and difficulties. Centrelink will also be available with some helpful information and to answer any questions about their service.

A Filipino interpreter will also be available.

Venue: Santa Maria Conference Centre
Cnr Kitchener St and Great Western Highway
Lawson

On: Friday 29th June 2007
To start at 9.30 and finish at 1 pm when lunch will be served.

Free refreshments and lunch will be provided.

If you would like to attend, please phone Diane Boyde by 22nd June on 4732 6301 for catering purposes or if you require transport to attend this session.
Ikaw ba ay nag-aalaga ng isang matanda at mahina?
Ikaw ba ay nag-aalaga ng isang matanda o batang may kapansanan?

Kung ikaw ay mula sa Pilipino background at naniniirahan sa Penrith, Hawkesbury o Blue Mountains gusto naming marinig ang iyong kailangan para matulungan ka sa pag-aalaga ng membro ng iyong pamilya o kaibigan.

Seguro nagamit mo na ang mga serbisyo at hindi iyon ang iyong kailangan o inaakala.

Kailangan naming ang tulong mo para mantindihan ang iyong sitwasyon.
Anumang impormasyon na iyong ibibigay ay mananatiling itim.

Ikaw ay inimbahahan sa isang sesyon kung saan puwede mong sabihin sa amin ang iyong eksperiensya at kahirapan. Ang Centrelink ay naroon din para magbigay ng makakatulong na impormasyon at para sagutilin ang anumang tanong tungkol sa karilangan mga serbisyo.

Mayroon ding Pilipinong tagapagsain na puwedeng gamitin.

Lugar: Santa Maria Conference Centre
Komener Kitchener St at Great Western Highway, Lawson

Kailan: Biyernes, 29 ng Hunyo, 2007
Magsisimula ng 9.30 ng umaga at matalapos ng 1.00 ng hapon
kung kailan ihahain ang tanghalian.

Libre ang merienda at tanghalian ihahain.

Kung gusto mong sumali, tawagan mo si Diane Boyd sa 4732 6301 bago matalapos ang 22 ng Hunyo para malaman ang ihahain sa iyo at kung kailangan mo ng transportasyon para sumali sa sesyon.
Appendix ix – Press Release

Strengthening Community Links
Auspiced by Penrith Disabilities Resource Centre
P.O. Box 185, Penrith NSW 2751

The Editor
Penrith Press

30 April 2007

Media Story

Greek Carers Talking about Caring for Family Members

Members of Greek communities throughout Penrith and the wider Nepean area will be getting together at the Greek Orthodox Parish of St Demetrius at 9 30 am on 11 May 2007 to talk about what they need to help them look after family members who are old and frail or have a disability. At the end of this discussion Centrelink will be on hand to provide information about payments and allowances and answer questions in relation to this issue.

According to Robyn Sedger, from the Nepean Strengthening Community Links Project, there are many people from Greek communities in the Penrith area who are already doing a wonderful job in taking care of a family member such as a parent, husband or wife or son or daughter who, because of an illness or disability, cannot take care of themselves. “People want to do all they can to care for their loved one, but without adequate support, the carers can sometimes become stressed or ill”, Robyn says.

Several community services such as home care and respite are available to assist carers of frail older people and younger people with a disability. Carers from culturally and linguistically diverse backgrounds, however, are not well represented among the people who access these community services. Without accurate information as to why this happens, service providers may get the impression that Greek carers don’t want to use existing services. Indeed, the opposite may be true. Carers may not know of the services that are available or they may have tried to use a service before without a clear understanding of how the service operates.

The focus group on 11th May has been organised through a collaborative effort by the Strengthening Community Links Project and Diane Boyde, from the Nepean Home and Community Care Access Project. Both project coordinators are very keen to hear about the experiences and any difficulties that Greek carers may have encountered in
accessing services. Diane Boyde says that we need help to understand exactly what the situation is. “This information needs to come from the Greek community themselves”, Diane says, “rather from someone else second guessing what the problem might be.” Those who attend are assured that they can remain anonymous and that anything they say will be confidential.

Greek interpreters have been organised for the morning and a free morning tea and lunch will be provided. If you would like to attend, please phone Diane Boyde by 4th May on 4732 6301 for catering purposes or if you require transport to attend this session.

Other focus groups for Macedonian, Filipino and Arabic speaking communities will also be held at later dates. Phone Diane for more information on these events.

For more information contact:
Robyn Sedger, Disability Worker
Strengthening Community Links Project
Phone: 4732 2363 (bus. hours)
Mobile: 0423 316 155 (bus. & after hours)