



# Cultural Diversity and Dementia in the Hunter and Central Coast

A Research Project  
for Northern Settlement Services Ltd

## FINAL REPORT

Alt Beatty Consulting

September 2011

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### Disclaimer

This report presents the results of work carried out between June and September 2011.

The information presented was the best available to the knowledge of the consultants at the time of the project.

Every effort has been made to reflect accurately the views of stakeholders consulted.



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## Acronyms

ADHC	Ageing, Disability and Home Care, NSW Department of Family and Community Services
BPSD	Behavioural and Psychological Symptoms of Dementia
CACP	Community Aged Care Packages
CALD	Culturally and linguistically diverse
CDN	Community Dementia Nurse
CNC	Clinical Nurse Consultant
COPS	Community Options Service
DAS	Dementia Advisory Service
DBMAS	Dementia Behaviour Management Advisory Service
DoHA	Australian Government Department of Health and Ageing
EACH D	Extended Aged Care at Home for people with Dementia
ECC	Ethnic Communities Council, Newcastle & Hunter Region Inc
HACC	Home and Community Care Program
LGA	Local government area
LPA	Local planning area (for HACC & Commonwealth aged care)
MAP	Multicultural Access Program
PLWD	Person living with dementia
NGO	Non-government organisation
NSS	Northern Settlement Services Ltd
OH&S	Occupational Health and Safety
YOD	Younger Onset Dementia

## Executive Summary

### The research project

This project arises from a goal of the Ageing, Disability and Home Care (ADHC) Department of Human Services NSW *Hunter Dementia Care in the Community Action Plan 2009-2011* “to increase dementia related knowledge of culturally and linguistically diverse (CALD) communities and associated service providers”.

Northern Settlement Services Ltd received a grant from ADHC under the Home and Community Care (HACC) program to undertake the project. It covers the understanding of and support needed by people with dementia and their carers from CALD backgrounds in the Hunter and Central Coast.

Northern Settlement Services (NSS) contracted *Alt Beatty Consulting* to undertake the project.

The project ran from June through September 2011. It included a scan of the literature, collation of available data and consultations with carers and community members and dementia service providers and other stakeholders. The project team was supported by a Project Advisory Group and an initial stakeholders meeting.

The area covered by the project is the ADHC Hunter region. It comprises the nine local government areas of the Hunter Local Planning Area (LPA) – Newcastle, Lake Macquarie, Cessnock, Maitland, Dungog, Port Stephens, Muswellbrook, Singleton and Upper Hunter – and the two local government areas of the Central Coast LPA – Gosford and Wyong.

### The target population

The Hunter and the Central Coast have low proportions of people from culturally and linguistically diverse backgrounds compared with many other areas of NSW. At the 2006 Census, 3.8% of people in the Hunter spoke a language other than English at home and 3.9% in the Central Coast. (Department of Immigration and Citizenship 2008) This compares with 24% of people across NSW speaking a language other than English at home.

There is considerable variation across the region: 7.2% of people living in Newcastle spoke a language other than English at home, compared with only 1% of people living in Dungog.

The top five languages spoken in the Hunter were Italian, Macedonian, Greek, German and Polish. In the Central Coast they were Italian, Spanish, German, Greek and Cantonese.

The three communities with the largest numbers of people over 65 years of age at the 2006 Census were the same in both the Hunter and the Central Coast: people born in Italy, Germany and the Netherlands.

Access Economics (2010) estimates that there are 13,928 people living with dementia in the region in 2011 and that this will grow to 19,256 by 2020. It estimates that there are over 4,000 new cases of dementia in the region each year and that this will increase to over 5,000 by 2017.

### **The literature on dementia and emerging models**

The small body of literature in Australia around people with dementia and their carers from a CALD background and their beliefs and perceptions about dementia indicates some common and disparate threads. They include:

- dementia is considered a normal part of ageing;
- dementia may be stigmatised as a mental illness;
- families are reluctant to admit the presence of dementia;
- social isolation is an issue for both the person with dementia and their carer;
- a strong preference for the person with dementia to stay at home; and
- residential care is not an option or only of very last resort.

Previous research gives some insight into CALD communities' attitudes to and usage of community care services. Views about caring are heavily influenced by culture. The role of carer is often not left to a single person, but taken up by a variety of people across a number of specific roles and tasks. Some tasks may be clearly delineated along gender lines. (CIRCA, 2008, Broughtwood et al, 2011, Cheng et al, 2009)

Awareness of services varies considerably across different cultural groups. Service providers report needing to spend a large amount of time building trust with people before they will consider accessing services. Many people do not access services until the person with dementia is in the mid to late stages of dementia.

CALD community organisations and community leaders may play an important role in linking individuals with mainstream dementia services. Partnerships between these stakeholders and dementia service providers can be important.

People who speak English as a second language often turn to only speaking their first language with the onset of dementia. Bilingual workers are important in this situation.

Service models which may be particularly relevant to supporting people with dementia and their carers from a CALD background include:

- **Early intervention initiatives**, for example, the Living with Memory Loss program run by Alzheimer’s Australia has been delivered in community languages in Sydney and other areas. Dementia cafés are another model received positively by people with dementia and their carers, including some small numbers of people from CALD backgrounds.
- **Partnership models** such as ‘Tastes to Remember’ based on a multicultural feast to raise awareness and provide dementia education and the Multicultural Respite Network which links mainstream respite providers and organised cultural groups to provide respite in familiar community settings.
- **Cultural specific models** such as structured group telephone counselling, ethno specific day care, social support and carer support.
- **Models for small client numbers**, including the engagement of bilingual workers and volunteers and training of mainstream staff in working with people from CALD backgrounds.
- **Respite and related support** delivered in more flexible or innovative ways, such as the overnight respite cottage model, host family respite and mobile respite services.

### Community views

Many of the themes from the literature were confirmed in the consultations, especially denial, stigma and the expectation that extended family will continue to support the person with dementia to remain living in the community.

Among the individuals consulted there is a wide range of understanding about dementia. People were particularly concerned that the person living with dementia not be ostracised and become socially isolated.

Many of the people consulted for this project had positive views of their experience with services. For some this came after negative experiences – such as inflexibility in service provision – or refusal of service by the person with dementia.

Carers stated that services seem disconnected and it is very confusing when trying to get help.

Consumers value education about dementia; carer support; using interpreters to communicate in their language; culturally appropriate food; bilingual social support; continence education; and respect and understanding of the person with dementia.

### The service system

Service providers and other stakeholders indicated barriers which may inhibit effective service delivery to people with dementia and their carers from a CALD background. They include language, small numbers of cultural groups, information and education about dementia, inadequacy of service response and inappropriate assessment.

However there are strengths within the service system and community which can help in addressing these barriers. They include Multicultural Access Program (MAP) workers and CALD specific services which can help people access the system; existing service responses such as culturally appropriate meals; and an overall push towards more person centred and enabling care.

Specific recommendations are provided below.

There are several key elements to strengthening the support of people with dementia and their carers from a CALD background in the Hunter and Central Coast:

- a) cultural awareness and competence across the service system;
- b) collaboration;
- c) effective utilisation of existing specialists and other resources; and
- d) commitment to person centred care.

## **Appendices**

The appendices of this report include a range of material for the planning and delivery of improved support to people with dementia and their carers from a CALD background: Census statistics on cultural diversity by Local Government Area (LGA); the current prevalence of dementia in the population and projected prevalence to 2020 by LGA; summaries of HACC-funded service usage; an organisational cultural assessment tool; listings of ethnic based community groups and of literature and other resources on cultural diversity and dementia.

## Recommendations

### Current service usage

**Recommendation 1:** A clearer picture of how people with dementia and their carers of CALD background are currently using services in the region be developed by:

- pursuing the request for data on service usage from the HACC MDS (Figure 4.1) – this request could be deepened with the addition of the unique client identifier to gauge multiple service usage;
- investigating other data items or reports which can be drawn from the HACC MDS and from Health databases;
- considering other ways of measuring the situation, such as a snapshot survey where providers count the number of people of CALD backgrounds with a dementia they are supporting;
- further analysis when any of the data above is available; and
- sharing this analysis across the sector.

These measures will increase shared understanding and provide a clearer evidence base for identifying service gaps and addressing needs (Section 4.2).

### Dementia awareness

**Recommendation 2:** Working together at the LPA or LGA level, MAPs, DAS and HACC DOs, develop local strategies to engage with CALD communities and individuals with the aim of:

- increasing awareness and understanding of dementia;
- assisting service providers to become more aware of their local population; and
- contributing to service providers efforts to offer services responsive to client differences.

The resources, knowledge and expertise of Alzheimer’s Australia NSW should be drawn on in this process.

Establishment of a CALD Dementia Working Party within the region may be a constructive way of implementing this recommendation.

[This recommendation relates to Actions 1.1.4 and 1.2.1 of the NSW Dementia Services Framework.] (Section 5.4)

**Recommendation 3:** Strategies to engage with people with dementia and their carers from CALD backgrounds include partnerships with cultural community groups and the Ethnic Communities Council (ECC) to test service models which have been successful in other situations. These models include ‘Tastes to Remember’ and dementia cafés. (Section 5.4).

### Assessment

**Recommendation 4:** Service providers, ADHC and Local Health Districts ensure that community care providers are able to provide or access a culturally competent assessment process. This will include:

- sensitivity to people’s fear of receiving a diagnosis of dementia
- ensuring assessment tools without cultural bias are used

- staff being trained and competent in accessing and using the interpreting service
- interpreters being ‘dementia aware’ and having the skills to participate effectively in the process.

Relevant information, such as accessing the interpreter service, could be loaded on HSNet. (Section 5.4)

### Carer support

**Recommendation 5:** ADHC and the Local Health Districts are facilitating dementia services planning across the region. Through this process the demand for the following services, and the funding they would require, should be considered:

- support group(s) for emerging carers groups, such as Filipino carers
- expanding the capacity of the Living with Memory Loss program to extend its coverage to CALD communities in the region, in partnership with interpreters
- extending carer education sessions to ‘hidden carers’ (those not accessing services) through partnerships, including with community groups identified in Appendix K.

[This recommendation relates to Actions 3.5.1, 3.6.1 and 3.6.2 of the NSW Dementia Services Framework.] (Section 5.4)

### Cultural competence of community care

**Recommendation 6:** The cultural competency of the community care sector in the region be strengthened through the provision of training in three areas:

- cultural awareness and competency for service managers and staff
- the use of interpreters for service managers and staff
- cultural awareness for volunteers.

Service providers should use the Organisational Assessment Tool (Appendix L) as part of their annual service planning and review. (Section 5.5)

### Collaboration

**Recommendation 7:** The need for collaboration across community care, health services and specialist multicultural agencies to deliver effective support to people with dementia and their carers from CALD backgrounds be reinforced through:

- dementia services planning and development
- service funding specifications
- the use of existing specialist and other resources available in the region.

(Section 5.5)

### Person centred care

**Recommendation 8:** Recognising that person centred and enabling care is at the centre of effective support for all individuals, service providers take up opportunities for training in person centred and enabling approaches.

(Section 5.5)

# 1 The Project

## 1.1 Background

This project arises from a goal of the *Hunter Dementia Care in the Community Action Plan 2009-2011* “to increase dementia related knowledge of culturally and linguistically diverse (CALD) communities and associated service providers” (p17). The plan also notes:

Knowledge and concepts of dementia in CALD communities in the Hunter is limited, which may influence the entry and access to dementia-specific community support services by CALD communities. Research and consultation is required to inform service planning in the Hunter Region to determine culturally competent service models, such as centre-based respite.

Northern Settlement Services Ltd (formerly the Migrant Resource Centre) received a grant from ADHC under the Home and Community Care (HACC) program to undertake this research project. It covers the understanding of and support needed by people from culturally and linguistically diverse backgrounds with memory loss or dementia and their carers in the Hunter and Central Coast.

Northern Settlement Services (NSS) contracted *Alt Beatty Consulting* to undertake the project.

The project scope is:

- a) undertake research on current best practice in dementia care;
- b) consult with local CALD communities about their beliefs and knowledge regarding memory loss and dementia;
- c) identify the services CALD communities are aware of and the ‘help’ they consider best for them; and
- d) collaborate with multicultural, ethno specific and mainstream dementia support services to identify any barriers for people from CALD communities in accessing services.

The area covered by the project is the ADHC Hunter region. It comprises the nine local government areas of the Hunter Local Planning Area (LPA) – Newcastle, Lake Macquarie, Cessnock, Maitland, Dungog, Port Stephens, Muswellbrook, Singleton and Upper Hunter – and the two local government areas of the Central Coast LPA – Gosford and Wyong.

## 1.2 Method

The project progressed from June through September 2011 through the following steps:

- A. a briefing and workshop of stakeholders from across the region (Appendix A);
- B. a meeting of the Project Advisory Group (Appendix B) to resolve the consultation strategy and other project logistics;
- C. a scan of the literature and information on service models to update earlier work on cultural diversity and dementia;
- D. collation of population data on dementia prevalence and cultural diversity by local government area;
- E. preparation of materials for consultations including discussion papers for people with dementia and their carers and for service providers;
- F. three workshops with service providers (Appendix C) covering cultural diversity awareness, barriers to effective service delivery for CALD consumers with dementia and their carers, service models and planning issues. People unable to attend a workshop were invited to respond to four questions directly to the project team;
- G. consultations with consumers and other stakeholders (see Appendix D);
- H. a report on progress;
- I. collation and analysis of all information gathered through steps C to G;
- J. preparation of draft project report;
- K. feedback on the draft report from NSS, the Project Advisory Group and other stakeholders; and
- L. finalisation of the project report and project completion.

## 2 The Target Population

*This chapter provides a statistical profile of the region in regard to the CALD population. It presents issues about demographics which have arisen during the consultations. Information and projections of dementia prevalence and incidence are also provided.*

### 2.1 The CALD Population

The Hunter and the Central Coast have low proportions of people from culturally and linguistically diverse backgrounds compared with many other areas of NSW. At the 2006 Census, 3.8% of people in the Hunter spoke a language other than English at home and 3.9% in the Central Coast. (Department of Immigration and Citizenship 2008) This compares with 24% of people across NSW speaking a language other than English at home.

There is considerable variation across the region: 7.2% of people living in Newcastle spoke a language other than English at home, compared with only 1% of people living in Dungog.

The top five languages spoken in the Hunter were Italian, Macedonian, Greek, German and Polish (Appendix E, Table E2).

The top five languages spoken in the Central Coast were Italian, Spanish, German, Greek and Cantonese (Appendix E, Table E1).

Proficiency in English is likely to be an issue for older people from culturally and linguistically diverse backgrounds. For example, the 2006 census identified that over 75% of all Italians living in Australia aged 65 years and over do not speak English well or do not speak it at all. For Polish people aged 65 years and over just over one in two people are in this situation (Department of Immigration and Citizenship, 2008).

The three communities with the largest numbers of people over 65 years of age at the 2006 Census were the same in both the Hunter and the Central Coast: people born in Italy, Germany and the Netherlands. People born in Italy were the largest community in the Hunter and people born in the Netherlands were the largest community in the Central Coast.

Community workers suggest that a younger community, people from the Philippines, may have a high proportion of carers.

Tables E1 and E2 in Appendix E show some of the diversity in the population by local government area. As these figures are all drawn from the 2006 Census they may not capture more recent demographic shifts and/or particular needs. For example, community workers have identified people from Croatia in the Port Stephens LGA as a significant group for carer support.

The four most populous LGAs in the region at the 2006 Census (in descending order) were Lake Macquarie (183,140), Gosford (158,157), Newcastle (141,755) and Wyong (139,803). These LGAs all have significantly more people speaking a language other than English at home than the other seven LGAs. Lake Macquarie had 6,001 people speaking another language (3.3% of its population), Gosford had 6,668 (4.2%), Newcastle 10,176 (7.2%) and Wyong 4,929 (3.5%). However it is the concentration of particular communities in Newcastle and Lake Macquarie which give those LGAs a stronger flavour of cultural and linguistic diversity.

## Issues

Data items used to identify cultural diversity, such as Country of Birth, Languages spoken at Home and English Proficiency, are important in understanding the make-up of a local population. However, focussing on these data items alone may underplay an individual's cultural preferences and identity. These will be influenced by a person's own history and experience of migration and settlement.

For example, some situations in the region described in consultations:

- Pacific Islander person – highly proficient in English, only language spoken at home. The Pacific is often considered an extension of Australia. However, as an older person who grew up in an Island community he/she has a strong sense of cultural practice in regard to care and who should be involved.
- Some men born in Poland, missed out in schooling as they were transported to child labour camps in Germany. There they learnt some German. They migrated to Australia in their early twenties. They settled in Newcastle, married Australian women and spoke only English from then on (ie for 50 or 60 years). These men do not speak Polish but have clear preferences for Polish food in a day care or respite situation.

These examples come from service providers assisting people from CALD backgrounds. Through giving this support they have learnt more about their clients and their preferences for service delivery.

The demographics and needs of CALD communities change over time. For example, the Italian and Polish communities in the Hunter and Central Coast have high proportions of people over 65. Whereas newer groups, noticeably people from the Philippines, have only small numbers of people aged over 65.

## 2.2 Dementia Prevalence

The proportion of the Australian population living with dementia is expected to more than double in the next 40 years: from 1.18% in 2011 to 1.31% in 2015 through to 2.76% by 2050 (Access Economics 2010).

While there will continue to be steady growth of people with younger onset dementia, the large numbers will be among people aged 85 and over.

Access Economics has produced estimates of the prevalence and incidence of dementia in the population for ADHC and Health regions (Access Economics 2009a). **Prevalence** is the number of people in the population with dementia. **Incidence** is the number of new cases of dementia in a year.

This project covers the ADHC region of Hunter, which includes the Central Coast. Figures for the whole region and for individual LGAs are provided. Access Economics estimates that there are 13,928 people living with dementia in the region in 2011 and that this will grow to 19,256 by 2020 (Appendix F, Table F.1). It estimates that there are over 4,000 new cases of dementia in the region each year and that this will increase to over 5,000 by 2017.

At the state electorate level, Wyong Electorate is projected to be the third highest electorate in terms of people living with dementia by 2050 – 6,236 people (Access Economics 2009a for Alzheimer’s Australia NSW).

The prevalence rates (percentage of people in the population with dementia) used for these estimates are shown in Table 2.1.

**Table 2.1: Dementia Prevalence Rates by Age and Gender**

Age Band	Estimated Prevalence Rate (% in population)	
	Females	Males
< 60	0.02	0.03
60 – 64	0.6	1.2
65 – 69	1.3	1.7
70 – 74	3.3	3.5
75 – 79	6.3	5.8
80 – 84	12.9	12.1
85 – 89	24.4	21.1
90 – 94	35.7	31.5
95 plus	47.3	37.2

Source: Access Economics 2009b.

Appendix F also includes current and projected estimates of dementia in the population for each local government area in the region.

In more recent work, Access Economics has lowered its estimates of dementia in the population due to revised population projections by the Australian Bureau of Statistics (ABS). “This has seen dementia prevalence projections revised downward, with the difference increasing over time. For example, dementia prevalence projections presented in this study are 0.3% lower for 2010, but are around 13.2% lower for 2050.” (Access Economics 2011) Revised estimates are not yet available for regions and LGAs. Consequently, the further into the future the figures in Appendix F, the more caution should be applied in using them.

To date there is no evidence that the prevalence of dementia is different among people of a CALD background than among the rest of the Australian population.

### 3 Views on dementia & emerging models

*This chapter draws together the literature and information from outside the region on beliefs and perceptions of CALD communities about memory loss and dementia and on service models for people with dementia and their carers from a CALD background.*

#### 3.1 Beliefs and perceptions

There is a small body of literature in Australia around people with dementia and their carers from a CALD background and their beliefs and perceptions about dementia. References are provided at Appendix M.

A study in Victoria (Alzheimer's Australia Vic. 2008) of five CALD communities described how dementia is perceived by those communities (Figure 3.1). These findings are generalisations and do not apply to all people in a particular group.

**Figure 3.1 Perceptions and Beliefs regarding Dementia**

<b>Culture</b>	<b>Perceptions and beliefs</b>
Arabic	Dementia is considered to be a normal part of ageing but associated with mental illness. There is reluctance to admit the illness, due to associated stigma. It is expected that the family, particularly children, will play a strong role in care due to strong family-orientation and religious beliefs. There is a strong preference for services that will allow the person with dementia to stay at home and residential care is not seen as an option, unless as last resort. Counselling services for dementia are generally not favoured.
Chinese	Understanding of dementia varies within the community, with dementia stigmatised as a form of mental illness in some sections of the community, and attributed to normal ageing in other sections. Dementia is not openly discussed and social isolation is a concern. The traditional 'filial piety' concept means that children often care for their parents with dementia. Chinese place great importance on peer support so Senior Citizens' groups, support groups and Planned Activity groups are highly valued, but residential care is still perceived negatively.
Serbian	There is little understanding of dementia in the community. Most see it as a form of mental illness and mental illness carries much stigma. For older members with low education, dementia may be attributed to past mistakes of the family. The primary carer is usually the spouse and residential care is not seen as an acceptable option. The most accepted form of therapy is medication.

<b>Culture</b>	<b>Perceptions and beliefs</b>
Italian	Views and opinions vary according to education level and English proficiency. Some perceive dementia as benign forgetfulness and a normal part of ageing. Social isolation is a major issue. Views on community care vary but the community is generally family-centred. Residential care is often not acceptable due to strong attachment to the home and stigma. Trust and building a strong relationship is considered to be a key to successful counselling.
Polish	Dementia is either seen as a usual sign of ageing, or with more severe symptoms, as mental illness. Dementia is highly stigmatised and denial is a common issue, and social isolation may occur. Because of stigma, there is a reluctance to seek support outside of the family network, and thus family remains the strongest support area. It is considered shameful to place a family member in residential care.

Source: Alzheimer's Australia Victoria (2008) as reproduced in Access Economics 2009b. Note these are generalisations and will not apply to all people in a particular group.

Other findings from the literature include:

- People seeing dementia as turning the person into a child. Arabic-speaking and Italian-speaking carers “described how they often had to orientate to the PLWD (person living with dementia) as a child, and Chinese-speaking and Arabic-speaking carers suggested they had a cultural tradition whereby the older person “becomes like a child again.” One Chinese carer suggested it would be helpful if more community members also understood dementia in this way rather than in the highly negative terms experienced” (Boughtwood et al 2011: 293).
- Language and proficiency in English may be a barrier to understanding the disease and their experience of it and to using services. The word ‘dementia’ may not have an equivalent in some languages. For example, in some communities it has caused confusion when translated as ‘one who is mad’ (Cheng et al 2009).
- People need access to information and community education about dementia that is culturally appropriate and in a range of community languages.

### **3.2 Experience of services**

Previous research gives some insight into CALD communities’ attitudes to and usage of community care services. This provides some context for appropriate service models. Many of the themes from the literature were discussed in the consultations.

### ***Caring role***

- Dementia is seen as a normal part of ageing and/or a mental illness and caring is considered as a duty and a part of the familial role.
- Views about caring are heavily influenced by culture. People from some CALD communities may not identify as a carer, and therefore not identify with the carer support models which have been traditionally provided.
- The role of carer is often not left to a single person, but taken up by a variety of people across a number of specific roles and tasks (CIRCA 2008). Carer support models or services need to accommodate this complexity.
- Family care provision may be clearly delineated along gender roles, especially in regard to women performing personal care. Male carers undertaking such tasks may be conscious of transgressing what is normally expected of them (Boughtwood et al 2011: 294).
- Grief and loss felt by carer(s) may require individual counselling or other one-to-one support.

### ***Service awareness and usage***

- Awareness of services varies considerably across different cultural groups (CIRCA 2008).
- Service providers report needing to spend a large amount of time building trust with people before they will consider accessing services. Many people do not access services until the person with dementia is in the mid to late stages of dementia (Alt Beatty Consulting & Alzheimer's Australia NSW 2009).
- There is a tendency for CALD communities to have a low take-up of mainstream services, especially basic HACC support. Within this limited usage scenario, particular service types are favoured by some communities. For example, community nursing is used by Italian and Chinese communities (CIRCA 2008).
- People born in non-English-speaking countries make relatively high use of care package services compared to Australian-born and people born overseas in English-speaking countries. More than one in three clients receiving packaged care was born overseas (Australian Institute of Health and Welfare 2010). This usage may relate to the range of service types available through packages and the use of brokerage models.

### ***Effective dementia support***

- CALD community organisations and community leaders may play an important role in linking individuals with mainstream dementia services. Partnerships between these stakeholders and dementia service providers can be important.
- People who speak English as a second language often turn to only speaking their first language with the onset of dementia. Bilingual workers are important in this situation.
- Community consultations in some areas (such as Metro South, Sydney) suggest most people from CALD backgrounds prefer to receive a service from someone with whom they can communicate in their own language and who understands their culture (Alt Beatty Consulting & Alzheimer's Australia NSW 2009).

- Other expressed needs include access to assessment and diagnostic services that are holistic and responsive to the cultural and linguistic needs of people and their carers. Delays in diagnosis and assessment may also be influenced by language barriers and proficiency in English (Cheng et al 2009).
- A person's cultural identity is unique and their language preference cannot be presumed. Providers need to be sensitive to individual preferences in accordance with a person centred approach.
- Resources about dementia have been developed in a range of community languages. For example, delivering Living with Memory Loss programs in a range of community languages. The gaps appear to be in translating and using this information in practice.

A study with carers from four CALD communities: Arabic-speaking, Chinese-speaking, Italian-speaking and Spanish-speaking, has examined their experiences and perceptions with regard to their care giving for a person living with dementia (Boughtwood et al 2011). "Analysis revealed that while considerable similarities exist across the experiences and perceptions of carers from all four CALD communities, there were nevertheless some important distinctions across the different groups."

All communities were heavily involved in the care for the person living with dementia (PLWD). However, Arabic-speaking and Chinese-speaking carers did not take an **advocacy role** in hospitals as described by the Italian-speaking and Spanish-speaking carers. Arabic-speaking and Chinese speaking carers also reported less **conflict with other family members** about care-giving decisions than Italian-speaking and Spanish-speaking carers. **Gender** was not described as impacting care decisions in these latter CALD communities to the extent that it was by the Italian-speaking and Spanish-speaking carers participating in the study. Arabic-speaking carers expressed much **emotion and grief** about the condition of the PLWD, worry about the future, and the impact of caring on themselves. However, Arabic-speaking carers were also less concerned about dementia-related **behaviours** than the other three groups. Unlike carers from the other CALD communities, Chinese-speaking carers did not report worrying about the **safety** of the PLWD (Boughtwood et al 2011: 295).

The authors relate their findings to service practice:

The research reported in this article has implications for practice and education. If CALD communities prefer to provide care at home, programs should be developed that enable carers to do so safely, in terms of mobilizing the PLWD as well as supporting carers themselves. .... Certain tasks, such as having to interpret doctor-patient or doctor-relative communication are likely to add to carers' stress. There are also the difficulties and ethics associated with using family members as interpreters. Clinicians dealing with family carers from CALD communities need to reflect on these issues and consider the ways in which they could possibly support such carers in the medical encounter. Clinicians also need to be prepared for the possibility of the involvement of multiple family members

in care giving decision making - a situation sometimes accompanied by conflict and emotion (Boughtwood et al 2011: 296).

### **3.3 Service models**

The NSW Dementia Services Framework (NSW Health 2011) identifies the full range of service models which represent good practice in dementia care. Further development of these services across NSW is important for all people living with dementia and their carers. The focus here is on models that have been developed or adapted in response to the particular needs of people from CALD backgrounds.

The situation remains that, as with many community care interventions, there is limited research, beyond feedback from clients, regarding the effectiveness of models supporting people with dementia and their carers from a CALD background.

... While there are dementia specific services and support programs for people from CALD backgrounds, qualitative research has not been undertaken into appropriateness and effectiveness of these services. Additionally, there is no Australian research on how to effectively improve awareness and education, and deliver caregiver support programs to CALD carers of people with dementia (Cheng et al 2009:8).

The following models are presented with that qualification. They do appear to have been well received by the target population.

#### ***Early intervention***

- Alzheimer's Australia NSW's Living With Memory Loss (LWML) program may be delivered in community languages by bilingual workers. The program aims to reduce the sense of isolation, distress and depression and increase the self esteem of people with or caring for someone with dementia, increase knowledge of local services and gain positive perceptions of dementia. At each session two groups meet concurrently, one for people with dementia, and one for their family members. (Alzheimer's Australia NSW [www.alzheimers.org.au](http://www.alzheimers.org.au))
- Dementia cafés which bring together people in the early stages of dementia to reduce social isolation and to offer education, support, informal advice and consultation by professionals and peers in a relaxed atmosphere. There is positive feedback to the model from people with dementia and their carers, including some small numbers of people from CALD backgrounds (see for example, Connections Coffee Club at Blacktown, pp 32-33, ADHC 2010b).

#### ***Partnership models***

- The 'Tastes to Remember' model in Melbourne involves a partnership between service providers, a multicultural organisation, local government, Alzheimer's Australia Vic and ethnic community groups.

‘Tastes to Remember’ Multicultural Feast approach is a community partnership model that brings together service providers and community leaders from CALD backgrounds to plan for open, informal, culturally supported table discussions about memory loss and dementia. It uses food and culture as a means of remembering special occasions associated with childhood memories, migration, and food for memory.

The Model has been delivered based on the key principle of multicultural feasts where a number of cultural groups gather together, enjoy ethnic meals, and talk about food, culture and memories. Applying adult learning principles of self-discovery and making choices, participants are encouraged to talk about types of food from their own country which are beneficial to maintaining a healthy brain (Forteza and Kung 2011).

This model was funded by the Department of Health and Ageing.

- The Home Care Service of NSW manages the Multicultural Respite Network in South West Sydney. The Network’s bilingual workers link with existing CALD community organisations to identify communities needing support and their key players, resources and capacities. Together they plan the provision of support which complements what the community can offer and which celebrates and reinforces the community’s culture. Support includes centre based and in-home respite, transport, carer support and advocacy. (Further details are in ADHC 2010b:24)

#### ***Cultural specific models***

- Structured group telephone counselling has been used by Co-As-It within the Italian community.
- CALD specific services, such as, ethno specific day care, CALD specific groups for social support.
- Multicultural carer support.

#### ***Models for small client numbers***

- Bilingual staff. This may be through direct employment, via a brokerage model to match bilingual workers from another organisation with a client or through accessing a ‘bilingual worker pool’.
- Training and mentoring for mainstream staff. Staff have specific training in working with people from CALD backgrounds so that mainstream providers become more culturally sensitive.

#### ***Respite and related support***

- Overnight respite cottages have found to be more accepted by CALD communities (Alt Beatty Consulting 2003) than more institutional forms such as residential respite.
- Other more creative approaches to respite, such as host family respite and mobile respite services, may be of particular interest (see Shanley2001).

## 4 Community Views

*This chapter covers consultations with carers of people with dementia and other members of CALD communities in the region. In all, 25 carers of people with dementia and community members were consulted through two forums (Erina and Hamilton) and written survey responses.*

### 4.1 Beliefs and knowledge

Many of the themes from the literature were confirmed from consultations, especially denial, stigma and the expectation that extended family will continue to support the person with dementia to remain living in the community.

Among the individuals consulted there is a wide range of understanding about dementia. Some have indicated that memory loss is a normal part of ageing and dementia is when memory loss increases. One person defined it as: “Imperfection of the memory due to old age or confusion of mental process which causes impaired memory, thinking and behaviour.”

Other people consulted indicated that dementia is a disease of the brain and it’s a disease for which there is no cure. Another person suggested that depression, isolation, diet and a sedentary lifestyle at old age contribute to the onset of dementia. A person who was born in Vietnam and had lived many years in New Caledonia indicated that the word ‘dementia’ was unfamiliar and it was not discussed in her culture.

Other comments by consumers about dementia included:

- Not all people with dementia are the same – service providers seem to act as though they are.
- People with dementia are often rejected as stupid. They should be respected and asked “Can I help you.” Don’t “lock them up”.
- It is particularly difficult when a couple both have dementia (an example was given of a couple who speak several languages).
- Using an interpreter is very important otherwise clinicians may think that all CALD people have dementia.

- People fear a diagnosis of dementia means they'll be put in a “frame” and no longer have their individual identity.

CALD service providers (ECC day centres and social support) mentioned that many of their clients view dementia as a mental illness. Some fear that it may be contagious. Myths surround dementia, such as, that it is caused by using aluminium saucepans.

Considerable stigma is attached to dementia and people try to conceal it. There is a concern that it inevitably leads to residential aged care.

Ethnic day care coordinators indicated that they notice much mixing of languages, especially among very old people (those aged 90 years and over). They suggested that about 20% of clients do not seem to revert to their first language.

## 4.2 *Service preferences*

### Consultations

Many of the people consulted in the project had positive views of their experience with services. For some this came after negative experiences – such as inflexibility in service provision – or refusal of service by the person with dementia.

People consulted did not seem aware of a broad range of services. They typically had made a strong link with a service provider and/or individual worker. Service knowledge appeared to be through direct experience.

Carers stated that services seem disconnected and it is very confusing when trying to get help. Some spoke of frustration in dealing with Centrelink and an apparent lack of connection between it and the care system.

A carer expressed concern that care workers did “not necessarily have adequate knowledge/training levels to cater to level of intense care needs to support” the person with dementia staying at home stay and their family care givers.

Some younger carers (for example, daughters) indicated they had been prepared to try services but the person with dementia was reluctant to do so. This situation creates a further need for carer support and for community based initiatives (such as the partnership models in Section 3.3) as a gentle introduction to a person using services.

Particular services and practices consumers indicated would be helpful include:

- Education – people at the Central Coast forum were keen to develop a better understanding of dementia and also be tested, say at a Memory Clinic.
- Carer support – to help with carer burden, including the loss of friends.

- Interpreters who assist their understanding and access by enabling them to communicate in their first language.
- Culturally appropriate food.
- Bilingual social support.
- Respite – as a critical threshold service to see whether sustaining the person living at home is feasible.
- Continence education.
- Understanding – care workers using a person centred approach and genuinely appreciating and supporting difference. “There are a lot of services out there without much understanding. They know but don’t understand. ‘One can learn a lot from a good book but not practice. It’s like learning swimming without water.’”
- Counselling – for both the person living with dementia and their carer.
- Appropriate residential care if it becomes necessary.

The Hunter New England Health Multicultural Liaison Worker shared her experience at a carers’ forum. She indicated that some cultures are reluctant to share their history. Support workers need to build trust and a relationship with individuals. Most families seek support too late – at a crisis point - when there is little alternative but residential placement. Often community care services have been offered but they have been declined. Early take-up of services could enable better transitions and delay admission to residential care.

Others have identified fear in seeking help early due to the perception that it means the person with dementia is not competent and may require residential care.

#### HACC service usage

During the project an attempt was made to identify usage of HACC services by people with dementia and their carers with a CALD background from the program’s Minimum Data Set (MDS). As dementia is not coded in the MDS a proxy indicator combining memory problems and requiring assistance with medication was used.<sup>1</sup>

A data request was made to ADHC (Figure 4.1).

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<sup>1</sup> The result of a helpful discussion with research analyst, Andrew Clark.

#### **Figure 4.1 Request for HACC MDS Data**

For each LGA and LPA:

1. Total number of HACC clients born outside major English speaking countries (ie not Australia, UK, New Zealand, Canada, USA, etc – see below\*) by gender.
2. A sub-group of 1: total number of HACC clients born outside major English speaking countries by gender with memory problems (yes), by require assistance with medication (yes, with help and yes, always).
3. Service usage: HACC clients born outside major English speaking countries by gender with memory problems (yes), by require assistance with medication (yes, with help and yes, always) by service type(s) used.
4. Total number of HACC clients by gender.

\* The MDS country codes to exclude are: 1101, 1102, 1199, 1201, 2102, 2103, 2104, 2105, 2106, 2201, 8102, 8104, 9999.

This data was not able to be retrieved within the timeframe of the project. The following information about HACC service usage was extracted from the HACC MDS collection for 2009/10 and made available to the project following submission of the draft report. That is, it was not available for consideration during consultations.

The data provided covers point 1 of the data request in a slightly different format. The other points of the request remain important to aid understanding of current service usage by people with dementia and their careers from a CALD background across the whole HACC system.

#### ***Clients by CALD status and age profile***

In 2009/10, 41,469 people in the Hunter region were recorded as using a HACC service (Appendix G, Table G.1).

‘CALD Status’ of HACC service users is derived in MDS reporting “by mapping each client’s Country of Birth to a 4-point scale for English Proficiency. This scale was derived from research undertaken by the Department of Immigration and Multicultural Affairs” (Australian Government Department of Health and Ageing and NSW Department of Ageing, Disability and Home Care 2007: 124). On this measure, 3,534 service users (8.5% of total users) were recorded as having CALD status.

HACC services in the Newcastle LGA recorded the highest proportion of CALD users at 11.9%. Somewhat unexpectedly, the next highest LGAs were Gosford and Wyong, both with 10.4% of HACC users recorded as having CALD status.

Appendix G also provides the age profile of HACC users recorded by the MDS in 2009/10 (Table G.2). The dominant age cohort is people aged 80 to 84 years old, comprising 8,972 individuals.

***Dementia specific service usage***

1,648 or 6.2% of users of dementia specific HACC funded services in 2009/10 were recorded as having CALD status (see Appendix H, Table H.1). This figure should not be interpreted as a precise count of people from CALD backgrounds with a diagnosis of dementia participating in HACC funded programs. These figures are conservative as:

- they do not include clients of providers funded as multi-service outlets (for example, the ECC);
- they do not include people with dementia who are supported by mainstream HACC services.

The dementia specific service types with the highest proportion of CALD service users recorded were multi-service outlets, not funded as such, (9.6%), case management (9.4%) and dementia monitoring services (8.6%).

***Recommendation 1:*** A clearer picture of how people with dementia and their carers with CALD backgrounds are currently using services in the region be developed by:

- pursuing the request for data on service usage from the HACC MDS (Figure 4.1) - this request could be deepened with the addition of the unique client identifier to gauge multiple service usage;
- investigating other data items or reports which can be drawn from the HACC MDS and from Health databases;
- considering other ways of measuring the situation, such as a snapshot survey where providers count the number of people of CALD backgrounds with a dementia they are supporting;
- further analysis when any of the data above is available; and
- sharing this analysis across the sector.

These measures will increase shared understanding and provide a clearer evidence base for identifying service gaps and addressing needs.

## 5 The Service System

*This chapter presents issues which have been identified as barriers for people with dementia and their carers from a CALD background accessing services. This is followed by strengths or enablers within the service system which may help in addressing the barriers. A preliminary indication of gaps in dementia services across the region is included. Service models which are already supporting people with dementia and their carers from a CALD background in the region are identified, along with models and practice which could be extended to do so. Finally, the implications for service planning and development are considered.*

### 5.1 Barriers

Service providers and other stakeholders indicated barriers which may inhibit effective service delivery to people with dementia and their carers from a CALD background, including:

#### **Language**

- Low proficiency in English may hide the presence of dementia and make it hard to detect in clients.

#### **Population density**

- The small numbers of people of some CALD backgrounds in the Central Coast and Muswellbrook, Singleton, Dungog, Cessnock and Upper Hunter local government areas mean that there is not necessarily an identifiable “community” and consequently community programs for that culture do not exist. Individuals may be very isolated. They may lack cultural connections or family support (sometimes deliberately). Geographic isolation may be an added barrier.

#### **Information and education**

- Only a limited amount of local service information is translated into community languages.
- The system is complex and this must impact on CALD communities.
- There appears to be a lack of understanding and awareness of dementia in CALD communities, including among carers of people from CALD backgrounds. Interpretations of what dementia is vary across different cultural communities. Some cultures do not use the word dementia.

- People may be suspicious of government and not distinguish service providers from “government interference”. They may also be confused about their pension entitlements and fear that using services will affect them.
- The stigma and fear of dementia exists for all cultures but it may be stronger in some communities.
- Services that do exist for CALD support are not always well known.
- Failure by some health care providers to recognise that acknowledgement of a diagnosis of dementia is important across the continuum of care for a person and that early diagnosis is central.
- Some primary health care providers do not know how to access the interpreter service.

### *Service responses*

- There is a need for more or greater knowledge of existing bilingual workers across the region. In Singleton, Dungog, Cessnock and Muswellbrook, there is a challenge in providing bilingual and bicultural workers, if requested by the client. (At the time of writing, the Hunter and Central Coast MAPs workers are finalising a HACC Bilingual Workers Research Report which will provide information on the bilingual workers throughout the region.)
- There is a strong expectation that family members will manage caring for a person living with dementia. Services tend to come in late and they need to be responsive to the continuing aspiration for the family to manage. For many there is a fear of handing that responsibility over and that by doing so they have a sense of loss of the family member.
- An absence of person centred care will be a barrier, as it is for most clients. The delivery of service needs to have a cultural construct and reflect an individual’s day to day rituals and behaviour, including eating, other activities and being able to speak their own language.
- Some service providers require use of the direct debit system for payment for services. This may be particularly inhibiting for certain communities.
- Staff attend cultural awareness and /or cultural competency training but come across barriers when trying to apply it in service planning and delivery due to a lack of strategies which can be readily applied, a lack of corporate support and/or day-to-day pressures of continuing service delivery.

### *Assessment*

- Inappropriate assessment or late assessment may hinder effective service responses. The Rowland Universal Dementia Assessment Scale (RUDAS) “is a short cognitive screening instrument designed to minimise the effects

of cultural learning and language diversity on the assessment of baseline cognitive performance” (<http://www.rudas.com.au/>).

There was discussion at some consultations about the use of the RUDAS. It was suggested that RUDAS should be used for all assessments of cognitive function of people from a CALD background, regardless of their English proficiency. This was recommended on the basis that the cultural assumptions implicit in other tools mean they are less appropriate for most people of a CALD background. Another assessor indicated that there was no effective tool to pick up early diagnosis.

Recent research examining the use of cognitive assessment tools translated into languages relevant to major CALD groups in Australia, Canada, the UK and the USA concluded: “The RUDAS, is a tool developed in the Australian setting to be “culturally fair”, has no copyright limitations, and warrants further investigation.” (Vrantsidis et al 2011)

In practical terms, the research implies that there is no reason not to use the RUDAS for assessment.

## **5.2 Enablers**

Strengths within the service system and community which can help in addressing these barriers include:

### ***Access***

- MAPs workers and CALD specific services, such as NSS and ECC, can be ‘cultural brokers’ for mainstream providers. They can connect organisations to cultural communities.
- A provider noted that people from CALD backgrounds may appreciate building their own support networks. The elders of the community often are the people encouraging their own to access services.
- The interpreter service.
- The Central Coast DAS reports more presentations of people with CALD backgrounds at Memory Clinics.
- Mainstream services appear willing to think about reaching out to communities rather than the communities having to find them.

### ***Service responses***

- Food services are able to provide culturally appropriate meals.
- Some services can provide cultural and language matching of clients and care workers or volunteers.

- Partnership models work well in other situations and may be a good approach for CALD support.
- Some agencies have significant experience in engaging CALD communities and have developed resources for them, particularly NSS and ECC.
- Providers are aiming to provide more person centred approaches in their care and support. A recurring comment in consultations was that being aware of a person's cultural preferences and being able to respond to them in a competent fashion is part of delivering person centred care. The importance of learning an individual's social history and building this into the assessment process with clients was also noted.

### **5.3 Gaps in dementia services**

As a step in understanding constraints people with dementia and their carers from a CALD background may have in accessing services, a preliminary gap analysis was made of dementia services in the two LPAs. The NSW Dementia Services Framework (NSW Health 2011) was used to provide the benchmark of optimum service provision.

The initial analysis drew on material provided by DAS and by ADHC, including from forums prior to this project and from dementia service plans. Service gaps were discussed at the service providers' workshops and amended on the basis of comments, corrections and clarifications provided there. As a 'state of play', the results remain preliminary, but may be useful in more in-depth dementia services planning processes taking place across the region. The consultants were able to contribute to the first meetings of these processes. The preliminary service gaps are indicated in Appendix I.

Aspects of this analysis which are particularly relevant to the expressed needs of people with dementia and their carers from a CALD background as heard through this project include:

- the need for more community awareness and understanding of dementia, including information about dementia, the different types of dementia and their symptoms, expectations about the progression of the disease, strategies for living at home with dementia and the support options available;
- flexible service provision which can respond to an individual's preferences.

## 5.4 Service Models & Practice

### Current models and resources

There are several service providers who have received HACC or other funding specifically to support people of CALD backgrounds, including those with dementia:

- Ethnic Communities Council and Newcastle COPS operate multicultural centre based day care in Newcastle and Lake Macquarie LGAs respectively;
- Coastlink (Central Coast) and Uniting Care (Hunter) have respite programs with priority of access for people with dementia and targets for supporting CALD clients;
- Northern Settlement Services has a multicultural social support service (Central Coast), a multicultural respite service covering Newcastle, Lake Macquarie, Maitland, Port Stephens, Cessnock and Upper Hunter LGAs and a CACP service covering the Hunter LPA.

The NSS respite service is a new model. It promotes attendance at day care by people experiencing difficulty in accessing a service. A bilingual worker assists with the support of an individual client in a mainstream or multicultural service. NSS brokers workers from other service providers. Support is provided in a culturally appropriate way in consultation between the user, the service and the carer. Information on dementia issues is provided to carers during a monthly meeting.

Details of these services are provided in Appendix J.

### Potential models and practice

Other models and practice are considered here under the relevant headings of the NSW Dementia Services Framework.

#### ***Dementia Awareness***

Consultations with local carers from CALD backgrounds and other community members demonstrated a clear need for and interest in information about dementia. Many identified a need for communities to improve their understanding of dementia and consequently help to change negative attitudes and responses to people living with dementia.

***Recommendation 2:*** Working together at the LPA or LGA level, MAPs, DAS and HACC DOs, develop local strategies to engage with CALD communities and individuals with the aim of:

- . increasing their awareness and understanding of dementia;
- . assisting service providers to become more aware of their local population; and
- . contributing to service providers' efforts to offer services responsive to client differences.

The resources, knowledge and expertise of Alzheimer's Australia NSW should be drawn on in this process.

Establishment of a CALD Dementia Working Party within the region may be a constructive way of implementing this recommendation.

[This recommendation relates to Action 1.2.1 of the NSW Dementia Services Framework.]

There are different ways this recommendation could be progressed. Strategies may initially target CALD communities in the region with higher numbers of people aged 65 and over (see Appendix E).

Section 3.2 outlined the partnership model ‘Tastes to Remember’. It may be particularly appropriate and efficient in bringing together people in a structured environment and building on a common interest in food – an issue which was mentioned repeatedly in consultations.

Another approach is the dementia café model which is already operating in the Hunter by Alzheimer’s, but not on the Central Coast. Dementia cafés have several key elements:

- bring together people in the early stages of dementia to reduce social isolation;
- offer education and support, informal advice and consultation by professionals and peers in a relaxed atmosphere (typically a conventional café);
- provide people living with dementia and their carers with some insight into their condition;
- give potential service users practical information to reduce their reluctance to seek professional support.

Details of established dementia cafés elsewhere in NSW are in the Better Practice Project handbook for community care (Ageing, Disability and Home Care 2010b). A partnership with one or more of the community groups from the larger populations in the region could test the model. For example, a partnership with the Italian, Dutch, German, Polish or Macedonian communities, all of which have considerable numbers of people over 65 in particular LGAs within the region (see Appendix E).

**Recommendation 3:** Strategies to engage with people with dementia and their carers from CALD backgrounds include partnerships with cultural community groups and the Ethnic Communities Council (ECC) to test service models which have been successful in other situations. These models include ‘Tastes to Remember’ and dementia cafés.

### ***Assessment, Diagnosis and Ongoing Management***

Having assessment and diagnosis of dementia happen “at the right time” is challenging for all people living with dementia and their carers and families. The stigma and fear of dementia, combined with many families of CALD backgrounds wanting to hide the diagnosis, gives added weight to the need to increase

understanding of and education about the impact of dementia and what can be done (Recommendation 2).

Consistent with a person centred approach, people have a preference for face to face assessments rather than telephone assessments and for the assessment to occur in the individual's preferred language.

**Recommendation 4:** Service providers, ADHC and Local Health Districts ensure that community care providers are able to provide or access a culturally competent assessment process. This will include:

- sensitivity to people's fear of receiving a diagnosis of dementia
- ensuring assessment tools without cultural bias are used
- staff being trained and competent in accessing and using the interpreting service
- interpreters being 'dementia aware' and having the skills to participate effectively in the process.

Relevant information, such as accessing the interpreter service, could be loaded on HSNet.

#### ***Information, Counselling and Carer Information***

Carers and other community members expressed interest in strengthening the support available to carers of CALD background. Carer support groups may be preferred to carer counselling, although one or two mentioned the need for counselling, especially around grief and loss.

It was suggested that information dissemination could be improved if information provided in community languages has the English version alongside it. This will help understanding by younger family members and aid the translation of sometimes difficult and unfamiliar concepts.

This project looked at a broad preliminary gap analysis of services for people with dementia in the Hunter and Central Coast. From the consultations with carers and community members some specific areas warranting further investigation were identified.

**Recommendation 5:** ADHC and the Local Health Districts are facilitating dementia services planning across the region. Through this process the demand for the following services, and the funding they would require, should be considered:

- support group(s) for emerging carers groups, such as Filipino carers
- expanding the capacity of the Living with Memory Loss program to extend its coverage to CALD communities within the region, in partnership with interpreters
- extending carer education sessions to 'hidden carers' (those not accessing services) through partnerships, including with community groups identified in Appendix K.

[This recommendation relates to Action 3.5.1, 3.6.1 and 3.6.2 of the NSW Dementia Services Framework.]

### ***Community Support***

Newcastle and Lake Macquarie appear to be the only two of the 11 LGAs which have the concentration of CALD communities to support ethnic specific or stand-alone multicultural services.

Given the small numbers of CALD population groups in the other nine LGAs and the presence of small numbers of many other CALD groups in Newcastle and Lake Macquarie, service models and practice of particular interest are those which can be adopted by mainstream service providers, including in partnership with multicultural agencies.

All the service models outlined in section 3.3 appear relevant to the Hunter and Central Coast as they do not rely on significant numbers of clients and could be replicated.

In addition, the MAPs workers have been identifying the location of bilingual workers and volunteers across the region with the view to producing and maintaining a register which could be accessed by all providers. This is an important initiative, consistent with maximising the use of existing resources.

Further suggestions for making services more person centred and responsive to people with dementia and their carers from a CALD background emerged during the consultations:

- **Top 5** – is for people who have difficulties with reasoning, memory or communication. It is a process of carers identifying the five most important things they think a service provider (community, hospital or residential care) needs to know to effectively deliver support. These issues form the ‘Top 5 Strategies to Support Care and Communication’. There are forms and tags provided so that all services supporting a person can refer to the Top 5. This initiative is promoted and practiced by Northern Sydney Central Coast Area Health. (The Coastlink service described in Appendix J uses Top 5.)
- Extending the **Community Visitor Scheme model** which operates in residential aged care to community care for CALD clients with the involvement of bilingual or bicultural workers and volunteers.

This could be achieved through an extension of neighbour aid’s home visiting component. The emphasis needs to be on matching the person with dementia and a volunteer with common interests, preferred language and gender. The need for such a scheme was mentioned by a carer: “Would have been helpful to have someone visit my husband and talk with him about things he was interested in, that is, cars, as he was a motor mechanic”.

- **Multicultural days** at mainstream day centres where clients of CALD background attend with non-CALD clients but the focus is on diverse cultures through food and activities.

- Using existing **cultural events** as an opportunity to raise awareness of dementia and promotion of services.
- Testing the **Safely Home program** with local communities. The program is a joint Alzheimer's Australia and NSW Police Force initiative. It provides rapid and accurate identification and the safe return home of a person who has wandered.

When a person at risk of wandering is registered with Safely Home, they receive a stainless steel bracelet to wear at all times. This bracelet features a toll free telephone number and a personal identification number that is linked to the NSW Police Force Safely Home Database. This database is accessible to police 24 hours a day, 7 days per week and includes a detailed description of the person, contact information, previous residential addresses and likely locations that they may visit. All information on the database is confidential.

When someone finds a lost person registered with the Safely Home Program, they simply call the toll free number and quote the personal identification number on the bracelet. The police then make arrangements to ensure the lost person is returned home safely. Carers can also use Safely Home to instigate the search for a lost person by contacting their local police station and filing a Missing Persons Report. Police then use the Safely Home database to initiate their enquiries.

([http://www.police.nsw.gov.au/community\\_issues/missing\\_persons/safely\\_home](http://www.police.nsw.gov.au/community_issues/missing_persons/safely_home))

- **Flexible food service** models, including using community restaurants as a way of connecting people and enabling them to eat the food they like.

In addition, developments in **enabling technologies** for our ageing society may soon reveal new models of support for all the community, including possibilities of technology aiding better support of people from CALD backgrounds. This is a case of “watch this space”. The National Enabling Technologies Strategy is considering the role of enabling assistive technologies, including new bio- and nano-technologies, to help older Australians live independently in their own homes and neighbourhoods ( [www.innovation.gov.au/nets](http://www.innovation.gov.au/nets)).

## 5.5 *Implications for service planning and development*

There are several key elements to strengthening the support of people with dementia and their carers from a CALD background in the Hunter and Central Coast:

- cultural awareness and competence across the service system;
- collaboration across service providers and other stakeholders;
- effective utilisation of existing specialists and other resources; and
- commitment to person centred care.

Given the demographics of the region, the strategies under each of these elements will differ. Strategies could be considered at three geographic levels:

Area A

- Newcastle LGA and Lake Macquarie LGA – well identified cultural communities exist, along with established multicultural and ethno-specific service provision.

Area B

- Central Coast LPA – lower numbers of people with CALD backgrounds, across a large geographic area.

Area C

- Cessnock, Dungog, Maitland, Muswellbrook, Port Stephens, Singleton and Upper Hunter LGAs – very low numbers of people of CALD backgrounds across very large areas.

***Cultural awareness and competence***

In Areas B and C, CALD clients currently constitute a small percentage of the client population for individual service providers. However, they are a special needs group in aged care funding.

Providers can think about cultural awareness and competency at the organisational level. All community care providers are expected to be responsive to the diverse social, cultural and physical experiences and needs of clients and potential clients. Providers can review their cultural competency by using an organisational cultural assessment tool such as that included at Appendix L.

Two specific areas for strengthening cultural capability are:

1. Having the **workforce with the appropriate skills** set. Two modules of training are relevant:
  - Cultural awareness and culturally competent service delivery; and
  - The use of interpreters, both by telephone and face to face.

The depth of training required may be greater for providers in Newcastle and Lake Macquarie than for those in other parts of the region.

Where there is high turnover in the care workforce, training and related programs and resources need to be run continuously as waves of people move through the sector.

Appropriate training for volunteers is also important.

Using recruitment processes, such as bilingual or multilingual skills being recognised as desirable criteria, is another strategy.

2. **Service planning and development** - Expected Outcome 1.4 of the Community Care Common Standards covers this area:

*“Community Understanding and Engagement* The service provider understands and engages with the community in which it operates and reflects this in service planning and development.”

Given large numbers of service providers and the small size of CALD populations in Areas B and C, a collaborative approach involving providers, MAPs workers, DAS and community groups may be an effective way of addressing this outcome. The expertise held by the multicultural workers and organisations needs to influence service practice in an ongoing fashion.

Engagement is also an important mechanism for identifying emerging needs. For example, the Philippines is one of the top five non-English speaking birthplaces for eight of the nine LGAs in the region. However, people from the Philippines have a younger age profile and do not yet appear to be presenting for aged and community care. Community workers have identified Filipino carers as an emerging group.

**Recommendation 6:** The cultural competency of the community care sector in the region be strengthened through the provision of training in three areas:

- cultural awareness and competency for service managers and staff
- the use of interpreters for service managers and staff
- cultural awareness for volunteers.

Service providers should use the Organisational Assessment Tool (Appendix L) as part of their annual service planning and review.

### **Collaboration**

Most of the service models which deliver support to people with dementia and their carers from a CALD background involve collaboration. It may be between several service providers; across service providers and community organisations; or between service providers, local government and specialist agencies.

For Areas B and C, collaboration could involve support of specialist resources at each level of the client pathway. For example, some services may be identified as having assessor(s) skilled in culturally appropriate assessment, others in forming partnerships with community organisations. A key aspect of this strategy is to avoid individual service providers ‘re-inventing the wheel’ for one or two CALD clients and their carers.

All community care providers are responsible for ensuring that service users participate in an assessment which considers their cultural and linguistic diversity (Community Care Common Standards, Expected Outcome 2.2). Part of this responsibility may be sub-contracted or brokered to another provider with the particular expertise.

Collaboration between agencies is also important at the individual client level. Continuity of care, including the quality and transfer of information between community care, health and residential systems is important “to ensure good work is not lost”. This is the case for all clients, and particularly for clients of a CALD background who may have been loathe to use services and are especially hesitant at transition points.

### ***Use of existing specialists and other resources***

Providers in the region have three sets of HACC funded services they can draw on to strengthen their support of people with dementia and their carers from a CALD background: Multicultural Access Projects (MAPs), Dementia Advisory Services (DAS) and HACC Development Officers (DOs).

**MAPs** workers can help with information, advice and support in accessing CALD communities and with developing culturally competent practices. **DAS** may assist with promoting public dementia awareness, providing information, conducting training and defining interagency protocols. **HACC DOs**, through their broad mandate of strengthening the capacity of HACC services to deliver quality services which respond to client needs, including special needs groups, are a source of information on good practice, initiatives and research.

The **Ethnic Communities Council** is another channel of communication with communities and an experienced provider of support. The ECC also has a resource centre – the Diversity Learning Centre – which “offers a range of multilingual, multicultural, and interfaith resources to promote inclusive practices, social justice & cultural harmony”

([http://members.optusnet.com.au/eccnhr/index\\_files/Page1051.htm](http://members.optusnet.com.au/eccnhr/index_files/Page1051.htm))

**Alzheimer’s Australia NSW**, in addition to providing services (such as the National Dementia Helpline 1800 100 500, a counselling service, carer education, professional education, a Living with Memory Loss Program and a risk reduction education program called Mind your Mind), has an extensive range of resources on dementia, particularly from the perspective of people living with dementia and their carers. Alzheimer’s operates a Chinese Helpline for speakers of Mandarin and Cantonese. It also provides help sheets in 23 different languages.

***Recommendation 7:*** The need for collaboration across community care, health services and specialist multicultural agencies to deliver effective support to people with dementia and their carers from CALD backgrounds be reinforced through:

- dementia services planning and development
- service funding specifications
- using existing specialist and other resources available in the region.

### ***Commitment to person centred care***

Recognising a person’s cultural preferences is an integral part of providing person centred care for people with dementia and their carers with a CALD background.

A person centred approach aims to maximise clients' and carers' capacity and confidence. Other elements of person centred care include:

- actively engaging, and collaborating with, clients and carers in goal-setting, care planning and service delivery;
- identifying and maximising clients' opportunities to do things for themselves;
- working with people's preferences and strengths, including by ensuring that clients' and carers' cultures and language preferences are supported;
- offering clients and carers choice and control;
- agreeing on clear timeframes for entry, exit and review processes;
- providing responsive and flexible services tailored to each client's needs and strengths; and
- using interagency care planning.

Examples of NSW HACC services implementing more person centred approaches are included in the *Handbook for community care services, Empowering people, enhancing independence, enriching lives* (ADHC 2010b). Practice ideas include seven from the region.

Of particular relevance to supporting people with dementia and their carers with CALD backgrounds are Hills CALD Social Day Programs (Practice Idea 7), the Multicultural Respite Network (Practice Idea 10), Fairfield Aged Day Care Fitness and Falls Program (Practice Idea 27), Illawarra Indochinese Day Care (Practice Idea 30) and Middle Eastern and Turkish Day Care, Wollongong (Practice Idea 5). All but two of these services are run by mainstream community care providers.

Culturally responsive service delivery invariably involves greater flexibility than 'standard' provision. Flexibility may mean:

- cultural and language matching between clients, carers and support workers and volunteers;
- sourcing food from a different supplier to meet cultural needs and preferences;
- being receptive to different roles for carers and other family members, including sharing care across many carers within a family;
- building connections with cultural groups to help support the client;
- using formal support services (eg HACC services) to connect the client and or carer into a local cultural or language community; and
- exploring options for activities that support a person's culture and language.

Flexibility for a particular service type has two dimensions: how the service operates internally within the constraints of its own funding, and how well the service is networked with other services to facilitate the best system possible for the local area (Shanley 2006). That is, cultural awareness and competence and collaboration across the system will be important to providing flexible, culturally responsive person centred care.

Training in awareness of enabling and person centred approaches in community care is being delivered across the sector in 2011/2012. ADHC has contracted the

Aged and Community Services Association (ACSA) NSW to manage this training program.

***Recommendation 8:*** Recognising that person centred and enabling care is at the centre of effective support for all individuals, service providers take up opportunities for training in person centred and enabling approaches.

## Appendix A Stakeholders Workshop

The project began with a workshop at Bonnell's Bay on 16<sup>th</sup> June 2011 involving the following participants.

NAME	ORGANISATION
Eileen Hetherington	Dementia Advisory Service Central Coast Local Health District
Katrina Bennett	Ageing, Disability & Home Care, Department of Family and Community Services NSW
Keiko Clements	Central Coast Disability Network
Marilyn Cassin	Community Care Services- Central Coast Ltd
Melina Psychas	Hunter New England Local Health District
Peter McCloskey	Community Care Services- Central Coast Ltd
Sally O'Loughlin	Alzheimer's Australia NSW
Sue Hristov	Northern Settlement Services Ltd
Valerie Woodman	Northern Settlement Services Ltd
Mary Myers	Newcastle/Lake Macquarie Dementia Advisory Service
Lynne Warner	Integrated Living Dementia Advisory Service
Tracey Kemmet	Integrated Living Dementia Advisory Service
Helga Merl	Hunter New England LHD
Carrie Hayter	Alt Beatty Consulting
Merilyn Alt	Alt Beatty Consulting

## Appendix B Project Advisory Group

NAME	ORGANISATION
Janine Slimmon	Wesley Mission
Jodi Livesley	Gosford City Council
June Morris	Newcastle/Lake Macquarie Dementia Advisory Service HNEHS
Katrina Bennett	Ageing, Disability & Home Care, Department of Family and Community Services NSW
Keiko Clements	Central Coast Disability Network
Mary Meyers	Newcastle/Lake Macquarie Dementia Advisory Service
Valerie Woodman	Northern Settlement Services Ltd
Milan Kurjakovic	ECC Newcastle and Hunter Region
Sally O'Loughlin	Alzheimer's Australia NSW
Sheree Conway	Integrated Living

## Appendix C Service Providers Workshops

19<sup>th</sup> July, Tumbi Umbi

NAME	ORGANISATION
Liz Morgan	UnitingCare Ageing Hunter, Central Coast and New England
Denise Knight	UnitingCare Ageing Hunter, Central Coast and New England
Sian Keane	Central Coast Local Health District
Alexandra Perkins	BCS Care Centre-Central Coast
Liz Payne	BCS Care Centre-Central Coast
Lorraine Williams	Sue Mann's Nursing
Trish Watts	Sue Mann's Nursing
Christine Curley	PCC Ageing & Disability
Sharon Dalla-Vecchia	Central Coast Meals on Wheels
Kellie Matterson	Multicultural Social Support Services, NSS Central Coast
Edna Wacher	Central Coast Local Health Network
Anne Kirchler	UnitingCare Ageing Hunter, Central Coast and New England
Lisa Sexton	Central Coast Meals on Wheels
Wade Penn	Dementia Care Service Division of Rehabilitation and Aged Care Central Coast Local Health Network
Eileen Hetherington	Dementia Advisory Service Central Coast Local Health District
Marilyn Cassin	Community Care Services - Central Coast Ltd
Peter McClosky	Community Care Services- Central Coast Ltd
Helen Roberts	Wyang Community Transport
Anne SAMMUT	Ageing & Disability Services, Central Coast Centacare Broken Bay
Selina Peters	Student, Cert IV Community Services
Keiko Clements	Central Coast Disability Network
Valerie Woodman	Northern Settlement Services
Merilyn Alt	Alt Beatty Consulting
Carrie Hayter	Alt Beatty Consulting

27<sup>th</sup> July, Cardiff

<b>NAME</b>	<b>ORGANISATION</b>
Annika Wirt	HNE Health HACC dietician
Deb Williams	Wesley Mission CBDC
Ana Santos	Wesley Mission CBDC
Julie Horner	Integrated Living
Sonia Lee	Integrated Living
Peta McGrath	Lake Macquarie Support Services
Kelly Naylor	Red Cross Australia
Denise McCallum	Lake Macquarie Home Care
Tracy Murtagh	Lake Macquarie Home Care
Janet Weaver	Lake Macquarie Home Care
Tima Oto	Northern Settlement Services
James Magin	Uniting Care Hunter
Miriam Low	Alzheimer's Australia – Hunter
Keiko Clements	Central Coast Disability Network
Val Woodman	Northern Settlement Services
Merilyn Alt	Alt Beatty Consulting
Carrie Hayter	Alt Beatty Consulting

28<sup>th</sup> July, Tenambit

NAME	ORGANISATION
Tracey Goodwin	Novacare Inc
Sharon Burns	Novacare Inc
Marg Sierek	Novacare Inc
Coral Spurway	Novacare Inc
Rosemary Maloney	Novacare Inc
Mim Stephens	Ourcare Services Inc
Patricia Stewart	Hunter Case Management
Wal Young	Novacare Inc
James O’Leary	Port Stephens HMM
Tracey Longworth	Port Stephens Community Options
Lyn Harvey	Integratedliving Australia Ltd
Loralee Lukes	Integratedliving Australia Ltd
Marlene Auld	Integratedliving Australia Ltd
Gayle Grayson	Ethnic Neighbour Aid
Mary Moore	Ethnic Neighbour Aid
Kaylene Bootland	Gardenia Grove HNE Health
Sue-Ellen Williams	Gardenia Grove HNE Health
Toni Olson	Gardenia Grove HNE Health
Karyn Porigneaux	Hunter Valley HACC DO
Sheree Conway	Hunter Valley HACC DO
Sally O’Loughlin	Alzheimer’s Australia
Meredith Powell	Newcastle/Lake Macquarie Dementia Advisory
Sue Hristov	Northern Settlement Services
Anne Alexander	ADHC
Carrie Hayter	Alt Beatty Consulting

## Appendix D Consumers & Other Stakeholders

**Table D.1 Consumer Consultations**

Respondents	Response Format
9 people	Central Coast focus group, 26 <sup>th</sup> July 2011
4 people	Hunter focus group, 10 <sup>th</sup> August 2011
15 responses	By paper survey (see Table D.2)

**Table D.2 Respondents to Community Survey**

Role:	Carer	Community Member		Total Respondents
	9	6		15
Gender:	Female	Male		
	11	4		15
Age:	Under 65	65 - 69	70 - 79	
	10	2	3	15
Speak a Language other than English at Home?	Yes	No		
	13	2		15
Languages Spoken:	Finnish, Lebanese, French (2), Greek, Malaysian, German (2), Italian (3), Macedonian, Tagalog, Japanese, Hungarian.			
Living in:	Gosford	Wyong	Newcastle	
	5	3	7	15

**Table D.3 Other Stakeholder Consultations**

Stakeholder Group	Location
ECC Day Care Coordinators and Cooks	Waratah, 25 <sup>th</sup> July 2011
Dementia Planning Workshops	Hunter (Maitland), 19 <sup>th</sup> July 2011 Central Coast (The Entrance), 26 <sup>th</sup> July 2011
Central Coast ACAT	By telephone, 26 <sup>th</sup> August 2011

## Appendix E Demographics

Table E.1 Cultural and Linguistic Diversity, Central Coast

<b>GOSFORD LGA</b>				<b>GOSFORD LGA</b>	
<b>Overseas Born: Top 10 NESB Birthplaces, 2006 Census</b>				<b>Languages Other than English Spoken at Home: Top 10</b>	
	Total Persons	People 65 plus			Total Persons
		%	No.		
Germany	638	37.9	242	Italian	553
Netherlands	630	47.5	299	Spanish	524
Philippines	542	5.9	32	German	502
Italy	383	48.6	186	Greek	400
China	372			Cantonese	371
India	325			Dutch	294
Malta	207			French	265
Greece	203			Mandarin	230
Malaysia	185			Arabic	222
Korea	174			Tagalog	184
<b>WYONG LGA</b>				<b>WYONG LGA</b>	
<b>Overseas Born: Top 10 NESB Birthplaces, 2006 Census</b>				<b>Languages Other than English Spoken at Home: Top 10</b>	
	Total Persons	People 65 plus			Total Persons
		%	No.		
Netherlands	506	47.2	239	Italian	523
Germany	471	43.3	204	Spanish	377
Philippines	451	4.2	19	Greek	285
Italy	427	49.9	213	Cantonese	281
Malta	398	40.2	160	German	277
China	234			Maltese	258
India	211			Dutch	207
Greece	142			Arabic	197
Egypt	137			Mandarin	164
Croatia	113			Tagalog	127
<b>CENTRAL COAST</b>					
<b>Languages Other than English Spoken at Home: Top 10</b>					
	Persons				
Italian	1076				
Spanish	901				
German	779				
Greek	685				
Cantonese	652				
Dutch	501				
Arabic	419				
Mandarin	394				
Tagalog	311				
French	392				

Table E.2 Cultural and Linguistic Diversity, Hunter

**HUNTER**

**Languages Other than English Spoken at Home: Top 10**

	Persons
Italian	1992
Macedonian	1822
Greek	1440
German	1250
Polish	986
Mandarin	809
Cantonese	688
Spanish	658
Arabic	467
Dutch	422

**NEWCASTLE LGA**

**Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Italy	822	66.9	550
FYROM	740	30.9	229
Germany	604	27.6	167
China	555	8.8	49
Philippines	470	6.6	31
Greece	461	51.8	239
Poland	439	63.6	279
India	354		
Malaysia	339		
Sudan	259		

**LAKE MACQUARIE LGA**

**Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	986	34	335
Netherlands	603	44.1	266
Italy	454	49.8	226
Philippines	387	4.9	19
Poland	297	58.9	175
FYROM	291		
China	241		
India	227		
Malaysia	216		
Austria	188		

**NEWCASTLE LGA**

**Languages Other than English Spoken at Home: Top 10**

	Total Persons
Macedonian	1303
Italian	1035
Greek	930
Mandarin	591
Polish	467
Cantonese	457
Arabic	355
German	313
Spanish	267
Croatian	266

**LAKE MACQUARIE LGA**

**Languages Other than English Spoken at Home: Top 10**

	Total Persons
Italian	600
Macedonian	519
German	514
Greek	345
Cantonese	333
Polish	304
Dutch	246
Spanish	244
Samoan	216
Mandarin	174

**CESSNOCK LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	196	27	53
Philippines	86	7	6
Netherlands	80	28.8	23
China	47	12.8	6
Italy	37	35.1	13
Austria	34		
India	33		
Malta	30		
Poland	29		
Malaysia	26		

**CESSNOCK LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
German	78
Cantonese	62
Italian	50
Mandarin	34
Dutch	33
Polish	32
Greek	29
Spanish	27
Filipino	25
Tagalog	24

**DUNOGG LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	25	12	3
Austria	13	30.8	4
Netherlands	12	33.3	4

**DUNOGG LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
German	24
French	13
Italian	10

**UPPER HUNTER LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	36	25	9
Netherlands	32	43.8	14
Philippines	27	11.1	3
Korea	19	0	0
Italy	15	46.7	7
India	12		
Malta	12		

**UPPER HUNTER LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
Korean	19
Italian	18
Cantonese	18
Arabic	11

**MAITLAND LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	288	25.7	74
Philippines	177	5.6	10
Netherlands	154	37	57
Poland	116	66.4	77
India	93	12.9	12
China	91		
Malaysia	54		
Italy	51		
Austria	46		
Thailand	41		

**MAITLAND LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
Cantonese	155
Polish	132
German	124
Italian	86
Arabic	76
Tagalog	72
Greek	49
Spanish	48
Dutch	47
French	36

**PORT STEPHENS LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Germany	312	32.1	100
Netherlands	244	40.2	98
Philippines	146	4.1	6
Malaysia	127	2.4	3
Italy	116	52.6	61
Croatia	91		
Malta	78		
Poland	58		
Austria	56		
India	50		

**PORT STEPHENS LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
Italian	160
German	156
Croatian	101
Greek	87
French	86
Dutch	75
Spanish	72
Cantonese	57
Polish	51
Tagalog	51

**MUSWELLBROOK LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Netherlands	29	31	9
Philippines	23	13	3
Thailand	21	0	0
Germany	18	16.7	3
China	17	0	0
Austria	14		
Ukraine	14		
Lebanon	12		

**MUSWELLBROOK LGA****Languages Other than English Spoken at Home: Top 10**

	Total Persons
Cantonese	29
Thai	17
Italian	16
German	13
Mandarin	10

**SINGLETON LGA****Overseas Born: Top 10 NESB Birthplaces, 2006 Census**

	Total Persons	People 65 plus	
		%	No.
Philippines	61	0	0
Netherlands	55	36.4	20
Germany	55	16.4	9
China	25	24	6
Iraq	22		
Malta	20		
Hong Kong	16		
Malaysia	16		
Egypt	15		
France	12		

**Languages Other than English Spoken at Home: Top 10**

	Total Persons
German	41
Cantonese	34
Afrikaans	34
Arabic	25
Dutch	21
Indonesian	18
Italian	17
Filipino	17
Maltese	17
Tagalog	16

Source: Data extracted and tables compiled from Department of Immigration and Citizenship 2008.

## Appendix F Dementia Statistics

Table F.1: Estimated Prevalence and Incidence of Dementia, Hunter (ADHC Region)

		2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2030	2040	2050	% change
		<b>Prevalence</b>															
<b>Hunter</b>	Males	4,970	5,198	5,437	5,664	5,896	6,130	6,378	6,644	6,923	7,195	7,486	7,779	11,668	16,653	21,336	329.3
	Females	7,895	8,198	8,491	8,796	9,114	9,404	9,724	10,055	10,406	10,754	11,099	11,477	16,550	23,693	30,089	281.1
	Persons	12,864	13,397	13,928	14,459	15,009	15,534	16,102	16,699	17,329	17,949	18,585	19,256	28,218	40,346	51,425	299.8
<b>NSW</b>	Males	32,977	34,646	36,326	38,011	39,694	41,383	43,160	45,023	46,998	48,943	50,929	53,016	79,213	112,079	143,850	336.2
	Females	51,172	53,316	55,418	57,491	59,514	61,574	63,827	66,124	68,485	70,781	73,131	75,682	108,918	155,359	197,565	286.1
	Persons	84,149	87,961	91,744	95,502	99,208	102,957	106,987	111,147	115,483	119,724	124,060	128,698	188,131	267,438	341,414	305.7
		<b>Incidence</b>															
<b>Hunter</b>	Males	1,398	1,511	1,587	1,657	1,727	1,798	1,884	1,977	2,075	2,156	2,252	2,354	3,735	5,678	7,643	446.9
	Females	2,264	2,421	2,508	2,601	2,696	2,790	2,908	3,018	3,136	3,236	3,349	3,487	5,189	7,647	9,910	337.7
	Persons	3,662	3,932	4,095	4,258	4,423	4,588	4,793	4,995	5,211	5,392	5,601	5,841	8,924	13,324	17,553	379.4
<b>NSW</b>	Males	9,146	9,940	10,472	11,005	11,528	12,060	12,677	13,332	14,041	14,636	15,298	16,036	25,412	38,202	51,372	461.7
	Females	14,658	15,729	16,358	16,992	17,587	18,249	19,076	19,829	20,613	21,276	22,041	22,973	34,154	50,121	64,974	343.3
	Persons	23,804	25,669	26,831	27,997	29,115	30,310	31,754	33,161	34,654	35,911	37,338	39,009	59,566	88,323	116,346	388.8

Source: Access Economics 2009a. ADHC's Hunter Region includes the Central Coast.

Table F.2 Dementia Prevalence, Gosford LGA

Males	2009	2011	2013	2015	2020
0-59	19	19	19	19	19
60-64	56	58	58	61	67
65-69	61	68	79	82	87
70-74	105	110	119	131	167
75-79	150	149	155	165	203
80-84	259	260	254	254	290
85-89	249	267	284	297	303
90-94	111	140	167	187	235
95+	32	43	52	66	112
<i>Total, Males</i>	<i>1,042</i>	<i>1,116</i>	<i>1,187</i>	<i>1,263</i>	<i>1,483</i>
Females					
0-59	15	15	15	15	15
60-64	31	32	32	33	36
65-69	53	57	67	71	74
70-74	118	124	130	142	183
75-79	205	201	209	219	263
80-84	400	396	378	364	405
85-89	480	502	515	526	506
90-94	289	334	387	429	471
95+	128	161	187	221	325
<i>Total, Females</i>	<i>1,719</i>	<i>1,824</i>	<i>1,920</i>	<i>2,020</i>	<i>2,278</i>
<i>Total, Persons</i>	<i>2,761</i>	<i>2,939</i>	<i>3,107</i>	<i>3,284</i>	<i>3,762</i>

Table F.3 Dementia Prevalence, Wyong LGA

Males	2009	2011	2013	2015	2020
0-59	17	17	18	19	21
60-64	47	51	53	57	66
65-69	59	63	74	79	90
70-74	100	109	115	124	163
75-79	142	142	149	162	198
80-84	223	237	242	243	293
85-89	202	219	241	263	286
90-94	90	115	141	166	221
95+	26	35	44	59	105
<i>Total, Males</i>	<i>906</i>	<i>989</i>	<i>1,077</i>	<i>1,172</i>	<i>1,443</i>
Females					
0-59	14	15	15	16	17
60-64	27	28	28	30	35
65-69	50	55	62	66	72
70-74	112	117	125	138	175
75-79	192	193	203	213	264
80-84	320	338	339	346	392
85-89	365	385	412	430	458
90-94	220	256	310	351	426
95+	98	123	149	180	295
<i>Total, Females</i>	<i>1,398</i>	<i>1,510</i>	<i>1,643</i>	<i>1,769</i>	<i>2,135</i>
<i>Total, Persons</i>	<i>2,304</i>	<i>2,499</i>	<i>2,719</i>	<i>2,941</i>	<i>3,578</i>

Table F.4 Dementia Prevalence, Newcastle LGA

Males	2009	2011	2013	2015	2020
0-59	19	19	19	19	20
60-64	46	49	50	54	60
65-69	49	55	64	68	76
70-74	82	87	94	104	135
75-79	114	111	117	125	156
80-84	197	194	189	184	212
85-89	193	211	221	232	233
90-94	86	110	130	146	180
95+	25	34	41	52	86
<i>Total, Males</i>	<i>810</i>	<i>870</i>	<i>924</i>	<i>983</i>	<i>1,157</i>
Females					
0-59	15	15	15	15	15
60-64	23	25	26	28	32
65-69	40	45	50	54	61
70-74	91	92	96	107	136
75-79	159	155	159	165	195
80-84	320	307	288	273	300
85-89	417	429	437	437	413
90-94	250	286	329	356	384
95+	111	137	159	183	265
<i>Total, Females</i>	<i>1,426</i>	<i>1,490</i>	<i>1,559</i>	<i>1,618</i>	<i>1,801</i>
<i>Total, Persons</i>	<i>2,236</i>	<i>2,360</i>	<i>2,483</i>	<i>2,601</i>	<i>2,958</i>

Table F.5 Dementia Prevalence, Lake Macquarie LGA

Males	2009	2011	2013	2015	2020
0-59	23	23	23	23	23
60-64	75	78	77	79	85
65-69	79	89	103	108	112
70-74	134	141	150	172	220
75-79	178	182	198	207	261
80-84	270	279	281	289	342
85-89	226	259	284	307	335
90-94	101	136	167	193	259
95+	29	41	52	69	123
<i>Total, Males</i>	<i>1,114</i>	<i>1,229</i>	<i>1,336</i>	<i>1,446</i>	<i>1,761</i>
Females					
0-59	18	18	18	18	18
60-64	37	40	41	42	45
65-69	65	72	82	87	95
70-74	139	150	158	175	221
75-79	226	227	246	266	325
80-84	384	393	389	387	467
85-89	440	472	495	514	530
90-94	264	314	373	419	493
95+	118	151	180	216	341
<i>Total, Females</i>	<i>1,692</i>	<i>1,837</i>	<i>1,982</i>	<i>2,125</i>	<i>2,535</i>
<i>Total, Persons</i>	<i>2,806</i>	<i>3,066</i>	<i>3,318</i>	<i>3,571</i>	<i>4,296</i>

Table F.6 Dementia Prevalence, Cessnock LGA

Males	2009	2011	2013	2015	2020
0-59	6	6	6	6	7
60-64	18	20	20	21	23
65-69	19	22	25	27	30
70-74	28	31	34	40	52
75-79	34	35	39	45	60
80-84	49	52	54	54	73
85-89	37	42	45	50	54
90-94	16	22	27	32	42
95+	5	7	8	11	20
<i>Total, Males</i>	<i>212</i>	<i>236</i>	<i>259</i>	<i>286</i>	<i>360</i>
Females					
0-59	5	5	5	5	5
60-64	9	10	10	10	11
65-69	14	17	19	21	24
70-74	27	29	33	39	53
75-79	48	48	51	53	76
80-84	77	76	77	80	90
85-89	94	96	97	98	101
90-94	57	64	73	80	94
95+	25	31	35	41	65
<i>Total, Females</i>	<i>355</i>	<i>376</i>	<i>401</i>	<i>427</i>	<i>518</i>
<i>Total, Persons</i>	<i>568</i>	<i>613</i>	<i>660</i>	<i>713</i>	<i>878</i>

Table F.7 Dementia Prevalence, Maitland LGA

Males	2009	2011	2013	2015	2020
0-59	9	9	9	10	10
60-64	21	24	25	27	31
65-69	21	25	29	33	39
70-74	31	35	40	47	67
75-79	41	42	45	50	73
80-84	61	66	68	72	90
85-89	54	61	71	77	90
90-94	24	32	42	48	69
95+	7	10	13	17	33
<i>Total, Males</i>	<i>268</i>	<i>304</i>	<i>342</i>	<i>381</i>	<i>502</i>
Females					
0-59	7	7	7	8	8
60-64	11	13	13	14	17
65-69	16	19	24	27	31
70-74	33	36	40	46	69
75-79	53	56	58	64	86
80-84	101	100	101	104	124
85-89	105	121	133	138	151
90-94	63	80	100	113	141
95+	28	39	48	58	97
<i>Total, Females</i>	<i>418</i>	<i>471</i>	<i>526</i>	<i>572</i>	<i>725</i>
<i>Total, Persons</i>	<i>686</i>	<i>774</i>	<i>868</i>	<i>953</i>	<i>1,227</i>

Table F.8 Dementia Prevalence, Port Stephens LGA

Males	2009	2011	2013	2015	2020
0-59	8	8	8	8	9
60-64	27	29	29	31	36
65-69	32	36	42	45	49
70-74	51	56	62	70	91
75-79	60	62	70	78	104
80-84	88	96	97	97	130
85-89	75	89	102	113	127
90-94	34	47	60	71	98
95+	10	14	19	25	47
<i>Total, Males</i>	<i>384</i>	<i>437</i>	<i>487</i>	<i>540</i>	<i>691</i>
<b>Females</b>					
0-59	6	6	6	6	7
60-64	14	15	16	17	19
65-69	24	29	33	36	40
70-74	49	52	58	67	90
75-79	71	76	83	89	120
80-84	115	122	125	131	162
85-89	130	148	162	177	199
90-94	78	98	122	144	186
95+	35	47	59	74	128
<i>Total, Females</i>	<i>522</i>	<i>593</i>	<i>664</i>	<i>741</i>	<i>951</i>
<i>Total, Persons</i>	<i>906</i>	<i>1,030</i>	<i>1,151</i>	<i>1,281</i>	<i>1,642</i>

Table F.9 Dementia Prevalence, Dungog LGA

Males	2009	2011	2013	2015	2020
0-59	1	1	1	1	1
60-64	4	4	4	4	4
65-69	4	5	5	5	6
70-74	6	6	7	7	9
75-79	7	8	8	9	11
80-84	10	9	10	11	15
85-89	6	7	7	7	8
90-94	3	4	4	4	6
95+	1	1	1	2	3
<i>Total, Males</i>	<i>41</i>	<i>44</i>	<i>47</i>	<i>50</i>	<i>61</i>
<b>Females</b>					
0-59	1	1	1	1	1
60-64	2	2	2	2	2
65-69	3	3	3	4	4
70-74	5	6	6	6	8
75-79	7	6	8	9	11
80-84	12	12	11	10	14
85-89	17	16	16	16	14
90-94	10	11	12	13	13
95+	5	5	6	7	9
<i>Total, Females</i>	<i>61</i>	<i>62</i>	<i>64</i>	<i>67</i>	<i>75</i>
<i>Total, Persons</i>	<i>103</i>	<i>106</i>	<i>111</i>	<i>117</i>	<i>136</i>

Table F.10 Dementia Prevalence, Muswellbrook LGA

Males	2009	2011	2013	2015	2020
0-59	2	2	2	2	2
60-64	5	5	5	5	5
65-69	5	6	7	7	7
70-74	7	7	8	10	13
75-79	8	9	9	9	14
80-84	11	12	12	13	15
85-89	10	10	12	13	15
90-94	4	5	7	8	11
95+	1	2	2	3	5
<i>Total, Males</i>	<i>53</i>	<i>58</i>	<i>65</i>	<i>70</i>	<i>87</i>
<u>Females</u>					
0-59	2	2	2	2	2
60-64	2	2	2	2	3
65-69	4	4	5	5	5
70-74	7	7	8	9	12
75-79	12	11	12	12	16
80-84	18	20	20	18	21
85-89	19	19	20	23	23
90-94	11	13	15	18	21
95+	5	6	7	10	15
<i>Total, Females</i>	<i>80</i>	<i>85</i>	<i>91</i>	<i>99</i>	<i>117</i>
<i>Total, Persons</i>	<i>133</i>	<i>143</i>	<i>156</i>	<i>169</i>	<i>204</i>

Table F.11 Dementia Prevalence, Singleton LGA

Males	2009	2011	2013	2015	2020
0-59	3	3	3	3	4
60-64	8	9	8	8	10
65-69	6	8	10	11	12
70-74	9	10	11	13	21
75-79	11	12	12	14	20
80-84	13	14	17	17	22
85-89	10	12	13	14	18
90-94	4	6	8	9	14
95+	1	2	2	3	7
<i>Total, Males</i>	<i>67</i>	<i>77</i>	<i>86</i>	<i>95</i>	<i>126</i>
<u>Females</u>					
0-59	2	2	2	3	3
60-64	3	4	4	4	5
65-69	4	5	6	8	9
70-74	9	9	11	11	19
75-79	16	15	16	17	21
80-84	24	27	27	26	29
85-89	29	31	33	36	38
90-94	17	21	25	29	35
95+	8	10	12	15	24
<i>Total, Females</i>	<i>113</i>	<i>124</i>	<i>136</i>	<i>149</i>	<i>183</i>
<i>Total, Persons</i>	<i>180</i>	<i>201</i>	<i>223</i>	<i>243</i>	<i>309</i>

Table F.12 Dementia Prevalence, Upper Hunter LGA

Males	2009	2011	2013	2015	2020
0-59	2	2	2	2	2
60-64	5	6	6	6	6
65-69	6	7	8	8	8
70-74	9	9	10	10	13
75-79	11	10	11	13	15
80-84	17	19	18	16	21
85-89	13	16	18	21	20
90-94	6	8	11	13	15
95+	2	3	3	5	7
<i>Total, Males</i>	<i>71</i>	<i>79</i>	<i>86</i>	<i>92</i>	<i>108</i>
<hr/>					
Females					
0-59	1	1	1	1	1
60-64	2	2	2	2	3
65-69	4	5	5	6	6
70-74	9	9	10	11	13
75-79	13	14	14	15	17
80-84	23	24	24	24	26
85-89	31	32	34	35	36
90-94	18	21	26	29	34
95+	8	10	12	15	23
<i>Total, Females</i>	<i>111</i>	<i>119</i>	<i>129</i>	<i>137</i>	<i>159</i>
<i>Total, Persons</i>	<i>182</i>	<i>198</i>	<i>215</i>	<i>229</i>	<i>267</i>

Source: Alzheimer's Australia NSW unpublished data provided by Access Economics

## Appendix G HACC service usage

Table G.1 CALD Status of HACC Service Users, Hunter Region

LGA	CALD Status	Not CALD	Unknown	Total Users	CALD Status as % Total HACC Users
Cessnock	88	2,347	31	2,467	3.6%
Dungog	10	482	1	493	1.9%
Gosford	763	6,482	105	7,350	10.4%
Lake Macquarie	681	8,226	125	9,032	7.5%
Maitland	219	2,478	39	2,736	8.0%
Muswellbrook	11	579	2	592	1.9%
Newcastle	835	6,091	96	7,022	11.9%
Port Stephens	190	3,121	36	3,348	5.7%
Singleton	26	798	10	834	3.1%
Upper Hunter Shire	17	898	5	921	1.9%
Wyong	693	5,898	84	6,675	10.4%
<b>Total</b>	<b>3,534</b>	<b>37,400</b>	<b>534</b>	<b>41,469</b>	<b>8.5%</b>

Source: HACC MDS report, provided by ADHC, 9 September 2011

Table G.2 Age Profile of HACC Service Users, Hunter Region

LGA	Age Band								Total
	0-64	65-69	70-74	75-79	80-84	85-89	90-94	95 plus	
Cessnock	592	224	286	427	480	331	105	22	2,467
Dungog	90	49	72	76	98	74	32	*	493
Gosford	1,254	512	737	1,153	1,599	1,328	595	172	7,350
Lake Macquarie	1,506	592	932	1,486	2,068	1,605	683	159	9,032
Maitland	596	186	295	444	563	466	134	50	2,736
Muswellbrook	137	48	75	102	105	80	30	15	592
Newcastle	1,360	403	634	1,052	1,582	1,272	559	160	7,022
Port Stephens	642	237	425	572	691	529	190	61	3,348
Singleton	207	53	96	149	182	106	37	5	834
Upper Hunter Shire	153	86	115	159	195	145	61	7	921
Wyong	1,311	546	747	1,157	1,409	960	427	118	6,675
<b>Total</b>	<b>7,848</b>	<b>2,936</b>	<b>4,414</b>	<b>6,778</b>	<b>8,972</b>	<b>6,897</b>	<b>2,853</b>	<b>771</b>	<b>41,469</b>

\* Values less than 5 are not reported.

Source: Assembled from HACC MDS report, provided by ADHC, 21 September 2011.

## Appendix H Dementia specific service usage

Table H.1 CALD Status of Users of Selected Dementia Specific Services, Hunter Region, 2009/10

HACC Service Type	CALD Status	No CALD Status	Total Users	CALD as % Service Users
Dementia Monitoring Services	21	223	244	8.6%
Dementia Advisory Services	33	729	762	4.3%
Respite Care	9	105	114	7.9%
Case Management	10	96	106	9.4%
Centre based day care	13	243	256	5.1%
Multi Service Outlet*	16	150	166	9.6%
<b>Total</b>	<b>102</b>	<b>1,546</b>	<b>1,648</b>	<b>6.2%</b>

\* Excludes users of multi-service outlets where the service provider is funded as a multi-service outlet.  
Source: Assembled from HACC MDS report, provided by ADHC, 9 September 2011.

## Appendix I    Gaps in services

The following two tables provide a preliminary indication of gaps in services for people living with dementia and their carers in the two LPAs. The material was used, commented on and amended during consultations.

Dementia service planning being facilitated by ADHC and NSW Health will consider service gaps further.

Services are considered under the headings of the NSW Dementia Services Framework:

[http://www.health.nsw.gov.au/policies/gl/2011/GL2011\\_004.html](http://www.health.nsw.gov.au/policies/gl/2011/GL2011_004.html)

Table I.1 Preliminary Indication of Service Gaps in the Hunter LPA

General Services	Dementia Specific Services
<b>1. Service Focus: Dementia Awareness (Community awareness &amp; risk reduction)</b>	
<ul style="list-style-type: none"> <li>☞ Exploring opportunities to provide more community information about dementia through existing local events ( eg local markets, Tocal field day)</li> </ul>	<ul style="list-style-type: none"> <li>☞ Awareness of dementia in CALD communities, particularly small isolated CALD communities in rural areas.</li> <li>☞ Raising awareness of the risks and risk assessment for people with dementia including people with younger onset dementia.</li> </ul>
<b>2. Service Focus: Assessment, diagnosis and ongoing management</b>	
<ul style="list-style-type: none"> <li>☞ Access to interpreters for assessment.</li> <li>☞ Health care providers knowing how to access interpreters</li> <li>☞ How geriatricians and GPs communicate the diagnosis of dementia to carers and people.</li> </ul>	<ul style="list-style-type: none"> <li>☞ Development and dissemination of Dementia Risk Assessment Tool that assists with the identification of risks faced by people with dementia living in rural communities</li> <li>☞ Need for culturally appropriate assessment tool</li> <li>☞ Seamless service support through transitional stages of dementia</li> </ul>
<b>3. Service Focus: Information, counselling and carer education</b>	
	<ul style="list-style-type: none"> <li>☞ Providing Early Intervention Support for people living with early stage Dementia and their carers.</li> </ul>
<b>4. Service Focus: Community case management</b>	
<ul style="list-style-type: none"> <li>☞ Multicultural CACPS, EACH packages</li> </ul>	<ul style="list-style-type: none"> <li>☞ EACHD packages</li> <li>☞ Access to bilingual workers</li> <li>☞ Transition of people with dementia and their carers between services</li> </ul>
<b>5. Service Focus: Community support services</b>	
	<ul style="list-style-type: none"> <li>☞ Dementia Specific day care in Maitland including carer support education and training</li> <li>☞ Research into appropriate male oriented activities in the Hunter focusing on men with early – moderate stage dementia</li> <li>☞ Education for dementia care workers in acute, sub acute, Residential Aged Care Facilities and the community</li> <li>☞ Developing support and services for people with younger onset dementia</li> <li>☞ Dementia Beliefs And Knowledge Among Culturally and Linguistically</li> </ul>

General Services	Dementia Specific Services
	Diverse (CALD) Groups ☞ Dementia-specific needs analysis of services for Aboriginal and Torres Strait Islander communities. To ascertain how to reach Aboriginal & Torres Strait Islander clients with dementia by using culturally safe and competent practices. To explore dementia-specific service needs of Aboriginal & Torres Strait Islander people living with dementia in the Hunter.
<b>6. Service Focus: Hospital care</b>	
	☞ Discharge planning for people with dementia and their carers
<b>7. Service Focus: Residential care</b>	
	☞ Waiting lists for high care beds. People have to move out of area to access high care residential aged care.
<b>8. Service Focus: Behavioural support</b>	
	☞ DBMAS: more resources above current two full time workers needed.
<b>9. Service Focus: Palliative care</b>	
☞ Advanced Care Planning*  ☞ Access to palliative care particularly when there is a crisis	☞ Best Practice Model for End-Stage Dementia Care for people living with end stage dementia, carers, families and support people across the continuum of care. Service providers in acute, sub acute, community and residential aged care (RAC) facilities.

Table I.2 Preliminary Indication of Service Gaps in the Central Coast LPA

General Services	Dementia Specific Services
<b>1. Service Focus: Dementia Awareness (Community awareness &amp; risk reduction)</b>	
	<ul style="list-style-type: none"> <li>☞ Education for community on planning ahead.</li> <li>☞ Translation of local information into community languages.</li> </ul>
<b>2. Service Focus: Assessment, diagnosis and ongoing management</b>	
<ul style="list-style-type: none"> <li>☞ More assistance to GPs in diagnosis role.</li> </ul>	<ul style="list-style-type: none"> <li>☞ No central referral point for diagnosis and assessment.</li> <li>☞ More CDNs and/or community CNCs needed.</li> <li>☞ Knowledge deficiency among key workers in Health service.</li> </ul>
<b>3. Service Focus: Information, counselling and carer education</b>	
	<ul style="list-style-type: none"> <li>☞ Younger onset dementia (YOD) carer support group and also support for children of people with YOD.</li> <li>☞ More staff needed for carer education.</li> </ul>
<b>4. Service Focus: Community case management</b>	
<ul style="list-style-type: none"> <li>☞ Unmet needs.</li> </ul>	<ul style="list-style-type: none"> <li>☞ Unmet needs.</li> </ul>
<b>5. Service Focus: Community support services</b>	
<ul style="list-style-type: none"> <li>☞ Across the LPA, wait lists for domestic assistance.</li> <li>☞ Poor or no transitions available to EACH packages.</li> <li>☞ Across the LPA, transport is ongoing issue, especially the cost.</li> </ul>	<ul style="list-style-type: none"> <li>☞ In Wyong Shire, gaps in supply of:               <ul style="list-style-type: none"> <li>• EACHD packages</li> <li>• Dementia Centre Based Day Care.</li> </ul>               (Providers identified vacancies in the Gosford LGA in EACHD packages, dementia day care and flexible respite.)             </li> <li>☞ Across the LPA, gaps in:               <ul style="list-style-type: none"> <li>• Respite, especially overnight, flexible and residential.</li> <li>• YOD appropriate services.</li> <li>• People with challenging behaviours (BPSD).</li> <li>• Early stage support.</li> </ul> </li> </ul>

General Services	Dementia Specific Services
<b>6. Service Focus: Hospital care</b>	
	<ul style="list-style-type: none"> <li>☞ Education of hospital staff regarding dementia and cultural diversity.</li> <li>☞ No wards for people with cognitive impairment.</li> </ul>
<b>7. Service Focus: Residential care</b>	
	<ul style="list-style-type: none"> <li>☞ Carer support through the transition from community to residential care.</li> </ul>
<b>8. Service Focus: Behavioural support</b>	
	<ul style="list-style-type: none"> <li>☞ Insufficient BPSD staff to ensure culturally appropriate education on person centred care and management.</li> </ul>
<b>9. Service Focus: Palliative care</b>	
	<ul style="list-style-type: none"> <li>☞ Need to implement good practice from nationally funded dementia palliative care projects (National Palliative Care Program).</li> </ul>

Note: The Central Coast Local Health Network has prepared a Dementia Services Framework covering health services in the area. It provides a detailed assessment of service gaps and solutions and resources required to address the gaps.

## Appendix J CALD specific services

The following community care services in the region support people with dementia and their carers from CALD backgrounds. Some are fully multicultural services including some clients with dementia, while others are dementia services with specific targets for supporting people from CALD backgrounds.

1. ECC Multicultural (Dementia) Centre Based Day Care
2. COPS Day Care
3. Coastlink Respite Care
4. UnitingCare In Home Respite
5. NSS Central Coast Multicultural Social Support
6. NSS Multicultural Respite Support
7. NSS Multicultural CACPs

1.

Name of service:	<b>Waratah Multicultural Centre Based Day Care</b>
Auspice organisation:	Ethnic Communities Council (ECC) Newcastle & Hunter Region Inc
Location:	2a Platt Street, Waratah
Target group:	✓ CALD people with dementia
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 90 years old</li> <li>• Youngest client: 63 years old</li> </ul>
Purpose of service:	To provide a stimulating day program for people with dementia of culturally and linguistically diverse (CALD) backgrounds in a culturally appropriate fashion. The aim is to provide a nutritional meal along with activities, guest speakers and occasional social outings.
Support provided:	Day care; meals; transport to and from centre.
Description of service:	<ul style="list-style-type: none"> <li>• The service was established in 2011.</li> <li>• The centre operates from 10am till 2pm on Tuesdays and Thursdays.</li> <li>• The service is similar to other ECC day care except for more of an individual focus. Clients and/or carers decide what would be the best support, given the profile of the client.</li> <li>• Clients come from the community and Tinonee Gardens self care units.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• The following services are for general HACC clients. Individuals usually move to dementia specific services if they reach mid stage dementia.</li> <li>• The ECC provides seven other day care programs around Newcastle: <ul style="list-style-type: none"> <li>○ Greek Community (Hamilton)</li> <li>○ Italian (Broadmeadow)</li> <li>○ Macedonian (Broadmeadow)</li> <li>○ Polish (Broadmeadow)</li> <li>○ Greek Holy Apostles (Hamilton)</li> <li>○ Ukrainian (Adamstown)</li> <li>○ Newcastle Multicultural (Mayfield)</li> </ul> </li> <li>• The fee is \$7 at all centres. Between \$6 and \$8 is charged for transport, depending on distance travelled.</li> <li>• Other services include: <ul style="list-style-type: none"> <li>○ Ethnic Neighbour Aid Project (ENAP) - Newcastle, Lake Macquarie, Maitland and Port Stephens areas</li> <li>○ Rural Ethnic Neighbour Aid Project (RENAP) - Greta, Kurri, Branxton, Cessnock, Singleton and other rural areas</li> <li>○ Multicultural Carer Support Groups – Newcastle and Port Stephens areas</li> <li>○ Maitland Multicultural Friendship Group.</li> </ul> </li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• Clients: 20</li> <li>• Clients include people of German, Dutch, Croatian, Spanish, Filipino, Welsh, Austrian, Polish and Italian backgrounds.</li> <li>• About 50% of clients have dementia.</li> <li>• Clients are 50:50 female to male</li> <li>• 2 staff (1 cook, 1 coordinator)</li> <li>• 2 volunteers and 1 student on placement</li> <li>• The service catchment is Newcastle LGA.</li> </ul>
Source of funds:	✓ HACC
Any other agencies involved:	<ul style="list-style-type: none"> <li>• Tinonee Gardens The Multicultural Village</li> </ul>

Interesting feature(s) of service:	<ul style="list-style-type: none"> <li>Ethnic food</li> </ul>
Replicating the service in HACC:	<ul style="list-style-type: none"> <li>ECC considers two elements are essential for this type of service: bilingual workers and culturally appropriate service delivery.</li> </ul>
Output / outcome indicators:	<ul style="list-style-type: none"> <li>The coordinator prepares a fortnightly report on progress.</li> </ul>
Results achieved to date against intended objective and outcomes:	<ul style="list-style-type: none"> <li>As this service is only a few months old, data analysis is just starting to happen.</li> <li>Supervision meetings also consider results.</li> <li>The service has been expanded from one day (initially Thursday) to a second day (Tuesday).</li> </ul>
Any documents available about the service:	<ul style="list-style-type: none"> <li>ECC's website provides information and a brochure on the service: <a href="http://eccnewcastle.org.au/downloads/daycarebrochure.pdf">http://eccnewcastle.org.au/downloads/daycarebrochure.pdf</a></li> </ul>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>It is challenging finding appropriate bilingual volunteers.</li> <li>Promotion of the service has recently expanded to include advertising in newspapers.</li> </ul>
Contact –	<p>Name: Mary Moore  Title: Centre Coordinator  Phone: 02 4960 8248  Fax: 02 4960 8249  Email: <a href="mailto:mary@eccnewcastle.org.au">mary@eccnewcastle.org.au</a></p>

2.

Name of service:	<b>Multicultural East and Westlake Centre Based Day Care</b>
Auspice organisation:	Community Options, Hunter New England Area Health Service (HNEAHS)
Location:	Booth Building, Wallsend Campus, Longworth Avenue, WallsendNSW
Target group:	<ul style="list-style-type: none"> <li>✓ CALD people</li> <li>✓ People with early stage dementia</li> <li>✓ Multicultural groups. Targets small emerging ageing communities who don't access day care.</li> </ul>
Age range of clients:	Frail aged
Support provided:	Day care; meals; transport can be arranged to and from centre
Description of service:	<ul style="list-style-type: none"> <li>• The service was established in 1996</li> <li>• The centre operates from 10am till 2:30pm.</li> <li>• Day care activities, talking and other activities, meals provided.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• COPS provides four ethnic specific/multicultural day care programs across Lake Macquarie: <ul style="list-style-type: none"> <li>○ Multicultural (Broadmeadow).</li> <li>○ Multicultural (Morisset)</li> <li>○ Multicultural (Toronto)</li> <li>○ Multicultural (Cardiff).</li> </ul> </li> <li>• The services operate two days a fortnight.</li> <li>• The fee is \$5 at all centres. Fees are charged for transport depending on distance travelled.</li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• Clients: up to 30 clients in each group</li> <li>• Mostly frail aged and some people have early stage dementia</li> <li>• Clients include people from a range of multicultural backgrounds including German, Dutch, Croatian, Austrian, Polish and Italian backgrounds.</li> <li>• Female/male - 60/40.</li> <li>• 2 part time staff who are bilingual</li> <li>• Volunteers: 2-3 who are bilingual</li> <li>• Catchment area is Lake Macquarie LGA.</li> </ul>
Source of funds:	✓ HACC
Replicating the service in HACC:	<ul style="list-style-type: none"> <li>• Need bilingual bicultural staff who can work in a context of diversity</li> </ul>
Results achieved to date against intended objective and outcomes:	<ul style="list-style-type: none"> <li>• Employ bilingual bicultural staff and volunteers who know how to connect and work with people from different cultural and language backgrounds</li> <li>• The service targets small multicultural ageing people who don't access traditional day care services</li> </ul>
Any documents available about the service:	<ul style="list-style-type: none"> <li>• There are brochures on the service.</li> </ul>
Contact –	<p>Name: Raquela de Santos  Title: Multicultural Day Care Coordinator  Phone: 02 4924 6099  Fax: 02 4924 6098</p>

3.

Name of service:	<b>Coastlink Respite Care</b>
Auspice organisation:	Coastlink, Gosford
Location:	Gosford and Wyong shires
Target group:	Frail older people, people with dementia, younger people with a disability and their carers.  <b>Priority of Access</b> ✓ Clients with dementia  <b>Special Provisions</b> <ul style="list-style-type: none"> <li>• 50% funding for people with dementia</li> <li>• 25% funding for people from CALD</li> <li>• 25% funding for standard respite services</li> </ul>
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 94</li> <li>• Youngest client: 48</li> <li>• Average age: 74</li> </ul>
Purpose of service:	To provide respite, including personal care and light domestic assistance to people who have dementia and their carers.
Support provided:	In-home respite including personal care and light domestic assistance. Community activities with a 1:1 support worker.
Description of service:	<p>The service is managed by a volunteer Board of Directors who have delegated the day to day operations of the organisation to the CEO. Coastlink does not broker out services but instead uses our own well trained and qualified employees.</p> <ul style="list-style-type: none"> <li>• The respite care service was established in 1985. Additional funding provided in 2010 includes a 25% target for CALD clients.</li> <li>• The service operates 24 hours, 7 days per week.</li> </ul> <p>For people with dementia we provide the following services:</p> <ul style="list-style-type: none"> <li>• Respite including personal care and domestic assistance;</li> <li>• Social and Peer Support;</li> <li>• Aged Day Care centre based activities</li> <li>• Life Choices and Active Ageing programs;</li> <li>• Programs for ageing carers</li> </ul> <ul style="list-style-type: none"> <li>• Service is delivered wherever the client wants it.</li> <li>• The client decides what activities will be delivered (depending only on the level of challenging behaviours or other issues which may prevent the service being delivered in a way the client may want).</li> </ul>
Other support offered / involved:	<p>We offer as much support as possible to all clients and carers to make them feel comfortable and happy with our service. This might include using an interpreter service, finding a worker who can speak a language a client can understand, delivering services in a culturally appropriate way in all cases.</p> <p><b>Transport:</b> Community access is part of who we are and we have purchased (over the years) 14 buses to ensure all of our clients get into the community as often as possible. All of our programs can and do provide transport and it is included in all respite programs with a 50 kilometre limit.</p>

	<p><b>Fees:</b> Respite is \$3 per hour and transport in bus or worker's car is included.</p> <p>If people are financially disadvantaged lower fees can be negotiated.</p> <p>Coastlink has an arrangement with a translation and interpreter service.</p>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• The respite service currently has 15 clients, 3 of whom identify as having CALD backgrounds: Polish, Greek and Romanian. The target is to support 4 CALD clients.</li> <li>• Two of the CALD clients are male and one female.</li> <li>• 3 to 4 workers are involved in this service.</li> <li>• Coastlink has 4 bilingual staff: Italian, Greek, Mandarin, Tagalog.</li> <li>• Catchment for the service: Gosford and Wyong Council areas.</li> </ul>
Any other agencies involved:	We liaise with lots of other agencies but operate as a stand-alone organisation.
Interesting feature(s) of service:	Dedication to providing community access to all clients regardless of age or disability. Our buses are all modified so we can transport people with physical disabilities. We are responsive to cultural preferences, especially food, and this may mean using different suppliers for different clients.
Replicating the service in HACC:	<ul style="list-style-type: none"> <li>• Staff require cultural competence training.</li> <li>• Sensitivity and responsiveness to clients' preferences. For example, although English is their second language and is apparent in proficiency levels, CALD clients have declined the use of interpreters and made clear their preferences to speak in English.</li> </ul>
Output / outcome indicators:	All clients are surveyed at least annually and mostly more frequently than that through phone calls and our QA coordinator attending shifts to check out if all is well and submitting a report to management.
Any documents available about the service:	<a href="http://www.coastlink.org.au">www.coastlink.org.au</a>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>• Challenge to get good experienced staff.</li> <li>• Increased funding would enable expansion.</li> <li>• However, can accommodate more CALD clients within existing resources.</li> </ul>
Contact – Name: Title: Phone: Fax: Email:	<p>Lynne Rainford CEO 43 211 022 43 211 077 <a href="mailto:lynne@coastlink.org.au">lynne@coastlink.org.au</a></p>

4.

Name of service:	<b>UnitingCare In Home Respite (IHR)</b>
Auspice organisation:	UnitingCare Ageing, Hunter Community Care
Location:	Mayfield
Target group:	<ul style="list-style-type: none"> <li>✓ Frail Aged</li> <li>✓ 10 priority places CALD people</li> <li>✓ Other – <i>Younger people with moderate to severe disability</i></li> </ul>
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 99yrs</li> <li>• Youngest client: 7yrs</li> <li>• Average age: over 65</li> </ul>
Purpose of service:	In Home Respite is to enable the usual carer 'respite' to be able to continue in the primary caring role; assisting to prevent carer stress and strain, premature placement or hospitalization.
Support provided:	Relieve primary carer of caring role; Respite care, socialization and companionship; Light domestic assistance as arises during course of respite (Eg make bed or wash up lunch dishes); Other incidental tasks to meet care recipients needs (Eg personal care) during the course of the respite and only if not exceeding purpose of 'respite' activities. Quality activities to engage recipient of respite for improved wellbeing.
Description of service:	<ul style="list-style-type: none"> <li>• Service coordinator and care staff</li> <li>• 2008</li> <li>• 24/7</li> <li>• Primary focus is socialisation and companionship, other tasks that can be provided are assistance with domestic tasks, personal care, meal prep, laundry. These tasks should be incidental to service provision and not the purpose of service provision.</li> <li>• Service is provided in the client's home.</li> <li>• Care plan is developed in consultation with client, carer and case manager</li> <li>• Carer and care recipient determine the tasks that are done and the services provided during a service visit.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• UnitingCare Ageing provides many other programs, however IHR is to provide respite care only.</li> <li>• If the client needs other services we contact referral agencies for the client to be referred to other agencies that may assist with meeting their other needs.</li> <li>• Transport is only provided if an occasional social outing is approved.</li> <li>• Contribution fee of \$10.00 per hour and this is negotiable to suit individual's financial situation.</li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• 73 clients across Lake Macquarie and Newcastle</li> <li>• 45 staff (pool staff): 4 male, 41 female, 5 CALD</li> <li>• No volunteers in this service.</li> </ul>
Source of funds:	✓ HACC/ADHC
Any other agencies involved:	Nil
Interesting feature(s) of service:	<ul style="list-style-type: none"> <li>• Provide quality activities during respite visit to engage in wellbeing;</li> <li>• Use of Top 5 tool to identify communicative behaviours.</li> </ul>
Replicating the service in HACC (what is required):	<ul style="list-style-type: none"> <li>• HACC Eligibility; Coordinator staff to Assess, Monitor, Care plan and Roster carer staff; Carer Staff training in Cert 4 Disabilities; Relationship with Community Care Access Point to receive referrals and other referral sources; Client contribution - Nil financial discrimination.</li> </ul>
Output / outcome indicators:	<ul style="list-style-type: none"> <li>• Reviews 3 monthly; surveys and feedback yearly if not more.</li> </ul>

	<ul style="list-style-type: none"> <li>Key indicators used to measure progress: Client / Carer Assessment and Review / Monitoring re meeting client / carer needs ongoing; Internal Audits and CQI Action Plans, external MOA, Monthly reports from carer staff and coordinator staff and budget requirements. MDS reporting re outcomes.</li> </ul>
Results achieved to date against intended objective and outcomes:	<ul style="list-style-type: none"> <li>High Occupancy; Meeting community need; Additional growth in program and funding – commenced 51 clients now 73; Continued ADHC support; Achieving MDS outcomes.</li> </ul>
Any documents available about the service:	<ul style="list-style-type: none"> <li>Website <a href="http://www.unitingcareageing.org.au">www.unitingcareageing.org.au</a></li> <li>Brochures, fact sheets available</li> </ul>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>LGA growth – into other areas of the Hunter.</li> </ul>
Contact –	Name: Rae Merritt Title: Service Manager Hunter Community Care Phone: 49675172 Fax: 49675169 Email: <a href="mailto:rae.merritt@uchunter.org.au">rae.merritt@uchunter.org.au</a>

5.

Name of service:	<b>NSS Multicultural Social Support Service</b>
Auspice organisation:	Northern Settlement Service
Location:	Bateau Bay
Target group:	CALD clients of 65 years and older or younger people with a disability and their carers. Some have mild dementia. Some have relatives with advanced dementia.
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 95yrs.</li> <li>• Youngest client: 38yrs</li> <li>• Average age: 75yrs</li> </ul>
Purpose of service:	Multicultural Social Support Service. Social Groups. Provision of transport and assistance with shopping, doctors' appointments, other appointments. Assistance with reading, bill paying or form filling, if required.
Support provided:	Monthly larger Social Groups. 3 x smaller weekly social groups. The 3 weekly groups are located at Lake Haven, Woy Woy and at Gosford. The latter location has just been established.
Description of service:	<ul style="list-style-type: none"> <li>• The service is managed and delivered by NSS MSSS Team Leader; Alex Burns.</li> <li>• The service was established in 2006.</li> <li>• The service operates Monday – Friday, 8am – 4.00pm.</li> <li>• Activities/ service provided: Social Support. Group outings. Picnics. Arts &amp; Crafts. Information sessions ie: legal advice, government incentives. Lunches. Art Gallery. Entertainment ie: performances or singing, support to visit services including Drs, etc..</li> <li>• Locations: At community centre. In hired rooms. In public places or parks. In restaurants and in shopping centres.</li> <li>• Who decides what activities will be delivered: MSSS Coordinators and team leader.</li> <li>• Client and/or carer involvement in decisions about the service - MSSS Coordinators ask for opinions, ideas and feedback. We try to meet clients &amp; carers requests, if appropriate.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• The service is part of a broader range of support provided by the organisation: Monthly &amp; Weekly social support. Referral and Information, Settlement support, Family Welfare, Community Development, Consultation on CALD ( Migrant and refugee needs), Cultural Awareness Training, Advocacy. NSS has Community Development, Welfare &amp; Immigration services also.</li> <li>• Transport is provided to or from the service, mostly by Volunteers. A small fee is charged.</li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• Clients: Approx; 100.</li> <li>• All CALD. Approx 75% women &amp; 25% men.</li> <li>• Staff (FTE): 2.5 coordinators. 1 x Part time admin &amp; 1 x accounts. 1x Welfare. 1x Community Development officer. 1 x team leader.</li> <li>• Volunteers</li> <li>• Service catchment: Gosford &amp; Wyong LGAs.</li> </ul>
Source of funds:	✓ HACC
Interesting feature(s) of service:	Uniquely a Multicultural Social Service.
Replicating the service in HACC (what needs to be in place):	<ul style="list-style-type: none"> <li>• Awareness of CALD community needs and services.</li> <li>• A volunteer base.</li> <li>• Cultural awareness. CALD Demographics. Aged &amp; disability care. Referral services.</li> </ul>
Output / outcome indicators:	<ul style="list-style-type: none"> <li>• Annual reviews. File notes. Progress notes.</li> </ul>

Results achieved to date against intended objective and outcomes:	<ul style="list-style-type: none"> <li>• Successful socialization and assistance for the clients.</li> <li>• More training for our volunteers to understand CALD community and aged care service.</li> </ul>
Any documents available about the service:	<ul style="list-style-type: none"> <li>• NSS website: <a href="http://www.nsservices.com.au">www.nsservices.com.au</a></li> <li>• Service brochure</li> <li>• Evaluation of service.</li> </ul>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>• Expansion would be possible with additional funding - More outings for our clients, ie; bus trips, lunches, group outings.</li> <li>• Additional funding would help with transport for bus trips or outings.</li> </ul>
Contact –	<p>Name: Kellie Matterson  Title: MSSS Coordinator  Phone: (02) 4334 3877  Fax: (02) 4334 3044  Email: <a href="mailto:kellie@nsservices.com.au">kellie@nsservices.com.au</a></p>

6.

Name of service:	<b>NSS Hunter Multicultural Respite Service</b>
Auspice organisation:	Northern Settlement Services Ltd
Location:	Hamilton
Target group:	<ul style="list-style-type: none"> <li>✓ CALD people with dementia</li> <li>✓ Carers of people with dementia or a disability from a CALD background.</li> </ul>
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 94</li> <li>• Youngest client: 65</li> <li>• Average age: 76</li> </ul>
Purpose of service:	Providing respite care for frail older people or people with dementia from non-English speaking backgrounds (NESB) experiencing difficulty in accessing Day Care Centres.
Support provided:	<p>Respite service in a linguistic and culturally appropriate way in consultation with the user, the service and the carer.</p> <p>Worker to assist with care of clients from NESB at Day Care Centres</p>
Description of service:	<ul style="list-style-type: none"> <li>• The service was established in 2005.</li> <li>• Clients receive 3 hours per week of support.</li> <li>• Providing respite care to aged client who have dementia in a day care settings</li> <li>• Support is delivered according to client's needs.</li> <li>• The clients are assessed with the assistance of their carers to determine the needs and assistance is delivered as per needs.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• The service is part of a range of support offered by NSS (see previous entry on NSS Multicultural Social Support Service).</li> <li>• The carers are benefiting from attending a once a month meeting coordinated by the Coordinator – information on dementia issues are being provided through the HACC Educare services, and lunch is provided free of charge to carers plus bus trips and occasional pamperers etc.</li> <li>• Transport is provided.</li> <li>• Fees: nil for respite; a \$5 charge per day for transport.</li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• 22 clients: 68% females &amp; 32% males</li> <li>• 10 staff who are contracted from other service providers.</li> <li>• 4 volunteers for the Carers Group</li> <li>• Catchment for the service: Newcastle, Lake Macquarie, Maitland, Port Stephens, Cessnock and Upper Hunter LGAs.</li> </ul>
Source of funds:	✓ HACC
Any other agencies involved:	No
Interesting feature(s) of service:	Welcomed and appreciated by the clients that receive the services in the Day Care Centres and also the Ethnic Communities Council who runs these Day Care Centres.
Output / outcome indicators:	<ul style="list-style-type: none"> <li>• An annual review of the service is sent to the Day Care Centre Coordinator and also to the staff who provides the service.</li> <li>• 6 monthly reviews of client's needs and of Day Care Centres'.</li> <li>• Care Plan for each client is updated according to needs.</li> </ul>
Results achieved to date against intended objective and outcomes:	We have so far managed to promote the service to providers and also to specific CALD providers such as Ethnic Communities Council, who manage Day Care Centres.

Any documents available about the service:	<ul style="list-style-type: none"> <li>• NSS website: <a href="http://www.nsservices.com.au">www.nsservices.com.au</a></li> <li>• Service brochure</li> <li>• Flyer: Multicultural Dementia and Disability Carer Support Group – promotion.</li> <li>• The annual review is conducted to get feedback regarding the service.</li> </ul>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>• Transport needed for clients who live further away and need regular attendance in a culturally appropriate Day Care Centre. For example, currently the Community Transport Service could only provide a fortnightly service to a client due to added costs on their part.</li> </ul>
Contact –	<p>Name: Tima 'Oto  Title: Coordinator  Phone: 0401189085  Fax: 49698299  Email: <a href="mailto:tima@nsservices.com.au">tima@nsservices.com.au</a></p>

7.

Name of service:	<b>Multicultural Community Aged Care Packages (CACP)</b>
Auspice organisation:	Northern Settlement Services Ltd
Location:	Hamilton - service covers Hunter Region
Target group:	CALD people eligible for packages - a significant proportion of whom are people who have dementia.
Age range of clients:	<ul style="list-style-type: none"> <li>• Oldest client: 98 years old</li> <li>• Youngest client: 71 years old</li> <li>• Average age: 80 years old</li> </ul>
Purpose of service:	To provide a package of in home assistance/ case management with the tasks of daily living to enable people to stay at home as long as possible.
Support provided:	Case management/ assistance with personal care/ medication supervision/ domestic assistance/ transport/ meal preparation /shopping/ social activities/ garden care/facilitating respite for carers.
Description of service:	<ul style="list-style-type: none"> <li>• NSS Coordinators retain the case management aspect and coordinate direct service provision through a brokerage model.</li> <li>• The service was established in 2001.</li> <li>• Office hours are Monday to Friday 9am-4pm. ONCALL for Coordinators - 24 hours/ 7 days per week. Services can cover 7 days per week if required.</li> <li>• Coordinators do assessments/ monitor changing needs/ amend care plans as required /coordinate services. Care workers who go to people's homes ( bilingual if required) assist care recipients with tasks of daily living ( see list under support provided).</li> <li>• Service is delivered in person's home or transport to appointments/ social activities at Day Care Centres.</li> <li>• Need an ACAT Assessment to come on CACP program then Coordinator jointly with care recipient/ family/carer designs Care Plan based on a person's needs and preferences.</li> <li>• Both care recipient and/or carers/ family participate in Care Planning.</li> </ul>
Other support offered / involved:	<ul style="list-style-type: none"> <li>• Multicultural CACP is part of a range of Aged Care programs at NSS : a CALD Centre based respite Project Hunter Multicultural Respite Service (HMRS) in the Hunter; Multicultural Social Support Program (MSSS) on the Central Coast, Multicultural Access Project Hunter and a CALD Community Visitors Program.</li> <li>• In Home assistance with the tasks of daily living, respite.</li> <li>• Transport is provided through CACP.</li> <li>• Fees: CACP - 17.5% of basic pension (currently \$58.70 per week maximum) for 5-6 hours of service. Fee reduction can be negotiated.</li> </ul>
Size of service / capacity:	<ul style="list-style-type: none"> <li>• 42 CACP packages clients: All CALD frail aged; the majority female.</li> <li>• Staff: 3 part time Coordinators</li> <li>• No volunteers involved in CACPs</li> <li>• The catchment for the service is the Hunter LPA.</li> </ul>
Source of funds:	✓ Commonwealth Department of Health and Ageing
Any other agencies involved:	Care workers are brokered from 5-6 agencies
Interesting feature(s) of service:	The use of the brokerage model gives us access to a greater pool of bilingual workers which enables us to more effectively meet the cultural and linguistic needs of our clients who are all from CALD backgrounds. It is also an effective way to provide services to isolated pockets in a geographically dispersed area such as the Hunter.

Replicating the service in HACC (what needs to be in place):	Flexibility and willingness to consider innovative approaches such as the brokerage model. (We believe the Carer respite centre also uses the brokerage model, but as far as we know we are the only local CACP provider who uses brokerage.)
Output / outcome indicators:	<ul style="list-style-type: none"> <li>• Regular reviews of care plans</li> <li>• Annual Client satisfaction Survey</li> <li>• Monthly quality indicators</li> </ul>
Results achieved to date against intended objective and outcomes:	We are able to meet the cultural/linguistic needs of our CALD target group. We are widely recognized as the specialist CALD provider in the community as well as being commended by the Department of Health and Ageing as a “best practice model” for providing service to people of diverse backgrounds in a regional area such as the Hunter.
Any documents available about the service:	<ul style="list-style-type: none"> <li>• NSS website: <a href="http://www.nssservices.com.au">www.nssservices.com.au</a></li> <li>• CACP brochure, also available in a range of community languages</li> <li>• 3 yearly Quality Improvement Review by the Department of health and Ageing</li> </ul>
Any identified areas for improvement with the model &/or deficiencies / difficulties:	<ul style="list-style-type: none"> <li>• More funding would enable us to meet the needs of the increasing number of people on waiting list for CACP.</li> <li>• At times have difficulty in finding workers from particular backgrounds e.g. Chinese.</li> <li>• Recruitment strategies that recognize and value being bilingual would help service delivery.</li> </ul>
Contact –	Name: Sue Hristov Title: Aged Care Team Leader, CACP Coordinator Phone: 49693399 wk or 0411590507 Mobile Fax: 49614997 Email: <a href="mailto:cacp@nssservices.com.au">cacp@nssservices.com.au</a>

## Appendix K CALD Community Groups

Table K.1 Community Groups, Central Coast

Country / Nationality	Organisation
Africa	<ul style="list-style-type: none"> <li>• Central Coast African Community</li> </ul>
China	<ul style="list-style-type: none"> <li>• Central Coast Chinese Association</li> <li>• Gosford Chinese Performing Arts</li> </ul>
Croatia	<ul style="list-style-type: none"> <li>• Croatian Group</li> </ul>
Dutch	<ul style="list-style-type: none"> <li>• The Dutch Group</li> </ul>
Fiji	<ul style="list-style-type: none"> <li>• Multicultural Fijian Association</li> <li>• Fijian Women's Association</li> </ul>
France	<ul style="list-style-type: none"> <li>• Alliance Francaise</li> </ul>
Finland	<ul style="list-style-type: none"> <li>• Central Coast Finish Society Of Gosford</li> </ul>
Germany	<ul style="list-style-type: none"> <li>• Central Coast Australian German Friendship Association</li> </ul>
Greece	<ul style="list-style-type: none"> <li>• Greek Hellenic Community Of The Central Coast</li> <li>• Australian Hellenic Association Inc</li> </ul>
Hungary	<ul style="list-style-type: none"> <li>• Central Coast Hungarian Connection</li> </ul>
Iran	<ul style="list-style-type: none"> <li>• Central Coast Iranian Community Inc</li> </ul>
Italy	<ul style="list-style-type: none"> <li>• Connecting Australian Italian Culture</li> <li>• Central Coast Australian Italian Friendship Society</li> </ul>
India	<ul style="list-style-type: none"> <li>• Ekta Mandir Inc (Indian Educational And Cultural Association of Australia)</li> </ul>
Japan	<ul style="list-style-type: none"> <li>• Central Coast Japanese Community Language School</li> </ul>
Korea	<ul style="list-style-type: none"> <li>• Korean Community Contact</li> </ul>
Malta	<ul style="list-style-type: none"> <li>• Maltese Group</li> </ul>
New Zealand	<ul style="list-style-type: none"> <li>• Maori Women's Group</li> </ul>
Papua New Guinea	<ul style="list-style-type: none"> <li>• Papua New Guinea Contact</li> </ul>
Phillipines	<ul style="list-style-type: none"> <li>• Australian Filipino Association</li> <li>• Ugnay Kabayan (People Link)</li> </ul>
Poland	<ul style="list-style-type: none"> <li>• Central Coast Polish Association of NSW</li> </ul>
South America	<ul style="list-style-type: none"> <li>• Latino's And Friends on The Coast</li> </ul>
Thailand	<ul style="list-style-type: none"> <li>• Thai Group</li> </ul>
Turkey	<ul style="list-style-type: none"> <li>• Turkish Group</li> </ul>

Source: Northern Settlement Services Limited, *Central Coast Migrant Services Directory*. Contact details of groups are available from NSS – Central Coast: Ph: (02) 4334 3877; Fax: (02) 4334 3044; Email: cc@nssservices.com.au.

Table K.2 Community Groups, Hunter

Country / Nationality	Organisation
Africa	<ul style="list-style-type: none"> <li>• African Women's Group</li> </ul>
American	<ul style="list-style-type: none"> <li>• Australian / American Association</li> </ul>
Arabic	<ul style="list-style-type: none"> <li>• Arabic Speaking Community</li> </ul>
Bosnia	<ul style="list-style-type: none"> <li>• Bosnian Community</li> </ul>
Burundi	<ul style="list-style-type: none"> <li>• Burundi Community</li> </ul>
China	<ul style="list-style-type: none"> <li>• Chinese Association</li> <li>• Chinese Community</li> </ul>
Congo	<ul style="list-style-type: none"> <li>• Congolese Community</li> </ul>
Croatia	<ul style="list-style-type: none"> <li>• Croatian Community</li> </ul>
Filipino	<ul style="list-style-type: none"> <li>• Filipino-Australian Society of the Hunter Valley Inc</li> <li>• Filipino Community</li> <li>• Filipino Community of the Hunter Region Inc. – FILCOHRI</li> </ul>
Germany	<ul style="list-style-type: none"> <li>• German Community Germania Club Newcastle Ltd</li> </ul>
Greek	<ul style="list-style-type: none"> <li>• Greek Community of Newcastle</li> <li>• Holy Apostles Greek Community</li> <li>• Greek Cypriot Community</li> <li>• Greek Macedonian &amp; Greek Orthodox Community</li> </ul>
India	<ul style="list-style-type: none"> <li>• Indian Association of Newcastle</li> </ul>
Indonesia	<ul style="list-style-type: none"> <li>• Indonesian Australian Community Newcastle &amp; Hunter Region Inc</li> <li>• Indonesian Community</li> </ul>
Iran	<ul style="list-style-type: none"> <li>• Iranian Community Organisation</li> </ul>
Italy	<ul style="list-style-type: none"> <li>• Italian Community Welfare Organisation</li> </ul>
Japan	<ul style="list-style-type: none"> <li>• Japanese Women's Group</li> </ul>
Khmer/ Cambodia	<ul style="list-style-type: none"> <li>• Khmer/ Cambodian Community</li> </ul>
Latin America	<ul style="list-style-type: none"> <li>• Latin American Ladies Support Group</li> <li>• Latin American Society "La Pena"</li> </ul>
Latvia	<ul style="list-style-type: none"> <li>• Latvian Community</li> </ul>
Liberia	<ul style="list-style-type: none"> <li>• Liberian Community</li> <li>• Liberian Youth</li> </ul>
Lithuania	<ul style="list-style-type: none"> <li>• Lithuanian Community</li> </ul>
Macedonian / FYROM	<ul style="list-style-type: none"> <li>• Macedonian Community</li> <li>• Macedonian Pensioners</li> </ul>
Maori	<ul style="list-style-type: none"> <li>• Maori Community</li> </ul>
Muslim	<ul style="list-style-type: none"> <li>• Hunter Muslim Women's Friendship Group</li> </ul>
Poland	<ul style="list-style-type: none"> <li>• Polish Association of Maitland</li> <li>• Polish Association of Newcastle</li> <li>• Polish Senior Citizens Association</li> <li>• Polish Welfare Group</li> </ul>
Romania	<ul style="list-style-type: none"> <li>• Romanian Community</li> </ul>
Russia	<ul style="list-style-type: none"> <li>• Russian Community</li> </ul>
Scotland	<ul style="list-style-type: none"> <li>• Hunter Valley Scots Club</li> <li>• Scots Club</li> <li>• Scottish Pipe Band</li> <li>• Scots Strath Hunter Dancers</li> </ul>

Country / Nationality	Organisation
Serbia	<ul style="list-style-type: none"> <li>• Serbian Community</li> </ul>
Thailand	<ul style="list-style-type: none"> <li>• Thai Community</li> </ul>
Tonga	<ul style="list-style-type: none"> <li>• Tongan Community</li> </ul>
Sierra Leone	<ul style="list-style-type: none"> <li>• Sierra Leone Community</li> </ul>
Ukraine	<ul style="list-style-type: none"> <li>• Ukrainian Community</li> </ul>
Vietnam	<ul style="list-style-type: none"> <li>• Vietnamese Catholic St Joseph</li> </ul>
Wales	<ul style="list-style-type: none"> <li>• Welsh Society of Newcastle Hunter Region</li> </ul>

Source: Northern Settlement Services Limited, *2011/2012 Migrant Services Directory*. Contact details of groups are included in the Directory.

## Appendix L Organisations Assessment Tool

The following tool was adapted by Cumberland Prospect Multicultural Access Project, downloaded from [www.cnet.ngo.net.au](http://www.cnet.ngo.net.au)

## Promoting Cultural and Linguistic Competency Self-Assessment Checklist



*A tool for community care service providers*

### How this tool can help

The purpose of this self-assessment tool is to encourage greater awareness of some of the issues that you as a service provider face when providing care to people from backgrounds different to your own, and to increase greater sensitivity to and understanding of issues and barriers faced by clients from diverse backgrounds. The tool provides practical examples of attitudes, values and practices, which promote cultural and linguistic competence at the individual and service level. It can help identify gaps and areas that need improvement, and can also assist in developing appropriate and effective interventions /strategies to better assist in the care of clients from CALD backgrounds.

Additionally, information included in this tool can be discussed at staff meetings/training to refresh prior knowledge of staff who have already had some experience in working with clients from CALD/NES backgrounds and at the same time it will provide new information to people with limited experience. It will also help identify needs for training. Some aspects of the tool, depending on the role of the staff member, can also be incorporated into your organisation's orientation program for new workers and your staff annual appraisal process.

### How to use this tool

The tool does not provide a good or bad score. You are the one who assesses cultural competency of your organisation/service and the staff, and sets up goals for future improvement. The assessment should be done with the involvement of staff members working on all levels of your organisation including Board of Directors / Management Committee Members, Managers, Coordinators, Team Leaders, Field Staff/Nurses, Drivers and Volunteers. Identified gaps and areas that require improvement need to be discussed collectively to ensure understanding and support from all your workers and volunteers. The progress can be made through a step-by-step process that is planned over the agreed period of time. It is suggested that a Plan of Action is developed to help you set up achievable goals, identify appropriate strategies and resources needed and monitor the progress. To be successful this process should have support of all your staff members working on every level of your organisation including volunteers and the management committee.

Answer each question using one of the following:

YES / NO

- |   |   |                               |
|---|---|-------------------------------|
| A | = | Things I do frequently/always |
| B | = | Things I do occasionally      |
| C | = | Things I do rarely or never   |

## 1. ORGANISATIONAL PURPOSE AND PHILOSOPHY

- Your service has a statement of purpose / mission statement that includes values related to access, diversity and inclusion.
- Your organisation understands that Access and Equity principals are the responsibility of everyone. Access and Equity is reflected in the duty/job description of every staff member (paid and volunteers) and all staff report on the Access and Equity strategies and achievements.
- Your Management Committee/Board of Directors includes representatives from various groups in the community including members of the various cultural and language groups as well as people with a disability.

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## 2. SERVICE PLANNING, DEVELOPMENT AND RESOURCES

- ❑ Your organisation has a plan of actions to improve access of people from CALD/NESB backgrounds to your service and this plan is regularly monitored and reviewed depending on the changing needs.

### Policies

- ❑ You have in place Access & Equity Policy, Client Grievance Policy, Policy on Refusal of Services and Equal Employment Policy and you have mechanisms to monitor their implementation.
- ❑ Your Access & Equity Policy is well understood by all staff and applied in practice as well as is regularly reviewed and updated.

### Recruitment and Employment of Staff

- ❑ Your organisation actively seeks to employ people from the community or groups it serves (including people from diverse cultural and linguistic backgrounds) and those workers are well supported through appropriate training, appropriate roles and non-discriminatory work practices.

### Knowledge of the Community

- ❑ You have a current knowledge of a number of NESB/CALD people and people with a disability living in your target areas and from what language groups and countries they come. (This can be found out from ABS data, local council or Multicultural Access Project)
- ❑ Your organisation/service determines the percentage of NESB clients to be provided care, based on CALD population data of your target areas, monitors the achievement and reviews the goal on regular basis.
- ❑ As a part of regular monitoring and planning your organisation/service gathers and analyses its own data of clients who use or enquiry about the service that includes information on cultural background and language spoken.
- ❑ You keep a record of your waiting list including info whether the prospective client is of NESB to determine the current needs for the service and the level of unmet needs.

### Outreach to and Communication with the Community

- ❑ You link with ethnic communities, services and other service providers to be aware of the needs of the whole community including CALD.
- ❑ Your organisation actively reaches out to the various groups in the community that are currently not using the service (information campaign, contact with key community members, consultations)
- ❑ You developed contacts with ethno-specific or multicultural services for referral and consultation purposes.
- ❑ Your service has a networking/ mailing list, which includes mainstream, multicultural and ethno-specific organisations.
- ❑ Your organisation belongs and actively participates in networks that are committed to improve clients' access to services (HACC / Community Care Forums, Migrants Interagency, Expos etc)

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## Resources

Your organisation makes the service more accessible to CALD clients through:

- budget allocation for working with interpreters,
- allocation of funds for translation of materials,
- purchase of multicultural resources
- employment of bilingual staff & volunteers
- allocation of funds for regular staff training on working with interpreters, cross cultural communication and cultural awareness and competency
  
- You have necessary resources for accessing people from NESB (e.g. ethnic community directories, cultural awareness calendar, demographic profiles and statistics, translated materials etc...).
  
- You have information about your service translated into community languages relevant to your area. This brochure includes info about fees and how to make a complaint.

## 3. WORK PRACTICES

- Your organisation has codes of ethics/behaviour and clear policies and procedures that support good work practices to ensure staff behaviour is appropriate and non-discriminatory (e.g. a code that states that interpreters will be used for people who cannot communicate in English or the discriminatory language and attitudes from staff will not be permitted and tolerated).

### Communication

When interacting with clients/prospective clients and their carers/families who are from NES backgrounds you:

- Check the person's preferred language
- Use an interpreter if necessary
  
- All the materials that are given to the client either:
  - given in the nominated language of the client
  - given in English but explained by an interpreter
  
- You conduct reviews and evaluations of your service with NESB clients in the language that the client understands and you check that the person / family / carer understood the proposed plan of action/care
  
- The cost of using professional interpreters to do assessments, reviews etc is calculated into your budget and it is not a barrier for NESB client to access your service.
  
- When clients and family carers are not fluent in English, you work with professional interpreters to inform about services that are available.
  
- Your service provides HACC Rights and Responsibilities leaflets to NESB clients in their community languages or if this is not available than the Right and Responsibilities are red out in English and explained while working with a professional interpreter.
  
- All your staff received training on how to access and work with TIS or other professional interpreter services.
  
- You use interpreters to communicate all important messages such as at the assessment and reassessment, fees, explanation of rights and responsibilities, complaints, care plan, case conference.
  
- You consider the gender and ethnicity when booking an interpreter. For example it can be inappropriate to provide a Serbian interpreter for a Bosnian Muslim, or a male interpreter for a female client or vice versa

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#### **Staff Attitudes towards Cultural Diversity**

- ❑ Do you respect diverse practices and requests without judgement?
- ❑ Do you assume you know what a client wants/needs and what is the best for him/her?
- ❑ You intervene in an appropriate manner when you observe other staff or clients within your service/program or agency engaging in behaviours, which show cultural insensitivity, racial stereotypes and prejudice.
- ❑ You seek information from individuals, families or other key community informants to assist you in service adaptation to appropriately respond to the needs and preferences of culturally and ethnically diverse groups served by your service/program.
- ❑ Before visiting or providing services in the home setting, you seek information on acceptable behaviours, courtesies, customs, and expectations that are unique to the culturally and ethnically diverse groups served by your service/program.

#### **Cultural Assessment and Needs**

- ❑ Programs/services that your organisation offers/provides are sensitive to the culture, language and needs of different groups of people and are flexible enough to meet individual needs.
- ❑ If possible you have an arrangement for brokerage or contracting out of services to achieve culturally relevant services for NESB clients.
- ❑ You discuss with clients/families their cultural needs and preferences in order to plan, arrange and provide the most appropriate and responsive services.
- ❑ Professional interpreters are used at the key stages of admission, assessment, care planning and review with clients and carers when English proficiency is a barrier to communicate.

#### **Consumer Participation**

- ❑ Your organisation is constantly improving quality of services through seeking feedback and suggestions from existing clients. This process is also accessible to clients from various language and culture backgrounds.

### **4. STAFF TRAINING AND DEVELOPMENT**

- ❑ The management, staff and volunteers in your organisation receive regular training to build their skills in working effectively with diverse background clients
- ❑ Training on Cultural Awareness and Competency
- ❑ Training on Cross Cultural Communication
- ❑ Training on Accessing and Working with Professional Interpreters
- ❑ Training on Performing Culturally Sensitive Assessment
- ❑ The access, equity and cultural sensitivity issues and topics are addressed and discussed regularly at planning and evaluation meetings, staff meetings and in supervision sessions.
- ❑ Your organisation/service organises guest speakers to increase staff's and volunteers' awareness and knowledge on cultural awareness and competency.

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## 5. SERVICE IMAGE AND PHYSICAL ENVIRONMENT

- ❑ Your organisation displays signs, posters, information and other physical features that reflect diversity of the community it targets and promote inclusiveness.
- ❑ Your organisation/service displays multilingual signage such as welcome.
- ❑ Your organisation/service displays information that it is the consumer's right to access an interpreter.
- ❑ You display pictures, posters, artwork and other décor that reflect the culture and ethnic backgrounds of clients served by your program/agency.
- ❑ Your organisation has a policy on Access and Equity and it is made public and accessible.

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