Submission to the Productivity Commission's Inquiry into Caring for Older Australians – 30 July 2010

About the Ethnic Communities' Council of NSW (ECC NSW)

The Ethnic Communities' Council of NSW (ECC NSW) is the peak body for all culturally and linguistically diverse (CALD) communities in New South Wales. The ECC NSW's focus is to :

- ensure the retention of individual communities' culture, language, religious practice, aged welfare or health services, sport and recreation and educational institutions
- promote and recognise multiculturalism as part of the Australian way of life and as a valued asset
- facilitate joint action and cooperation between ethnic communities
- advocate on behalf of communities to improve access to services

This submission reflects the considered opinion of the ECC NSW and is not comprehensive. It is intended as an addition to, and not a replacement for, submissions from CALD communities or multicultural aged care services or community workers in New South Wales which will reflect their specific circumstances and aged care needs.

Most of the information about the aged care needs are identified through consultations, workshops, needs analyses of local CALD communities, collective knowledge of the Multicultural Access Project (MAP) Network and recently a joint CALD ageing forum. The aged care needs of CALD communities are diverse, driven by their migration stage and pattern, cultural distance between their origin and host country, knowledge of and

responsiveness to aged care services, level of English proficiency and literacy, and rate of ageing in individual communities.

Our submission focuses on the 'service delivery framework', one of the five foci of the Inquiry with crossover to the other four foci.

SERVICE DELIVERY FRAMEWORK

a. Language services

One of the more effective interpreter services in New South Wales, as identified by the HACC Multicultural Access Project Network (MAP), is the Health Care Interpreter Service (HCIS) (http://www.wsahs.nsw.gov.au/services/hcis/index.htm) funded by NSW Health and available in all Area Health Services. NSW Health-funded health care providers as well as a number of eligible non-government organisations and external agencies can use the service. Home and Community Care services in some regions including the eighteen Local Government Areas of Northern Sydney, Cumberland Prospect and Nepean Planning Areas of Ageing, Disability and Home Care (ADHC) Metro North Region have free access to HCIS. CALD patients and clients can be provided with professional health interpreters when accessing and using health, HACC and other services and agencies that are eligible to use HCIS.

HCIS is designed to *assist clients* from culturally and linguistically diverse backgrounds (CALDBs) to access health services and facilitate communication between CALD consumers and health care providers. With more than 120 languages, NAATI credited translators and interpreters, 24 hours/7 days a week onsite and telephone interpreting services and videoconferencing (during normal business hours), the service appears to respond to the needs of patients, clients , health professionals and service providers (SWAHS 2007).

HCIS	
Advantage:	Free to eligible services under the Home & Community Care program in specific geographic regions of ADHC (in addition to a range of HCIS' clients) Interpreters have high skill level of medical terminology Professional trained interpreters and abide by a professional code of ethics

	Easy to access, simple booking procedures, relatively short booking time
	Interpreters can be arranged at short notice (if available)
Disadvantage:	Not accessible to all aged care programs and services in an Area Health Service
	Not accessible directly to patients, clients and public
	Available only to service providers

Translating and Interpreter Service (TIS), (http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/) funded by Department of Immigration and Citizenship is the often used interpreter service in HACC and related services for older people but it is on a fee-for-service basis. As a national service that is available to a wide range of agencies, it is a high demand service.

TIS	
Advantage:	Free to non-English speaking consumers when they access government-funded departments and agencies
	Free to government-funded services where the organisation *does not* receive funding to provide interpreting services
Disadvantage:	Not free to the majority of government-funded services as assumes that there is a funding component for translating and interpreting service
	Not free to consumers if the organisation does not accept responsibility for charges of interpreting services
	Generic interpreter service
	Requires pre-booking for on site / face-to-face interpreting (anecdotal evidence indicates 3 months pre-booking time and it is expensive)
	Does not require pre-booking for telephone interpreting, however due to high demand the waiting time to be connected to the requested interpreter can be long (more than 20 minutes)

With the increasing diversity of New South Wales' older and younger population, there is a need for the costs of translating and interpreter services to be given higher recognition in funding allocation by government as well as improved accountability of the utilisation of such services by not-for-profit community

organisations that provide services to older people. In addition, the cost of face-to-face interpreting services should have higher priority over telephone interpreting services in funding allocation. The interpreting service model that operates in ADHC Sydney Metro North Region through HCIS is an example of a good practice that can be considered when planning for language services for the aged care sector.

Language services should be de-centralised with more specific geographical funding of language services as some areas have higher numbers of older people from CALDBs. With changing demographics in some areas, sometimes quite rapidly as a result of environmental, social or economic pressures, local or geographic services can respond in a more targeted and effective manner. For example, Blacktown in Western Sydney has a relatively new emerging community of a small number of older Bhutanese who are severely isolated by language, transport and cultural expectations of services for older people. The responsibility of their care falls to community leaders who have lived longer in New South Wales but who are limited in their understanding of services for older people. If a model similar to HCIS is funded across the Health Services or Aged Care Sector for example, the Bhutanese community could be supported to get qualifications to become professional or recognised interpreters. In this way, new and emerging communities' needs could be addressed in a shorter timeframe.

The Health Care Interpreter Service (HCIS) funded by a NSW Area Health Service is one model that can have universal application across all Area Health Services so that **all** health and aged care services and programs (currently split between state and federal) can have free access to trained health interpreters regardless of funding and geographical location. The advantage of HCIS is that interpreters have higher level of skills in medical terminology therefore they are better suited to communicating about preventative services for older people from CALDB.

Language services for older people could be enhanced by models adopted in other agencies such as Centrelink's multilingual call service where people talk to the agency

directly in their own language and have their questions answered directly by agency employees (Centrelink 2009). This sort of service avoids the use of interpreters which could then be free to provide face-to-face services for more complex situations. It is also important that prior to considering a multilingual call service, the Centrelink multilingual service is evaluated for its effectiveness, gaps and successes so that any issues can be identified for a similar service providing information about aged care services to older people from CALDB.

b. Single access point

The 'one-stop shop' as an information access point has some merit but should not in itself be the only point. It is more than likely that this service could suffer the limitations of the current Commonwealth Respite and Carelink Centre (http://www9.health.gov.au/ccsd/index.cfm, a single access point for information about aged care services in a geographically bound region.

There is not sufficient public information to determine the efficacy of such a Centre in dealing with information for people from CALDBs or have proven to be effective in enabling people from CALDBs to access HACC and related services. An information service, whether face-to-face or telephone or by alternate technology, without corresponding advisory and advocacy service will have narrow gains for people from CALDBs. The 'one-stop shop' assumes that people are mobile, able to make decisions from an array of choices and manage their care. The 'one-stop shop' appears to be no different to services provided by Centrelink or other human service agencies. There is certainly anecdotal evidence to indicate that, despite the wealth of public information, carers of older people from CALDB miss out on income support where they most need it. There is therefore little argument for a single access point which could be a barrier or enabler depending on the end user's ability and capacity to negotiate the aged care service system.

The aged care service system needs a number of pathways to aged care services including :

- Community development workers such as the HACC Multicultural Access Program model that works with local communities and service providers to identify and respond to local needs

- Improved funding of language services (interpreter and translation services with recognition of both face-to-face and telephone options)
- Multilingual call service for basic advice about aged care services
- Website with information about aged care services in different languages with culturally-appropriate images rather than a single image across all translated publications about a specific service (e.g. Options in Aged Care in 37 languages uses a single image, http://www.culturaldiversity.com.au/Default.aspx?tabid=237)
- Partnerships between ethno-specific community organisations and mainstream services to respond to local needs
- Funding of bilingual and bicultural aged care workforce (including bilingual educators) including improved wages and benefits
- Aged care services that build on the IMPACT principles where services are flexible, person-centred and goal driven; a service that focuses on preventative care

For example, dementia in CALD communities is likely to reach unprecedented levels with increasing life expectancy. While information and education about dementia as an illness could be a health or dementia-specific services' responsibility, there is also the social and care aspect of dementia. Carers are likely to be across the age spectrum and not necessarily older than 65 years. Who will assist carers who are younger than 65 years to manage their care and the care of their family or friends with dementia?

Recently, some members of the MAP Network have started to look at ways that CALD carers of people with dementia or those with early stage dementia access aged care services. It is more likely that people from CALD backgrounds access services at a much later stage due to denial, stigma and shame associated with such an illness. For most people in CALD communities, dementia remains a 'hidden' disease associated as a problem rather than a stage of life (Migliorino 2010). The MAP Network, along with other support groups, is effective in working with carers and in disseminating information about HACC to support carers of people with dementia as the impact of caring falls hardest on this social group. It is important that Access Workers are seen as an effective interface between health/aged

services and communities so that information and other resources continue to be adapted or developed to meet local rather than generic needs.

c. Myths of care: home or residential facility?

In some CALD communities there is a perception that ethno-specific residential facilities will continue to be funded if demand can be identified and/or funds raised to support such a facility.

There is also a common misconception that older people from CALDB are cared for by their family without recognition for that quality of care. There is sufficient anecdotal evidence to indicate that care for older people in some communities means that an older person has food, shelter and obligation to share care of grandchildren or other family members. Some older people experience financial and social abuse when they are restricted access to income or choice to live as they want.

Equally, there is insufficient understanding about what quality of care could mean within CALD communities particularly when aged care services are provided on a voluntary basis without linkages to formal aged care services in the community. In some cases the ethno-specific organisations act as 'gatekeepers' to services in the wider community or even create dependency with narrow gains for older people and their supporting family and friends.

The myth of family and ethno-specific community care is often a barrier for mainstream service providers when they take on the high and often complex needs of caring. A transfer to residential care or care at home by external services is often deemed as inappropriate for the older person as services are unable to meet the cultural and linguistic needs of that individual from a CALD community.

The Community Partners Program (CPP) has been effective in some way to break down barriers through education and awareness raising programs to CALD communities about residential care and flexible community care. In addition, CPP works with residential providers to respond to the cultural demands of older people from CALDB.

Equally the HACC Multicultural Access Program has been effective in working with local, regional and state-wide CALD organisations and community workers to identify barriers and needs of the target population.

While the degree of resistance by the CALD population to aged care services is not so different from the wider Australian community, what is different is that migrant communities often do not have the same exposure to aged care services in their countries of origin. Education, information and grassroots services need continued focus so that migrants who are ageing have access to choices (home, community and/or residential care) in how they want to be cared for as they become more aged rather than have their needs determined by cultural expectations, 'gatekeepers', myths and limited options. As the aged care sector moves towards the likelihood of adopting individualised payments for aged care services, education and support in CALD communities will take on a greater focus.

d. Advocacy

The 'age split' of services between the two levels of government and other strategies to deal with the future of the sector does not recognise the role of advocacy in CALD communities to have a voice in the determination of aged care services.

The complexity of management of aged care services might be reduced as a result of the split but it may not recognise the changing needs of communities as a result of changing environments.

It is likely that with the increasing pressure of urban environments, future migration is likely to shift to outer and regional New South Wales changing local demographics including that of older people. The 'sea change' phenomenon of recent years gives us some evidence that health and community services are slow to respond to changing demographics. Even the major funder of aged and disability services does not appear to recognise the more complex environments that limits aged care providers or access workers to reach out to older people

from CALDBs living in such areas. The level of complexity of needs and demands will rise substantially as people move further from better serviced areas like metropolitan Sydney.

We need to recognise that Aged Care Access Workers are an important component of the aged care system as they are often the ones that advocate for their communities' need for services particularly where people are unable to recognise or articulate their need for services.

e. Cultural shift in aged care

Current practice in the aged care sector is to shift responsibility for the needs of people from CALDBs where they are not specifically funded to deliver care to that social group. Ethno-specific organisations in NSW like Co.As.It. or Spanish and Latin American Association for Social Assistance are funded to provide specific projects such as the Community Partners Program or community organisations like SydWest Multicultural Services provide a range of HACC and CPP services.

The aged care sector could benefit from a cultural shift in caring where care and services are provided irrespective of a person's cultural and linguistic diversity so that the person becomes the focus of services.

f. Retirement village and congregate housing

People from CALD communities focus on 'in-home family care' rather than 'congregate care' with the potential to move to residential care (nursing home) as the demands of caring increase. Often CALD communities' perceptions of services for older people is rooted in their experience and understanding of services in their country of origin at the time of migration. Congregate care is fast becoming an option even in economically developing countries like India where online internet searches now reveal a plethora of residential options to meet different socio-economic needs.

However, several submissions to this Inquiry so far have highlighted the financial and regulatory complexities of living in congregate facilities. Unless the sector is regulated, people from CALDBs are likely to suffer some disadvantage due to language or lack of capacity to advocate on issues due to lack of knowledge of this segment. Older people from CALDBs often have a passive experience with services (health and community) and tend not to question therefore further limiting their needs and options.

The physical environment including access to quality social and private housing for older people is one of the determinants of health (WHO 2010). While many older people from CALDBs are asset-rich or live with families, there is certainly a need to look at alternate residential options that can support people to age in place rather than have a single option for end of life (nursing home) and to continue to live in areas that they are connected to. A good example is the recently publicised seniors complex in Fairfield to deliver an age-specific housing option with the potential for older people to remain connected with the local community (FCC 2010). Aged care services for some social groups needs to work across different government levels and across government to deliver a more holistic service for all but disadvantaged people in particular (Housing NSW, Centrelink, DIMA). This type of housing is more likely to support people from the GLBTI community, people from homeless background with strong inner city connections, those drug and alcohol dependent, all with the added layer of a complex cultural and linguistic identity.

As people age, the fear of crime and feeling unsafe can influence people's socialisation patterns and in turn their health and wellbeing. Some older groups (women, GLBTI, people with disabilities) are at greater risk than others and experience a disproportionate level of fear as a result of their environments. They are also likely to experience higher levels of mental illness and have lower levels of trust (ABS 2010c).

Future housing options for older people from CALDBs need to be considered within a framework of interactive, safe and sustainable environments that create local employment,

reduce car-based commuting and is environmentally or socially responsive (water tanks, wind farms, communal cooking, sewing and gardening). Future older CALD Australians may not be passive service recipients and may demand a higher level of services that meet their needs. It is critical therefore to continue conversations about housing with CALD communities, access worker and government at different levels. (Dolan 2010).

While the financial implications of any changes in housing could put added stresses on government funding, the social and health benefits could possibly outweigh the negative effects of dislocation of older people from their local communities.

g. Alignment of health and community sector

The current strategy to split aged care services along 'age' may have value under the National Health and Hospitals Reform provided there is an alignment between health and community services.

Anecdotal evidence suggest that people from CALD backgrounds are unaware of mental health services and supports available or lack the knowledge to access appropriate services or are resistant to seek information as a result of the stigma and shame of mental illness. Only a small number of people with mental illness access HACC services and that number is even smaller or negligible for those from CALD backgrounds. There is no evidence in the HACC MDS that identifies a person with mental illness who may access HACC services. It is likely that a carer of a person with mental illness may access HACC services but again there is insufficient data that identifies CALD carers of people with a mental illness. Access Workers like the HACC MAP Workers do not work directly with the mental health system but may indirectly support ethno-specific mental health workers to promote HACC and mental health services to their target population.

Refugees and refugee-like people at earlier stages of settlement have their needs met through a range of state and federal agencies. This group is likely to age much earlier due to their refugee experiences and likely to have a high demand for aged-care like services as a

result of chronic health conditions (diabetes, obesity, HIV) associated with changed environments. For some CALD communities, ageing is a new life stage especially when removed from old environments. With the 'age split' of HACC, this specific group of 'older' people may access disability services funded by State Government but not have recognition of their needs as older people which could disempower their experience of ageing.

We therefore need an effective alignment between health and community services so that responses to specific situations that might be provided by health particularly mental health services or chronic health conditions (HIV, diabetes or obesity) can be supported by a network of community services.

h. Ageing in regional and rural NSW

While there is a relatively small number of older people from CALD backgrounds in Rural NSW (ABS 2008a,b), what is clear is that there are small numbers of diverse migrant communities who will grow older but not necessarily have access to culturally appropriate care should that be their choice. For example, ABS' NSW Rural Balance by country of birth indicates a broad spread of people from Argentina to Chile to China. We can expect a growth in the diversity of people living in R&R NSW for several reasons including a change in government's immigration policy that encourages settlement away from coastal regions.

It is currently difficult to estimate the numbers of older people from CALDB who access aged care services and even worse statistics for older people from CALDB in Rural NSW. Older people from CALDB who do not access aged care services continue to remain a hidden group who are not assisted. In 2006, about 547,000 people were identified living in Rural NSW with about 65,000 aged over 65 years. We can assume that at least 10% of this cohort will be from a CALD background who might not necessarily identify as CALD but use mainstream aged care services in R&R NSW. While this is not necessarily a bad option but if 'choice' is a determinant of care, then older people from CALD B miss out on having their needs met. In addition, choice of residential or community aged care is limited in R&R NSW which again inhibits real choice for older people from CALD B.

It is therefore vitally important that Access Workers such as the MAP Workers are a key resource in working with local council, migrant interagencies and other local networks to assist HACC and local community services to meet the needs of people from CALDB. Resource sharing and provision of information and advice as well as advocacy services are critical in enabling people from CALDB to access HACC and other aged care services and specifically to receive culturally appropriate care. For example, the ECC NSW was successful under the 2009-10 Positive Ageing Grants to implement a project in Orange (NSW) that will increase the visibility of older people from CALDBs. The project is an opportunity to work across a range of local services to identify and link older people from CALDBs with appropriate services.

i. Capacity building

The current system's strength, despite some limitations, offers opportunities to build capacity in HACC services, among workers, within CALD communities and between community services in local regions through partnerships and resource and knowledge sharing.

Some CALD communities continue to view mainstream providers as unresponsive due to lack of culturally appropriate care and services. This assumption is premised on the notion that service providers (or government) must respond and fit to the individual rather than the CALD community or older person from a CALDB adapt to a non-ethno specific service. Generally, CALD communities establish ethno-specific services to meet the needs of their target population, sometimes alone or in partnership with local councils or mainstream agencies or guided by Access Workers. Often the model of care is based on 'charity', usually free services by volunteers at home or in a community setting, often in conflict with the philosophy of caring in the broader community (enabling, independence).

Irrespective of philosophical differences, often local councils and regionally-based access workers are critical to assist newer communities to learn about HACC and related services and guide them to meet the needs of older people. Additionally, Access Workers also advise

CALD community leaders about changes in the aged care system so that they are not isolated and importantly, not isolating their community from the broad range of social and community services.

CALD communities are necessary partners in developing culturally-appropriate services and creating inclusive communities in their local regions. Food services or meals-on-wheels are seen as unresponsive to the needs of CALD communities. However, with extensive support (not short-term or one-off funding), there is the potential of a real partnership between CALD communities or ethno-specific organisations and mainstream food services. Such partnerships however need grassroots support from Access Workers to build CALD communities' capacity to participate in care for older Australians from CALDBs.

HACC day centres are a popular access point for CALD communities but are limited in their engagement with CALD communities. Access Workers are able to use a initiative and freedom to explore inter-state and overseas programs. Examples include the potential to work with relevant HACC peaks (such as Neighbour Aid and Social Support Association) to introduce culturally-appropriate physical activity and other ethno-specific tools to create a sense of belonging and connection for CALD communities.

In addition, Access Workers such as the Multicultural Access Program Workers are integral to building capacity in the aged care service system when they provide cultural competence training to service providers, work collaboratively with CALD communities to develop HACC Handbooks in relevant languages or provide support and advice to CALD communities to deliver culturally-appropriate services to their target population.

j. Special needs groups

There is insufficient data in any government publications to indicate the number of older people from CALD backgrounds who are homeless or suffer mental illness or are drug dependent or at risk of one or more disadvantage. Equally there is little data that tells us

about numbers of GLBTI from CALD backgrounds other than anecdotal evidence. Each of these social groups is at risk of not accessing services and not receiving culturally-appropriate services that respond to their language and lifestyle.

Therese Findlay (2010) quite rightly pointed out that the provision of aged care in a locality should respond to a cross-section of the community thereby reflecting the 'flavour' of that community or area or region. 'Ageing in place' would then mean more than providing care across the continuum of ageing within a facility. It would include the community and infrastructure that one is familiar with. Although anecdotal, in discussions with Australian Federation of Aids Organisations (AFAO), there is some evidence to suggest that CALD populations with HIV/AIDS are unable to live and age safely in their community due to inherent discrimination. This cohort are forced to remain 'hidden' and live in areas which are more accepting of their difference yet apart from family and friends or live in fear of exposure particularly their cultural community. What we need is a person-centred approach in aged care services with appropriate levels of funding to ensure that individuals' needs are met as well as a cultural shift in the aged care sector to achieve real outcomes (AFAO 2010).

k. Culturally competent sector

Aged care services need a diverse workforce that include English-speaking as well as bilingual/bicultural paid workers and bilingual/bicultural volunteers. The general assumption is that a bilingual workforce would lead to an increase in consumers from CALD communities. While this is true to some extent, what we need is a workforce that is culturally competent and responsive to its diverse community.

Another assumption is that older people from CALDBs need ethno-specific workers to meet their needs. What we need is a workforce that is culturally cognizant of the diversity of cultures thereby broadening people's understanding of other cultures and sharing cultural knowledge. Some CALD communities, due to their

lived experiences, do not have that experience of living with and caring for old people in the same way that people from Anglo-Australian or other CALD communities experience ageing within their communities (think African communities with very small number of older people due to civil wars). The mismatch of clients and workers can have negative impact on 'caring'.

The aged care sector needs to be adequately funded to train and continuously learn so that its workforce and management move toward achieving cultural competency at organisational and service level. Perhaps recognition of such competency should be rewarded through Awards, similar to the State Awards for Excellence in Aged Care that recognises excellence in a range of areas that contribute to the quality of life for older people or the Positive Living in Aged Care Awards that recognises strategies of residential aged care providers to improve living conditions of residents.

l. Evolving services to meet the needs of people

Aged care services to date are largely defined by government and providers but this cannot continue as at the heart of services is the end-user (consumer, client) who is an older person and/or their carer. The HACC split suggests a return to centralised management and delivery of aged care services. What is critical is the need to see how well it addresses the needs for whom it is designed and to what extent citizens have a voice to articulate their values and preferences in relation to issues that most affect them. Briggs argues that government is still fumbling with citizen engagement models but we hope that the Inquiry will allow citizens to influence the future of caring in a meaningful way (Briggs 2009).

In New South Wales, a small group of aged care providers across residential and community care, peak organisations and special needs groups (Aboriginal and CALD) are influencing government and the sector to adopt a new philosophy of care that is fast gaining acceptance and support by Ageing, Disability and Home Care, Department of Human Services NSW (ADHC). IMPACT Group works with ADHC to ensure that IMPACT principles of care are central to future programs and services in support of client-centred

care. It would be worthwhile for the Commissioners to consult with the IMPACT Group in due course (www.impactnsw.com).

m. Gendered services

High levels of parent migration, increasing numbers of older people from CALDBs in metropolitan NSW and smaller but a more diverse cohort in regional and rural NSW and longer life expectancy, suggest that gender is a critical component of service delivery. Generally, women are the dominant users of HACC and related services but as men's health improves at older ages, the future caring of older Australians from CALDBs needs to focus on gender-specific services that respond to men's needs. This will encourage positive behaviours like exercise, nutrition and health service use. In this way, negative behaviours or risks could be reduced which in turn could positively impact on carers and other significant people in CALD communities. ABS Australian Social Trends (2010) suggest that the most vulnerable groups of men, other than from Indigenous communities, are men with disabilities and male prisoners who make up the vast majority of those incarcerated. Information for men needs to focus on preventative health and improved health at different life stages including across the older life stage. Again, there is little research that identifies the needs and gaps in services for men from CALDBs. Consultation and research with this social group is critical in the caring of older Australians (ABS 2010 a,b,c).

SUMMARY OF NEEDS FOR OLDER AUSTRALIANS FROM A CALDB IN NSW

- Well funded models of language services (face-to-face interpreters, multilingual call service) across all aged care programs with an older person focus
- Access Workers such as the HACC Multicultural Access Program Network as an effective interface between service providers and CALD communities and between service system and funding agency.
- Options in aged care that include ethno-specific and mainstream services that are supported by government at different levels across a range of agencies

- Better linkages between health and community sector particularly for mental illness
- CALD communities as partners in developing culturally-appropriate services
- Person-centred approach in aged care services with appropriate funding to sustain needs
- Cultural shift in the sector towards person-centred care with an outcomes orientation
- Cultural competency at all levels so that understanding and appreciation of differences (gender, ethnicity, age and sexuality) is central to service delivery

Further communication

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