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HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern: *Issues for Aboriginal and Torres Strait Islander People and People from Culturally and Linguistically Diverse Backgrounds*

Alt Beatty Consulting
for Community Care (Northern Beaches) Inc.

FINAL REPORT

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This project was commissioned by Community Care (Northern Beaches) Inc. on behalf of the NSW Department of Ageing, Disability & Home Care, Metro North Region.

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Acronyms

ACCA	Australian Chinese Community Association
ALO	Aboriginal Liaison Officer
CALD	Culturally and linguistically diverse
COASIT	Comitato Assistenza Italiani - Italian Association of Assistance
DADHC	Department of Ageing, Disability & Home Care
DAS	Dementia Advisory Service
HACC	Home and Community Care Program
LGA	Local government area
LPA	Local Planning Area
MAPS	Multicultural Access Project Service
MOW	Meals on Wheels
NGO	Non-government organisation
STARTTS	Service for the Treatment and Rehabilitation of Torture and Trauma Survivors
YOD	Younger onset dementia

Note:

The term Aboriginal is used for easier reading, recognising that comments made may refer to both Aboriginal and Torres Strait Islander people.

Executive Summary and Recommendations

This report presents the findings of a consultation project to assess the relevance and completeness for Aboriginal and Torres Strait Islander People and People from Culturally and Linguistically Diverse Backgrounds (CALD) in the Metro North region of Sydney of the recommendations of the report, *Appropriate HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern*.

The findings draw on consultations with HACC service providers, consumer representatives and other stakeholders and a brief literature review.

A central issue for HACC in providing better service to both Aboriginal and CALD communities is strengthening the cultural competence of mainstream HACC services. This means putting culture at the heart of what people do and respecting, engaging and understanding a person's culture.

Key messages from the **Aboriginal consultations** included:

- The concept of holistic health and wellbeing and the connection to family and community was seen as fundamental to policy, program and service developments.
- When considering dementia, mental health is seen as a priority of which dementia is a part.
- Local research could identify culturally appropriate models for HACC services for Aboriginal people that are specific to each community.
- As a population group, Aboriginal people are more likely to have experienced higher rates of imprisonment, head trauma and brain injury, higher alcohol and drug use rates and poorer nutrition which could impact on an increase in the number of people acquiring younger onset dementia.
- Dementia is not well known or understood within Aboriginal communities.
- Many local resources are not reaching Aboriginal people due to a lack of specifically targeted information.

- Culturally sensitive assessment tools are needed and are critical in developing service responses in relation to dementia.

- People were concerned that current practice models were based on a premise of ‘risk assessment’ rather than ‘keeping people safe’. Cultural safety and respect was seen as an important consideration for the development of policy and programs.

- The majority of Elders prefer to be cared for at home, or in a place where people could readily access their families.

- Transport and its relationship to accessing services is important.

Key messages from the **CALD consultations** included:

- The Metro North region is culturally and linguistically diverse. This means it is important to have CALD specific services as well as build capacity within mainstream HACC services to meet the needs of CALD communities.

- There are people with younger onset dementia from CALD communities who have been supported by a number of HACC services and dementia specific services in the Metro North region. They tend to be in smaller numbers and often require one to one support from workers who are bilingual and culturally competent and can develop activities and supports that are culturally appropriate.

- Some services are also supporting people with dementia and behaviours of concern from CALD backgrounds some of whom are refugees who have experienced torture and trauma.

- Further research work on the experience of dementia for carers and people from CALD communities is needed in addition to work commenced by DADHC looking at the needs of carers and people in the Italian, Vietnamese and Chinese communities.

- The Dementia Advisory Services, perhaps with the support of Alzheimer’s Australia NSW, need to extend their efforts in Metro North communities to educate CALD communities about dementia. This need is particularly strong for the Hindi Indian and Filipino communities.

- The recruitment of bilingual and culturally competent workers is challenging for many organisations in Metro North. However, for some organisations that have close relationships to their community, this is not such an issue.

- Mainstream information services need to work with particular CALD organisations to provide information in appropriate and accessible formats.

Recommendations

The recommendations of the first report are generally supported. However in many cases they need to be given an additional dimension or interpretation to have best effect. Responses to those recommendations are reported under the results of the Aboriginal and CALD consultations.

The following overarching recommendations highlight areas for action which appear likely to improve HACC service delivery for people from Aboriginal and CALD communities in Metro North with younger onset dementia and/or dementia and behaviours of concern.

It is **recommended** that:

1. *DADHC assist the HACC service system to more consistently deliver services in a culturally competent fashion.*

   For CALD service delivery, a positive start would be to roll-out the action kit and other materials for service providers contained in the *HACC Cultural Competence Framework* which was not widely available at the time of this project. For Aboriginal service delivery, the development and dissemination of a similar set of practical tools (or expansion of the Framework to include service delivery to Aboriginal people) would be an important step to assist mainstream service providers. Resources for development and training will be required.

   These actions could culminate in the development of a Cultural Respect Framework for HACC: a set of principles that guides policy development and service delivery and expands on the HACC National Service Standards by aiming to strengthen relationships between communities and service providers.

2. *HACC service providers be encouraged to strengthen their connections with community agencies representing Aboriginal and CALD communities, including through communication, consultations and partnerships.*

   This recommendation will also assist eligible people from diverse communities to access HACC services successfully.

3. *Funds be allocated to enable localised action research to identify appropriate service models for people with dementia within specific communities and to implement new approaches to service delivery. Such research needs to be grounded in and driven by the local community.*

   This recommendation reflects the diversity of community needs and preferences for service delivery, the variation in HACC infrastructure across the region and different understandings of dementia which all reinforce the inapplicability of 'one size fits all' in service design. It also recognises that additional resources may be required for different service models.

4. *DADHC encourage and assist Dementia Advisory Services, Alzheimer's Australia NSW and other relevant agencies to work in partnership with Aboriginal and CALD community bodies and service providers to promote awareness of and education on dementia in their communities.*

   A consistent message from the consultations was the limited understanding of dementia among community members. Any campaigns will need to be sensitive to the way dementia is considered in different communities. This is discussed in Chapters 3 and 4.

5. *In future planning and service development activities, DADHC allow more lead time and calendar time for consultations.*

   Stakeholders were keen to participate in the project but pointed to a preference for more elapsed time so that they could consult with more people within their communities as a contribution to the project. Others noted the difficulty of meetings late in the calendar year.

6. *DADHC consider creating additional Aboriginal HACC Development Officer positions across Metro North to assist the service system respond to the needs of Aboriginal clients.*

   There is currently a position in the Mt Druitt area with Gilgai Aboriginal Services. Similar positions could be located in the Blue Mountains and the Northern Beaches.

1 The Project

1.1 Project brief

In 2006/07 *Alt Beatty Consulting* conducted research in DADHC's Metro North Region to identify the key elements of Home and Community Care (HACC) service models appropriate for two groups of people with dementia and special needs:

- people with younger onset dementia; and
- people with dementia and behaviours of concern.

The report of that project was *Appropriate HACC Services Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern.* A report recommendation was that its findings be tested through further discussion and consultation with Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CALD) client representatives and service providers to ensure they are inclusive of their needs.

This report presents the results of a consultation project to test the recommendations. The project:

- Briefly reviewed additional literature and previous research to better understand the issues relating to the two target groups people with younger onset dementia and people with dementia and behaviours of concern as experienced in CALD and/or Aboriginal communities.
- Completed a thorough consultation process with CALD and Aboriginal client representatives and service providers within Metro North Region in relation to the findings of the report *Appropriate HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern.*
- Documented the feedback from the consultation process.
- Identified additional considerations which need to be given to service models for people with younger onset dementia and dementia and behaviours of concern for CALD and Aboriginal population groups.

- Determined appropriate changes required to make the existing report more inclusive of the needs of people from CALD and Aboriginal backgrounds. (DADHC 2007)

1.2 Consultation method

Consultations aimed to include each Aboriginal and CALD Specific HACC funded organisation within Metro North and a representative selection of CALD and Aboriginal client representatives.

- The approach involved prior circulation of a brief paper (Appendix B) which summarises the report, *Appropriate HACC Services Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern,* and its recommendations.
- Key concerns were to indicate which recommendations are important in service delivery to Aboriginal and CALD populations and to identify any other issues which need to be reflected in service models.
- Consultations included focus groups and face to face and telephone interviews.
- Where appropriate, consultations linked up with planned meetings of the targeted groups.
- Consultations were informed by DADHC's equity and access policy units.
- The emphasis within the consultations aimed to reflect the distribution of the Aboriginal population and different language groups across the region.

Participants in the Aboriginal community consultations are listed in Chapter 3 and participants in the CALD community consultations in Chapter 4.

1.3 Scope of report

Framework for consultations

The question of cultural competency underlies the capacity of the HACC service system to deliver service in appropriate ways to Aboriginal people and people from CALD backgrounds. The next chapter draws on the literature and discussions during the project to consider cultural competency.

Testing of recommendations

Chapters 3 and 4 present the results of the two sets of consultations. The findings are related to the 16 recommendations of the first report and to other issues which emerged during the consultations.

Terminology

Throughout the project and throughout this report, the two groups of people with dementia under consideration are described as ‘people with younger onset dementia’ and ‘people with dementia and behaviours of concern’.

The earlier research project noted that other terms, including ‘early onset’ and ‘challenging behaviours’ are used both in the literature and in the field. That project was guided by its Advisory Committee in the terms selected. “Without detailing the relative merits of the alternatives, defining the terms used and applying them consistently appears to have helped in ensuring the focus of the project has been well understood throughout the consultations.” (Alt Beatty 2007)

Definitions

People with younger onset dementia are people aged under 65 years old with a diagnosis of dementia. In the case of the Aboriginal population, they are people aged under 45 years old with a diagnosis of dementia. This reflects the approach in HACC of considering Aboriginal people as possibly frail aged from 45 onwards.

Behaviours of concern are usually defined as behaviours which are disruptive, aggressive or socially unacceptable such that the person with dementia has difficulty in the home, in the community and in accessing mainstream services.

Behaviours of concern may occur at any age of the person with dementia or at any stage of the dementia.

Metro North Region covers approximately half of Sydney: from the Northern Beaches in the east to the Blue Mountains in the west.

2 Cultural Competence in HACC Services

2.1 Cultural and Linguistic Diversity in Australia

Within Australia's culturally diverse population, two groups are regularly identified by governments as having special needs: recent migrant populations and Aboriginal people. Australia has one of the most diverse migrant populations in the world and has increasing numbers of older people from culturally and linguistically diverse backgrounds. The reality of ageing for people from CALD backgrounds is influenced by a range of factors including cultural and language barriers and the experience of migration which can affect their financial circumstances and geographical location (Roa, Waburton and Bartlett, 2006).

Aboriginal communities comprise many different language groups, as is evident in the Metro North region which covers the traditional homelands of several groups.

The numbers of people in both CALD and Aboriginal communities with dementia is likely to increase over the next 20 years. Access Economics (2006) completed a study on the prevalence and incidence of dementia in Australians who do not speak English at home. The study found that between 2001 and 2050 there is projected to be a fall in the proportion of Australians speaking English (83.8% to 82.4%) and other European languages (7.6% to 6.0%), with a greater proportion speaking Asian (6.0% to 8.3%) and Middle Eastern (1.8% to 2.3%) languages. It is therefore likely that there will be increasing numbers of people with dementia from a culturally and linguistically diverse background.

The number of Aboriginal people with dementia is uncertain. However, there are currently major studies being undertaken in NSW and Queensland to determine the prevalence of dementia. However what is known is that the health and life span of Aboriginal people is improving and as more adults survive to mid-life, dementia may be a major health problem.

The changing demographics of the Australian population, as well as the changing demographics in the Metro North region, are important in the planning and development of dementia services.

2.2 What is cultural competence?

Cross et al (1989) define cultural competence "as a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations". Cross cultural competence requires organisations and workers to have the capacity to:

- value diversity;
- conduct self-assessment;
- manage the dynamics of difference;
- acquire and institutionalize cultural knowledge; and
- adapt to the diversity and cultural contexts of the individuals and communities served.

Cultural competence exists at the individual worker level, at the organisation or program level, at the state and at the national level. Individual workers need skills and knowledge and awareness in understanding their own culture and how this affects their practice and how they engage with people from cultural backgrounds that are different from their own. Programs and organisations need to develop systems to support individual workers to be culturally competent in practice.

One of the first steps in working from a framework of cultural competence is to acknowledge that culture and ethnicity guide and affect behaviour and that all people are cultural beings. Part of this process is getting people to become aware of their own cultural attitudes and beliefs and identifying that these cultural beliefs and practices shape the way in which they interpret and understand the world (Dolores et al, 2003).

In discussing cultural competency the concepts are framed as 'cultural respect' and 'cultural safety'. Cultural Respect is about shared respect and is achieved when service systems provide a safe environment for clients and cultural differences are respected. It is a commitment to the principle that the construct and provision of services offered will not wittingly compromise the legitimate cultural rights, practices, values and expectations of Aboriginal and CALD communities. The goal of Cultural Respect is to uphold peoples' rights to maintain, protect and develop their culture and achieve equitable service outcomes.

Cultural Safety is about creating an environment where the individual is not only treated well and in a culturally respectful manner, but they are also empowered to actively participate in interactions, believing they are valued, understood and taken seriously and supported to carry out culturally significant tasks as part of service delivery.

Cultural competence exists in a continuum of cultural practice and begins with *cultural awareness*, having the knowledge and understanding of cultural differences and history, to *cultural competence,* that is, services being sensitive and developing appropriate policies that allow for effective programs to be developed and implemented which leads to *cultural safety* which is grounded in trust and genuine partnership by all stakeholders.

It is important that individual workers and organisations work from a foundation of understanding cultural competence and how to build services that are culturally competent for people with dementia.

2.3 Culture and Dementia

A person's culture, life experiences and religious beliefs may affect their understanding of dementia and perceptions of the care giving role. This may affect how or whether carers seek out informal and formal support.

Mackenzie (2006) studied the impact of community and family obligation, religious beliefs and culture on carers from eastern European, Pakistan and India in the United Kingdom. This study explored the effect of stigma on carers of people with dementia. The study found that the understanding of dementia by carers is affected by the stigma of having dementia which in turn affects how family carers engage with formal and informal support services. For the Eastern European carers (primarily from Poland and Ukraine) people with dementia and their carers were deeply affected by war experiences. The carers in the study described keeping the family as an important symbol of survival. Going public about having a family member with dementia could lead to stigmatisation within their community.

The cause of stigma among Pakistani and Indian carers was different from the Eastern European families. Dementia was classified as a mental illness and the stigma associated with dementia was "primarily rooted in religious ideology" which meant that caring was identified as a religious obligation (Mackenzie, 2006:242). The combination of religious and spiritual influences on the nature and origin of dementia create fear about what dementia is. The study concluded that it is important for clinicians to be aware of different cultural understandings of dementia. More research is needed on the impact that service use may have on the way that carers and their relatives are perceived in their community in supporting a person with dementia.

Braun and Browne (1998) explored the views of dementia in the Asian and Pacific Islander population in America. The study found significant differences between different communities. For example, recent immigrants from a Chinese background view dementia symptoms as mental illness (which is shameful), as an imbalance of yin and yang, as an improper alignment of the house (according to Feng Shui) and as possession by an evil spirit. The Filipino people involved in the study reported that children are expected to care for the parents until death and it was acceptable that a parent live from time to time with one child and then with another (Braun and Browne, 1998:268). The study concluded that more research is needed to understand

how culturally linked values affect health and help seeking behaviours related to dementia.

The needs of refugees and people who have experienced torture and trauma and have dementia also need to be considered. NSW Health (2006), in a study on caring for older refugees in NSW, highlights their needs in terms of accessing health care, aged care and community care services. It indicates that settlement should be considered a lifelong process and a whole of government approach is needed to support older refugees. Torture and trauma and war can affect people throughout their life course.

The report argues that refugees should be considered as a special needs category in terms of access to health and aged care services. It identifies the difficulties of older refugees in accessing services. The report suggests that partnerships should be developed to encourage aged care providers and health services to work more closely with ethnic community organisations and with specialist services that are already working with older refugees, such as STARTTS, Transcultural Mental Health Centre and the NSW Refugee Health Service. It is important that HACC services are aware of the needs of people with dementia who have experienced torture or trauma and are able to refer people for appropriate support.

The issue of culture and dementia for Aboriginal communities is affected by the historical and contemporary issues impacting on their wellbeing. Issues such as people being denied the right to practice their culture and therefore a culture almost lost, forced removal of children from homelands resulting in the Stolen Generation, systemic and institutionalised racism and various forms of abuse are all factors that impact on the day to day reality for many Aboriginal people and their capacity to access services of all descriptions. Understanding the impact of trans-generational and intra-generational trauma and the link with illnesses such as dementia is crucial to developing service responses that are culturally competent.

2.4 Understanding behaviour in the context of culture

Understanding behaviour in the context of a person's culture is critical to understanding and supporting people with dementia.

Elliot and Minno (2007) undertook a study on exploring the cultural clashes for Chinese people in an Alzheimer's centre in California. The study found that the lack of familiarity with Chinese culture meant that the culturally mainstream American clinicians at the centre were more likely to misinterpret the behaviour of older Chinese speaking people and suggest culturally inappropriate recommendations. The study highlighted that clinicians need to:

- incorporate cultural knowledge into the diagnostic process;
- pause at what seems abnormal behaviour and ask if culture is critical; and
- seek input and feedback from the family and carers at all stages.

For Aboriginal people, understanding the behaviour of someone with dementia should be examined from an holistic perspective. This includes acknowledging the person's cultural place in the community, particularly if they are an Elder, and giving consideration to how younger family and community members provide support.

2.5 Embedding cultural competence in practice

There are a number of strategies that DADHC will need to consider in order to embed culturally competent practices into HACC service delivery and policy and program development. One strategy is the development of a Cultural Respect Framework. The Framework is a set of principles that guides policy development and service delivery and, in particular, is aimed at strengthening the relationship between stakeholders in the sector, across communities and service providers.

In the context of this project, embedding cultural competence in practice can be progressed through the employment of Aboriginal Access Workers or Development Officers, who would have a similar role to the Multicultural Access Workers. In identifying potential locations for these positions, it will be important to consider a number of supporting factors such as existing infrastructure and local community service systems, both organisations and workers. It would seem beneficial if such positions existed in key parts of the region. The existing position in the Blacktown LGA could be complemented by positions in the Northern Beaches and the Blue Mountains.

DADHC (2005:2) has developed a strategy to improve services for people from culturally and diverse communities. The strategy has four key aims to:

- improve the participation by representatives from culturally diverse community groups in the Department's planning and decision making;
- promote opportunities for older people, people with a disability and carers from culturally diverse backgrounds to participate equally in service programs in the community;
- improve participation by people from culturally diverse backgrounds in DADHC –operated and funded services and programs;
- improve the appropriateness of DADHC's services and programs to servicing the needs of people from CALD backgrounds.

DADHC has already made considerable investment in this area in the form of a HACC Cultural Competence Framework which includes an Action Kit. The first step in the Kit

> is to complete a cultural assessment of your organisation. By completing an assessment of your service, you'll be able to identify where the organisation currently

> is in terms of cultural competence, your strengths, weaknesses and areas for further development. You can then tailor the components of the *Action Kit* to focus in on the specific needs of your service. (Patterson 2006.)

The material which forms the Framework – five documents in all, including literature review, analysis of cultural competence and action for service providers – was not available to this project and was only able to be accessed at the time of finalising this report. The framework focuses on CALD clients, but its structure could be extended to incorporate Aboriginal clients.

3 Aboriginal Consultations

3.1 The Aboriginal population in Metro North

Metro North region contains the largest Aboriginal population in NSW, with the Blacktown Local Planning Area (LPA) containing the highest proportion of the region's Aboriginal population.

The Aboriginal community in the region is diverse and contains a number of distinct communities each with their own cultural identity specific to their locality. The Metro North region spans the traditional home lands of the Darug, Gundungarra, Tharawal and Guringai people. The region sits within the boundaries of a number of Local Aboriginal Land Councils who play a key role in accessing communities.

The region has an Aboriginal Home Care service, Wangary, located at Penrith, and a small number of Aboriginal community organisations delivering a range of HACC and other services.

According to the Northern Sydney Aboriginal Social Plan, the Northern Sydney region had a population of 1,763 Indigenous people in 2001. 1,551 were Aboriginal and 156 were Torres Strait Islanders and 56 identified as both.

The Aboriginal population in the Blue Mountains made up about 1.2% of the total Blue Mountains population in 2001. This is a young population with an average age of around 20. The largest group are living in the Upper Mountains.

According to the 2006 Census (DADHC report):

- The Aboriginal population in Cumberland/Prospect LPA is 9,867 (1.3%). Blacktown has the highest proportion of the Aboriginal population within the LPA, with over 7,000 people identifying as Aboriginal or Torres Strait Islander.

- The Aboriginal population in the Nepean LPA is 6,155 (2.0%). Within this LPA, Penrith has the highest proportion of Aboriginal people, with over 1,200 people identifying as Aboriginal or Torres Strait Islander.

- The Aboriginal population in the Northern Sydney LPA is 1,873 (0.2%). The numbers for the Aboriginal population in this area are quite low. However there are emerging communities in the Hornsby/Ku-ring-gai area.

- The percentage of people of Aboriginal background aged over 45 years in Cumberland/Prospect is 16%, in Nepean 15.5% and in Northern Sydney just over 15%.

- There are Aboriginal specific HACC services in Cumberland/Prospect and Nepean LPAs. While there are currently no Aboriginal specific HACC services established in Northern Sydney, funding has been identified for Aboriginal specific services in this LPA in the 2007/08 HACC Plan.

3.2 Consultation method and participants

Service providers and client representatives were consulted either by participation in forums, by individual telephone interviews or in face to face meetings.

Table 3.1 indicates the range of people consulted as part of the project.

Table 3.1 Aboriginal Consultations

Name	Organisation
Nicole Winters	Gilgai Aboriginal Centre
Mariann Smith	Gilgai Aboriginal Centre
Brad Moore	Blue Mountains Aboriginal Respite Centre
Carol Cooper	Blue Mountains Aboriginal Respite Centre
Julie Hendicott	Northern Beaches Aboriginal community
Lois Birk	Northern Beaches Aboriginal community
Susan Moylan-Coombs	Northern Beaches Aboriginal community
Eddie Goodall	Northern Beaches Aboriginal community
Jessica Birk	Northern Beaches Aboriginal community
Caroline Glass-Pattison	Northern Beaches Aboriginal community
Bruce Lowrie	Northern Beaches Aboriginal community
Maxine Conaty	Wangary Aboriginal Home Care
Robert Leslie	Blacktown City Council
Christine Atkins	Chesalon Community Care Nepean
Joy Cooper	Chesalon Community Care Nepean
Marisa Galizzo	Care Connect
Debra Mills	North West Disability Services
Ruth Willick	Sydney West Area Health Service
Virginia Curnow	Alzheimer's Australia
Sheree Freeburn	Carer's NSW
Joanne Scott	Indigenous Disability Advocacy Service

3.3 Comments against recommendations

HACC System Improvements

Recommendation

1. *DADHC request HACC service providers in local planning areas to develop a protocol for providers to receive support and advice in regards to clients with younger onset dementia and for clients with behaviours of concern within their area.*

Comment

The development of a culturally appropriate service protocol was seen as an important document to be developed more broadly around the broad spectrum of HACC issues including dementia.

Recommendation

2. *HACC program administrators encourage both Carelink and individual HACC providers to keep up to date with local referral processes and with services which can provide special support to people with younger onset dementia and people with dementia and behaviours of concern.*

Comment

This recommendation was supported, however it was considered that the HACC program administrators need to become better informed about the Aboriginal community contacts which will assist with local referrals.

Recommendation

3. *The Dementia Advisory Services be promoted as a primary point of contact for people with younger onset dementia. This will enable:*

    i. *central collation of demand for younger onset services through the Dementia Network or by DADHC; and*
    ii. *promotion of a simple message to neurologists and neurology services that people should contact their nearest DAS following a diagnosis.*

Comment

There was concern expressed around the Dementia Advisory Services (DAS) being seen as the only central point of contact as most Aboriginal people won't use the DAS initially. They are more likely to use an Aboriginal-specific community organisation and then seek their assistance in accessing the DAS. Whilst it was recognised that the DASs play a critical role in referral and awareness raising, it was evident that the DASs will need to work in closely with local Aboriginal organisations to ensure Aboriginal clients access their services.

Recommendation

4. *Across NSW, HACC program administrators facilitate some flexibility in how service funding is used and applied, within minimum output and targeting requirements, so that providers can respond better to the needs of particular clients. Strategies here may include:*

   i. *encouraging HACC providers to contact DADHC when they face a rigidity in their funding relative to clients' needs; and*
   ii. *producing guidelines and a good practice manual demonstrating flexible approaches.*

Comment

Flexibility of funding was raised continually in the consultations by both community stakeholders and service providers. There seemed to be a common view that the funding available for HACC programs is so structured it limits the capacity of services to develop programs that meet the cultural needs of particular clients.

It was suggested that when information materials are being developed that consideration be given to developing Aboriginal specific products in partnership with local communities.

Recommendation

5. *HACC program administrators actively promote, support and improve incentives for collaboration across providers to offer complementary and seamless support to people in these two target groups.*

   Funding could support collaborative initiatives such as:

   i. *supporting day centres to agree on and publicise their respective strengths and specialisations for particular HACC client sub-groups; and*
   ii. *promoting cross-agency, complementary problem solving, care coordination and client support, irrespective of whether relevant agencies are HACC funded or not. This may involve development of local protocols. It is particularly important for service gaps, such as transport.*

Comment

This recommendation was supported. The issue of collaboration is strongly recommended particularly given the small numbers of Aboriginal people in comparison with the mainstream and CALD communities. Services such as Gilgai and the Blue Mountains Aboriginal Respite Centre are keen to improve cross-agency partnerships.

It was suggested that a pilot project be developed around Cultural Brokering which could focus on supporting and developing collaborative practices to assist with cross agency service provision and improve coordination of service delivery. Aboriginal organisations could be engaged to take on the role of a cultural brokerage service

between Aboriginal communities and mainstream dementia services. It would be important to ensure adequate input from communities into developing this approach.

It is important to note that Aboriginal services understand the complexities of cultural service delivery and could act as a conduit between Aboriginal clients and communities and mainstream services.

Recommendation

6. *HACC program administrators request that HACC/Community Care Forums review exit strategies being used by service providers with a view to developing and implementing common, good practice across community care.*

Comment

Supported.

Recommendation

7. *HACC program administrators strengthen the sharing of leading practice material, models and lessons across the region and from elsewhere in NSW and Australia. Strategies may include:*

   i. *targeted training for providers;*
   ii. *using HACC/Community Care forums as a vehicle for disseminating material; and*
   iii. *reinforcing to providers the role of Alzheimer's Australia NSW as a specialist resource in this field.*

Comment

There are a number of best practice models being developed and implemented in response to dementia within Aboriginal communities including the Kimberley Indigenous Cognitive Assessment tool and radio advertisements to raise the awareness of dementia. These models could be adapted to suit the needs of communities in the Metro North area. Research into the burden of dementia in urban dwelling Aboriginal people and into assessment and better care outcomes for urban Aboriginal people by the Dementia Collaborative Research Centre, University of New South Wales, may assist in this regard.

Sharing information and collaboration with other services was seen as a significant gap and one that could be improved upon. Information could be shared across the Aboriginal service system through the following methods:

- Western Sydney Koori Interagency – presentations and information sharing;
- Email network – the members do not want the list distributed but instead the information is managed by the Blacktown City Council Aboriginal Liaison Officer;
- via a website – a number of Koori Inter-agencies are involved in www.sydneykin.org.au;

- attendance at HACC forums – HACC Development Officer to provide updated information on existing and new initiatives and programs; and

- the Koori Care Team produced a book discussing local services. This is a collaboration between HACC, NSW Health, DADHC, Gilgai and others.

HACC Good Practice (Section 4.2)

Recommendation

8. *HACC providers be reminded of the importance of the following HACC Outcomes in assisting people with younger onset dementia and people with dementia and behaviours of concern:*

   1.1 Formal assessment occurs for each consumer.
   1.2 Consumers are allocated available resources according to prioritised need.
   1.3 Access to services by consumers with special needs is decided on a non-discriminatory basis.
   2.2 Consumers are aware of services available.
   2.3 Consumers are informed of the basis of service provision, including changes that may occur.
   3.1 Consumers receive appropriate services provided through the processes of ongoing planning, monitoring and evaluation of services.
   4.1 Each consumer receives ongoing assessment (formal and informal) that takes all support needs into account.
   4.2 Each consumer has a service delivery/care plan which is tailored to individual need and outlines the service he or she can expect to receive.
   4.3 Consumers' cultural needs are addressed.
   4.4 The needs of consumers with intellectual difficulties, including dementia, memory loss and similar disorders, and intellectual disabilities are addressed.
   4.5 Consumers receive services which include appropriate coordination and referral processes.

Comment

Supported. However there was general agreement that HACC providers need to be mindful of cultural aspects when assisting people with dementia, such as families feeling obliged to care for clients particularly when many Aboriginal people with a form of dementia don't tend to see themselves as being sick and therefore do not access services until crisis points.

Recommendation

9. *DADHC discuss the recommendations of this project with Aboriginal and CALD service and client representatives to identify any additional considerations which need to be given to people with younger onset dementia and dementia and behaviours of concern for those population groups.*

Comment

At each consultation, the issue of timing was raised and it was recommended that DADHC needs to look seriously at timeframes provided for consultation and research work. The communities were not happy with the time of year the project is running and the short length of time. Communities would have liked to have seen more time for consultations and more opportunities for discussion with different groups in the community.

Recommendation

10. *HACC program administrators recognise the episodic or irregular nature of many behaviours of concern and offer enhanced capacity or flexibility to allow providers to offer:*

    i. *periods of intensive, targeted support between periods of "maintenance" support; and*
    ii. *wherever possible, continued care during these times of concern, or positive, flexible and sensitive re-entry to maintenance services once strategies are developed to manage or minimise behaviours.*

Comment

Supported.

Recommendation

11. *HACC program administrators and providers ensure that workers supporting people with younger onset dementia and/or behaviours of concern have appropriate competency based training.*

Comment

The issue of culturally competent service delivery was raised continually throughout the consultations from both clients and service providers. Gilgai and the Guringai Aboriginal Education Consultative Group currently provide cultural awareness training in a number of capacities. It is suggested that funding be provided to enable the organisations to extend these programs to others in the HACC industry.

The development of a set of minimum cultural competence service standards will assist with Aboriginal-specific service needs being embedded in work practices eg reminders to families about the transporting issues and pick up times and the issue of language.

It was suggested that DADHC advocate at the national level for the inclusion of an eighth standard in the National Service Standards that relates to culturally competent service delivery.

Recommendation

12. *DADHC communicate the findings of this project to HACC service providers across NSW and to the Commonwealth and request that any national campaigns on dementia include the issue of younger onset.*

Comment

This recommendation is supported, however it was suggested that there needs to be a concerted effort undertaken in the Metro North region to raise the issue of dementia among Aboriginal communities. Community education should promote dementia awareness, assist families and clients regarding acceptance of the diagnosis and use Aboriginal HACC brochures and other 'branded' products. Gilgai have developed an information leaflet which could be adapted in different locations with a greater emphasis on informing the community about dementia.

HACC Service Initiatives (Section 4.3)

Recommendation

13. *Social support services for people with younger onset dementia be funded equitably across the Metro North region. This recommendation is reliant on a transport component.*

Comment

This recommendation is supported. One of the issues facing the Aboriginal community across the region is the issue of equity, particularly given that the larger Aboriginal population is in the Cumberland Prospect area. The Northern Beaches community especially felt disadvantaged in relation to allocation of funding and services specifically for Aboriginal people.

Recommendation

14. *A 'club model' of day care be funded in several day centres across the region catering for strong and physically active people with dementia, that is, not specific to a particular age group. Key elements of the model include:*

    i. group excursions;
    ii. client choice regarding activities;
    iii. enhanced capacity to cater to interests not necessarily covered by the day centre on other days;
    iv. promotion of 'active ageing'; and
    v. a higher staff client ratio than is usual in HACC day care.

    This could be funded through the Centre Based Day Care, Dementia Specific, funding stream.

Comment

This recommendation is supported. However given the infrequency of clients with dementia accessing services, it was suggested that funding could be made available for Aboriginal organisations to develop programs similar to a 'club model' when necessary to provide activities specific to meeting the client's needs at that particular time.

Recommendation

15. *HACC and NRCP program administrators ensure that each area has a specialist, quick response worker or team capacity to assist workers and carers experiencing difficulties with people with dementia and behaviours of concern. Such a service would aim to assist carers and workers to understand the behaviours and to design, trial and implement strategies to minimise or prevent their recurrence. It should be part of the existing service infrastructure such as within a Dementia Advisory Service. The service needs to link in with health pathways which include mental health and targeted programs such as BASIS and SAFTE.*

Comment

Supported.

Recommendation

16. *DADHC and NSW Health trial one or two dementia cafés along the lines of the Victorian and European models as a means of bringing people with dementia and their carers together with trained staff, in a stress-free environment. The cafés promote self-reliance and self-help and follow on from Living With Memory Loss Clinics.*

Comment

This recommendation is supported. However there is the issue of Aboriginal people with dementia attending what is likely to be a mainstream service. It was suggested that an Aboriginal service could be provided with the opportunity to pilot an Aboriginal specific dementia cafe. Services from the Blue Mountains and Penrith noted that they would be keen to take clients to an Aboriginal service as opposed to a mainstream 'café'.

Recommendation

17. *HACC program administrators and providers evaluate the results of the Northern Sydney Dementia Nutrition Pilot Project to determine whether an alternative service model or supplementary approach in food services could assist people with dementia and behaviours of concern. The model is expected to include the employment of a community based dietician to assist all services, along with expansion of services' capacity to assist clients with eating and to return some hours later to assist them with a second meal.*

Comment

The recommendation was generally supported.

3.4 Other issues raised

- Aboriginal people have significant levels of trans-generational disadvantage, affecting employment, education, income and a range of social issues. In each consultation, people raised the issue of mental health believing that it is related to people acquiring certain types of dementia.

- Mental illness in the Aboriginal community can be complex and multi-faceted involving a range of issues that have the capacity to impact on people acquiring a form of dementia. Traumatic experiences such as domestic violence, relationship breakdown, deaths of family and friends, incest, abuse, assault and accidents are endemic in many families and impact on mental health issues.

- The issue of the Stolen Generation and the impact of forced removal on individuals, families and communities and how this relates to mental health and dementia was continually raised during consultations. An example of this is the 'mental illness' associated with events such as the removal of Aboriginal children from their families and the associated abuse that may have been received in institutions. The trauma and grief experienced by removed individuals can trigger mental illnesses. Mental illness attributed to substance abuse issues may also be linked to the effects of cross generational disadvantage within the Aboriginal community.

- Elders believe that their cultural roles and responsibilities will be compromised if they are unable to function in a way that allows them to be the elder statesperson in their community. These roles and responsibilities require Elders to provide guidance and support to the community, participate in decision making, cultural activities or ceremonial events, share stories, offer advice and pass on key information about their heritage.

- There are no Aboriginal specific Residential Aged Care facilities in the region despite the significant Aboriginal population that resides in Metro North.

- Transport is a key issue for each distinct community.

- A need for more Aboriginal people working in the aged and disability services area. Specific training to be provided for the Aboriginal community in these areas with the view to enhancing the existing local workforce.

- There are issues with people not wanting to leave their home to attend a Centre Based Day Care Service. Suggestions included funding to develop more flexible Social Support models when applied as Neighbour Aid, Peer Support and Dementia Monitoring Models in Cumberland Prospect and Nepean LPAs for their Aboriginal communities.

- The issue of service provision to Aboriginal communities is very time consuming, intensive and more complex than for the mainstream population. Family crises often have to be sorted out before services can be organized for the client or their carer. It was suggested that consideration be given to greater flexibility in reporting on outputs in relation to DADHC reporting requirements.

3.5 Key messages from Aboriginal consultations

A key message from the Aboriginal consultations was the concept of holistic health and wellbeing and the connection to family and community which was seen as fundamental to policy, program and service developments. Moylan-Coombs (2006:29) states that *'in considering and addressing Aboriginal health issues it is important to understand the cultural dimensions of Aboriginal wellbeing and the integral connections between Aboriginal health, spirituality and connection to land and country. A relationship exists between positive social networks and interactions and overall mental wellbeing*.'

- In discussing dementia, participants continually brought the conversations back to the issue of mental health. It was clear that in considering dementia, mental health is seen as a priority of which dementia is part.

- Suggestions were made that local research needs to be undertaken by Aboriginal people that live and work in the different locations across the Metro North region.

  The purpose of the local research is to:

  - identify culturally appropriate models for HACC services for Aboriginal people that are specific to that community and improve access to dementia and other services;
  - research the views and experiences of Aboriginal people and the process of ageing and the impact of historical and trans-generational trauma on people in the current context of urban communities;
  - determine the prevalence of dementia in the Aboriginal communities across the region and identify potential risk factors.

- The engagement of a Local Aboriginal specific Community Advisor in the Northern Beaches area was proposed to support the opportunities for local Aboriginal people to better access services, to assist services become better informed of key issues impacting on the community and to raise awareness of groups in the area. This was seen as essential particularly given that in other areas across the region, there is usually an Aboriginal person who is in this type of position in one capacity or another eg the Aboriginal Liaison Officer at Blacktown Council or the Community Facilitator at Hornsby Council.

- Within the Aboriginal community, dementia was generally not seen as a medical issue but rather more as a natural part of the ageing process. This view is also evident in the literature.

- In some communities, particularly the Northern Beaches area, supporting someone with younger onset dementia could be a problem particularly when most Aboriginal people were not living within their extended family environment and generally not accessing services due to them not knowing of the existence of services or fear of attending a service due to a previously negative experience.

- As a population group, Aboriginal people are more likely to have experienced higher rates of imprisonment, head trauma and brain injury, higher alcohol and drug use rates and poorer nutrition which could impact on an increase in the number of people acquiring younger onset dementia.

- Not many Aboriginal people know about dementia, unless they are caring for a family member who has dementia, and have little understanding of how the potential risk of dementia might be reduced.

- Aboriginal families tend to care for the person with dementia which places a burden on the carer and family. Although it was not viewed as this by the family. It was viewed as *'you just do it, it is part of our family responsibilities', w*hich often means that carers are not accessing respite or other services until the later stages of dementia.

- Many local resources are not specifically targeting Aboriginal people. Factual information needs to be provided to services and community organisations to assist with developing brochures and information packages specific to their community and location.

- Culturally sensitive assessment tools are needed and are critical in developing any type of response to issues in relation to dementia. The research in this regard into the experience of urban Aboriginal people by the Dementia Collaborative Research Centre at the University of New South Wales may provide a helpful starting point.

- People were concerned that current practice models were based on a premise of 'risk assessment' rather than 'keeping people safe'. Cultural safety and respect was seen as an important consideration for the development of policy and programs covering the following areas:

    - prevention behaviours – lifestyle changes to reduce the likelihood of acquiring dementia
    - difficult behaviours of clients
    - isolating behaviours – loneliness of carers and clients with dementia
    - cross cultural behaviours – people need skills to provide a service with sensitivity and cultural competence.

- The majority of Elders prefer to be cared for at home, or in a place where people could readily access their families. Therefore service models that are culturally appropriate need to be developed in partnership with local Aboriginal community groups.

- The issue of transport and its relationship to accessing services was continually raised. This is particularly an issue when Aboriginal clients need to access transport services within the mainstream and they are refusing to get on because they may be the only Aboriginal person on the bus. This causes anxiety to other clients, to carers and to the client.

- More work needs to be done between HACC and Health to develop training for care workers that is relevant to Aboriginal people with dementia and to successful ageing.

- In relation to improving the understanding of dementia in Aboriginal communities, the following was suggested:

  - providing community education and training to increase peoples' awareness of dementia;
  - developing and implementing culturally appropriate models of care, including information for adult, children and community organisations that play a key role as information access points; and
  - supporting the role of culturally specific organizations in being able to provide information, organize training for service providers and work in a 'cultural brokering' capacity in relation to transitioning Aboriginal people with dementia into mainstream services when necessary.

Issues for the workforce

Key issues raised during the community consultations included some issues that impacted on the workforce:

- A perception by workers that dementia is not considered by funding agencies as an area worth investing in.

- Increased opportunities for local dementia research in the area.

- More information on risk factors is needed to expand Health and HACC workers knowledge about dementia.

- People working in isolation.

- Families of clients considered by mainstream agencies as part of the workforce because they needed their assistance to manage their Aboriginal clients.

- More cross cultural training for aged care facilities and other relevant services.

- Creation of partnerships with key stakeholders ie government, NGO sector and communities.

- Greater access to professional development.

- The value of Aboriginal Interagency forums in supporting both workers and effective service delivery.

Best practice examples

There are a number of good practice models operating in communities that raise the awareness of dementia and improve service delivery for Aboriginal people.

- Setting up Elder Groups and/or Support Groups and focusing on social activities.

- Promoting opportunities for people to express and experience their culture as a method of enhancing wellbeing.

- Adapting appropriate mainstream models and services to suit Aboriginal values.

- Developing informal and formal partnerships with other services.

- Facilitating and participating in cross cultural training.

- Providing debriefing and support to carers, families and friends.

- Researching dementia related issues particularly from an urban perspective.

- Brisbane Indigenous Media Association (QLD):
    - radio advertisements to raise community awareness about dementia;
    - project to be undertaken nationally; and
    - could link into existing community education opportunities eg Koori Radio.

- Frontier Services (Northern Territory)
    - culturally appropriate phone counselling and service protocols;
    - community education;
    - actively seeks input from clients regarding access; and
    - actively develops networks.

- Booroongen Djugan, Kempsey, is an Aboriginal aged residential and community care service that also provides a training college.

3.6 Summary of considerations for Aboriginal HACC clients

Community Awareness

- Community education programs to improve understanding about dementia
- Development of innovative community education products
- Aboriginal dementia symposium in partnership with DAS.

Service Improvements

- Adaptation of existing services eg the Living with Memory Loss Program
- Culturally competent service delivery
- Workforce issues – increase Aboriginal workers in the sector.

Research

- Cultural issues that influence how services are being accessed
- Trans- and inter-generational trauma and its impact on acquiring dementia.

4 CALD Consultations

4.1 The CALD population in Metro North

The Metro North region is culturally and linguistically diverse (CALD) and covers three distinct local planning areas: Cumberland/Prospect, Nepean and Northern Sydney. Each of these areas is culturally and linguistically diverse.

Cumberland Prospect

In the Cumberland Prospect LPA, according to the 2006 Census, more than a third of people were born overseas and the top five languages other than English spoken at home[1] were:

- Arabic languages (including Lebanese) – 6.4%
- Cantonese - 3.6%
- Tagalog, including Filipino – 2.9%
- Mandarin – 2.6%
- Hindi – 1.9% (ABS:2006).

In Cumberland/Prospect, 6.4% of the population reported having limited proficiency in English. For people aged 65 years and over this rises to just over 14% of the population (ABS, 2006). Anecdotal evidence from HACC service providers also indicates that people of an Indian background who speak Hindi or are from a Filipino background are not aware of services and that there are low numbers of these people who access HACC services.

Nepean

In the Nepean LPA, one sixth of the population (16%) were born overseas and 8% of people speak a language other than English. The top five languages in Nepean are:

- Arabic (includes Lebanese) – 0.9%
- Tagalog (includes Filipino) – 0.8%
- Italian – 0.7%
- Maltese – 0.6%
- Greek – 0.5%.

[1] At the time of finalizing the project, a further release from the 2006 Census was expected to provide an age breakdown for languages other than English spoken at home.

The number of people who reported their proficiency in English as not well was 1.1% of the population, much less than in Cumberland/Prospect (ABS 2006).

Northern Sydney

In the Northern Sydney LPA approximately one third of the population was born overseas and 13.6% of people speak a language other than English. The top five language groups are:

- Cantonese – 3.8%
- Mandarin – 2.7%
- Korean – 1.4%
- Italian – 1.4%
- Japanese – 0.8%.

Approximately 2.9% of the population reported that they were not proficient in speaking English. This is higher than the Nepean LPA but less than in Cumberland/Prospect (ABS 2006).

Given the demographics of the three LPAs in Metro North, the project consulted with a number of CALD specific HACC funded services that provided services to a range of communities. Consultations were also held with service provider representatives or community representatives that worked with the following communities across the Metro North region:

- Arabic speaking community
- Chinese speaking community
- Italian speaking community
- Hindi speaking community
- Filipino and Tagalog speaking communities.

4.2 Consultation method and participants

Service providers and client representatives were consulted either by face to face interviews, telephone interviews or by attending existing forums or gatherings. A special service provider consultation was held in Chatswood in December and six people attended this consultation.

Table 3.1 indicates the range of people consulted as part of the project.

Table 3.1 CALD Consultations

Name	Organisation
Niveen Nassif	MidWest Community Care
Azza Ahmed	Tripoli and Menai Association
Nayef Hajej	The Association of Bhanin El Minieh – Australian Arabic Community Welfare Centre
Ruth Willick	ADC & HACC Planning Coordinator, Primary Care and Community Health Network, Sydney West Area Health Service
Michael Magro	Willyama Cottage – Special Needs Aged Day Care Centre
Gulsen Sabuncuoglu	Hevington House, Aged Day Care Sydney West Area Health Service
Irene Turnbull, Roscellita Ann Lacsina	Hills Community Care
Noel Chiu	Aged Day Centre Co-ordinator, Sydney West Area Health Service
Joyce Ma	Multicultural Health Worker, Sydney West Area Health Service
Jay Raman	Sri Om Foundation. Federation of Australian Indian Associations
Amy Chan	Australian Chinese Community Association
Thomas Camporeale, Alessandra Martino, Lucy Merret	COASIT
Lina Cabaero	Philippine Australian Community Service Inc (PACSI)
Amy Butcher	Blacktown Migrant Resource Centre
Dr Yash Bhasin	Australian Hindi Indian Association
Robyn Lord	Tallowood, Dementia Aged Day Care, Sydney West Area Health Service
Maria Avgoulas, Katerina Petridis	Greek Welfare Association
Clare Etherington	Mercy Community Care
Elizabeth Atkin	MS Society
Stephanie Henstack	Aged and Disability Support Services
Heather Farmer	Baptist Community Services
Jenny Gillespie	Nepean Food Services
Greg Wyatt	Holroyd Community Food Services
Than Ho	Auburn Meals on Wheels
Valerie Huddleton	Blacktown Meals on Wheels
Chititra Mukerjee, Sardra Nana	Manager (joint), CALD Policy Equity Unit, DADHC
HACC service providers	Blue Mountains HACC Forum
Yvonne Santalucia	Ethnic Aged Care Adviser, South West Sydney Area Health Service
Members of Philippine Australian Community Service (Inc)	Philippine Australian Community Service Inc (PACSI)

As provided in the project brief, the consultations focused on service providers and representatives from particular CALD communities. In the future it would be useful to undertake more consultations with carer and consumer representatives to further explore issues of dementia and caring for people from CALD communities.

4.3 General themes and comments

- The consultations identified that there are People from CALD backgrounds with younger onset dementia currently being supported by HACC services. Service providers reported supporting one or two people from different CALD backgrounds. The major challenge was having bilingual and culturally competent staff to support this person and provide services on a one to one basis that could meet individual needs.

- The notion of dementia and how it is understood and discussed is heavily influenced by culture. For example, the word dementia translates differently depending on the language and this also affects how people and communities understand and talk about dementia. The cultural differences in understanding dementia need to be considered when designing and delivering community awareness training as well as when providing services.

- There are differences between communities in terms of how people are cared for and whether people may access services. For example, in conversations with the Hindi Indian community, it was reported that families will care for people with dementia and tend to only access services in a crisis. This issue was also raised in conversations with the Filipino and Italian communities. The provision of care is influenced by culture.

- Services reported particular challenges in supporting people with dementia who are refugees and have experienced torture and trauma. People may not speak about their experiences. Some services reported working with people who were experiencing flashbacks from experiences of being a refugee. This area requires specialist support for HACC services to work with the person and understand their experiences.

- In conversations with some of the Arabic Muslim communities, difficulties in accessing culturally appropriate services, particularly for high levels of care required to support people in the home, were reported. An example was given of some people with dementia not being able to access the services they needed and returning to live in Lebanon to get the care that was required.

- Many services reported difficulties in accessing bilingual workers to support people with younger onset dementia as well as people with behaviours of concern. There were, however, examples of services that did not report having difficulties in recruiting and retaining bilingual workers.

- The cost of providing culturally appropriate services was raised by a number of HACC services. Additional costs are incurred in supporting bilingual and

culturally competent staff, in providing food, in finding resources and programming materials in supporting people with dementia and in translating information.

- Some of the communities consulted need more information about HACC services and community awareness programs and information about dementia. This would include the Filipino and Hindi Indian communities. However, it appears that all CALD communities in Metro North would benefit from more community awareness on dementia.

4.4 Comments against recommendations

This section provides feedback from the consultations on the recommendations of the initial report (Alt Beatty 2007). Some of the recommendations are more generic and specific to HACC services and are therefore not commented on in terms of working with CALD communities.

HACC System Improvements

Recommendation

1. *DADHC request HACC service providers in local planning areas to develop a protocol for providers to receive support and advice in regards to clients with younger onset dementia and for clients with behaviours of concern within their area.*

Response from consultations

This recommendation was supported by people and organisations that were consulted through the course of the project. However, it appears that in some communities (particularly the Indian and Filipino communities) more work is needed in connecting these communities to understanding HACC services and dementia.

Comment

It appears that more community awareness and community development work is needed in the Filipino community and the Hindi Indian community in connecting organisations to work in partnership with HACC services as well as undertaking more community development and community awareness work in understanding dementia. The Multicultural Access Project Officer of Cumberland/Prospect is currently working with the Philippines Australian Community Service Inc (PACSI) to identify needs for the community. This is a constructive starting point to developing further relationships and services in the future.

The consultant attended a Seniors Group organised through the Australian Hindi Indian Association. People present had heard about dementia but wanted more information about how to prevent dementia and there were many questions after the consultation. People were also interested in hearing about aged care and HACC services.

COASIT reported running community awareness programs in dementia which were well attended. Programs had also been run in the Arabic speaking and Chinese community which were well attended. CALD specific organisations that were consulted through this project were keen to do more work in educating people in their community about dementia and to work in partnership with Dementia Advisory Services and Alzheimer's Australia NSW.

Recommendation

2. *HACC program administrators encourage both Carelink and individual HACC providers to keep up to date with local referral processes and with services which can provide special support to people with younger onset dementia and people with dementia and behaviours of concern.*

Response from consultations

People from CALD specific organisations reported that due to language barriers many people from CALD backgrounds do not access Carelink. CALD organisations, such as COASIT, Australian Chinese Community Association and Philippines Australian Community Service Inc (PACSI), act as a central information point for people in their community and may access information about services on the behalf of individuals.

Comment

It is important for HACC services and Carelink to consider developing relationships and connections with CALD specific services or organisations to ensure that information is provided in accessible formats to particular communities.

Recommendation

3. *The Dementia Advisory Services be promoted as a primary point of contact for people with younger onset dementia. This will enable:*

   i. *central collation of demand for younger onset services through the Dementia Network or by DADHC; and*
   ii. *promotion of a simple message to neurologists and neurology services that people should contact their nearest DAS following a diagnosis.*

Response from consultations

A number of the different CALD communities and some of the CALD specific services were not aware of Dementia Advisory Services. Further connections and education work is needed with some communities about the role of Dementia Advisory Services. This is particularly important for the Hindi Indian, Arabic and the Filipino communities.

Comment

Dementia Advisory Services reported a range of efforts to support CALD communities. Further efforts to increase their profile across the region may include a collaborative strategy with the Multicultural Access Project Workers to promote Dementia Advisory Services to different communities. This could be part of a broader community education strategy around dementia and dementia awareness in particular CALD communities.

In the consultations, CALD services gave examples of supporting people with younger onset dementia from CALD backgrounds and the difficulties this posed in terms of diagnosis as well as providing culturally appropriate care. One of the biggest barriers was having bilingual and culturally competent staff to support people with younger onset dementia in providing culturally appropriate services.

Recommendation

4. *Across NSW, HACC program administrators facilitate some flexibility in how service funding is used and applied, within minimum output and targeting requirements, so that providers can respond better to the needs of particular clients. Strategies here may include:*

    i. *encouraging HACC providers to contact DADHC when they face a rigidity in their funding relative to clients' needs; and*

    ii. *producing guidelines and a good practice manual demonstrating flexible approaches.*

Response from consultations

CALD specific service providers commented that there were often additional costs in providing dementia specific services to CALD communities which are not recognised in government funding. This includes the cost and time of developing and promoting services to particular communities, getting resources that are culturally appropriate, the provision of culturally appropriate food and employing and supporting bilingual and culturally competent staff.

Comment

There were a number of examples given about this throughout the project. For example, Hills Community Care provides a social support/ day care dementia specific service for Korean people. They reported that the cost of providing food for people in this service was $12 per head as they source food from a Korean restaurant in the Parramatta region. The provision of culturally appropriate food was a critical component of service delivery as people would not attend without appropriate food. In setting up the Korean specific service the organisation worked in partnership with the Korean community to recruit bilingual staff. The organisation recognises the language skills of staff through encouraging them to be accredited interpreters and translators through the National Accreditation Authority for Translators and Interpreters and by paying staff higher levels of remuneration in recognition of their language skills.

Other costs include sourcing culturally appropriate activities. Workers report that this can take extra time and money to find programming activities for people with dementia that are culturally relevant and in appropriate community languages. One worker who runs a Chinese dementia specific group reported that it was easier to access resources from Hong Kong to support people with dementia.

Recommendation

5. *HACC program administrators actively promote, support and improve incentives for collaboration across providers to offer complementary and seamless support to people in these two target groups.*

   Funding could support collaborative initiatives such as:

   iii. *supporting day centres to agree on and publicise their respective strengths and specialisations for particular HACC client sub-groups; and*
   iv. *promoting cross-agency, complementary problem solving, care coordination and client support, irrespective of whether relevant agencies are HACC funded or not. This may involve development of local protocols. It is particularly important for service gaps, such as transport.*

Response from consultations

In discussions with NSW Health auspiced dementia specific day care centres, some staff reported challenges in supporting people with dementia in a day care setting from different cultural groups due to the lack of bilingual staff who understand the culture of particular clients. For example in Cumberland/Prospect, the cultural and linguistic diversity of the area means that it is difficult to recruit staff who speak a diverse range of languages. Some centres reported trying to cluster people into similar cultural and linguistic groups. However, this may be difficult if there are small numbers of people of one group and particularly of people with younger onset dementia.

Managers of the day centres reported having some bilingual staff (particularly Arabic, Chinese and Italian speaking) but in many cases they found it difficult to access bilingual workers across a range of language groups. The issue of understanding cultural and religious differences in supporting people from a CALD background was also raised. For example, the Tripoli Mena Association that provides community care services to people from Arabic Muslim backgrounds spoke about the need for services to understand how to provide appropriate personal care to a person from an Arabic Muslim background.

Staff from the day centres recognised that this situation was not ideal, but that the centres appear to be constrained by the labour market situation.

Comment

Some people from a CALD background with dementia will lose their English skills and resort to their first language as part of having dementia. It is important therefore to consider strategies to attract and retain workers who are bilingual, culturally competent in their work and trained in understanding dementia. The cultural and linguistic diversity of the Cumberland/Prospect and Northern Sydney LPAs is such that there may need to be further consideration of how to support and sustain services in attracting and retaining bilingual and culturally competent staff. This could be through the development of a bilingual workers pool or developing partnerships with particular communities to recruit bilingual staff. A community development approach in working with particular communities is often the best way to recruit bilingual staff.

For example, COASIT recruits from the Italian community and reported no difficulty in attracting and retaining bilingual staff.

Recommendation

7. *HACC program administrators strengthen the sharing of leading practice material, models and lessons across the region and from elsewhere in NSW and Australia. Strategies may include:*

   iv. *targeted training for providers;*
   v. *using HACC/Community Care forums as a vehicle for disseminating material; and*
   vi. *reinforcing to providers the role of Alzheimer's Australia NSW as a specialist resource in this field.*

Response from consultations

The consultations identified examples of practices that work in supporting people from a CALD background with dementia. These examples and practical strategies for HACC services and dementia specific services need to be disseminated and shared. Developing materials and training for services in dementia and cultural competence was also raised as needing more work and development. People were aware of some of the resources developed by Alzheimer's Australia NSW for CALD communities. However, training for HACC services needs to apply practical skills and knowledge in cultural competence as well as understanding dementia.

Comment

More work needs to be undertaken in providing training in cultural competency and dementia to support services in understanding the needs of people from culturally and linguistically diverse communities. Partnerships could be developed with Alzheimer's Australia NSW to ensure that dementia training includes core competencies on cultural awareness and on understanding how to be culturally competent in practice.

HACC Good Practice (Section 4.2)

Recommendation

8. *HACC providers be reminded of the importance of the following HACC Outcomes in assisting people with younger onset dementia and people with dementia and behaviours of concern:*

   1.1 Formal assessment occurs for each consumer.
   1.2 Consumers are allocated available resources according to prioritised need.
   1.3 Access to services by consumers with special needs is decided on a non-discriminatory basis.
   2.2 Consumers are aware of services available.
   2.3 Consumers are informed of the basis of service provision, including changes that may occur.
   3.2 Consumers receive appropriate services provided through the processes of ongoing planning, monitoring and evaluation of services.
   4.4 Each consumer receives ongoing assessment (formal and informal) that takes all support needs into account.

4.5 Each consumer has a service delivery/care plan which is tailored to individual need and outlines the service he or she can expect to receive.
4.6 Consumers cultural needs are addressed.
4.4 The needs of consumers with intellectual difficulties, including dementia, memory loss and similar disorders, and intellectual disabilities are addressed.
4.6 Consumers receive services which include appropriate coordination and referral processes.

Response from consultations

Providing culturally appropriate care and services to people from CALD backgrounds requires all HACC services to be aware of the HACC Outcomes as well as systems that support services to provide culturally appropriate care. It is important to build the capacity of both the CALD specific services as well as the mainstream HACC services to provide culturally appropriate services.

During the consultations, some of the CALD specific services reported that sometimes mainstream HACC services expect that the CALD specific services will support all the clients from CALD backgrounds. While CALD specific services have expertise in providing culturally appropriate care it is equally important that mainstream HACC services build capacity in providing services to CALD communities. For example, COASIT and the Australian Hindi Indian Association were keen to work with HACC services.

Comment

It is important to build the cultural competency of the mainstream HACC services in both understanding and supporting people with younger onset dementia and people with behaviours of concern in the context of a person's cultural and linguistic background. This can be achieved through the provision of training and support and through the systematic monitoring of HACC services through the Integrated Monitoring Framework of DADHC. It is especially important to check that the distribution of service outputs reflects the composition of local and regional target groups.

HACC services also need to be aware of the demographics of the community they service and identify gaps in service delivery and develop strategies to outreach to particular communities.

Recommendation

11. HACC program administrators and providers ensure that workers supporting people with younger onset dementia and/or behaviours of concern have appropriate competency based training.

Response from consultations

The consultations and interviews identified that understanding a person's cultural and linguistic background is at the core of providing appropriate care and support to people with dementia. Workers gave many examples of needing to know the subtlety of a person's culture in the context of supporting a person with younger onset dementia or a person with dementia and behaviours of concern. This includes how different communities understand dementia and the stigma associated with dementia as well as how the word dementia gets translated into different languages. For

example in Greek and Italian it translates as senile illness and in the Chinese languages it translates as crazy illness. Understanding the context of cultural difference and how this affects people with dementia, particularly people with younger onset dementia, is critical.

Comment

Any training that is provided in understanding people with younger onset dementia and/ or behaviours of concern needs to include training on understanding culture from a cultural competency perspective and how this influences an understanding of dementia, behaviour and caring roles.

HACC Service Initiatives (Section 4.3)

Recommendation

13. *Social support services for people with younger onset dementia be funded equitably across the Metro North region. This recommendation is reliant on a transport component.*

Response from consultations

The interviews and consultations identified examples of people from a CALD background (including Korean, Sri Lankan, Arabic speaking, Afghani) who have developed younger onset dementia. As in the broader population of people with younger onset dementia, the number of people from a CALD background with younger onset dementia is small but their needs are quite significant. The social support model could work in supporting people with younger onset dementia from CALD backgrounds as long as workers were bilingual and understood the cultural needs of clients. Some of the NSW Health auspiced day centres reported difficulty in meeting the needs of people with younger onset dementia from CALD backgrounds, reporting that their needs were quite different to older people with dementia.

Comment

The social support model that uses bilingual and culturally competent staff to support people from a CALD background with younger onset dementia could be considered as a service delivery option. Undertaking a community development approach to work alongside communities to identify issues as well as recruiting bilingual and culturally competent staff is important.

Recommendation

14. *A 'club model' of day care be funded in several day centres across the region catering for strong and physically active people with dementia, that is, not specific to a particular age group. Key elements of the model include:*

    i. *group excursions;*
    ii. *client choice regarding activities;*
    iii. *enhanced capacity to cater to interests not necessarily covered by the day centre on other days;*
    iv. *promotion of 'active ageing'; and*
    v. *a higher staff:client ratio than is usual in HACC day care.*

This could be funded through the Centre Based Day Care, Dementia Specific, funding stream.

Response from consultations

The interviews and consultations identified that these models could work for CALD communities. In areas of Metro North where there are larger numbers of people from CALD communities, consideration could be given to providing culturally specific services to people from particular communities. Decisions on which communities to target need to be informed by consultations with the various communities and by demographic data.

Comment

It would be important to work with particular CALD communities in local areas as well as local service providers to identify which communities to target and how services can be delivered in a culturally appropriate manner. For example, in the Cumberland/Prospect LPA there is a significant number of people of Arabic speaking background who may benefit from a club model. However it would also be important to acknowledge the religious and cultural diversity within the Arabic speaking community.

Recommendation

15. *HACC and NRCP program administrators ensure that each area has a specialist, quick response worker or team capacity to assist workers and carers experiencing difficulties with people with dementia and behaviours of concern. Such a service would aim to assist carers and workers to understand the behaviours and to design, trial and implement strategies to minimise or prevent their recurrence. It should be part of the existing service infrastructure such as within a Dementia Advisory Service. The service needs to link in with health pathways which include mental health and targeted programs such as BASIS and SAFTE.*

Response from consultations

Feedback from the consultations is that workers would access this kind of service but carers may not if there is a language barrier. Services reported that families and people with dementia would tend to come to the CALD specific service first and that service would then access the Dementia Advisory Service for the family. This needs to be considered when designing and delivering such services.

Comment

It is important for any quick response team and the Dementia Advisory Services to work with local CALD communities and CALD specific services to consider how they can work together to better promote access to these services for carers of people from CALD backgrounds.

Recommendation

16. *DADHC and NSW Health trial one or two dementia cafés along the lines of the Victorian and European models as a means of bringing people with dementia and their carers together with trained staff, in a stress-free environment. The cafés*

promote self-reliance and self-help and follow on from Living With Memory Loss Clinics.

Response from consultations

There were some workers who thought a dementia café may not be appropriate in particular communities. Consultation would need to happen in the planning stages with communities to identify if and how it could work. An Arabic speaking worker queried how this model would differ from going to a local café as some of the Arabic people she supports like going to local cafés. This model needs further consultation and piloting to see how it may or may not work with particular communities.

Comment

Any future dementia cafés in the Cumberland/Prospect LPA will require discussion with the range of communities in their development and partnership with particular CALD communities in their implementation. Particular CALD communities should be involved as partners in any dementia café to explore whether this service model could be developed to meet the needs of their community. This needs to begin during the planning process.

Recommendation

17. *HACC program administrators and providers evaluate the results of the Northern Sydney Dementia Nutrition Pilot Project to determine whether an alternative service model or supplementary approach in food services could assist people with dementia and behaviours of concern. The model is expected to include the employment of a community based dietician to assist all services, along with expansion of services' capacity to assist clients with eating and to return some hours later to assist them with a second meal.*

Response from consultations

The Food Services consulted through this project in the Metro North region identified that providing food services to people with younger onset dementia and with behaviours of concern is difficult. Volunteers often do not have the time to spend with the person with dementia to ensure that the food is adequately heated and eaten. Food services also reported that some people with dementia may ring five times per day forgetting when food will be delivered which can be difficult for staff and volunteers.

Comment

There are some challenges in terms of the provision of culturally appropriate food for people from CALD backgrounds. Research by the NSW Meals on Wheels Association identified there are a number of different models that can be used to provide culturally appropriate food services. The research also identified that this takes time and additional funding to develop culturally appropriate food services (NSW Meals on Wheels Association 2003).

The provision of culturally appropriate food is a critical component of service delivery and could be supported by using bilingual workers and trained volunteers.

4.5 Other issues raised

There is **huge diversity both within and between communities** in terms of cultural and linguistic diversity which needs to be acknowledged and recognised in terms of supporting people with younger onset dementia and people with behaviours of concern. For example, within the Arabic speaking community there is religious and cultural diversity, including both Muslims and Christians. While people from Italy may all speak Italian there are also regional dialects and different cultural practices between regions. People from a Chinese background may speak Cantonese or Mandarin or a number of different dialects depending on where they are from in China and this can also lead to cultural differences. Understanding these differences and how this affects the understanding and acceptance of dementia is critical.

Services supporting people with younger onset dementia and behaviours of concern need to **understand cultural differences** and how to support a person with dementia from a CALD background. A critical aspect is training as well as developing networks and relationships with local CALD specific organisations (such as the Chinese Australian Services Association, COASIT or Greek Welfare) to work in partnership to build the cultural competency of staff and develop ongoing partnerships. Some CALD specific organisations commented that some HACC services seem to expect that the CALD agencies had the capacity to service all people in their community and that mainstream HACC services did not need to support these people because of the existence of the CALD specific services. The CALD specific services (such as COASIT and Greek Welfare) are happy to work in partnership with local HACC services to promote services as well as train mainstream services in working with particular communities.

Discussions with some communities, particularly with representatives of the Filipino and Indian communities, suggested that there needs to be more community development to **understand HACC services** as well as issues concerning dementia. The Philippines Australian Community Service Inc also works closely with a number of seniors groups across western Sydney. Opportunities could be developed to provide information about HACC services as well as undertake broader community education about dementia. This could occur through the relationships currently being developed between the Multicultural Access Project Officer and the Dementia Advisory Services. While most people with dementia are cared for by their family, it was considered important for people to know about the services available and how they can access them if needed.

Representatives from the Indian community also raised concerns about the growing number of older people in their community and the difficulties in getting information to them about **services they can access**. It was reported that most people with dementia are cared for by their family and often do not access services until crisis point. The Australian Hindi Indian Association also run a seniors group that meets on a monthly basis and some months can attract up to 150 people and were very keen to have guest speakers and more information on dementia and how people can prevent dementia. The representatives from the Australian Hindi Indian Association were very keen to work with local services to provide more information to people that attended the senior citizen groups.

Within the cultural and linguistic diversity of the Metro North region are a number of **emerging communities**. That is there are certain areas where the population of different CALD or Aboriginal groups is increasing. It is important that the needs of emerging communities in terms of supporting people with dementia are considered and monitored over time. Some of these communities may be ageing and have significant needs in terms of supporting people with dementia. Emerging communities may have specific needs and this needs to be monitored on a systematic basis over time.

A number of the services reported having supported people with both younger onset dementia and people with dementia with behaviours of concern from CALD backgrounds who were **refugees** and who had experienced torture and trauma. A recent study by NSW Health (2006) identified that there are significant health needs of older people who are refugees and strategies and protocols need to be put in place to address some of these issues.

A number of services gave examples of supporting Arabic speaking people and people from Afghanistan with younger onset dementia who had experienced trauma as a result of war. One worker reported that a man had a young family and would hide under the bed shouting that people were coming to kill his family. This was quite distressing for the person, their family and the worker supporting the family.

There needs to be closer relationships or protocols between HACC services particularly those supporting people with dementia and people with younger onset dementia and **torture and trauma services** such as the NSW Service for the Treatment and Rehabilitation of Torture and Trauma Services (STARTS). Understanding the relationship between torture and trauma and dementia is quite a specialised area and needs specialist expertise and services to support people in developing appropriate support strategies.

This issue also relates to **understanding behaviours of concern**. Behaviours of concern can be very subjective and related to context. If workers do not have an understanding of the cultural context of behaviour then it is very easy to make assumptions about behaviour rather than understanding its root cause.

The issue of access to suitably **trained and skilled bilingual workers** was raised on a number of occasions by the NSW Health auspiced dementia day care centres. A number of the centres reported having a diverse client base. While some had tried to cluster and group people with dementia into cultural and language groups, the challenge was providing culturally appropriate care to people while not necessarily having access to bilingual and culturally competent staff. For example, a service reported it was difficult to recruit and find one staff member from a Korean speaking background to support one Korean client.

The experience of some of the non government organisations in terms of attracting and retaining bi-lingual staff was different from the NSW Health auspiced day centres. For example, COASIT and the Australian Chinese Community Association (ACCA) reported no difficulty in attracting bilingual staff fluent in Italian (for COASIT) and Chinese languages for ACCA. The experience of Hills Community Care was also

positive in attracting and retaining Korean speaking workers and Maltese speaking workers. However, they reported that they paid bilingual staff at higher rates in recognition of their language skills and cultural competency skills. They have also developed services from a community development approach/model with the local community.

Some of the NSW Health auspiced dementia day care services in Cumberland/ Prospect reported staffing shortages and having long waiting lists for people with dementia to access day care services. Tallowood, which is a NSW Health auspiced dementia specific day care centre in Mt Druitt, currently has 23 people on the waiting list for services. Two other dementia specific day care centres, affiliated with this centre and managed by the Western Sydney Area Health Service, also are understood to have waiting lists for their services.

Issues were also raised about the **pathway for people with dementia** from CALD backgrounds in terms of identification, assessment, diagnosis, treatment and management. This pathway was much more difficult to navigate for people from CALD backgrounds. Most of the communities that were consulted reported having relationships with GPs from their particular community who assisted them on part of the pathway. However, once diagnosis occurred there may be difficulty for some people from a CALD background in knowing how to access services. This is where some of the CALD specific organisations worked with families to assist them in navigating the HACC and community care system.

4.6 Summary of considerations for CALD HACC clients

- The Metro North region is culturally and linguistically diverse. Given this diversity it is important to have CALD specific services as well as build capacity within mainstream HACC services to meet the needs of CALD communities. Without appropriate training of HACC services in understanding cultural competency and dementia it will be difficult to build this capacity. DADHC also needs to monitor HACC services to ensure that service reflects the demographics and diversity of the local community.

- There are people with younger onset dementia from CALD communities who have been supported by a number of HACC services and dementia specific services in the Metro North region. They tend to be in smaller numbers and often require one to one support from workers who are bilingual and culturally competent and can develop activities and supports that are culturally appropriate.

- A number of services are also supporting people from CALD backgrounds with dementia and behaviours of concern some of whom are refugees who have experienced torture and trauma. HACC services need to be aware of where to refer people and where to get experienced support. Torture and trauma services such as NSW Service for the Treatment and Rehabilitation of Torture and Trauma Services (STARTTS) may provide such assistance.

- Further research on the experience of carers of people from CALD communities with dementia is needed. DADHC has recently commenced work in this area looking at the needs of carers and people in the Italian, Vietnamese and Chinese communities which will be useful. However further work is needed in other communities to understand cultural differences and how this affects perceptions of caring and understanding of dementia.

- The Dementia Advisory Services, perhaps with the support of Alzheimer's Australia NSW, need to extend their efforts in Metro North communities to educate CALD communities about dementia. All the communities consulted through the course of this project were keen to work in partnership to provide more information to their communities about dementia. This need is particularly strong for the Hindi Indian and Filipino communities.

- The recruitment of bilingual and culturally competent workers is an issue for many organisations in Metro North. However, for some organisations that have close relationships to their community, this is not such an issue.

- In terms of the provision of information, CALD specific organisations reported that they acted as information and referral agencies because of language and cultural barriers. Information services need to work with particular CALD organisations to provide information in appropriate and accessible formats.

Appendix A Project Advisory Committee

Eliza Pross	Manager, Planning and Development Community Care (Northern Beaches) Inc
Cathy Buining	Project Officer, Planning Team Metro North, DADHC
Grace Chan	Multicultural Access Project Service (MAPS), Northern Sydney & Central Coast Area Health Service
Nicole Winters	Gilgai Aboriginal Service
Diane Boyde	TRI Community Exchange Inc
Monika Latanik	MAPS, Sydney Western Area Health Service
Prue Sky	Executive Officer Community Care (Northern Beaches) Inc

Appendix B Consultation Background Paper

PEOPLE WITH YOUNGER ONSET DEMENTIA & PEOPLE WITH DEMENTIA & BEHAVIOURS OF CONCERN

Metro North HACC Project

CONSULTATIONS ON SERVICE DELIVERY FOR PEOPLE WITH CULTURALLY & LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS

QUESTIONS FOR DISCUSSION

HACC System Improvements

1. **Do you think these recommendations (1 to 7, see page 5) will assist better service delivery to CALD people with younger onset dementia and CALD people with dementia and behaviours of concern?**

2. **Are there other improvements to the HACC system needed to better support people with younger onset dementia and people with dementia and behaviours of concern for people from CALD backgrounds?**

HACC Good Practice

3. **Do you think these recommendations (8 to 12, see page 6) will assist better service delivery to CALD people with younger onset dementia and CALD people with dementia and behaviours of concern?**

4. **Are there any particular priorities within these recommendations?**

HACC Service Initiatives

5. **Do you think these recommendations (13 to 17, see page 7) will assist better service delivery to CALD people with younger onset dementia and CALD people with dementia and behaviours of concern?**

6. **Are there other service initiatives needed to better support people with younger onset dementia and people with dementia and behaviours of concern for people from CALD backgrounds?**

Discuss these questions at:

10:00-1:00 pm Tuesday **4th December** 2007
Dougherty Community Centre, 7 Victor Street, **Chatswood**
Enquiries: Ruth Jacka (9415 4855) **RSVP**: ruthj@nsforum.org.au
Any further comments to Carrie Hayter [carrieh@iprimus.com.au] by **Friday 7th December 2007.**

CONSULTATION PAPER

The project

- In February 2007, *Alt Beatty Consulting* completed a project for the Metro North region of DADHC on appropriate HACC service models for people with younger onset dementia and people with dementia and behaviours of concern. The full report of the project is available on the DADHC website under the left hand side navigation bar: Publications/ Research/Completed Research.
- A recommendation of that report was to consult with Aboriginal and Torres Strait Islander (ABORIGINAL) and Culturally and Linguistically Diverse (CALD) service providers and client representatives to test that its recommendations cover the needs of those target groups.
- Community Care (Northern Beaches) Inc. (CCNB) has received additional funding to undertake this work. CCNB has engaged *Alt Beatty Consulting* to conduct the project, which will draw heavily from consultations with ABORIGINAL and CALD service providers and client representatives across the Metro North region.

This consultation paper

- This paper gives a brief background on younger onset dementia and behaviours of concern, outlines the key findings of the previous project report, *Appropriate HACC Service Models for People with Younger Onset Dementia & People with Dementia and Behaviours of Concern,* and sets out the recommendations from that report.
- The paper has been produced to stimulate discussion and assist consultations during November and early December 2007. In particular, it will help to test the relevance and importance of the recommendations and identify any gaps in them, including different service models.

PEOPLE WITH YOUNGER ONSET DEMENTIA

1. Definition

- People with younger onset dementia are people aged under 65 years old with a diagnosis of dementia. Indigenous people may be under 45 years old.

2. What we know about people with younger onset dementia

- There are relatively more men than in older groups.
- Small numbers – but uncertain and may be under-estimated.
- May have Alzheimer's Disease, but more likely than older people to have other dementias including vascular, frontotemporal and alcohol related. People with Down Syndrome are likely to develop dementia.
- Generally active, mobile and physically capable.
- May have younger partners and carers, dependent children at school or studying, ageing parents. Many in workforce when symptoms first apparent.
- Have experienced considerable delay in obtaining a diagnosis of dementia; usually multiple assessments. Often an initial diagnosis of depression or other mental illness.
- Often the dementia progresses more rapidly than for an older person. Though for some it is a long term condition.

- Experience loss on several fronts: selfhood and self-esteem; changed relationship within family structure (unexpected dependency); sense of social isolation and exclusion; and lack of meaningful occupation.
- Younger people do not tend to search for appropriate services in the "aged" sector as they and their carers do not identify with this age group. This is especially relevant for people from an Indigenous background who might be considerably younger than 65.
- Generally have concerns about work, finances, family support and driving and access to genetic counselling.

PEOPLE WITH DEMENTIA & BEHAVIOURS OF CONCERN

3. Definition

- Behaviours of concern are usually defined as behaviours which are disruptive, aggressive or socially unacceptable such that the person with dementia has difficulty in the home, community and in accessing mainstream services.
- Behaviours of concern may occur at any age of the person with dementia or at any stage of the dementia.

4. What we know about people with dementia and behaviours of concern

- The behaviour is often a sign of unmet needs and misinterpretation including pain, constipation, frustration (mis-communication, disorientation) and/or fear / anxiety. Tapper (1997) identified that problem behaviours are emotional responses.
- Behaviours arise from a "whole personhood of lived experiences" (Caron and Goetz, 1998) needing to be seen within a "whole person" context, including consideration of each person's personal history and psychological background. They may be a direct result of physical or social factors beyond the person's, carer's or worker's control and may not be a direct consequence of the dementing process.
- Behaviours may be of short duration (episodic).
- Behaviours may be of concern to carers or families and not for providers and others, or vice versa.
- People with behaviours of concern are likely to need 1:1 support while they are most unsettled.
- Unfortunately the most common response to such behaviours by services is exclusion rather than support and inclusion.
- Often the person with the behaviour of concern does not want services.
- Transport presents a huge safety issue.

THE FEBRUARY REPORT

5. Key messages

- Service users (clients) and their carers in these two dementia situations would like what most users would like: **flexible service responses** which can go some way to addressing their particular needs.

- The two groups share the characteristic that they are both outside what often seems to be considered the norm for a HACC client: a very frail woman aged over 80 (HACC Minimum Data set 2004/05).

- Many of the particular needs or circumstances of these two groups of people which differ from other HACC users would be met by agencies following what might be commonly considered **good practice**. That is, offering client responsive services. However in being responsive, some different skill sets and different service responses may be required.

- *People with younger onset dementia* need services and workers to understand their **very different life stage**. This group of people do not identify as aged care clients being younger than aged pensioners and often having been forced into an unplanned, early retirement. They are also likely to have significant physical strength and capacity and want and need significant exercise.

- The need for **significant physical activity** is also common for some *people with dementia and behaviours of concern*. This can strain traditional models of day centre respite which may be designed around fairly sedentary activities and clients. It also means that a service needs **transport** capable of accommodating clients, including tall and sometimes large people.

- There is some level of **subjectivity in what are behaviours of concern**. In a pragmatic sense they are behaviours which mean the person cannot be readily accommodated by services or about which the carer is especially concerned. Some such behaviours may be readily resolved through analysis and the development of strategies, whereas others are going to require ongoing, episodic assistance when the behaviour is heightened.

- Dementia is a **national health priority** and much effort is being put into better understanding the service responses which are most effective. Metro North has several initiatives already in place for people with younger onset dementia and people with dementia and behaviours of concern.

- This project identified **three specialist service models** in the region which meet the expressed needs of these two groups and which could be replicated: a social support model for younger onset dementia, a club or excursions oriented model for both groups and a quick response capacity for behaviours of concern. Within the Metro North region, these models currently only exist in Northern Sydney.

- While the project was focussed on HACC service provision and systems, it also identified the need for better links between **Health pathways** and HACC. This is especially the case for people with younger onset who may not be given a diagnosis of dementia for several years and who then need to be linked into local support and advice, such as may be provided in the first instance by a Dementia Advisory Service (DAS).

- A common theme across the project was the need, when developing new initiatives, to utilise existing infrastructure complemented as necessary by specialist services. Such a strategy maximises the resources going to direct service delivery and promotes increased responsiveness of the whole community care system. **Collaboration** and **capacity building** across providers should be promoted, along with efforts to avoid further fragmentation in what is already a complex system.

THE REPORT'S RECOMMENDATIONS

HACC System Improvements (Section 4.1)

1. *DADHC request HACC service providers in local planning areas to develop a protocol for providers to receive support and advice in regards to clients with younger onset dementia and for clients with behaviours of concern within their area.*

2. *HACC program administrators encourage both Carelink and individual HACC providers to keep up to date with local referral processes and with services which can provide special support to people with younger onset dementia and people with dementia and behaviours of concern.*

3. *The Dementia Advisory Services be promoted as a primary point of contact for people with younger onset dementia. This will enable:*

   i. *central collation of demand for younger onset services through the Dementia Network or by DADHC; and*
   ii. *promotion of a simple message to neurologists and neurology services that people should contact their nearest DAS following a diagnosis.*

4. *Across NSW, HACC program administrators facilitate some flexibility in how service funding is used and applied, within minimum output and targeting requirements, so that providers can respond better to the needs of particular clients. Strategies here may include:*

   i. *encouraging HACC providers to contact DADHC when they face a rigidity in their funding relative to clients' needs; and*
   ii. *producing guidelines and a good practice manual demonstrating flexible approaches.*

5. *HACC program administrators actively promote, support and improve incentives for collaboration across providers to offer complementary and seamless support to people in these two target groups.*

   Funding could support collaborative initiatives such as:

   v. *supporting day centres to agree on and publicise their respective strengths and specialisations for particular HACC client sub-groups; and*
   vi. *promoting cross-agency, complementary problem solving, care coordination and client support, irrespective of whether relevant agencies are HACC funded or not. This may involve development of local protocols. It is particularly important for service gaps, such as transport.*

6. *HACC program administrators request that HACC/Community Care Forums review exit strategies being used by service providers with a view to developing and implementing common, good practice across community care.*

7. *HACC program administrators strengthen the sharing of leading practice material, models and lessons across the region and from elsewhere in NSW and Australia. Strategies may include:*

   vii. *targeted training for providers;*
   viii. *using HACC/Community Care forums as a vehicle for disseminating material; and*
   ix. *reinforcing to providers the role of Alzheimer's Australia NSW as a specialist resource in this field.*

HACC Good Practice (Section 4.2)

8. *HACC providers be reminded of the importance of the following HACC Outcomes in assisting people with younger onset dementia and people with dementia and behaviours of concern:*

   1.1 Formal assessment occurs for each consumer.
   1.2 Consumers are allocated available resources according to prioritised need.
   1.3 Access to services by consumers with special needs is decided on a non-discriminatory basis.
   2.2 Consumers are aware of services available.
   2.3 Consumers are informed of the basis of service provision, including changes that may occur.
   3.3 Consumers receive appropriate services provided through the processes of ongoing planning, monitoring and evaluation of services.
   4.7 Each consumer receives ongoing assessment (formal and informal) that takes all support needs into account.
   4.8 Each consumer has a service delivery/care plan which is tailored to individual need and outlines the service he or she can expect to receive.
   4.9 Consumers cultural needs are addressed.
   ***4.4** The needs of consumers with intellectual difficulties, including dementia, memory loss and similar disorders, and intellectual disabilities are addressed.*
   4.7 Consumers receive services which include appropriate coordination and referral processes.

9. *DADHC discuss the recommendations of this project with Aboriginal and CALD service and client representatives to identify any additional considerations which need to be given to people with younger onset dementia and dementia and behaviours of concern for those population groups.*

10. *HACC program administrators recognise the episodic or irregular nature of many behaviours of concern and offer enhanced capacity or flexibility to allow providers to offer:*

   iii. *periods of intensive, targeted support between periods of "maintenance" support; and*
   iv. *wherever possible, continued care during these times of concern, or positive, flexible and sensitive re-entry to maintenance services once strategies are developed to manage or minimise behaviours.*

11. *HACC program administrators and providers ensure that workers supporting people with younger onset dementia and/or behaviours of concern have appropriate competency based training.*

12. *DADHC communicate the findings of this project to HACC service providers across NSW and to the Commonwealth and request that any national campaigns on dementia include the issue of younger onset.*

HACC Service Initiatives (Section 4.3)

13. *Social support services for people with younger onset dementia be funded equitably across the Metro North region. This recommendation is reliant on a transport component.*

14. *A 'club model' of day care be funded in several day centres across the region catering for strong and physically active people with dementia, that is, not specific to a particular age group. Key elements of the model include:*

    i. *group excursions;*
    ii. *client choice regarding activities;*
    iii. *enhanced capacity to cater to interests not necessarily covered by the day centre on other days;*
    iv. *promotion of 'active ageing'; and*
    v. *a higher staff:client ratio than is usual in HACC day care.*

    This could be funded through the Centre Based Day Care, Dementia Specific, funding stream.

15. *HACC and NRCP program administrators ensure that each area has a specialist, quick response worker or team capacity to assist workers and carers experiencing difficulties with people with dementia and behaviours of concern. Such a service would aim to assist carers and workers to understand the behaviours and to design, trial and implement strategies to minimise or prevent their recurrence. It should be part of the existing service infrastructure such as within a Dementia Advisory Service. The service needs to link in with health pathways which include mental health and targeted programs such as BASIS and SAFTE.*

16. *DADHC and NSW Health trial one or two dementia cafés along the lines of the Victorian and European models as a means of bringing people with dementia and their carers together with trained staff, in a stress-free environment. The cafés promote self-reliance and self-help and follow on from Living With Memory Loss Clinics.*

17. *HACC program administrators and providers evaluate the results of the Northern Sydney Dementia Nutrition Pilot Project to determine whether an alternative service model or supplementary approach in food services could assist people with dementia and behaviours of concern. The model is expected to include the employment of a community based dietician to assist all services, along with expansion of services' capacity to assist clients with eating and to return some hours later to assist them with a second meal.*

Appendix C HACC Standards

HACC National Service Standards

	Standard		Outcomes
1	Access to services	1.1	Formal assessment occurs for each consumer.
		1.2	Consumers are allocated available resources according to prioritised need.
		1.3	Access to services by consumers with special needs is decided on a non-discriminatory basis.
		1.4	Consumers in receipt of other services are not discriminated in receiving additional services.
		1.5	Consumers who reapply for services are assessed with needs being prioritised.
2	Information and consultation	2.1	Consumers are aware of their rights and responsibilities.
		2.2	Consumers are aware of services available.
		2.3	Consumers are informed of the basis of service provision, including changes that may occur.
3	Efficient and Effective Management	3.1	Consumers receive appropriate services provided through the processes of ongoing planning, monitoring and evaluation of services.
		3.2	Consumers receive services from agencies that adhere to accountable management practices.
		3.3	Consumers receive services from appropriately skilled staff.
4	Coordinated, planned and reliable service delivery	4.1	Each consumer receives ongoing assessment (formal and informal) that takes all support needs into account.
		4.2	Each consumer has a service delivery/care plan which is tailored to individual need and outlines the service he or she can expect to receive.
		4.3	Consumers cultural needs are addressed.
		4.4	The needs of consumers with intellectual difficulties, including dementia, memory loss and similar disorders, and intellectual disabilities are addressed.
		4.5	Consumers receive services which include appropriate coordination and referral processes.
5	Privacy, confidentiality and access to personal information.	5.1	Consumers are informed of the privacy and confidentiality procedures and understand their rights in relation to these procedures.
		5.2	The release of consumer information occurs with the consent of the consumer or their advocate or legal guardian.
		5.3	Consumers are able to gain access to their personal information.
6	Complaints and disputes	6.1	Consumers are aware of the complaints process.
		6.2	Each consumer's complaint about a service, or access to a service is dealt with fairly, promptly, confidentially and without retribution.
		6.3	Services are modified as a result of 'upheld' complaints
		6.4	Each consumer receives assistance, if requested, to help with the resolution of conflict about a service that arises between the consumer and his/her carer.
7	Advocacy	7.1	Each consumer has access to an advocate of his/her choice.
		7.2	Consumers know of their right to use an advocate.
		7.3	Consumers know about advocacy services – where they are and how to use them.
		7.4	The agency involves advocates in respect to representing the interests of the consumer.

Appendix D References

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