

House Standing Committee on Health and Ageing – Inquiry into Dementia: Early diagnosis and Intervention

Submission from Doutta Galla Community Health – Moonee Ponds Victoria

Doutta Galla Community Health Service (DGCH) is a well-established community health organisation. We have extensive expertise in providing high quality primary community and specialist health services. Recently we were awarded the *Primary Health Service of the Year* at the 2011 Victorian Public Healthcare Awards in Melbourne.

Our focus is on *working together with our communities* to understand their needs and design programs including treatment, early intervention, health promotion and social support initiatives that build trust and ensure positive outcomes.

We work in the inner west of Melbourne with a population of over 170,000, including 6,000 public housing units with an estimated 14,000 residents. We aim to address health disparities and prioritise access to our services - primary, community and mental health - to those in greatest need including:

- people in marginal housing / homeless
- adults with mental illness
- people with complex alcohol /drug issues
- public housing residents
- frail older adults
- new / emerging communities
- Aboriginal and Torres Strait Islanders
- people with chronic illness and complex care needs

We provide services from four main accessible locations - Kensington, Moonee Ponds, Niddrie and North Melbourne, from five residential sites and we outreach to public housing estates and the CBD. Last year, 289 staff provided services to over 17,500 clients.

DGCH is set in Victoria's North-West metropolitan region (covering the local government areas of the City of Melbourne and the City of Moonee Valley) which has, and is projected to retain, the largest number of older adults in Victoria by 2050. In addition, older adult CALD populations are projected to increase in number, almost twice as fast as their Anglo-Australian counterparts (*ECCV Discussion Paper Vol1;2, 2011*).

In addition, DGCH at the whole of organisation level and through its Board, CEO and Senior Management Group is committed to:

- meaningful consumer participation into service and program direction

- advocacy to ensure the voices of the more marginalised populations in local communities are heard, understood and better responded to in policy and program design, as evidenced in :
- The establishment of Australia's first ethno-specific diabetes support groups, for Chinese and Vietnamese communities
- Successful implementation of the "Making A Move" home based falls prevention project for older adult Culturally And Linguistically Diverse (CALD) residents
- A successful service merger with Essendon Adult Day Care Service - a principle (high level) Planned Activity Group (which incorporates Dementia Care)
- Successful implementation of the "Café Style Dementia Support" project targeting two separate community groups in 2011 – recent-diagnosis and Chinese clients, with Italian and Greek community pilot groups to be conducted in 2012.
- Supporting a long-established community-based Dementia Carer Support Group.

The latter three service programs above inform this submission content.

As a long-established Dementia Carer Support Group provider, DGCH was invited to and successfully applied for 2010/11 Victorian Department of Health *Dementia Support Cafe* funding. To address recognised community need, DGCH trialled two community support pilot projects – initially targeted to 'Recently Diagnosed' & 'Chinese-background' residents, respectively.

Pilot project findings confirmed

- Dementia knowledge & awareness
- diagnosis & assessment, and
- continuum of care services & pathways, including ongoing support

were significant areas of unmet need both within DGCH and the broader community service sector, for both groups.

In addition, project findings clearly demonstrated both Dementia- and CALD-specific services in our region are struggling to meet an escalating need for even-basic population dementia information and care. While peak body Alzheimer Australia Victoria (AAV) provide essential community education its coverage is limited and cannot meet the growing community need – particularly for CALD residents.

Evaluation of the *DGCH Café style Support* project clearly identified gaps in the delivery of dementia support services and for CALD populations in particular, including:

- delayed diagnosis
- poor understanding and acceptance of dementia within the community
- poor access to information and support
- confusion with navigating the aged care system and
- carer burden.

These service gaps correspond tightly with the Dementia Service Pathways 2011 report from DoHA KPMG.

More specifically :

- There is a hesitancy amongst the population to accept the diagnosis of dementia and seek advice and assistance
- Diagnoses of dementia are often not made until the symptoms are quite advanced and the person and their carers have been having difficulties managing the symptoms for some time without knowledge and assistance
- There is poor knowledge and many misconceptions amongst the general population and health care workers about memory loss and dementia.
- There is an uncoordinated approach to assistance from clients with dementia and their carers.
- People lack knowledge about the basic services that are available for people with dementia and their carers, such as Carer's Victoria and HACC services. Doctors do not always know about or refer their patients to existing services.
- AAV has acknowledged that it is difficult to provide services to the West because of the difficulties presented by the high CALD population.
- Carers' Victoria conduct information workshops for clients but these are only run when they have 8 or more participants. These sessions are run predominantly in English and do not cater well for CALD populations (due to an absence of translated health literacy material and consistently high quality interpreter services).
- DGCH as a primary care service has potential to be a conduit role for people with dementia and their carers to form groups which could then access available resources and services –

such as Carers' Victoria. workshops and potentially the AAV "Living with Memory Loss" program.

- Participant feedback indicated there is a desperate need for carers to have practical strategies to cope on a daily basis, such as addressed in "Creative Ways To Care" programs; however to our knowledge this program is not run anywhere in the West.
- With funding support DGCH could run the "Creative Ways To Care" program catering to different groups – English-speaking, Chinese and other CALD community groups.
- Project partners, such as the Cognitive Dementia and Memory Service (CDMS) have indicated there is a there is great need for dementia support services for Italian community members in our region, post diagnosis and intervention.
- From our experience running the Chinese café style support service, it is absolutely essential to have bilingual workers present, especially those who have close links to that particular CALD community to support access to forums which address essential dementia awareness raising and potential service intervention/support.
- In addition, Chinese community participants expressed a great deal of appreciation for the information and support offered during cafe sessions and noted that they had known nothing beforehand about the services available, even though they were unsure about their ability to access them because of the language difficulties. The project workers believed that if the group could meet monthly, these services could be talked about over time and with encouragement and support, more easily accessed.

To summarise, common issues that affect CALD communities particularly, include:

- Late diagnosis of dementia, often at crisis point, due to lack of knowledge about the early symptoms of dementia, where to go for help or being ashamed of being labelled.
- Lack of knowledge about dementia and its symptoms and causes.
- Variations in perceptions of dementia
- Stigma associated with dementia or lack of understanding of dementia, resulting in people being marginalised and isolated from their own communities.
- Communication problems caused by many people from CALD backgrounds having low literacy levels in English language and also in their own language.
- Lack of knowledge or acceptance of the service system by members of CALD communities who are often unfamiliar with dementia services and aged care services in general as well

as how to access them, often due to either language barriers or a lack of culturally appropriate services.

In an attempt to address these important issues DGCH submitted a *2011 DoHa "Aged Care Service Improvement and Healthy Ageing Grant"* to:

- Reduce gaps in the delivery of services, especially at key transition points;
- Improve the timeliness and accuracy of diagnosis;
- Enhance understanding and acceptance of dementia within the community and sector;
- Reduce the burden on carers;
- Improve access to information and support;
- Support people with dementia and their carers and families with navigating the aged care;
- Provide learning and reflection about the pre-conditions and enablers-barriers for improving pathways across the service system to the broader sector.

If funded, this project hopes to specifically:

1. Implement an internal service change process to capacity build health service provider knowledge, awareness and response to Dementia care, encompassing CALD-sensitive practice.
2. Implement an internal change process to capacity build GP knowledge, awareness, and response to Dementia care in daily practice, including diagnosis and assessment, with a CALD-sensitive focus.
3. Facilitate and support, in partnership, external service-provider (including select GP clinics in the catchment) Dementia knowledge and response capacity, with a CALD-sensitive focus,
4. Facilitate and extend, in partnership, mainstream and particularly CALD community awareness of Dementia to support early diagnosis and treatment.
5. Identify and develop Dementia community support options, which include and address CALD-specific needs, such as Dementia-specialist workers and language services.
6. Trial and evaluate recommended 2011 DoHA Dementia Services Pathway interventions, on the ground, to expand both Dementia and CALD-sensitive practice within a primary health service setting.
7. Develop a quality Best Practice Dementia continuum of care & integrated mainstream service model for primary care and CALD-sensitive practice, which is transferable, and could be replicated across the wider community service sector.

DGCH has also identified a need for additional community support interventions which support initial dementia awareness, early diagnosis and intervention – particularly for CALD residents, such as:

- Expanded CALD-specific community education and support programs (as piloted in the Dementia Support Cafe programs), which for example clearly identified the need for an ongoing (Ethnic) Chinese Planned Activity Group in our region
- Increased CALD-sensitive HACC services (active recruitment of key language group workforce) which can help identify the need for consumer early diagnosis/intervention
- Mandated Aged/health sector workforce training and development in dementia awareness and referral – including cultural sensitivity training – perhaps linked to key system change and primary care service models such as the Active Service Model (ASM) and GP divisions
- Bilingual/cultural workforce recruitment in both aged/health sectors, and

more broadly:

- Increased CACPs package access (as waiting lists are prohibitive)
- Improved flexibility and increased funding limits for low-level CACPs
- Increased EACH-Dementia packages (as waiting lists are prohibitive), particularly for CALD-residents who may only seek intervention/support late in the disease process
- Expansion of services within Essendon Adult Day Centre High needs Planned Activity Groups to provide services to clients with an early diagnosis of dementia and their carers.

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