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Version 1.0

Operational Performance Directorate
Ageing, Disability and Home Care
Department of Family and Community Services NSW
May 2012



**Family &
Community Services**
Ageing, Disability & Home Care



Appropriate HACC
Service Models for
People with Younger Onset
Dementia
& People with Dementia and
Behaviours of Concern

Alt Beatty Consulting

FINAL REPORT

February 2007

Appropriate HACC
Service Models for
People with Younger Onset
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& People with Dementia and
Behaviours of Concern

for the NSW Department
of Ageing, Disability & Home Care
Metro North

February 2007

Acknowledgments

This project would not have achieved its brief without the assistance of the Advisory Committee (Appendix A) in organising focus groups and other consultations. Service providers and carers participated in the focus groups and in commenting on draft recommendations. We thank them all.

Disclaimer

This report presents the results of work carried out from August 2006 to February 2007.

The information presented was the best available to the knowledge of the consultants at the time of the evaluation. Every effort has been made to present the views of stakeholders involved and of the literature and other information collated.

This project was commissioned by the NSW Department of Ageing, Disability & Home Care, Metro North Region.

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Acronyms

AA	Alzheimer's Australia
AIHW	Australian Institute of Health and Welfare
ATSI	Aboriginal and Torres Strait Islands
BASIS	Behavioural Assessment and Intervention Service
BPSD	Behavioural and psychological symptoms of dementia
CALD	Culturally and linguistically diverse
CACP	Community Aged Care Packages
COPS	Community Options Service
DADHC	Department of Ageing, Disability & Home Care
DAS	Dementia Advisory Service
DHS	Department of Human Services (Victoria)
EACH	Extended Aged Care at Home
HACC	Home and Community Care Program
HSNet	Human Services Net (information technology system for human services providers in NSW)
LGA	Local government area
MOW	Meals on Wheels
NGO	Non-government organisation
NRCP	National Respite for Carers Program
SAFTE	Sub-Acute Fast Track of the Elderly
YOD	Younger onset dementia

Executive Summary

This report covers a project in the Metro North region of Sydney 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 NSW Department of Ageing, Disability and Home Care (DADHC) contracted *Alt Beatty Consulting* to undertake the project during 2006/07.

The focus of the project was on how the HACC system in Metro North can better address the needs of these two groups of people with dementia and the extent to which improved service delivery can be achieved within existing structures.

Method

The project was guided by an advisory committee comprising dementia advisors, HACC/Community Care development workers, a HACC service provider, a representative of Alzheimer's Australia and a DADHC representative. The consultants drew on the considerable expertise and practical experience of the committee, along with a scan of the literature and contact with HACC program administrators in other States and Territories, to identify the key issues for consultation purposes.

A set of consultation questions and a background paper were developed and distributed widely through regional HACC and dementia networks. Four focus groups were held across the region at Regentville, Baulkham Hills, Mona Vale and Chatswood. 78 participants, mainly service providers but including five carers, contributed to the discussions.

Drawing on these consultations, a draft set of recommendations was developed with the advisory committee. These draft recommendations were distributed widely for comment over the period 20 December 2006 to 19 January 2007. 27 responses were received. Most respondents agreed with the recommendations. Comments were mainly reasons for supporting the recommendation or wording to clarify and strengthen the proposal. 14 of the respondents had not attended focus groups, bringing the total number of individuals contributing to the process to 92.

The response to the draft recommendations and a draft report were considered by the advisory committee and the project finalised. Newsletter articles were provided during and at the completion of the project.

Key messages

Users and their carers in these two 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. 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.

Recommendations

These recommendations focus on the HACC program and HACC service provision within the Metro North Region of Sydney. However they sit within the context of broader developments for the HACC program nationally, such as consideration of:

- more opportunities for therapeutic support of clients rather than the current emphasis on maintenance; and
- local, statewide and national ongoing research and initiatives related to people with dementia, including those with younger onset and behaviours of concern.

Some initiatives will enable HACC to better support both people with younger onset dementia and people with dementia and behaviours of concern. Some recommendations will benefit not just these two target groups but also other people with behaviours or needs which present particular challenges to HACC service providers. Some recommendations are a response to the particular situation of one of the two groups.

Discussion of the recommendations, their rationale and likely cost impact is provided in Chapter 4.

It is **recommended** that:

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:

- 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.*
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:*
 - 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.*

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.*
 - 3.1 *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.*
- 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:*
 - 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.*
- 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 and be complemented with appropriate transport funding.*
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.*

1 The Project

1.1 *Project brief*

The project is to identify the key elements of 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 brief frames several questions to be addressed:

- What are the key characteristics of these groups?
- What are their needs?
- What are the distinct characteristics of a service model that would satisfy the needs of these groups?
- Can these service characteristics be incorporated within or as part of the existing HACC infrastructure?

The project was commissioned by the Metro North region of the Department of Ageing, Disability and Home Care (DADHC). It arose from HACC planning processes, dementia advisors and others identifying the need for the service system to better support people with younger onset dementia and people with dementia and behaviours of concern.

A Project Advisory Committee (membership is at Appendix A) contributed their views and suggestions to the project at each stage. Members also played a significant role in distributing project information and in the organisation of the focus groups.

NSW Health was invited to join the advisory committee. A representative was not available to attend meetings but was sent all the papers developed during the project for comment.

1.2 *Project method*

Alt Beatty Consulting was contracted by DADHC in August 2006 to undertake the project. It proceeded through the following steps:

Project scoping and issues identification

- briefing with the Department's project manager and organisation of the Project Advisory Committee;
- a scan of the literature, local conference presentations and websites;
- an initial meeting with the Advisory Committee to scope the project and test key issues using work by the UK Alzheimer's Society;
- consultation with HACC authorities in other States and Territories to identify relevant models, issues and research;

Consultations

- a visit to Mercy Community Care, which auspices a HACC social support project for younger onset dementia, to meet with clients, carers, staff and several dementia advisors;
- meetings and telephone discussions with other service providers targeting people with dementia and either younger onset dementia or behaviours of concern and with managers of Home Care Service Centres;
- preparation of a background paper for consultations and consideration of the paper by the Advisory Committee;
- revision of the paper (Appendix B) and distribution of it via HACC and dementia networks for discussion at focus groups;
- facilitation of four focus groups at Regentville, Baulkham Hills, Mona Vale and Chatswood comprising 78 participants (Appendix C);

Development of recommendations and project report

- preparation of an interim report and consideration of it by the Advisory Committee;
- distribution to the sector of draft recommendations for service models and other initiatives by HACC;

- drawing from the consultations, the 27 responses to the draft recommendations and the other previous steps, preparation and submission of a draft project report and discussion of it by the Advisory Committee;
- revision and completion of the project report on the basis of feedback from the Department and Advisory Committee.

1.3 *National context*

Dementia epidemic

Access Economics has developed projections of dementia in Australia. Their most recent data report in 2005 indicated that in that year the number of Australians with dementia passed 200,000 and reached 1.0% of the population (Access Economics 2005). The report also indicated:

- By 2050, the total number will exceed 730,000 (2.8% of the projected population) – a fourfold increase since 2000.
- In 2005, we project there will be nearly 52,000 Australians newly diagnosed with dementia.
- By 2050, there are projected to be over 175,000 new cases every year, more than the total number of people with dementia in Australia in 2000.
- 1 in 3 Australians with dementia (around 70,000 people) live in New South Wales, projected to increase to 227,200 by 2050.

An earlier report by Access Economics (2003) identified “people with younger onset dementia and people with behavioural and psychological symptoms of dementia” as two of five special needs groups needing to be addressed in a national strategy.

National Framework for Action on Dementia 2006-2010

Following extensive consultations across Australia, Health Ministers in 2006 agreed to a new National Framework for Action on Dementia (Australian Health Ministers’ Conference 2006). The structure of the framework is reproduced in Figure 1.1. Detailed actions and lead agencies are identified in the framework document. The priorities and principles reflect the findings of this project in Metro North.

Figure 1.1 National Framework for Action on Dementia 2006-2010

Vision

A better quality of life for people living with dementia and their carers and families.

Objectives

Australians working together to make a positive difference to the lives of people with dementia, their carers and families.

Australian Governments, along with service providers and the broader community, working together to create an accessible, seamless pathway for people with dementia, their carers and families.

Principles

1. People with dementia are valued and respected. Their right to dignity and quality of life is supported.
2. Carers and families are valued and supported and their efforts are recognised and encouraged.
3. People with dementia, their carers and families are central to making choices about care.
4. Service responses recognise peoples' individual journeys.
5. All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.
6. A well-trained supported workforce delivers quality care.
7. Communities play an important role in the quality of life of people with dementia, their carers and families.

Priorities for Action

Priority Area 1: Care and Support services that are flexible and can respond to the changing needs of people with dementia, their carers and families.

Priority Area 2: Access and Equity to dementia information, support and care for all people with dementia, their carers and families regardless of their location or cultural background.

Priority Area 3: Information and Education that is evidence-based, accurate and provided in a timely and meaningful way.

Priority Area 4: Research into prevention, risk reduction and delaying the onset of dementia as well as into the needs of people with dementia, their carers and families.

Priority Area 5: Workforce and Training strategies that deliver skilled, high quality dementia care.

Developments in Community Care

Both internationally and in Australia, the emphasis in community care, at least in the literature, has shifted to more of a strengths and opportunities approach as encapsulated by the World Health Organization's *Active Ageing Framework* (2002).

Active ageing is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.

The active ageing approach is based on the recognition of the human rights of older people and the United Nations Principles of independence, participation, dignity, care and self-fulfillment. It shifts strategic planning away from a "needs-based" approach (which assumes that older people are passive targets) to a "rights-based" approach that recognizes the rights of people to equality of opportunity and treatment in all

aspects of life as they grow older. It supports their responsibility to exercise their participation in the political process and other aspects of community life.
(World Health Organization 2002)

Services which assist people with dementia living in the community are funded primarily by the joint State-Commonwealth Home and Community Care (HACC) Program and by the Australian Government programs: Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) and the National Respite for Carers Program (NRCP).

Reviews of these programs in recent years, especially *The Way Forward* process, have involved governments and other concerned parties working on proposals for change, including around seamlessness of service delivery and collaboration and co-ordination in assessment and other processes. Submissions to the most recent review, the current Australian Government Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs, have endorsed the active ageing theme (for example, the submission from COTA Over 50s).

Active Ageing is also reflected in initiatives to test the contribution of short term restorative care or therapy for new clients before resolving ongoing care. Examples include implementation of the Transition Care Program, the piloting of the Active Service Model in Victoria's HACC program and Silver Chain's Home Independence Program in Western Australia.

Interest in consumer directed care, including carer selection of worker and entitlement based respite, and other options for promoting choice within community programs and between community and residential programs is also linked to more of a rights-based approach. The call for submissions to the current Review of Subsidies and Services (Australian Government Department of Health and Ageing 2006) invites the public to consider how service requirements may change into the future with greater promotion of choice.

1.4 Scope of report

Target groups

Both here and throughout the project, people with younger onset dementia and people with dementia and behaviours of concern are considered as two different groups for the service system to consider. Of course the two groups are not always mutually exclusive. Given the higher incidence of frontotemporal dementias among younger people there appears to be a greater likelihood of behaviours of concern than among the older population with dementia.

In the next two chapters, the groups are considered separately. In Chapter 4, the issues which affect both groups and the HACC system broadly are addressed.

Metro North

The DADHC region, Metro North, comprises 19 local government areas in the northern half of Sydney. It runs from Manly in the east to Blue Mountains in the west. It covers the three HACC Local Planning areas of Nepean, Cumberland-Prospect and Northern Sydney. The region has a population of just under two million people, of whom over 146,000 are estimated to be within the HACC target population. Table 1.1 shows the composition of the region's population by local planning area.

Table 1.1 Metropolitan North Region, Population Estimates

Local Planning Area	HACC Target Population (2006/07)	Projected Total Population (2006/07)	Projected Population aged 65plus (2006/07)
Cumberland/Prospect	55,589	772,737	79,921
Nepean	23,381	330,268	31,763
Northern Sydney	67,410	819,139	115,078
Total, Metro North	146,380	1,922,144	226,762

Source: p 15, Australian Government Department of Health and Ageing and DADHC 2006

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'. Other terms, including 'early onset' and 'challenging behaviours' are used both in the literature and in the field. The project was guided by the 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.

2 People with Younger Onset Dementia

2.1 Characteristics and needs

Definition

People with younger onset dementia are people aged under 65 years old with a diagnosis of dementia.

Population

The 2003 Survey of Disability, Ageing and Carers provided the first estimate of the number of people with dementia in the population under 60. On this self reporting, the survey showed an estimated 1,700 Australians under 60 with dementia in 2003 (0.01% of Australians under 60), albeit with a very high standard error. Access Economics (2005) argued that these results were very conservative and subsequently revised the prevalence rates on the basis of evidence from the literature.

In January 2007, the Australian Institute of Health and Welfare released new estimates and projections of dementia in Australia (AIHW 2007) which show slightly lower figures for younger onset than those of Access Economics. Table 2.1 shows the AIHW projections for dementia in the population by age and gender for Australia and relates them to ABS population projections to produce prevalence rates.

Table 2.1 Projected Number of People with Younger Onset Dementia, Australia

	2003	2006	2011	2021	2031
Males					
0-64	5,500	5,900	6,700	7,600	8,000
Total, Males under 65	8,738,745	8,992,000	9,346,500	9,811,700	10,147,900
% of Males with Younger Onset	0.06%	0.07%	0.07%	0.08%	0.08%
Females					
0-64	2,600	2,900	3,300	3,800	4,000
Total, Females under 65	8,587,478	8,828,200	9,181,000	9,587,600	9,845,000
% of Female Population	0.03%	0.03%	0.04%	0.04%	0.04%
Persons					
0-64	8,100	8,800	10,000	11,400	12,000
Total, under 65 Population	17,326,223	17,820,200	18,527,500	19,399,300	19,992,700
% of Population	0.05%	0.05%	0.05%	0.06%	0.06%

Source: AIHW 2007 & Australian Bureau of Statistics 2006 & 2004.

Applying the prevalence rate for younger onset dementia of 0.05% (1 in 2,000) in 2006 from Table 2.1 to the population of Metro North suggests that there may be in the order of 847 people with younger onset in the region. The breakdown of these figures by local planning areas is shown in Table 2.2. **These figures should be treated as broad estimates only.**

Table 2.2 Metropolitan North Region, Population and Younger Onset Estimates

Local Planning Area	HACC Target Population (2006/07)*	Projected Total Population (2006/07)*	Projected Population aged 65plus (2006/07)*	Projected Population aged under 65 (2006/07)	Estimated population with younger onset dementia (June 2006)#
Cumberland/Prospect	55,589	772,737	79,921	692,816	346
Nepean	23,381	330,268	31,763	298,505	149
Northern Sydney	67,410	819,139	115,078	704,061	352
Total, Metro North	146,380	1,922,144	226,762	1,695,382	847

Sources:

* p 15, Australian Government Department of Health and Ageing and DADHC 2006

Estimate based on 0.05% of population aged under 65 who may have younger onset dementia, based on AIHW prevalence rates of Table 2.1 and the under 65 Series B population projection for Australia in June 2006 from Australian Bureau of Statistics 2006 *Population Projections Australia Reissue 2004 to 2102*, 3222.0.

Characteristics

Younger people with dementia are more likely than older people to have dementias other than Alzheimer's Disease, including vascular, frontotemporal and alcohol related.

Frontotemporal dementia is a term used to describe a group of neurodegenerative disorders that includes Pick's disease. It accounts for approximately 10 per cent of dementia cases and is particularly common in younger age groups, usually developing between the ages of 35 and 75 years, with no gender differences. (Draper 2004)

Symptoms of Fronto Temporal Lobar Degeneration (FTLD) include hyperorality (loss of normal controls, ie excessive eating, indiscriminate putting things in one's mouth) and disinhibition.

Early symptoms can affect behaviour, and sometimes language. People may show a change in their character and in their social behaviour. For example, they may show insensitivity when they have previously been very considerate of others. A person with FTLD may become obsessive and repeat the same action over and over again. Language problems often occur early in the disease and may range from limited speech to total loss of speech. Repeating phrases over and over, or echoing what others have said are also common symptoms. Instead of being able to find the right word to describe an object, a person with FTLD may give a description of it instead. For instance, instead of naming a watch, the person may refer to something you tell the time with. (Alzheimer's Association 2005)

People with Down Syndrome are more likely than the general population to develop dementia before they turn 65. “The risk that a person with Down’s syndrome will develop Alzheimer’s disease increases with age at a similar rate as it does in the general population but 30 to 40 years sooner than is the case for people without Down’s syndrome.” (Down’s Syndrome Association, UK, 2005)

People with younger onset dementia are generally active, mobile and physically capable. Many are working full or part-time when the symptoms first become apparent and they may have had an expectation of continuing in the workforce for some years. They may have younger partners and carers, dependent children at school or studying and ageing parents requiring their support. (Alzheimer’s Society 2005)

They may have experienced considerable delay in obtaining a diagnosis of dementia. This may have involved multiple assessments and often appears to follow an initial diagnosis of depression or some other mental illness.

For many the dementia may progress more rapidly than for an older person. Though for some it is a long term condition.

People with younger onset dementia experience loss on several fronts: their selfhood and self-esteem; a changed relationship within the family structure (unexpected dependency); a sense of social isolation and exclusion; and lack of meaningful occupation. They generally have concerns about work, finances, family support and driving and access to genetic counselling.

The stress of younger onset dementia is likely to be particularly intense in those culturally and linguistically diverse (CALD) communities which have strong expectations of adult family members carrying a responsibility for an extended family.

Not surprisingly, given their chronological age and life-stage, people with younger onset dementia do not tend to search for appropriate services in the “aged” sector as they and their carers do not identify with this age group.

Finding people in the community with younger onset dementia has therefore been fairly challenging. They are a hidden population of individuals who present with a wide range of conditions and don’t associate with the services offered to older Australians. (Crump & Hayes 2005)

The literature is limited on the nature and extent of dementia in Aboriginal and Torres Strait Islands (ATSI) people. New research by the Primary Dementia Collaborative Research Centre (Professor Tony Broe) will go some way towards addressing the issue. The research project “will undertake a systematic review of the literature and other evidence to examine the nature and extent of dementia, the experience and meaning of dementia for Aboriginal communities, risk factors and protective factors for cognitive decline, assessment methods and instruments, and provision of care” (Dementia Collaborative Research Centre 2006).

2.2 Relevant initiatives and developments

Metro North models

Four HACC funded services supporting people with younger onset dementia have been identified in Metro North region. They include two social support services specifically for younger onset and two day centres offering an excursion day for younger people:

- Mercy Community Care Younger onset social support;
- Chesalon Barrenjoey Younger onset social support;
- Hope Healthcare Saturday Horizons program for ‘early age, early stage’ dementia; and
- Mercy Day Centre catering for younger onset on one day.

The following pages provide an overview of each of these initiatives.

Figure 2.1 Horizons: A service model for people with younger onset dementia and people with dementia and behaviours of concern

Name of service:	Horizons program
Auspice organisation:	Hope Healthcare
City/ town / suburb:	North Sydney
State / Territory:	NSW
Particular target group:	Early age, early stage'. Clients have ranged in age from 23 to 76 years old. Emphasis is on early stage dementia with high level of physical functioning and behaviours of concern. Most have frontal lobe dementia. People who cannot attend mainstream day care.
Specialist or mainstream model:	Model which is delivered within and by mainstream service
Goal of service / innovation:	To provide a therapeutic environment within a social setting.
Description of service / innovation:	The Saturday Horizons program is managed by the Tom O'Neill Centre (10 Edward Street, North Sydney) as one of its day care programs. Horizons operates from 10am to 4pm, 49 weeks of the year. (Tom O'Neill also provides an in-home respite service for carers and people with dementia.) Horizons is an excursion type program offering a club atmosphere. Excursions include picnics, barbecues, gallery visits, etc and involve a lot of exercise. Transport is by community bus. In-centre activities include music and poetry readings. Activities are decided by small groups of clients.
Types of support offered / involved:	Horizons offers day centre activities, socialisation and respite care for 6 people living on the Lower North Shore of Sydney (North Sydney, Lane Cove, Mosman and Willoughby local government areas) Clients need to be transported privately to and from the service.
Size of service / capacity:	2 staff and 6 clients with current funding, giving a client: staff ratio of 3:1. 5 of 6 current clients are men.
Funding:	\$35,000
Source of funds:	HACC
Any other agencies involved:	Nil. Totally managed by Tom O'Neill Centre
Innovative features of service/model:	Clients choose where they want to go on their outings and the activities they want to undertake. The staff facilitate their agreement. One staff member has a degree in conflict resolution. The clients consider the service to be like a club.
Features most appropriate for replicating in HACC:	The program could be replicated in other HACC day centres, PROVIDING staff are well trained in facilitating client decision making and working with clients with very difficult behaviours, typical of people with frontal lobe dementia.
Output / outcome indicators:	Regularly evaluated via quarterly quality reviews, annual survey of clients and carers, dementia care mapping and the HACC Integrated Monitoring Framework.
Results achieved to date against intended objective and outcomes:	Group is up and running successfully with a social "club" model of care in a therapeutic environment. Activities are chosen by clients. Regularly evaluated via quarterly quality reviews, annual survey of clients and carers, dementia care mapping and the HACC Integrated Monitoring Framework.
Any documents available about the innovation:	Brochure distributed to GPs, clients, other agencies.
Any identified areas for improvement with the model &/or deficiencies / difficulties:	Could expand to 3 days per week with funding. Difficult to get staff to work on Saturdays. Need to have bus driver's licence. Transport resources for carers (eg taxi vouchers) or additional staff funding to enable pick up of clients. All need to be at centre by 10 to allow time for outings given Saturday traffic. Target group means demanding work. Carers under more stress than most other carers. Access to emergency (same day) in-home respite needed when client refuses to attend program.
Contact –	Name: Sandra Dodwell Title: Manager Phone: 02 9957 3224 Fax: 02 9954 4621 Email: sdodwell@nscchahs.health.nsw.gov.au

Figure 2.2 Chesalon: A service model for people with younger onset dementia

Name of service:	Younger Onset Social Support
Auspice organisation:	Anglicare Chesalon
City/ town / suburb:	Avalon
State / Territory:	NSW
Particular target group:	People with younger onset dementia
Specialist or mainstream model:	Model which is delivered within and by mainstream service
Goal of service / innovation:	To assist people keep active and remain engaged in their community.
Description of service / innovation:	<p>A weekly or fortnightly outing. May be in one on one situation or group setting. Clients come from across the Manly Warringah Pittwater Area. Also may involve transport to appointments and is prearranged with centre at least 2 weeks prior.</p> <p>The service operates from Chesalon Barrenjoey Day Centre, 18 Old Barrenjoey Road, Avalon, between 9.00am-2.30pm Monday to Saturday.</p> <p>It caters for physically frail and/or disabled elderly persons and physically active elderly people suffering from dementia. Physiotherapy, speech, podiatry, occupational and diversional therapy are provided. Activities include outings, craft, visiting speakers, cards, scrabble, mah jong, music, carpet bowls, outside deck game, mini golf and music.)</p> <p>One gentleman with younger onset participates with older clients as transport for outing not available on other days and client's family in need of respite.</p>
Types of support offered / involved:	Support designed to assist in maintaining healthy lifestyle for those who wish to remain in their own community.
Size of service / capacity:	Up to six people with younger onset dementia. Whole family is seen as the client.
Funding:	\$69,000
Source of funds:	HACC social support funding
Any other agencies involved:	N/A
Innovative features of service/model:	Clients actively participate in all aspects of the outings – discuss and choose locations and activities as a group to arrange the next outing. This allows for discussion of what is and is no longer safe for them to do and has provided a positive social network for the clients. Over time they have become a good peer support group for each other and help each other through life stage changes that affect them.
Features considered most appropriate for replicating in HACC:	Social support is very general but one which is essential to keep replicating because it provides so much support particularly for younger onset people as they work through the rapid changes of the disease.
Output / outcome indicators:	6 hours / twice per week
Results achieved to date against intended objective and outcomes:	It has been hard to source the appropriate clients for this service and there needs to be a raised awareness not just in the general community but with the general practitioners and other primary health providers
Any documents available about the innovation:	N/A

Continued over page....

Figure 2.2 Chesalon continued....

<p>Any identified areas for improvement with the model &/or deficiencies / difficulties:</p>	<p>Difficult to locate target group.</p> <p>Transport is a major issue and cost to the service given its geographic area. Clients don't like to feel that they are "disabled" so close attention needs to be given to the naming of the service and how it is presented to clients. In particular clients who have held professional positions need time to adjust to their change in circumstance and be supported to maintain as much independence as possible. Top priority is to help them maintain their dignity and make them feel as though they still have a place in society. They don't need pity. Their families also need to feel that the client is a part of the family so decisions should be made as a family unit rather than being "dictated" to. Needs to be person focused and flexible to meet their unique needs which are different to older people with dementia.</p> <p>Respite needs to be longer hours as often spouse is working or has had to return to work and respite needs to accommodate working hours.</p> <p>Another addition would be the ability for carers to place their family member in a service in their local area based on where they live and/or work. Sometimes they work a distance from home and being able to take the client to a service near where they work may be a preferred option.</p>
<p>Contact –</p>	<p>Name: Kirsten Noble Title: Co-ordinator Phone: 02 9918 0799 Fax: 02 9973 1723 Email: knoble@anglicare.org.au</p>

Figure 2.3 Mercy Social Support: A service model for people with younger onset dementia

Name of service:	Younger Onset Dementia Social Support
Auspice organisation:	Mercy Community Care, Catholic Healthcare
City/ town / suburb:	Waitara
State / Territory:	NSW
Particular target group:	People with younger onset dementia
Specialist or mainstream model:	Specialist model specifically for target group
Goal of service / innovation:	To provide a social support service for people diagnosed with Younger Onset Dementia living within the Hornsby and Ku-ring-gai local government areas. The goal is to support clients to participate within the community through regular social activities, reducing social isolation to enhance a client's quality of life and well-being. Social support is provided by a community care worker or volunteer who facilitates access to community activities, to participate in regular social/sport activities and/or attend appointments.
Description of service / innovation:	It is an innovative, flexible service, which is individually focused. Clients and carers develop a service plan with the coordinator which outlines weekly social outings such as recreational activities, social activities with friends and family, and transport assistance to attend social activities or appointments.
Types of support offered / involved:	One to one and group social support including transport to participate in social activities and to attend appointments.
Size of service / capacity:	Current capacity 10 clients.
Funding:	\$81,875, comprising \$69,125 social support and \$12,750 for transport.
Source of funds:	HACC
Any other agencies involved:	Liaison with community sport and recreational clubs and services
Innovative features of service/model:	The service recognises that people with Younger Onset Dementia have social needs and interests and are physically able to participate in activities. Social isolation can be a significant factor for people with Younger Onset Dementia and the program addresses this through regular, planned and innovative programmed activities which focus on supporting individual interests on an individual and group activity basis. Staff are trained to support people with Younger Onset Dementia as their support needs differ significantly from frail aged clients. The service is integrated with other services including, counseling/ carer support groups, dementia day care program and pastoral care.
Features most appropriate for replicating in HACC:	A service that is: -based on individual needs -has a specific focus on community activities which are client focused and client initiated. -utilises natural community supports whilst also maintaining current community supports/friendships/church group etc. - provides both individual and group programming. - provided by staff that are trained to understand to specific needs of this client group.
Output / outcome indicators:	2,765 support hours and 850 transport trips per annum.
Results achieved to date against intended objective and outcomes:	Total Hours of support provided- 1/07/2005- 30/06/2006: 3,832
Any documents available about the innovation:	Eliza Pross, <i>Two Years On: Findings from the Younger Onset Dementia Social Support Program 2004-2006</i> , A Report For Mercy Community Care, June 2006.
Any identified areas for improvement with the model &/or deficiencies / difficulties:	Significant development time was required to market the program to potential service users and to develop referral pathways.
Contact – Name: Title: Phone: Fax: Email:	Nicole Nevin Co-ordinator 94871632 94896543 nnevin@chcs.com.au

Figure 2.4 Mercy Day Program: A service model for people with younger onset dementia

Name of service:	Dementia Day Centre
Auspice organisation:	Mercy Community Care, Catholic Healthcare
City/ town / suburb:	Waitara
State / Territory:	NSW
Particular target group:	People with younger onset dementia
Specialist or mainstream model:	Model which is delivered within and by mainstream service
Goal of service / innovation:	<p>To provide a day care service for people diagnosed with Younger Onset Dementia living within the Hornsby and Ku-ring-gai local government areas. The goal is to support clients to participate in a weekly recreation based day program with a peer group to facilitate socialization, retention of social skills and to engage in meaningful activities, to reduce social isolation, and provide physical activity, to enhance a clients' quality of life, health and well-being.</p> <p>Support is provided by recreation activity officers and volunteers who facilitate social interaction, support physical participation in activities and provide assistance.</p>
Description of service / innovation:	Support for clients to access the community in a comfortable and supportive group. DVDs sent home to family with photos of client participating in activities. The service uses Chantal dementia day centre as a base, and this venue can be used as a backup if bad weather forces a change in plans. The service is integrated with other support services including, counseling/ carer support groups, individual social support program and pastoral care.
Types of support offered / involved:	Outings, transport using a small bus (including pick up and trip home), recreation and physical activities, social support, lunch, assistance with personal care, regular communication with family carers.
Size of service / capacity:	Maximum of 8 clients
Funding:	\$134,464 program funding for 3 days centre based dementia day care – 1 day is scheduled for Younger Onset Dementia clients.
Source of funds:	HACC
Any other agencies involved:	Liaison with local and disability recreation and sporting groups.
Innovative features of service/model:	Weekly outing program planned in consultation with clients and carers
Features considered most appropriate for replication in HACC:	Flexible, regular weekly activities that are planned and valued by clients and their families. Facilitate and support appropriate social interaction within the group and between clients and people in the community. Staff trained in supporting people with Younger Onset Dementia.
Output / outcome indicators:	2288 hours and 830 trips
Results achieved to date against intended objective and outcomes:	<p>High attendance level with no withdrawal from the program. Clients participate socially, are sharing their experiences together, building social relationships and maintaining or increasing physical activity levels.</p> <p>Family carers state they value input on program activities and regular feedback on participation levels.</p>

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Figure 2.4 Mercy Day Program continued....

Any documents available about the innovation:	NA
Any identified areas for improvement with the model &/or deficiencies / difficulties:	Type of activities provided is restricted by funding levels. Service can only be provided one day per week within the current 3 day centre based day care service.
Any other comments about ways these service characteristics could be incorporated within or as part of the existing HACC infrastructure:	Provision of specific training to day services staff to target programming to meet the needs and interests of people with Younger Onset Dementia. Program planning to focus on activities that are provided in the community, are meaningful and valued, and include physical activity. Liaise closely and support family carers.
Contact – Name: Title: Phone: Fax: Email:	Joanne Nienhuis Senior Co-ordinator (02) 9489 3592 (02) 9489 7003 jnienhui@chcs.com.au

Dementia planning

Over the last few years, dementia planning and service development has been occurring across Metro North. One of its outputs has been strategic plans. The plan for the Northern Sydney HACC planning area, *the Northern Sydney Dementia Services Strategic Plan and Action Plan*, (Pross 2005) was available to this project. The areas of Nepean and Cumberland/Prospect had combined on a Western Sydney strategic plan which was being finalised at the time of writing.

The Northern Sydney plan identifies younger people with dementia and their carers as one of three “specific groups of focus whose needs will be a focus of planning and development processes”.

Younger Onset Dementia HACC Training Pilot Project

Mercy Community Care received one year, non-recurrent funding from the Office of Ageing in 2005/06 for this project. It involved the development of training resources, piloting a one day training session in three regions - Central West, Hunter and Northern Sydney, evaluation of the program and recommendations for future training needs of HACC sector staff on the needs of people with Younger Onset Dementia and their carers. The training package was developed in collaboration with Aged and Community Services Association (NSW & ACT) and delivered by one of the Mercy Community Care Dementia Advisors, supported by the Younger Onset Dementia Social Support Co-ordinator.

The evaluation of the pilot project is being presented to the Office of Ageing in March 2007. A decision on roll-out of the training program is yet to be made.

Alzheimer's Australia National Project on Younger Onset Dementia

The Australian Government provided funding to Alzheimer's Australia (AA) “to conduct a national project to identify and map the needs of younger people with dementia and to develop recommendations for future initiatives in this area”. (<http://www.alzheimers.org.au/content>)

The project included employment of a policy officer at the AA NSW office. (The officer was also a member of this project's Advisory Committee.) The policy officer consulted widely on issues related to younger onset dementia and identified a range of areas for possible attention by AA and/or Government. This project is likely to suggest that government consider further awareness raising in the community about dementia and that such efforts include the medical community as well as the broader community and incorporate images of younger people with dementia. Issues such as financial incentives for service providers to meet the needs of younger people may also be canvassed.

AA has two publications in production on younger onset dementia, one for the general public and the other for the medical community.

Models in other States and Territories

From enquiries with HACC authorities in other States and Territories, Victoria appears to have made the most progress in addressing the needs of people with younger onset dementia.

The background paper developed for the focus groups (Appendix B) outlined different services operating in Victoria by respite services and Alzheimer's Australia. The younger onset service models comprise:

- group excursions, covering a range of activities of mutual interest such as walks, picnics, pub lunches, art gallery visits, etc for people with younger onset dementia and respite for their carers;
- residential retreats for the person with dementia and their carer, providing the opportunity to establish new social networks with people in similar circumstances;
- art therapy classes; and
- partners' or carers' networking and discussion opportunities.

In addition, Alzheimer's Australia Victoria has developed a café inspired by the Dutch Bere Miesen model (see below) to provide a follow-on to its Living with Memory Loss program. The Memory Lane Café aims to provide:

- a forum for social/emotional support for people in the early stages of dementia, their families and carers;
- support and prevent isolation by enabling people to communicate with others in a similar situation; and
- a forum for informal advice and consultation with staff from Alzheimer's Australia Vic.
(Mather 2005b)

The café has operated in three locations.

The cafés are aimed at people in early stages of dementia. Generally, members with dementia fall into the older age group, but many people from our Younger Onset programme attend as well. Family members and carers come from all ages. Transport to the venue can be arranged and paid for as necessary and no one is excluded due to financial constraints. Attendance at two of the cafés ranges from 60–80 and the third has about 40–45 people. There are usually three or four staff members and a volunteer to help with seating, taxis and any support issues.

Underlying principles: The Memory Lane Café complements existing services with the sharing of information and ideas amongst the participants leading to greater and more effective use of local services. It also contributes to increasing a sense of belonging to their community. This programme is formulated with the underlying principles of empowerment for people to be given access to information and encouraged to identify their own needs and ways of meeting them. (Mather 2005b)

International experience

The Alzheimer's Society in London has had a strategy for people with younger onset dementia since 1996. One of its more recent publications, *Younger people with dementia: a guide to service development and provision*, (Alzheimer's Society 2005) informed the early stages of this project. This document is a practical resource which would also be useful to service providers in Australia implementing services for this group.

Social support

A service model mentioned in the Alzheimer's document is The Clive Project in Oxford which provides a One-to-One Support Service for people with younger onset dementia.

Our aim here is to offer a very positive choice of 'things to do' for the person with dementia. A trained support worker partners the person, and they develop a trusting relationship. Once this is established then we work regularly alongside the person, encouraging, supporting, and pursuing activities that bring pleasure and satisfaction. The rich range of activities can be anything that is significant to the person, from warm companionship to fulfilling lifetime ambitions, and anything in between. In practice, the sessions are usually 2-4 hours each week, with flexibility built in. Being with an experienced support worker offers reassurance through periods of change in condition and abilities, and particularly if the person has respite breaks or moves to a care home.

The service is for people who have experienced the symptoms of dementia whilst under the age of 65 years, and live in, or on the borders of, Oxfordshire. Once introduced to the service, age is irrelevant, and we continue until the person no longer benefits from the active service provided. Anyone can refer a person to the service, with their agreement. (<http://www.thecliveproject.org.uk/whatwedo.htm>)

The Project also operates 'The Clive Project Club', which involves social events throughout the year in locations across Oxfordshire. This provides opportunities for clients, their partners and families to enjoy time together, supported by The Clive Project team. The Project also provides individual and group support for the family and friends of people with younger onset dementia.

Dementia cafés

While not only catering for people with younger onset, dementia cafés are seen as an option which may particularly appeal to this group and their carers. First launched in the Netherlands by psychiatrist, Bere Miesen, and colleagues, they now operate in a number of other countries.

Alzheimer cafés offer education and support, informal advice and consultation by professionals and fellow sufferers, in a relaxed atmosphere. Service users are encouraged to attend a series of ten monthly meetings. The content of each meeting is agreed in advance, but it generally covers the course of dementia. The café concept is based on a fixed structure of five half-hour sessions:

- arrival and introduction

- information
- live music
- group discussion
- rounding off.

The information sessions generally take the form of interviews with patients, family and experts, in front of the group, led by the discussion leader. The information and peer advice offered by this service can provide clients and carers with some insight into the condition. It can also give them practical information and reduce their reluctance to seek professional support. Alzheimer cafés are currently available in Australia, Belgium, Germany, Greece, the Netherlands, the United Kingdom and the United States (Miesen and Jones 2002 as quoted in Nies and Berman 2004)

An evaluation of a dementia café in England (Capus 2000) examined how the café was meaningful to participants.

The results from the group discussions and from our experience in setting up and organizing the café suggest that it provides an important venue in which, through meeting with others in a similar position, carers may be helped to normalize the emotions that the experience of caring has evoked in them and the changes in relationships that have occurred since the onset of dementia. People with dementia may be helped to normalize their changes in functioning and supported in coming to terms with living with dementia. For families who find themselves becoming increasingly socially isolated, the café may provide a secure base and provide a new and different social network. Finally, the café experience, with its emphasis on providing a non-clinical, non-didactic, non-pathologizing, non-stressful and unstructured ambience offers a unique environment for those involved in dementia care and those who are living with dementia to meet as equals and share understanding and insights, co-working towards solutions.

2.3 *Appropriate service models*

Key messages from the consultations

Discussions at the focus groups confirmed the characteristics of service models to meet the needs of people with younger dementia as outlined in the background paper. Participants emphasized that the models which are likely to work well and be given priority:

- involve specific funding for people with younger onset dementia so that supportive structures and services can be built for them.
- focus on abilities rather than functional deficits and on maintaining the lifestyle of the person. Generally this means being activity and mobility focussed, but also centred around each person's interests. This may involve partnerships for HACC service providers outside the usual. For example, the Metropolitan Museum of Art in New York has an afternoon for people with dementia. It also may involve considering other constructive activities such as supported volunteering or supporting clients in sustaining employment. Language needs to use an abilities, rather than limitations, emphasis.

- cater for the person and their whole family, recognising that this is likely to include children and working carers. Services may include respite breaks for couples, such as weekend retreats.
- offer counselling for people with younger onset dementia and their carers and families and peer support to link them with others in similar situations.
- provide effective outreach to the younger person living alone, especially to reduce their social isolation.
- are based on a sustainable level of flexible funding which can meet individual needs rather than being 'recipe based'. This may involve brokerage or top-up funding which can be operated flexibly like a CACP or an EACH. It also involves flexibility in hours of operation and possibly a 1:1 or 1:2 staff:client ratio. Mental health models may provide some guidance in this regard. The Baptist Community Service model of a home host service, derived from family day care, may be worth examining. Group day care services may also need complementary alternative respite options for those times where a client cannot or will not participate in a group activity.
- are accessible to younger people with a disability who develop dementia.
- provide an early point of contact from the time of diagnosis such as is available from DAS.
- need to incorporate one-on-one respite complemented by other outreach services, such as is common through the National Respite for Carers Program (NRCP), and by overnight respite in community based services such as respite cottages.
- have a very different "feel" to conventional HACC congregate services reflecting the preferences of younger people, for example, the dementia cafés of the Netherlands. Services for people with younger onset dementia may also need to incorporate more physically demanding and more community based activities than the activities generally offered for frail aged people. They also need a name which is sensitive to the stigma of 'aged care' felt by younger people and their families.
- try to build capacity across services rather than adding to fragmented services.
- involve approaches other than day care, especially social support.
- support carers with the right information and education at the right time. This may include greater use of the internet for dissemination both for the carer and the person with dementia.
- use skilled workers within a low client:staff ratio setting;

- provide additional training in younger onset dementia for all workers involved in supporting this group, recognizing its particular emotional and other impacts on workers, as well as on clients and carers.
- recognize that transport to services may not be difficult for some people in this group as their carers may have the capacity to drive them to services, but that it may be a barrier to access, especially for those living alone and for those living in parts of the region which are remote from services such as in outlying areas of the Hawkesbury Shire.

2.4 Responses from HACC

Key messages from the consultations

Participants suggested HACC could better support people with younger onset dementia in the following ways.

Carers:

- By supporting carers and asking them what they need. Support needs to recognise the additional family, financial, workforce participation and other difficulties such families with younger members face and needs to include recognition of the loss and grief felt by families and the possible negative attitudes they are experiencing from society.
- By promoting continuity and seamlessness of support for both clients and carers.

Access:

- By providing specifically targeted funding consistently across the region that can address individuals' needs, including support normally considered outside of the mainstream of HACC services. Allowances for transport need to be included.
- By continuing to strive to improve interfaces with GPs and other services so that people and their carers are aware of services sooner rather than later. This would include promotion of specialist services to GPs, Divisions of General Practice and the Pharmacy Guild.
- By trying to streamline services to reduce system complexity for this group (and other potential clients).
- By taking a more flexible approach to interpreting HACC guidelines and eligibility, especially for those under 65 years of age. National or state clarification that younger people who acquire dementia, including those with a pre-existing disability, are part of the HACC target population would greatly assist access, support and seamlessness.
- By assisting people to link into appropriate HACC and non-HACC referral pathways, including access to neuro-psychiatric services.

Workforce:

- By recruiting male support workers where appropriate, to work with male clients.
- By using dementia advisory services (DAS) to link people with younger onset dementia and their carers into services. This initiative would be complemented by a mapping of client pathways and implementing enhancements to improve access to services.

Other issues that participants suggested need to be considered by HACC include:

- dual diagnosis – resolving how people in this situation are responded to by HACC, including identifying lead agencies and a case manager and linking with mental health.
- making better connections between specialist services and mainstream services to improve the capacity of mainstream services to respond to people with younger onset dementia and to improve the flow of referrals to specialist services.
- supporting national media campaigns raising awareness about dementia in younger people. The television campaign on younger people in nursing homes was cited as a good example. Awareness among employers is particularly important for people with younger onset and for their carers.
- raising the issue of opportunities for supporting people in this group in employment.
- expanding the role of ACATs to include assessment of people with younger onset dementia, that is, people aged under 65.
- ensuring effective linkages with palliative care services as for many people their period of living with dementia (especially following diagnosis) may be relatively short.

3 People with Dementia and Behaviours of Concern

3.1 *Characteristics and needs*

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.

Population

Rosewarne and others (as described in Access Economics 2003) have defined behaviours into four strata. This work was primarily related to assessment and placement of people in residential care:

- B1: problem behaviours requiring basic management and occasional intervention;
- B2: episodic problem behaviours requiring frequent intervention and expert management;
- B3: continuously disruptive problem behaviours requiring frequent intervention and expert management;
- B4: continuously disruptive problem behaviours requiring management in specialist psychiatric facilities.

The 'Brodaty triangle' (as described in Access Economics 2003) estimated the proportion of people with dementia and behaviours of concern or behavioural and psychological symptoms of dementia (BPSD):

- 1 no dementia (M) - 93.4% of older Australians;
- 2 dementia no BPSD (D) - 39% or 63,000 people with dementia;
- 3 mild BPSD (DB1) - 29% or 47,000 people with dementia;
- 4 moderate BPSD (DB2) - 21% or 34,000 people with dementia;
- 5 severe BPSD (DB3) - 10% or 16,000 people with dementia;

- 6 very severe BPSD (DB4) – 0.9% or 15,000 people with dementia
- 7 extreme BPSD (DB4) – 0.1% or 200 people with dementia.

Five tiers (3 to 7) cover Rosewarne’s B1 to B4 strata and it has been suggested that tiers 6 and 7 would combine into B4.

We can make some broad estimates of the numbers of people with dementia and behaviours of concern in Metro North if we presume that tiers 3 and 4 are most likely to be living in the community. That is, approximately 50% of people with dementia (29% plus 21%) or an estimated 8,650 people in Metro North may have mild or moderate behaviours of concern (Table 3.1).

Table 3.1 Metropolitan North Region, Population and Behaviour of Concern Estimates

Local Planning Area	HACC Target Population (2006/07)*	Projected Total Population (2006/07)*	Projected Number of People with Dementia (2006)#	Estimated population with mild or moderate behaviours of concern (2006)~
Cumberland/Prospect	55,589	772,737	6,955	3,477
Nepean	23,381	330,268	2,972	1,486
Northern Sydney	67,410	819,139	7,372	3,686
Total, Metro North	146,380	1,922,144	17,299	8,650

Sources:

* p 15, Australian Government Department of Health and Ageing and DADHC 2006

Estimate based on 0.9% of total population (AIHW 2007).

~ Based on Brodaty triangle, ie 29% mild and 21% moderate behaviours of concern.

Characteristics

Behaviours of concern may include resistance to care, agitation, distress, restlessness, wandering, inappropriate sexual behaviour, inappropriate toileting practices, hyperorality, social withdrawal and/or verbal or physical aggression.

Behaviours arise from a “whole personhood of lived experiences” (Caron and Goetz 1998, cited in Wirth 2001) needing to be seen within a “whole person” context, including consideration of each person’s personal history and psychological background. The behaviours 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). They may be of concern to carers or families and not to providers and others, or vice versa.

People with behaviours of concern are likely to need one to one support while they are most unsettled. Often the person with the behaviour of concern does not want services. Transport may present a significant safety issue.

3.2 Relevant initiatives and developments

Metro North models

The background paper (Appendix B) identified a range of initiatives in the region which support people with dementia and behaviours of concern. In addition, Hope Healthcare has been funded for the past three years, by the Commonwealth's National Respite for Carers Program (NRCP), to provide Flexible Carer Respite Solutions. Figure 3.1 gives an overview of this service.

Figure 3.1 A service model for people with dementia and behaviours of concern

Name of service:	Flexible Carer Respite Solutions
Auspice organisation:	Hope Healthcare
City/ town / suburb:	North Sydney
State / Territory:	NSW
Particular target group:	People with dementia and behaviours of concern
Specialist or mainstream model:	Specialist model specifically for target group
Goal of service / innovation:	To provide flexible respite solutions, education and behaviour management strategies for carers of people with dementia and associated challenging behaviours.
Description of service / innovation:	The service provides an initial home visit during which the Behaviour Management Specialist discusses needs and issues with the carer and the Respite Coordinator gets to know the person with dementia. The carer and specialist develop and implement strategies appropriate to the care recipient, home and individual circumstances to mitigate behaviours of concern, with supporting education offered to the carer if necessary. The Specialist also works with mainstream dementia providers to develop and implement strategies to allow the person with behaviours of concern to be integrated / re-integrated into their services. Music Therapy at home or in day centres augments the care provided for clients who are anxious, depressed, angry and/or aggressive or where it is thought it will enhance carer / client communication. The service covers the local government areas of Lane Cove, Willoughby, North Sydney, Mosman, Ryde and Hunters Hill.
Types of support offered / involved:	Flexible respite with experienced and trained workers; Music therapy to increase communication and promote expression of emotion; and Advice and support by a behaviour management specialist to carers and to mainstream dementia service providers having difficulty supporting people with dementia and behaviours of concern.
Size of service / capacity:	3 staff supporting 23 carers per week
Funding:	\$253,000 per annum
Source of funds:	National Respite for Carers Program
Any other agencies involved:	The service works closely with GPs and ACATs. At times, medication may be required if the person with dementia is depressed or in pain, or has behaviours that pose a serious danger to themselves or to others. The Behaviour Management Specialist and mainstream dementia services work together to implement strategies for mitigating the behaviours of concern and education is provided.
Innovative features of service/model:	Carers of people with behaviours such as high anxiety, aggression or wandering are not easily able to access "mainstream" dementia specific services such as day centres. The service has facilitated that access.
Features most appropriate for replicating in HACC:	The program could be replicated by other HACC providers experienced with flexible respite, PROVIDING expertise in behaviour management is included in the service team.
Results achieved to date against intended objective and outcomes:	After 12 months, 80% of the service's clients were accessing mainstream dementia services.
Any documents available about the innovation:	Griffiths Nicola, Glenda Carter, Olwen Assehton and Kerryn Treversi 2006. <i>Innovative Practice Creating Culture Change in Dementia Care</i> . A poster presentation for ACSA National Conference. Community and Aged Care Services, Hope Healthcare, Sydney
Any identified areas for improvement with the model &/or deficiencies / difficulties:	
Contact –	<p>Name: Nicola Griffiths</p> <p>Title: Manager Community And Aged Care Services</p> <p>Phone: 9903 8366</p> <p>Fax: 9436 0130</p> <p>Email: ngriffit@nscchhs.health.nsw.gov.au</p>

Northern Sydney Dementia Nutrition Pilot Project

While covering all people with dementia this project may be of assistance to people with behaviours of concern. It is a 12 month pilot project funded for 2006-07 by Metro North Region of DADHC, in collaboration with Meals on Wheels (MOW) Hornsby, MOW Ku-ring-gai and Mercy Community Care (MCC). A steering committee with project partners, a carer and clinical nurse specialist is managing the project.

A range of strategies are being trialled to support people with dementia who live alone in Hornsby or Kuring-gai LGAs and whose nutritional needs are not adequately met by current HACC service arrangements. For some clients, specifically recruited and trained volunteer involvement is being trialled to support the work of community care workers who have expertise in dementia care. Strategies include mealtime assistance and prompting, and eating with the person if necessary, some meal preparation, nutritional counselling and advice, provision of non MOW food, supplementing the diet, going out to cafes, centre based meals, designing finger food and snack packs, breakfast packs, and clear lids on MOW meals. These strategies are designed to meet individual needs including social support, and include assessment of the person's nutritional needs for the week, meal planning with a dietician and close collaboration between MOW, dementia services and Community Options case managers.

AA Education Program

Alzheimer's Australia NSW runs courses both for families and carers and for community care workers on understanding and managing behaviours of concern. The courses are run from AA's head office in the region as well as from other locations across the State.

Dementia planning

Implementation of the Northern Sydney Dementia Services Strategic Plan and Action Plan includes a Challenging Behaviours Working Party. Objectives with associated strategies and actions particularly relevant to community care and behaviours of concern include:

- maximise accessibility of community and residential services to people with dementia and challenging behaviours;
- increase the number of workers who are trained in the management of behaviours considered challenging to their carer;
- increase access for carers to information and training in the management of behaviours they consider challenging; and
- improve access to residential and in-home respite for carers of people with dementia and behaviours considered challenging. (Pross 2005)

Two recent initiatives provide assistance to service planning and practice improvement for people with behaviours of concern:

- Dementia design guidelines for the HACC Capital Works Program (Hodges et al 2006). These guidelines for architects, planners, builders and funding applicants will apply to all capital grants for HACC funded centre-based day care facilities.
- The NSW Health report, *The management and accommodation of older people with severely and persistently challenging behaviours* (NSW Health 2006). While the emphasis of the report is on residential care, its proposed model of care includes integrated specialist assessment:

Behavioural Assessment and Intervention Services (BASIS) (building on the ACAT model). These services would provide joint assessment by specialists in mental health and aged care for older people with severe, persistent and complex behavioural symptoms, and consultation/liaison and case management services to identified clients, where appropriate.

National initiatives

The background paper (Appendix B) listed national resources for workers and families to assist with behaviours of concern. A subsequent announcement may be of assistance to some carers of people with dementia and behaviours of concern:

Dementia Carer Education and Training Pilot Project

As part of the Dementia Initiative, the Australian Government has commissioned Alzheimer's Australia to undertake a pilot project that will provide skills enhancement activities designed specifically to meet the needs of carers of people with dementia and their families who access Commonwealth Carer Respite Centres (CCRCs).

The skills enhancement activities will be provided through a range of flexible delivery modes to carers who can not have their training needs met by existing modes of education and support.

CCRCs will be responsible for identifying carers training needs and organising venues for training delivery. Alzheimer's Australia will broker and fund training providers to deliver the skills enhancement activities from November 2006 until August 2007.

The pilot project will be evaluated by a National Evaluator allowing its success and impact to be measured and also to inform recommendations on the future delivery of a range of skills enhancement activities through CCRCs. (Australian Government Department of Health & Ageing 2006)

3.3 Appropriate service models

Key messages from the consultations

Participants indicated that the models that work well involve:

- Positive and collaborative problem solving, care planning and relationships between the people with dementia, their carers and generalist and specialist workers. Such relationships are built on positive communication between these parties and greater understanding of their respective strengths, capacities and difficulties.
- Staff specifically trained in working with people with dementia and behaviours of concern. Remuneration needs to better reflect the challenges of this work.
- Flexibility in the services provided to the person and may include shopping, assisting with online shopping, meal set up and so on. This may be achieved through creative combinations of funding from HACC and other programs, particularly NRCP. Again higher staff:client ratios may be required.
- Working at improving access to mainstream services for people with behaviours of concern, such as is being pursued through the Community Care Northern Beaches respite project.
- Smoother interfaces for clients across different parts of the community care and health system so that consistency of response can be aimed for. For example, the Central Coast's IT system which links across hospitals and the broader health and community care system.
- Being clear with the person with dementia and their carer about what support can be provided.
- Having a case manager or case worker who can link in with services and be able to review care provided and suggest adjustments in light of client behaviours.
- Competency in supporting CALD clients in the local community so that mainstream services may be able to assist them.

3.4 Responses from HACC

Key messages from the consultations

Participants pointed to models of HACC service provision in two areas as being particularly important in better supporting people with dementia and behaviours of concern:

- **Food services:** developing social support models specifically catering for people with dementia across the region, such as the Hornsby MOW pilot and introducing a nutrition consultant to advise food services on alternative ways of addressing the nutritional needs of people with behaviours of concern.

- **Day centres:** developing appropriate social activities for this group with well trained staff. Ensuring that the built environment is suitable to meet the needs of people with dementia and behaviours of concern.

Participants suggested that HACC could support people with dementia and behaviours of concern better by:

- Strengthening HACC services' and workers' capacities to establish and maintain effective, collaborative, ongoing and understanding relationships between workers and clients with behaviours of concern and their carers and families.
- Improving the understanding among workers of what can be managed in the home and what can't and providing appropriate training.
- Increasing the availability of in-home, overnight respite.
- Improving capacity to support people with dual diagnoses such as dementia and mental health or dementia and a disability.
- Strengthening relationships with residential care so that people have a better transition and experience of residential respite. This may involve a HACC worker briefing residential staff on strategies that work well with a client and residential care or NRCP paying for some of the worker's time.
- Establishing a response team (or individual specialist for an area) to help HACC services and carers better understand behaviours and to assist them to develop management strategies which can be readily implemented by carers and workers.
- Raising awareness of the Dementia Advisors among HACC service providers and of the assistance they can provide.
- Promoting use of the National Dementia Behaviour Advisory Service or equivalent as a useful resource for providers.
- Ensuring training of staff in dementia competencies happens across all services.
- Ensuring HACC services are aware of support teams at health interfaces, especially ASET (Aged Services Emergency Team) and BASIS (Behavioural Assessment and Intervention Service) and other specialist services such as the Cognitive Disorders Clinic at Concord Hospital.
- Using each of the above strategies to better guarantee equity of access across the region and continuity and seamlessness of support.

4 Findings

Several of the themes emerging from the project in relation to both people with younger onset dementia and people with dementia and behaviours of concern relate to other people with dementia and/or to HACC quite broadly. They also may be of benefit to people who are HACC eligible but do not fit into conventional service offerings.

The recommendations are presented firstly in the draft form in which they were circulated to the sector. This is followed by the response to the draft recommendations and consideration of the issues raised. Then a recommendation in final form is proposed along with its likely cost implications. Several new recommendations are included which were identified in discussion of the draft report with the Advisory Committee.

4.1 HACC system improvements

This set of recommendations covers ways in which existing HACC services and infrastructure and the HACC program could assist in meeting some of the needs of people with younger onset dementia and people with dementia and behaviours of concern.

Draft Recommendation re provider support

DADHC request HACC service providers in local planning areas to identify the process for providers receiving support and advice in regards to younger onset dementia and behaviours of concern within their area. For example, in some areas the first step may be to contact the local Dementia Advisory Service. A subsequent step may be raising the issue with an At Risk interagency meeting. The process then needs to be communicated to all providers in the area to remove any uncertainty as to how and by whom local assistance may be provided to these two groups.

Response from the sector

26 of the 27 respondents agreed with this recommendation and the other did not indicate a preference. Six people commented on the recommendation. Several

strongly supported the idea of a clearly identified process or protocol and some encouraged the involvement of the DAS. There was some confusion with the example being seen as the model to be implemented. Two people pointed out that At Risk interagency meetings don't exist in all areas. One suggested that it may be difficult to involve all providers in the communication process where interagency meetings don't exist. This respondent suggested greater use of HSNet or a similar electronic system. One queried whether DAS would have the necessary skills to assist with behaviours of concern.

Comment

Developing a protocol seems to be well supported and addresses carers' experience of some service providers not knowing how to assist.

Final 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.

In some areas the protocol may be the same for the two groups, while in others it may be different. In some areas the first step of the protocol may be to contact the local Dementia Advisory Service. A subsequent step may be raising the issue with an At Risk interagency meeting. The process then needs to be communicated to all providers in the area to remove any uncertainty as to how and by whom local assistance may be provided to these two groups. Areas need to develop a protocol which relates to the systems and services they have in place.

Cost implications

In some areas there will be negligible costs arising from this recommendation as protocols may already be in place. In others, time will need to be devoted in HACC/Community Care forums to developing a protocol. Carelink may be able to assist in communicating the local protocol.

Draft Recommendation re provider information

HACC program administrators encourage both Carelink and individual HACC providers to keep up to date with local referral processes and services which can provide special support to people with younger onset dementia and people with dementia and behaviours of concern. A well briefed Carelink is an important part of implementing these arrangements and needs to be reinforced as a first point of contact for enquiries across community care.

Response from the sector

25 respondents agreed with this recommendation, one disagreed and one did not indicate a preference. The person who disagreed considered these responsibilities were already allocated: "aren't Carelink funded to do this work and to make regular enquiries to HACC services and networks to update their database? Carelink may

need to be more proactive in the process. However I agree HACC services also have a responsibility to inform Carelink about changes to their service”.

Other comments concerned:

- shortcomings in Carelink’s website as searching on the phrase “dementia services” produces nil results;
- this recommendation needing to sit alongside recommendation a), especially regarding the first point of contact generally being a Dementia Advisory Service;
- Carelink staff needing training in local referral processes; and
- the value of providers using networking/information gathering opportunities as provided in local forums in addition to Carelink.

Comment

In the best of all possible worlds, this recommendation would be unnecessary. However a recurring experience of this project was service providers in an area not being aware of services offered by others and this was confirmed from carers’ experiences. It was also suggested that both State and Commonwealth governments need to support Carelink and the service sector by advising full details of new funding when announced.

Final 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.

DADHC needs the assistance of the Commonwealth to implement this recommendation.

Cost implications

Minimal.

Additional recommendation re Dementia Advisory Services

Given the relatively small numbers of people with younger onset dementia and the delays in diagnosis which appear to occur, respondents stressed the need for people to be linked into the community service system as soon as possible following diagnosis. A critical element here is for community care to become a step in the client pathway which health services may suggest to clients. Promoting DASs through distribution of a contact list to health services, especially to neurological services, accompanied by a clear message that they are an appropriate first call for community support would be a helpful starting point.

New 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.*

Cost implications

Minimal, as may be progressed by NSW Health and Dementia Advisors Network.

Draft Recommendation re flexibility

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 the sector

All respondents agreed with this recommendation. Comments covered:

- the need for this action to be statewide;
- a suggestion for a centralised decision-making/appeal process to assist continuity across regional offices;
- uncertainty as to “what I can and can’t do”;
- the need to balance flexibility with some targeting. “There are a range of often diverse needs within the dementia target group, and it is unrealistic to expect services to be able to respond to all groups all the time - the development of specialised services (particularly for YOD and BOC) is really important. As long as there are enough services, geographically spread to respond to these groups, specific targeting is not a bad thing.”

Comment

Service type reviews being conducted in NSW will be producing good practice manuals as an output.

Final 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.*

Cost implications

Minimal.

Draft Recommendation re collaboration

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

- i. support day centres to agree on and publicise their respective strengths and specialisations for particular HACC client sub-groups; and*
- ii. promote 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 the sector

26 respondents agreed with this recommendation and one did not indicate a preference. Comments were:

- funding needs to give service providers the capacity to pursue greater collaboration;
- concerns that the practice of collaboration sometimes “is compromised by a competitive market of service tendering (particularly for ‘like’ services in close proximity geographically to one another). Rather than promoting seamless support, services compete for some clients, and avoid others. Funding allocation in recognition of this tension may be the incentive... Saying this, there is a high level of communication and collaboration in our sub-region, and I would suggest regionally also.” Another expressing similar sentiments indicated that cross-agency coordination may be hindered by the need to give ‘wait lists’ as evidence for funding;

- a single point of contact and/or one waiting list could be created for day centres;
- better use needs to be made of HSNet for referral purposes;
- day centre co-ordinators need to attend the Dementia Care Network meetings;
- decision makers within HACC funded organisations need to attend HACC sub-regional forums and other network meetings; and
- a query as to what incentives for collaboration might be developed.

Comment

The issue of competition between providers was raised during consultations. Generally the response was that collaboration is greater than competition. However, the issue is one that needs to be considered by program administrators. Special funds could be provided episodically for initiatives to reinforce collaboration.

Final Recommendation 5

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

Funding could support collaborative initiatives such as:

- supporting day centres to agree on and publicise their respective strengths and specialisations for particular HACC client sub-groups; and*
- 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.*

Cost implications

Modest. Once-off HACC funding or joint HACC/NRCP funding for particular initiatives.

Additional recommendation re exit strategies

Further consideration could be given to exit strategies by service providers. Stakeholders advise that such strategies were introduced energetically some years ago and play a role both in demand management and in continuity of care. Review of exit strategies may now be timely, including consideration of common strategies across different community care programs.

New 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.

Draft Recommendation re sharing leading practice

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.*

Response from the sector

26 of the 27 respondents agreed with this recommendation and the other disagreed. The person who disagreed did not give any reason for doing so. Comments supporting the recommendation indicated:

- “On the job training would be very helpful because each service is providing such different models of care.”
- DAS be considered as a resource for information dissemination and training.
- A proviso that “Alzheimer's Australia does not get territorial around resources, that it coordinates with other information services such as Carelink”.
- Strengthened training requirements:
 - Make Certificate 111 in Community Care/HACC the basic entry level for direct care workers.
 - Employee and employer have joint responsibility for dementia training and ongoing training.
 - Work towards dementia training being delivered by accredited organisations.

Comment

This type of recommendation is common to many community care studies. It needs to remain on the agenda, especially given the evolution of new service models and changing expectations of clients and the community. Focus group participants expressed disappointment that national dementia training being rolled out is only available to the staff of Commonwealth funded community care and not to their HACC colleagues.

Final 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.*

Cost implications

The cost of this recommendation may be considerable in terms of the cost to HACC of rolling out the training and the cost of relief for staff to attend the training.

However, development costs could be reduced if Commonwealth funded national dementia training initiatives could be extended in the future to the HACC workforce.

Items ii. and iii. have minimal resource impact.

4.2 HACC good practice

This set of recommendations relates to issues which are covered by the HACC National Service Standards (see Appendix D). In other words, they relate to already accepted good practice, but due to resource constraints, competing demands or for other reasons, they are not always achieved. They are presented here in the interests of continuous improvement and of recognising that good practice helps to meet the needs of the “less common” or “challenging” clients.

Draft Recommendation re client information

HACC providers communicate clearly to potential and current clients and carers that help is available. In addition to the referral processes of recommendation 1, this requires a capacity in each planning area to support people with younger onset dementia and the availability of experts/specialists to help design and implement effective strategies for the management and support of people with behaviours of concern. Effective distribution of existing materials is also important.

Response from the sector

25 respondents agreed with this recommendation and two disagreed. One person who disagreed indicated that it would be very difficult for providers to achieve unless specialist resources are available and the other suggested that this is the role of Alzheimer's Australia and the DAS and queried whether the DAS role regarding distributing existing material needs to be strengthened or expanded.

Three respondents expressed surprise that the need for communication had to be spelt out. One suggested that the issue was more the lack of appropriate services for people with younger onset dementia.

Two people were unsure of what was intended by “existing materials”.

One respondent suggested that good communication was more likely to be achieved where providers had partnership arrangements with experts and specialists and emphasis was placed more on funding direct service than feasibility studies and consultancies.

Another indicated that initial diagnosis of younger onset dementia needs to be better and quicker so that individuals can benefit from available programs, as their dementia often develops very quickly.

A respondent who strongly agreed with the recommendation noted: “Hopefully, in the future, HACC service providers will **automatically** advise carers / clients about the role DAS can play in regard to YOD and people with dementia and behaviours of concern ie providing advice and support, and linking them into dementia specific support services being developed in their local area.”

Comment

This recommendation relates directly to HACC Outcome 2.2.

Draft Recommendation re consumer focussed service

DADHC reinforce the HACC program’s fundamental expectations of consumer focussed, flexible, responsive and seamless service provision of good quality. In particular, it needs to be clarified that any special conditions in Service Description Schedules for HACC funding are about targeting of service delivery and not excluding people who are HACC eligible but do not meet this target.

This guidance is particularly relevant in the application of age boundaries applied to service access, where people have similar support needs but different chronological ages; and to younger people with a disability and dementia. This issue should be addressed in DADHC’s review of HACC Service Description Schedules. It also needs to be addressed through the training of DADHC’s monitoring teams to ensure there is consistency of message and application through the monitoring process.

Response from the sector

25 respondents agreed with this recommendation and two disagreed. One disagreed on the grounds of mixing older and younger physically active people with dementia in the same service as she was concerned that over time the focus on younger onset may be diluted. “Say what one likes, the interests, needs and concerns etc of Younger Onset are and must be very different to older people.” This was echoed by one of the people who agreed with the recommendation: “it seems that services work best when people with like ages/interests/support needs are grouped - particularly in the YOD group. Nonetheless, flexibility between services is essential.”

The other person who disagreed prefers to see assessment of the services already operating in the region to determine whether or not they could be implemented in other locations. The suggestion was also made that age be removed altogether and there be a continuum of care based on need.

Comments made by those supporting the recommendation were:

- Clients should not be excluded when they no longer meet eligibility criteria, especially if there is no service to address ongoing need.
- “Often it is difficult to know what our boundaries can be as service providers. Also, can we provide service to younger people with brain injury (including memory loss), people with some memory loss due to MS etc etc. Do the clients have to have a diagnosis of dementia???”
- “**Strongly agree** in regard to flexibility re age and people with dementia and behaviours of concern. Many clients with challenging behaviours are automatically ruled out because of safety issues to care workers, with very little consideration given to addressing underlying causes of behaviour.”
- “HACC service providers can hide under these Service Descriptions to not assist clients that do not meet the target, however they should be able to refer clients to an appropriate service. This requires knowledge and referral skills.”
- The need to consider local area or catchment boundaries for services. For example, carers of people with younger onset dementia may have greater capacity to travel to access a specialised service.
- Disability and dementia need to be taken up as an issue with HACC local planning areas. This issue needs further research and development in relation to service provision, particularly for dementia and physical disabilities. Unsure as to whether the main issue in relation to this group is more about funding complexity (and perceived ‘double dipping’- eg HACC and DSP) and service capacity to physically respond to this group (eg access, staffing, facilities), than about age distinctions.
- Education to providers may be more important than adjusting Service Description Schedules.

Comment

This recommendation relates to HACC Outcomes 1.1, 1.2, 1.3, 4.1, 4.2, 4.3, 4.4 and 4.5.

Draft Recommendation re service flexibility

HACC service providers should aim to:

- review service operations to identify and implement greater flexibility of operations, eg service delivery hours;*

- ii. *communicate clearly to clients and their carers at the start of service delivery the expectations they may have about the duration of service, including the need to exit when needs change; and*
- iii. *ensure the transition from their HACC service to another service is as smooth as possible by providing advance notice of the end of support, assisting exiting clients and their carers to locate other suitable services, including accessing short term services before longer term service may be available, and briefing the new service provider as appropriate.*

Response from the sector

26 of the 27 respondents agreed with this recommendation and the other did not respond. Respondents noted:

- Flexibility in service operations may be constrained by low pay and the use of volunteers. (“For example, MOW who already see themselves as being flexible but restricted by guidelines and MDS reporting.”)
- Effective transitioning may be hindered by the absence of a service to move to, less than full knowledge of existing services, poor communication between service providers and “dumping” of clients.
- The need for more collaboration with residential service providers to identify the most suitable facilities available to meet client’s needs when the transition into respite or more permanent care is required.
- Points ii and iii should be happening now and if not, should be addressed through DADHC’s monitoring to ensure they occur.

Comment

This recommendation relates to HACC Outcomes 2.3, 3.1 and 4.2.

Final Recommendation 8 (covering the three draft recommendations above)

HACC providers be reminded of the importance of HACC Outcomes 1.1, 1.2, 1.3, 2.2, 2.3, 3.1, 4.1, 4.2, 4.3, 4.4 and 4.5 in providing assistance to people with younger onset dementia and people with dementia and behaviours of concern and their carers:

- 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.*

New Recommendation re inclusiveness

No representatives of CALD clients or services attended the focus groups, nor did representatives of Indigenous communities and services. Efforts were made to consult separately with Aboriginal services but the December/January timetable and the closure of services meant that was not possible. Consequently, it is proposed that:

Comment

This recommendation relates to HACC Outcome 4.3 “Consumers cultural needs are addressed”.

New 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 from those population groups.

Draft Recommendation re interrupted support

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 concerns.*

Response from the sector

All 27 respondents supported this recommendation. A few added comments:

- “Agreebut it is all about quantum. You have to fund the hours required. 1 or 2 extra hours is useless. These carers may require 20-30 hours a week at times. They may also need time out where the patient is cared for in a residential setting every now and then, similar to aged care.”
- Need episodic case management as a primary service model for facilitating this type of support.
- Such a service already exists in the lower North Shore for people with behaviours of concern: **Flexible Carer Respite Solutions** funded by the Department of Health and Ageing through the NRCP auspiced by Hope Healthcare Limited (HHL) – covers Lower North Shore and Ryde Hunters Hill LGAs. It has the flexibility to allow this type of service. (See description in section 3.2)

Comment

This recommendation relates to HACC Outcome 3.1 “Consumers receive appropriate services provided through the processes of ongoing planning, monitoring and evaluation of services”, arguing for more recognition of the need for more flexibility in mainstream services. The strong response from the sector suggests that this is appreciated. The issue of a more intensive, specialist service is taken up in Recommendation 15.

Final 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.*

Cost implications

Not quantified. However greater flexibility in service provision usually comes at some cost which could mean a marginal increment to mainstream funding, especially respite.

Draft Recommendation re Training

HACC administrators and providers ensure that workers supporting people with younger onset dementia have appropriate competency based training. This may be achieved through ensuring that national dementia training initiatives cover younger onset, behaviours of concern and people with a disability. Also, distribution of the Mercy Community Care/Aged & Community Services Association training package to Dementia Advisory Services would be a constructive start.

Training of staff in the different needs and situations of people with younger onset dementia and behaviours of concern was a recurring theme through the focus groups, in the literature and in discussions with clients and carers.

Response from the sector

All respondents agreed with this recommendation. Comments reinforced the need for this training. Two respondents indicated they were not aware of the Mercy training package and another noted uncertainty about the most appropriate material to be used.

Two respondents referred to the free dementia competency training funded by the Commonwealth for workers in Commonwealth funded services and suggested this be extended to workers in other programs and include a unit on younger onset dementia.

One of these respondents pointed to the need to include cultural awareness training relating to CALD and Indigenous communities.

Another respondent confirmed the need but pointed to service providers resistance “to releasing staff for training as time and money are so tight”.

Comment

Common training across the sector whether people are working in Commonwealth funded or jointly funded programs aligns with the objectives of *The Way Forward*. This objective also aligns with Key Priority Area 5: Workforce and Training in the National Framework for Action on Dementia (Australian Health Ministers’ Conference 2006) and its outcome of “a skilled and informed workforce is available to care for and support people with dementia, their carers and families”.

This recommendation relates to HACC Outcome 3.3 “Consumers receive services from appropriately skilled staff”.

Final 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.

A positive step towards this recommendation would be if the Mercy Community Care/Aged & Community Services Association training package were distributed to DAS via the Dementia Professional Development Network in a train-the-trainer model. DAS could then use the package with service providers. Negotiating with the Commonwealth around the national dementia training initiatives (see Recommendation 7) and ensuring that any resultant training covers younger onset, behaviours of concern and people with a disability is also important.

Cost implications

Costs in curriculum additions are likely to be modest as dementia training packages are being developed progressively. Universal coverage however is likely to involve considerable funding.

Draft Recommendation re Awareness

HACC administrators improve awareness among service providers and the public of the incidence of younger onset dementia. This would include supporting national awareness campaigns on dementia which include younger people.

Response from the sector

25 respondents agreed with this recommendation, one did not respond and one disagreed. The person who disagreed considered it “a useless exercise”. Other comments were:

- agreed with DADHC raising awareness among service providers but unsure that it was their role to do public awareness;
- the role may be performed by Alzheimer's Association;
- awareness raising is important to improve earlier diagnosis; and
- awareness raising "needs to happen at a local level as a component of all dementia education/training initiatives".

Comment

Other research indicates that broad awareness raising is most effective through national media campaigns including television. The National Project is likely to recommend including younger onset in national campaigns on dementia.

Final 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.

Cost implications

National campaigns are expensive but the Commonwealth has managed to run several in recent years including around the role of Carelink. The costs are likely to be borne by the Commonwealth. The National Framework includes as a priority for action under Information and Education: "Undertake community awareness programs based on agreed key messages including targeted information campaigns to specific community groups." The Australian Government is the lead agency for this action.

4.3 HACC service initiatives

This set of recommendations involves some new service delivery initiatives which in many cases can build on existing infrastructure.

Draft Recommendation re social support

Four outings based, social support services for people with younger onset dementia be funded across the Metro North region. One of the services needs to include flexible responses to people living in outlying areas of the region.

Both the consultations throughout this project and the literature confirm the importance of some services focusing on people with younger onset dementia. However, given the low numbers of people in this target group a small number of services may be sufficient.

As outlined in section 2.2, two social support services exist in the Northern Sydney local planning area and two day programs offer outings in a group setting for people with younger onset. No external HACC evaluations of these services have occurred to date. The Hope Healthcare's North Sydney service has been evaluated through quarterly quality reviews, an annual survey of clients and carers, dementia care mapping and the HACC Integrated Monitoring Framework.

The Waitara service has been reviewed by an independent researcher contracted by the provider, Mercy Community Care. The review found strong support for the service from users and concluded:

The most appropriate and effective service model for this target group is one which aims to identify individuals' strengths, support individuality, and promote community participation.

In response to the identified needs of people with YOD and their families, service models should be developed that are:

- Flexible;
- Holistic; and
- Strengths-based. (Pross 2006)

The Mercy service and the Chesalon service aim to provide a "whole of family" service model. All services aimed to give maximum independence and choice to clients, for example, with Horizons facilitating clients' choice through its weekly outings service and other "club activities".

Response from the sector

All 27 respondents agreed with this recommendation. One respondent doubted that four services were sufficient, especially given transport needs, while another suggested it was a good beginning and another pointed out the existing Hope Healthcare Horizons program.

Other comments were:

- Establish a specific project that runs the four services to prevent fragmentation.
- Local DAS need to work in with these services and link people with younger onset to them.
- A query as to how such services will work with CALD clients.
- The suggestion that consideration also needs to be given to "younger onset dementia specific residential-based respite options, as most residential care facilities are inappropriate for YOD target group, both in meeting the needs of the person with dementia and as perceived by their carers and children – creates greater stigma around respite when it's provided alongside much older people with dementia".

Comment

A distinct feature of this service model is the one-to-one support it involves, this is particularly important for the different nature of issues the person with younger onset dementia is dealing with, including financial, employment, dependent children and so on.

The issues of fragmentation and co-ordination are taken up earlier in Recommendation 5. The residential respite option is addressed in the national project as one of a variety of service responses which need to be designed in a way which is more appropriate to the needs of younger people.

This recommendation needs to be considered along with the next (Recommendation 14) regarding a day program.

Demand across the younger onset services in the Northern Sydney local planning area has fluctuated. As this project was being finalized, a grant was announced for Mercy Community Care to operate a social support service for people with younger onset in the Ryde and Hunters Hill local government areas. This means that all areas of that planning area, except the Lower North Shore, have a younger onset service.

A parity basis for the rest of the region based on the HACC target population in the other two planning areas (Table 2.2) suggests they could support one or two younger dementia social support services in Nepean and two or three in Cumberland/Prospect.

Key elements of the younger onset social support model were outlined in the report on the Waitara project (Pross 2006). In summary, the model:

- is based on a person centred approach;
- values the individual and their strengths;
- aims to meet the needs of the individual and their family;
- supports community participation;
- facilitates community access; and
- provides enjoyable social experiences for people with younger onset dementia.

The model is based on the World Health Organisation's concept of 'active ageing'.

Key functions of the social support service include:

- facilitating and encouraging socialization for the person with dementia and their carer, including by linking into mainstream community activities;
- assisting with appointments;
- information and advocacy in relation to future planning, including financial support and employment issues;

- organising appropriate respite, including active outings;
- linking into other services as appropriate; and
- assisting networking among clients and their carers.

Final Recommendation 13

Social support services for people with younger onset dementia be funded equitably across the Metro North region and be complemented with appropriate transport funding.

Cost implications

The experience of the two existing services in Northern Sydney suggests that the region could benefit from up to seven services in all. In funding services, consideration needs to be given to how best to assist people living in outlying parts of the planning areas. The cost to HACC of this service model may be in the order of \$90,000, including transport and depending on existing infrastructure.

Since 2002-03, NSW has been implementing a strategy to move local areas to equitable HACC funding allocations. The following table shows that the three areas of Metro North are now close to equity in their HACC allocations. As a result, the strategies outlined in this document would have to be achieved from future growth allocations.

Table 4.1 Metropolitan North Region, HACC funding share and equity position

Local planning area	Actual share for 2005-06	RAF share for 2005-06	Equity position
Cumberland/Prospect	8.4%	8.5%	Near equity
Nepean	3.8%	3.8%	At equity
Northern Sydney	10.8%	10.7%	Near equity

Source: p 16, Australian Government Department of Health and Ageing and DADHC 2006

Table 4.2 shows the HACC expansion allocation to the region in 2006-07 of some \$4.3 million. If similar levels of funding were to be allocated in future years, this recommendation could require up to about 8% of the annual growth allocation for four additional services.

Table 4.2 Metropolitan North Region, 2006-07 HACC Funding

Local planning area	2006-07			
	Base regional budget	Expansion allocation	Cost indexation	Total regional budget
Cumberland/Prospect	\$33,065,469	\$2,259,000	\$1,091,119	\$36,415,588
Nepean	\$16,952,820	\$206,000	\$559,422	\$17,718,241
Northern Sydney	\$42,965,370	\$1,843,000	\$1,417,803	\$46,226,173
Total	\$92,983,659	\$4,308,000	\$3,068,344	\$100,360,002

Source: p 24, Australian Government Department of Health and Ageing and DADHC 2006

Draft Recommendation re club models

A 'club model' of day care be funded in several day centres across the region to complement the outings based service. Such a model could cover both people with younger onset dementia and with behaviours of concern. The model may involve a higher staff: client ratio and cater for interests not necessarily covered by the day centre on other days. It may particularly assist people with dementias not involving memory loss.

Response from the sector

24 respondents agreed with this recommendation, one did not respond and two disagreed. Of the two who disagreed, one indicated that very few dementias don't involve memory loss, so he was not sure which clients the service will be targeting. The other person did not give a reason for disagreeing.

People supporting the recommendation suggested:

- Rewording of "not involving memory loss" to "behaviours of concern other than memory loss" or "people with dementias not involving behaviours related to significant memory loss".
- "Some types of dementia are not really appropriate for day centres, as they are so disruptive to the other clients and can easily trigger challenging behaviours, fear, lack of self esteem etc amongst the other clients. For these clients 1:1 or very small group outings, activities etc will be more appropriate."
- "Feedback from people with younger onset dementia confirms the need for a model which gives flexibility for a more interactive focus versus passive recipients of an imposed program."
- The Horizon's program auspiced by Hope Healthcare and funded by DADHC works on a "club" type model where members decide on activities and day programs etc.

Comment

This recommendation focuses on group activity rather than the one-to-one emphasis of the social support model. It seems to be generally supported as a model providing

another option for these two groups of people. The Hope Healthcare Horizons program uses this club model of operation and the Mercy younger day group provides a complementary service to their social support for most of their younger clients.

Final 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.

Cost implications

The cost to HACC of this initiative will depend on how many day centres are involved and how many days of service are offered. One day per week is likely to cost in the order of \$35,000 to \$50,000, depending on transport provision. Extending the existing level of service in Northern Sydney across the region would again suggest two services in Cumberland/Prospect and one in Nepean. That is, five across the region. The total cost would be up to \$250,000 or an additional \$150,000.

As with all excursion based services, attention needs to be given to risk management in detailing the model for implementation.

Draft Recommendation re specialist capacity

A specialist, flying squad worker or team capacity be built / funded to assist with workers and carers experiencing difficulties with people with dementia and behaviours of concern. Such a service would be linked with Dementia Advisory Services and would aim to assist carers and workers to understand the behaviours and to design, trial and implement strategies to minimise or prevent their recurrence.

Response from the sector

23 respondents agreed with this recommendation, one did not respond and three disagreed. Those rejecting the recommendation suggested that it would be better to put the resources to existing systems:

- training existing care workers and co-ordinators and strengthening existing training programs and resource materials; and

- linking to the existing SAFTE (Sub-Acute Fast Track of the Elderly) model which is being trialled. “Additional resources could then perhaps be added to the model when dementia is the main concern. Many of the crises are related to delirium and require a medical evaluation first. The GPs and ambulance service are also linked with this approach.”

Some of those agreeing with the recommendation suggested:

- Using “current service information to build partnerships with relevant stakeholders to help carers and workers to access existing assistance and information and work collaboratively toward prevention strategies and allow time for planning and implementation of identified gaps from this process.”
- This “will require intensive promotion of a specialist team or service to many HACC dementia service providers who baulk at accepting challenging behaviours of any kind.”
- The capacity be built into an existing service such as the DAS. One respondent indicated this is what DAS is already doing in their area.
- Hope Healthcare’s Flexible Carer Respite Solutions service “has the flexibility to allow this type of service”.

Comment

The need for this function seems to be unquestioned, the issue is more the agency which is going to provide it, with a practical desire to build on existing systems. The experience of the Flexible Carer Respite Solutions service and the DAS which provide this function already needs to be communicated across the region.

Final 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.

Cost implications

Uncertain at this stage as the extent to which this service model is already being met by existing services needs to be further tested.

Draft recommendation re dementia cafés

One or two dementia cafés be trialled along the lines of the Victorian and European models as a means of bringing people with dementia and their carers together with trained staff, including psycho-geriatricians, in a stress-free environment. The cafés promote self-reliance and self-help and follow on from Living With Memory Loss Clinics.

Response from the sector

25 respondents agreed with this recommendation and two disagreed, one of whom provided a reason:

- “A high cost and basically useless exercise. There are very few psycho-geriatricians around with spare time on their hands able to sit around in cafes.”

Comments supporting the recommendation, included mentions of similar initiatives already happening in Metro North:

- Two people suggested that the Chill Out Café at North Sydney for people with mental illness would be a possible venue and that the Council may be interested in pursuing such an initiative.
- “I would love to give this a go (with training). Having run a centre for early onset dementia (as opposed to young onset), based on clients who had just completed the Living with Memory Loss Courses, I know how difficult it is to get these people with dementia to attend a day centre. If they were attending with the carer it would certainly help.”
- “Maintaining social connection for people with Younger Onset is critical. However large numbers of people and noise could impede the benefits of social connection and strategies to manage this would need to be put in place for it to be successful.”
- “We have already instigated a social group who meet at a local café following on from the Living with Memory Loss for carers and people with dementia and this appears to be working well.” (A Northern Beaches respondent.)

Comment

The experience of dementia cafés in Victoria and Europe was outlined in section 2.2. A key aspect of the service model is that they involve people qualified to facilitate discussions among people with dementia as well as provide information and advice to carers.

This recommendation includes socialising for people with dementia and their carers. It may be particularly attractive to those people who are looking for such opportunities together. That is, it is not a form of respite. A suitable venue and the ability to get appropriately qualified personnel involved are critical to this model.

While it may not be practical to have a psycho-geriatrician attend every opening, their direct involvement in steering the initiative would be important. NSW Health would desirably be a key sponsor of such an initiative.

At the time of finalising the project, Alzheimer's Australia NSW released their booklet, *Free activities around NSW for people with dementia, their families and friends*. A Café Club – Younger Onset is scheduled once a month from February to June 2007, that is, for five mornings at Alzheimer's Ryde premises. The booklet advertises:

Drop in and socialise with younger people with dementia and their carers. Share experiences and meet new friends in a relaxed and friendly environment.

This provides one element of the dementia café model – socialising. It needs to be clarified whether information and education by trained staff will be included. Ryde may be convenient for people in Northern Sydney but more difficult to access for people in the western side of the region. Given its experience, Alzheimer's Australia NSW may be an appropriate partner in any dementia café initiative.

Final 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.

Cost implications

The cost will depend on whether there are one or two cafés tested and how frequently they operate. Once per month over twelve months in any one location may be sufficient for testing the value of the concept in Metro North.

Draft Recommendation re meals support

Provide funding for a dietician to assist Meals on Wheels services support people with behaviours of concern. In addition to appropriate serving of food, strategies may include a model of support which involves assisting with eating and returning some hours later to assist with a second meal.

Response from the sector

This was the least popular recommendation. 21 respondents agreed with the proposition, one did not respond and five disagreed. Comments from the latter were:

- did not see that the recommendation would assist people with behaviours of concern;
- considered that Dementia Monitoring was set up to address this;

- did not consider it feasible for volunteers to return to assist with another meal, and if, alternatively, it is to involve paid workers then a large injection of funds would be required;
- questioned the need for the service on the basis that most clients with MOW also receive either HACC domestic assistance, CACPs or EACH and those who don't receive other services would be referred to an appropriate service as soon as it is reported and assessed by a MOW co-ordinator as necessary;
- disagree with the function being performed by volunteers; and
- a respondent who is the coordinator of a large food service preferred to use dieticians available with the existing food supplier and expressed concern about the need for a separate group of trained volunteers. She suggested the model may require a more stable paid workforce to be viable, would need to be integrated with MOW Association guidelines and also raises issues concerning training, OH&S, time constraints and vehicles.

Comment

This was a very particular recommendation which emerged through the consultations. It is relevant to all people with dementia and not just the two groups addressed here. The responses raise some very practical issues about viability which extend beyond the scope of this project. Consequently a more tentative recommendation is proposed.

In any new models of food services to support people with dementia, the spectrum of tasks involved needs to be mapped and consideration given to which tasks are appropriate to be performed by volunteers and which are not appropriate. Functions requiring a mix of volunteers and paid staff may also be identified.

Final Recommendation 17

*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 A Project Advisory Committee

Rochelle Waterhouse	Acting Manager, Planning Team Metro North Region, DADHC
Libby Palmer	Northern Beaches Dementia Advisor Community Care (Northern Beaches) Inc
Christine Atkins	Nepean Dementia Advisor Anglicare
Sue Tolhurst	Social Worker, Dementia Advisory Service Western Sydney Area Health Service
Ruth Jacka	HACC Development Officer Northside Community Forum Inc
Noel Hiffernan	Regional Resource Worker - Community Care Western Sydney Community Forum
Pauline Armour	Director Mercy Community Care
Marguerite Tyson	Alzheimer's Australia NSW

The committee was supported at different stages by DADHC staff:

Naomi Watson, Tessa Duncan and Cathy Buining

Appendix B Consultation Background Paper

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

Metro North HACC Project

QUESTIONS FOR DISCUSSION

People with Younger Onset Dementia

1. Do you have any suggestions for how HACC services and the HACC program could better support people with younger onset dementia?
2. What models work well? What needs to happen to make such models work?
3. Which service models are a priority for this group?
4. Are there other issues HACC needs to address to better support people with younger onset dementia?

People with Dementia and Behaviours of Concern

1. Do you have any suggestions for how HACC services and the HACC program could better support people with dementia and behaviours of concern?
2. What models work well? What needs to happen to make such models work?
3. Which service models are a priority for this group?
4. Are there other issues HACC needs to address to better support people with dementia and behaviours of concern?

Discuss these questions at:

10:00-12:00, Tuesday 7th November 2006
Regentville Hall
6 Jeanette St
Regentville
Enquiries: Christine Atkins (4731 8399)
RSVP: christineatkins@anglicare.org.au

2:30-4:00, Thursday 9th November 2006
Community Care (Northern Beaches Inc)
Level 1, 10 Park St
Mona Vale
Enquiries: Libby Palmer (9979 7677)
RSVP: libby@ccnb.com.au

9:30-11:30, Thursday 9th November 2006
Orange Blossom Cottage
68 McKillop Drive
Baulkham Hills
Enquiries: Sue Tolhurst (9845 6903)
RSVP: Sue_Tolhurst@wsahs.nsw.gov.au

2:00-4:00, Thursday 16th November 2006
Dougherty Community Centre
7 Victor Street
Chatswood
Enquiries: Ruth Jacka (9415 4855)
RSVP: ruthj@nsforum.org.au

Any further comments to malt@bigpond.net.au and diannebt@ozemail.com.au by Friday 17th November 2006.
Thank you.

BACKGROUND PAPER

The project

- Dementia Advisory Services and HACC service providers in Metro North have identified barriers for two groups in accessing HACC services: people with younger onset dementia and people with dementia and behaviours of concern.
- The Department of Ageing, Disability & Home Care (DADHC) has contracted *Alt Beatty Consulting* to look at:
 - a. The characteristics and needs of these two groups;
 - b. The distinct features of a HACC service model or models which can meet these needs; and
 - c. whether or not these features can be incorporated within the existing HACC service structure.

This background paper

- This paper outlines key issues identified to date through consultations, the literature and contact with other States and identifies possible service models to assist these two groups. It is focussed on the implications for HACC service delivery and does not attempt to cover all the issues across the broader health, aged and community care service system for these two groups of people. It also does not attempt to map the full array of services and assistance which may be available.
- The paper has been produced to stimulate discussion and assist consultations during November 2006 with service providers, clients and carers, dementia advisors and others with an interest in these issues.
- For this project we are using the terms 'younger onset dementia' and 'behaviours of concern' as recommended by the project advisory committee.

PEOPLE WITH YOUNGER ONSET DEMENTIA

1. What we know about people with younger onset dementia

- They are under 65, primarily in the range 45-64. There are relatively more men than in older groups.
- Small numbers – but uncertain and may be under-estimated. No major epidemiological study in any country has examined the prevalence and incidence of all forms of younger onset dementia. Perhaps 1 in 1,000 of the population develop dementia before age 65. Some estimate up to about 10% of all people with dementia are under 65, and between 10,000 and 20,000 people in Australia have younger onset.
- 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.

2. What people with younger onset dementia and their carers are looking for

- Support that fits their needs.
- Appropriate respite and not being surrounded by much older people. One to one respite may be more appropriate.
- Access to appropriate overnight respite – “too young for aged care”; “not psychiatric”.
- Help with dealing with loss and grief issues, including counselling.
- Carers of younger people with dementia report higher levels of stress than their older counterparts, thus requiring more intensive help and support throughout the continuum of their caregiving experience. (UK)
- Carers from CALD communities may need a worker from an ethno-specific organisation to assist them to access relevant or specialist services.
- Companionship and support from other carers in similar situations. In many cases, due to having lost or not feeling comfortable with their longer term friends and acquaintances.
- Carers want assistance in ways which supports and/or strengthens their relationship with their partner.
- Carers of people under 50 are usually significantly affected as they are often in a busy stage in their life, and find that they may have to place the person with dementia into care sooner than expected, as they have other commitments in their life.

3. Some of the services to support people with younger onset dementia

In Metro North

- **Living with Memory Loss (LWML)** Program (Alzheimer’s Australia NSW) is an education and support program aiming to maximise the health and well-being of people living with early stage dementia, and their carers. The program is free of charge and runs over seven weekly two-hour sessions at the same time each week. One of the Younger Onset programs has run in the evening. In a group format participants can:
 - Tell their story of memory loss
 - Reflect on the impact of their diagnosis
 - Develop an understanding of the importance of self-care
 - Enhance their skills for communicating with others
 - Learn techniques for problem solving
 - Extend their knowledge about legal and financial issues.
- Two social support projects have been funded by HACC:
 - **Mercy Community Care Younger Onset** social support. The goal of the service is to support clients with Younger Onset Dementia (YOD) to participate within the community through regular social activities. Thus reducing social isolation whilst enhancing clients’ quality of life. The service covers the Hornsby/Ku-ring-gai local government areas. The YOD social support service is an innovative, flexible service, which is individually based. Clients and the coordinator devise a service plan which outlines weekly social outings including recreational activities, undertaking social activities with friends and family and transport to attend social activities or appointments. Support is in both one to one and group settings. The service has capacity for 10 clients. Clients have access to overnight respite at Chantal, Waitara. Carers are linked and provide support to each other.
 - **Anglicare Chesalon Younger Onset** social support has clients from across the Manly Warringah peninsula. Clients are keen to keep active and service responses have been designed to support people in their community. The core of the service is a weekly or fortnightly outing. Support is provided both one to one and in group settings. Transport is a major issue and cost to the project given its geographic area. The service transports clients to outings, appointments, etc.
- **Dementia Day Centre, Mercy Community Care, Waitara.** A flexible regular (weekly) outing, including lunch out, for up to 8 people with younger onset dementia. Programming in response to individuals’ interests has

included bushwalking, picnics, going to the movies and sailing. DVDs and/or photos are taken of events for later discussion with the carer and others. The aim is recreation and socialization with peer group. Most clients are from Mercy social support program.

Elsewhere

- **Carinya Respite Service** (Villa Maria, Melbourne) runs an Out and About Group for younger people with Dementia on Mondays. 8 clients attend (all men) and the program is planned around activities of interest eg including fishing, BBQs, Walks, lunches in pubs. The service has a list of good weather programs and wet /cold weather programs. "Response is amazing." The service is planning another men's group and has a number of women ready to start a Chat and Chew program based around females' interests. The service links with the Living with Memory Loss program as being the start of participation in activity in the community that is supported. Carinya has overnight accommodation and is considering one weekend a month for younger people to stay to give families a break.
- **LWML Retreats** (Alzheimer's Australia Victoria). Three day residential retreats for 11 people with younger onset dementia and a carer. Aims to bring people and their partners together to share experiences of life and dementia; to discuss the complexity of living with dementia; and to form new social relationships and provide a positive social and recreational experience. Funded by National Respite for Carers Program (NRCP).
- **Partners Group** (Alzheimer's Australia Victoria). A regular discussion group for partners of people with younger onset dementia.
- **Art Therapy** (Alzheimer's Australia Victoria). A monthly class specifically for people diagnosed with younger onset dementia.
- Carer Links West, Melbourne, provides:
 - a **weekend recreational program** – a fortnightly Saturday program that initially was designed for younger people with dementia who were not able to access existing group activities that were suitable to their needs. Over time this group has needed to widen its eligibility criteria as new referrals were sporadic.
 - a **getaways program** - a monthly group getaway to Daylesford for a group of 12. Carers are able to access this respite program once per year. These groups are specifically matched to people with similar care issues and younger people have been grouped together.
 - a fortnightly weekend **Outings Program** available to carers on a bi-monthly basis due to high demand. This group has suited people with younger onset dementia due to its emphasis on socialisation and the travel component.

4. Some of the resources to assist HACC service providers, workers and volunteers

- **Dementia Advisors:** Nepean, Cumberland Prospect, Northern Beaches, Hornsby/Ku-ring-gai, Lower North Shore, Ryde/Hunters Hill.
- Hammond Care is delivering free, Commonwealth funded **competency based training in Dementia Care** throughout NSW, over 3 days. The training can be on the job and is available to anybody who delivers service to Commonwealth funded clients, including for-profit workers who offer support via brokerage funds. The course is nationally recognised and is delivered at Certificate III level, based on the national competency: CHCAC15A: Provide care support which is responsive to the specific nature of dementia.
- Alzheimer's Australia NSW has a **Dementia Competency Training Resource Kit**, developed by Alzheimer's Australia Vic, which can be used by Registered Training Organisations and services to deliver Unit CHCAC15A.
- Mercy Community Care received one year, non-recurrent funding for a **Younger Onset training program** in 2005/06. It involved the development of training resources, the pilot provision of three one day training sessions, and evaluation of the pilot training and recommendations for future training needs in relation to Younger Onset. The training package was developed by Aged and Community Services Association (NSW and ACT). The Program is currently being evaluated.

- A CD rom, *Time to Think About Dementia*, A Dementia Care Guide for GPs, sponsored by the Office for Ageing and Pfizer. Available through Dementia Advisors.
- *Forthcoming*: the Australian Government has provided funding for the **Dementia Training Resources for People with Special Needs project** to several agencies. The project is to develop training resources for health, aged care, community and other workers and volunteers to increase their knowledge, understanding and skills of people with dementia and special needs. Younger onset dementia is one of the special needs to be covered.
- Information on **other resources** may be available from Carelink and from the National Dementia Network Update. To subscribe email: dementia@health.gov.au.

5. Some key characteristics of service models to meet the needs of people with younger onset dementia

- Service response developed from individual needs. Service seeks input from younger people and carers in its overall design.
- Identifies individual's strengths, supports individuality, and promotes community participation. Encourages socialization and other active forms of social support. "Flexible; Holistic; and Strengths-based." Maintains existing skills and links in the community, valuing and understanding the individual's stage of life, interests, history and relationships.
- Provides opportunity for community activities which are client focused and client initiated. Is community not centre based and promotes individual choice.
- Provides opportunity for one-on-one support as well as group activities.
- Staff have specific training in working with people with younger onset dementia.
- Service draws on individual's existing community links or desire to participate with an existing community group/club/church as a means of meeting needs and reducing isolation.
- Assists carer and family members, including teenagers and young adults, to meet with others in a similar position, to access education and counselling, where desired.
- Case coordination, including a capacity to assist working carers.
- Active referral seeking of clients as they are easily 'lost' in the service system.
- Recognises the needs of emerging groups of people with younger onset, particularly people with intellectual disabilities.

Other key considerations are likely to be identified in the Alzheimer's Australia National Project on Younger Onset Dementia. A report on the literature and extensive consultations in NSW will be available in the next few months.

6. Suggestions for how HACC could better address the needs of this group

Generalist HACC services

- a. Training for service managers, care workers and volunteers in awareness of and competency in younger onset dementia, services available, and communication with people with younger onset dementia and their carers. ("Challenge is maintaining a balance between delivery pressures and training of staff.")
- b. Workers being more aware of what is available to make appropriate referrals; to make use of available advice, support, training and information; and to promote effective care coordination, problem solving and/or case management. That is, strengthen knowledge of existing services – referrals have tended to

be slow for this group. Carers suggest this is due to late diagnosis and confusion as to what they can access.

- c. By recognising that in-home respite is often a particularly appropriate response for this group.
- d. By creating support options for working carers.
- e. By using the social support model to assist this group.
- f. By introducing more flexibility in the hours of operation of services, especially respite services.
- g. Learning from the experience of the disability sector and their models of service delivery, such as, individualised services that focus on people's abilities rather than their functional deficits.
- h. Revisiting DADHC Service Description Sheets which may be overly targeting frail aged and giving the perception that some flexibility in funding is lost.
- i. Clarifying where people with younger onset dementia sit within the aged and community care and disability sectors, as they may fall through the gaps.

Specialist services: possibilities

- j. Funding more specialist services for people with younger onset dementia across the region. This could be achieved by replicating the two social support projects auspiced by Mercy Community Care and Anglicare. The model includes a younger onset specific program backed up by a Dementia Advisory Service, COPS, CACPs, carer support group and individual counselling, personal care/ domestic assistance, in home respite, and a day centre allocating one day of funding for people with younger onset.
- k. Identifying a key worker/specialist in each agency to be the referral point for people with younger onset dementia.
- l. Introducing a specialised team which can assist service providers, the person with younger onset dementia and their carers when younger onset is identified.
- m. Earmarking flexible brokerage funds for this group to be used to purchase individualised respite options or social support.
- n. Exploring alternative models which target the needs of this group and sub-groups within it. For example, the concept of "The Men's Shed", which provides a comfortable environment for a group of males, coordinated, supervised and supported to engage in active and productive pursuits.
- o. Accessing overnight respite through the community house model (where available) as more appropriate than an aged care home for residential respite.

PEOPLE WITH DEMENTIA & BEHAVIOURS OF CONCERN

1. What we know about people with dementia and behaviours of concern
 - Behaviours of concern may occur at any age of the person with dementia or at any stage of dementia.
 - The behaviours are usually defined as behaviours which are disruptive, aggressive or socially unacceptable such that the person has difficulty in the home, community and in accessing mainstream services. They may include resistance to care, agitation, distress, restlessness, wandering, inappropriate sexual behaviour, inappropriate toileting practices, social withdrawal and/or verbal or physical aggression.
 - 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 cited in Wirth, 2001) 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.

2. What people with dementia and behaviours of concern and their carers are looking for

- They often are reluctant to use services.
- Carers may be reluctant to describe the full extent of the behaviour(s) out of embarrassment or because they are “often overwhelmingly tired, angry, feeling very alone and have been shunted from one place to another with doors closing all the time behind them. They feel that if they tell the full story, we will refuse them too”. (Benevolent Society)
- Carers of people with dementia and behaviours of concern tend to be less proactive and more worn out.
- In relation to respite, the Benevolent Society experience is that they most frequently want weekend respite and regular overnight respite.

3. Some of the services to support people with dementia and behaviours of concern

In Metro North

- **Dementia Advisors:** Nepean, Cumberland Prospect, Northern Beaches, Hornsby/Ku-ring-gai, Lower North Shore, Ryde/Hunters Hill.
- **The Safely Home Project** is a joint project of Alzheimer’s Australia NSW and the NSW Police. It is a 24X7 program which allows carers to start a search for a person who has dementia and who has wandered from home by ringing a 24 hour hotline and quoting the person with dementia’s personalised number. This number is on a bracelet and is linked to the Safely Home database managed by NSW Police, which holds details to help find the missing person, including a recent photo, written physical description and the places where the person may wander. (Information kit available from the Dementia Helpline on 1800 100 500)
- **Clinical advisors** such as: in Nepean, Clinical Nurse Consultant (Psychogeriatrics).
- **Short term intervention support** for people identified at particular risk eg **COMPACKS** which could be of immediate help to plan and coordinate care for people with dementia and behaviours of concern being discharged from hospital to home. **Sub Acute Fast Track Elderly (SAFTE)** is being trialled in four hospital areas of NSW, including Hornsby Hospital. SAFTE is linked to COMPACKS and aims to keep elderly people well and out of hospital. GPs and other service providers can refer clients, 7 days a week, to assist with fast tracking diagnosis, diagnostics and clinical assessment of patients. Within 48 hours of referral the client is assessed where they reside by a clinician such as a nurse and a Community Options Case Manager. A community case manager assists the older person to manage at home by introducing support services such as cleaning, personal care assistance and transport. This may provide a quick response for newly identified people with dementia and behaviours of concern.

- **NRCP funding for respite for carers** of people with dementia and behaviours of concern: providers include Northern Beaches Community Care and Hope Health Care.
- **Working Carers funding:** agencies include Anglican Retirement Villages, Baptist Community Services, Northern Beaches Community Care and Northern Sydney Carer Respite and Carelink Centre.

Elsewhere

- **Benevolent Society Community and in Home Flexible Respite Service**, in South Sydney, funded by NRCP. The brokerage service provides in-home and out-of-home respite services for people diagnosed with dementia and behaviours of concern which restrict their access to existing services. It offers a variety of caring hours, overnight, late evening, weekend as well as full and part day and 24 hour care. Up to 2 self care units within the Society's retirement villages can be used for short and long term respite stays. Up to 20% of funding is allocated to emergency respite in consultation with the South East Sydney Carer Respite Centre. Volunteers are also used for social support.
- Specialist, troubleshooting teams, centres and techniques such as:
 - **Mobile Respite Team** in the Bega Valley is an innovative short-term service for people with dementia and their carers in the community. It provides specialist information, support and education and direct care for a person with dementia and behaviours of concern. It has the capacity for two team members to respond quickly and appropriately with in-home education and support.
 - **Carunya Dementia Day Therapy Unit**, Illawarra: day hospital approach to assessment, management and carer education using social management techniques. The service is integrated with PGU dementia support services, ACAT and Geriatric Medicine. It offers intensive assessment, trialling of interventions including medications, aggression management, staff and carer education, research, case management and discussion of strategies and techniques for care at home, in day and acute care services and residential care. Target group: people with moderate to severe dementia related behaviour that cannot be case managed with usual services, with referral via ACAT.
 - **Dementia Behaviour Assessment and Management Service**, based in Wagga Wagga but supporting large area of Greater Southern Area Health Service. Funded as an Innovative Aged Care Pilot for dementia. Provides a model of regional outreach and intermediate care (within an 8 to 10 week timeframe) for people with dementia and dementia-related behavioural symptoms with the aim of increasing carer and care worker confidence and competence in managing behavioural issues. It also offers early intervention and community based assessment and a model of care which involves the client, carer, provider and GP in assessment and management. The target group is people with dementia assessed by ACAT as eligible for high level residential care, who would benefit from the provision of a specialised assessment and behaviour management plan, as they exhibit behaviour which cannot be managed in their home or in residential care.
 - **Mobile Dementia Respite Team** in three rural areas of Western Australia. Similar to the Bega model, over 8 weeks the team develops and demonstrates strategies and practical interventions to reduce behavioural occurrences. Education, support, information, respite (including in-home, host family, peer support and out of home) offered to carers and families.
 - **Dementia and Memory Community Centres**, run by Alzheimer's Australia in Brisbane and 8 regional Queensland centres offer resources, information, public drop-in, training, counselling, support, advice and links to other services.
- **E-learning** eg E-Learning in a Team Based Health Environment, University of Ottawa and SCO Health Service Partnership, Canada.

4. Some of the resources to assist HACC service providers, workers and volunteers

- Hammond Care is delivering free, Commonwealth funded **competency based training in Dementia Care** throughout NSW, over 3 days. The training can be on the job and is available to anybody who delivers service to Commonwealth funded clients, including for-profit workers who offer support via brokerage funds.
- DADHC Metro North is producing a **Behaviour Training Calendar** for funded / brokered agencies. This is based on a model from the old Western Sydney area which is being extended to the whole of Metro North.

- **National Dementia Behaviour Advisory Service (NDBAS), 1300 366 448:** This confidential telephone service offers advice on managing behaviours of concern to those who care for a person with dementia. It operates 24 hours a day, 7 days a week and aims to help the caller gain an understanding of the observed behaviours; identify factors which trigger these behaviours; develop strategies to reduce their frequency or impact; and contact services and other support. The quarterly **Investigator Newsletter** of the NDBAS provides updates about the latest developments in managing behaviours that occur during respite.
- **Behaviours Guide ReBOC- Reducing Behaviours of Concern** developed by the NDBAS is available for \$15 from NDBAS. It contains information about dementia and its stages, problem solving, contributing factors, strategies, resources and behaviour charts.
- **Dementia Training Institute of Australia** provides customised training, including on appropriate management of behaviours of concern, for professional staff who care for people with dementia at their centre or on residential care sites.
- Mercy Community Care has entered into a **partnership with Ryde mental health team** as one means of better addressing behaviours of concern. It has enabled Mercy teams to work with a clinical nurse consultant, who is a VET approved trainer, to strengthen their skills and approaches in supporting people with behaviours of concern.
- DADHC Publications: *At home with dementia* and *Better building, better care. A planning guide to improving an aged care facility for people with dementia*, 2000. The latter is also relevant to centre based services.
- *Forthcoming:* the Department of Health and Ageing has funded the National Ageing Research Institute (University of Melbourne) to develop a **dementia care kit** for workers, volunteers and carers. It will be a practical kit containing evidence-based dementia care information, resources, tools, guidelines and best practice principles. It will include support for people with behaviours of concern.
- Information on **other resources** may be available from Carelink and from the National Dementia Network Update. To subscribe email: dementia@health.gov.au.

5. Some key characteristics of service models to meet the needs of people with dementia and behaviours of concern

- Models need to offer person and carer centred approaches including:
 - Approaches designed for each individual rather than "cookbook" approaches;
 - Approaches designed with the person with dementia and his/her carer;
 - Sound assessment;
 - Use of techniques that can be easily replicated by others involved in a person's care as approaches to behavioural management must be consistent;
 - Holistic support is needed as a person's behaviour comes from more than one domain;
 - Enablement approaches which focus on a person's remaining abilities in a positive way;
 - Linkages with related community care and other needs eg medical care and treatment, and appropriate and informed referral;
 - Care planning, coordination and if necessary, case management;
 - Support for carers;
 - Information, advice, peer support and counselling.
- In home support rather than group support when behaviours are causing concern.
- Calm and appropriately designed physical environments, or modifications/ aids in the home.
- Pleasurable experiences for the person with dementia.
- Access to flexible, community transport.
- Brokerage models potentially allow greater capacity to respond to individual needs, including particular needs of Indigenous people and people from other culturally and linguistically diverse backgrounds.
- Care plans are likely to need to involve:

- Ongoing, perhaps mainstream, maintenance support during times when behaviours of concern are not causing difficulty or not occurring; complemented by
- Episodic, intensive intervention designed to assess the behaviours; to identify triggers; and to plan, communicate, train all involved, and implement, appropriate behaviour minimisation or reduction strategies.
- So funding must be flexible to allow intensive, top up funding for fixed term / episodic problem solving support and sufficient to allow purchase / delivery of some expensive weekend and after hour respite options and possibly 1:1 support while the person with dementia and behaviours of concern is most unsettled.
- Collaborative provision and financing with other related agencies required (eg with direct support providers, Community Options, Carer Respite Centres and specialist assessment, advice, management and counselling services).
- Safety issues for people with dementia, for carers and for workers must be addressed.
- Need “particularly skilled, intuitive, calm, smiling and relaxed staff” – that is trained staff who can ease a tense situation rather than compound it. Training is needed so that staff can contribute to a safe environment for people with dementia and for themselves.

6. Suggestions for how HACC could better address the needs of this group

Generalist HACC services

- a. Training for service managers, care workers and volunteers in awareness of and competency in behaviours of concern, services available, and communication with people with dementia and behaviours of concern and their carers.
- b. Workers being more aware of what is available to make appropriate referrals; to make use of available advice, support, training and information; and to promote effective care coordination, problem solving and/or case management.
- c. Collaborative work and care planning and coordination with specialist agencies to use HACC resources and staff to complement specialist services when additional resources are required such as 1:1 support in home or in day centres.
- d. Collaboration across agencies to ensure consistency of approach when supporting an individual. This should be developed from observation, identification of trigger points and a common response.
- e. More flexible funding arrangements to allow the development of responsive and collaborative service models, which support episodic intensive care needs and expensive respite options, as well as enabling ongoing support, including cross program initiatives.
- f. Allocate sufficient resources to support the additional costs of people with dementia and behaviours of concern, including the need for smaller client to staff ratios and smaller groups in respite services.
- g. Fund a dietician to work with food services to assist them meet the needs of people with dementia. Strategies may include day packs of ‘dementia meals’.

Specialist services: possibilities

- h. Dementia advisory services across Metro North be adequately resourced to support this group.
- i. Develop several mobile assessment and behaviour management support teams across the region. The teams would assess people with behaviours of concern and design and implement behaviour management strategies with them and their carers in their own homes and with their workers in the places that support them, such as day care centres.
- j. Extend the network of day centre / overnight respite community houses, jointly resourced by HACC and other funding programs, as they offer more appropriate respite than residential respite.

Appendix C Focus Group Participants

Regentville, 7 November 2006

Name	Organisation
Robyn McKinney	Winmalee Day Program
Narelle Bossard	Home Respite Service (Anglicare)
Chris Highman	Baptist Community Services
Helen Colla	CACP/EACH Coordinator
	Bodington Community Care
	Catholic Healthcare
Kylie Crnek	HACC Development Officer
	Macarthur/Wingecarribee HACC
	Development Project
Maree Robb	Benevolent Society
Kylie Marsden	Aged/Disability Team Leader
	Holroyd City Council
Jenny Fahy	Our Lady of Consolation
Peter Squire	Our Lady of Consolation
Marcela Carrasco	KinCare Community Services
Karen Blomfield	Mondeval Day Centre
	SWAHS
Athena Kandris	Aged and Disability Services
	Officer
	Penrith City Council
Tessa Duncan	DADHC, Metro North
Ruth Willick	Sydney West Area Health Service
Colleen Provost	Sydney West Area Health Service

Name	Organisation
Julie Hicks	BCS
Sue Tolhurst	Dementia Advisory Service, Western Sydney
Ivy Yen	CareConnect
Trish Furlong	Kincare
Jeanette West	Hills Community Care
Lorraine Dunn	Hills Community Care
Rose Xeurub	SWAHS Aged & Chronic Primary Health Care CNC
James Turner	SWAHS Clinical Nurse Consultant - Psychogeriatrics
Wendy Blaxland	Aged Care Psychiatry Service
Michael Magro	Social Worker, Westmead ACAT
Linda Morgan	Willyama Day Centre
	DADHC, Metro North

Name	Organisation
Melissa Perrett	Spastic Centre
Marjorie Reid	Just Better Care
Marie Osterberg	Carer-DY Carer Support Network
Eric Osterberg	Client- DY Carer Support Network
Prue de Neville	Legacy
Rochelle Waterhouse	DADHC
Liz Bruce	Community Care Northern Beaches
Vanessa Rapkins	OT Mona Vale Hospital
Mark Newlan	CCNB
Jan Smithies	ARV Community
Yolanda Couchman	ARV Community EACH
Robyn Jennings	Northern Beaches Police, Dee Why
Dr Sushmita Hunter	Psychogeriatrician
Mark Woolvan	Spastic Centre
Jenny Dunbar	Daughterly Care
Prue Sky	CCNB
Trish Noakes	JBC
Libby Palmer	CCNB -DAS
Denise Taylor	Carers Support network
Anne Colette	Mona Vale ACAT
Margaret William	Nth Beaches Food Services
Tom Miles	Manly MOW
Angela Doolan	Warringah Council
Andrea Sneesby	ACE NBHS
Christine Mill	MWP Community Aid
Anne Kalva	Uniting Care
Vicki Southgate	Carer's Support Health
Janet Flower	Anglicare Chesalon Care
Jill Elias	Alz Aust (carer)
Kirsten Noble	Anglicare Chesalon Care
Lyn Silverstone	
Eliza Pross	CCNB
Arthur Crago	NB Health Social Worker

Chatswood, 16 November 2006

Name	Organisation
Wendy Hillsdon	Carer
Ann Yeates	Carer
Lucille Bloch	Carer
Zimia Sagall	Jewish Care
Mary Clifton	Mercy Community Care (DAS)
Denise Lethbridge	Mosman A.D.S.
Natalie Ryan	Mercy Community Care (DAS)
Nicola Griffiths	Hope Healthcare
Marguerite Tyson	Alzheimer's Australia NSW
Pam Davis	Mercy Community Care (DAS)
Jill Elias	AA Consumer Representative
Mary Kerr	DADHC
Denise Fahey	Mercy Community Care
Vicki Gibb	Mercy Community Care
Judy Clarke	Lane Cove Community Aid Service
Shirley Cameron	Alzheimer's Australia
Mary Kelly	Northside Community Forum
Ruth Jacka	Northside Community Forum

Appendix D 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.

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