National evaluation of the Aged Care Innovative Pool Dementia Pilot

Final report

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National evaluation of the Aged Care Innovative Pool Dementia Pilot

Final report

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Contents

Part A Main report

Part B Project reports

List of tables (Part A)

(Tables for Part B, pp. 155–404, are not listed)

List of figures (Part A)

(Figures for Part B, pp. 155–404, are not listed)

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Abbreviations

ABS	Australian Bureau of Statistics
ACAS	Aged Care Assessment Service (the name used for ACAT in Victoria)
ACAT	Aged Care Assessment Team
ADL	Activities of daily living (for example, eating, bathing/showering, dressing, grooming, toilet use, bladder and bowel continence management, walking or wheelchair use, transfers, negotiating stairs)
AIHW	Australian Institute of Health and Welfare
BPSD	Behavioural and psychological symptoms of dementia
CACP	Community Aged Care Packages
CSI	Caregiver Strain Index
DBAMS	Dementia Behaviour Assessment and Management Service
DCAS	Dementia Care in Alternative Settings
DRAH	Dementia Rehabilitation at Home
DTC	Day Therapy Centre
DVA	Australian Government Department of Veterans' Affairs
EACH	Extended Aged Care at Home
EARS	Emergency After Hours Response Service
FCS	Flexible Care Service
GHQ-28	General Health Questionnaire (28-item version)
GP	General practitioner
HACC	Home and Community Care Program
IADL	Instrumental activities of daily living (for example, shopping, housework, travelling away from home, medication use, using the telephone, managing personal finances)
MBI	Modified Barthel Index
MMSE	Mini-Mental State Examination
NEDID	North East Dementia Innovations Demonstration
NGO	Non-government organisation
NRCP	National Respite for Carers Program
OARS	Older American Resources and Services (IADL scale)

RAC	Residential aged care
RCS	Resident Classification Scale
SBGC	South Brisbane and Gold Coast Innovative Dementia Care Pilot
VHC	Veterans’ Home Care

Summary of findings

The Aged Care Innovative Pool Dementia Pilot became operational across Australia in the two years 2003–2004 as a set of projects under the administration of the Australian Government Department of Health and Ageing. This made available a pool of flexible care places outside the annual Aged Care Approvals Round to trial new approaches to care for older people with dementia. Operational management of projects has been the responsibility of the respective State Offices of the Department of Health and Ageing. Pilot services are administered according to the requirements of the *Aged Care Act 1997*.

This report presents the findings of an evaluation of nine projects in five mainland states—two in New South Wales, two in Victoria, three in Queensland and one each in South Australia and Western Australia. The national evaluation was completed by the Australian Institute of Health and Welfare (AIHW) under a schedule to the Memorandum of Understanding between the AIHW and the Department. Findings from the AIHW evaluation are to inform the Department's broader review of the Dementia Pilot. The Hammond Care Group commissioned its own evaluation of the Short Term Intensive Community Care Service and that report is available upon request from The Hammond Care Group.

National evaluation commenced in June 2004 and data collection was completed in mid-2005. Approval for the evaluation was given by the AIHW Ethics Committee (Register Number 353 and 354).

Three questions were set for the evaluation to address:

1. **Do the pilot services offer new care choices which meet the needs of older Australians?**
2. **Do the pilot services enable clients to either re-join or live longer in the community (defined as long-term living arrangements other than residential aged care and hospitals)? This question may not be relevant in the case of those Innovative Pool services which aim to provide more appropriate residential aged care services for people with dementia.**
3. **What is the cost of the services per client per day (both in absolute terms and relative to other service options available to clients)?**

In addition, this report discusses a range of issues highlighted by the Pilot that could help to inform policy on community care for people with dementia.

Quantitative and qualitative methods were used to collect relevant data and information about clients, family carers and pilot projects. In total, 249 care recipients and 219 family carers contributed to the evaluation.

The nine projects were found to be offering a variety of dementia-specific, short-term interventions of a planned duration of 8 to 12 weeks and longer term interventions that continue for the duration of the project or until a care recipient can no longer benefit from the type of care offered.

Short-term care interventions:

1. Dementia Behaviour Assessment and Management Service (DBAMS), Wagga Wagga, New South Wales (Southern Area Health Service)
2. Dementia Rehabilitation At Home (DRAH), Northern Rivers area, New South Wales (North Coast Area Health Service)
3. Flexible Care Service (FCS), Melbourne, Victoria (*annecto*—the people network, formerly WiN Support Services)
4. North East Dementia Innovations Demonstration (NEDID), Melbourne (Austin Health)

Long-term care interventions:

5. RSL Care Innovative Dementia Care Pilot, Brisbane and Ipswich/West Moreton, Queensland (RSL Care Queensland)
6. South Brisbane and Gold Coast Innovative Dementia Care Pilot, Queensland (Islamic Women's Association of Queensland in partnership with the Queensland Multicultural Communities Council and Queensland Transcultural Mental Health Centre)
7. Ozcare Innovative Dementia Care Packages, Rockhampton/Gladstone and Bundaberg, Queensland (Ozcare, formerly St Vincent's Community Services)
8. Dementia Care in Alternative Settings (DCAS), Perth, Western Australia (Southern Cross Care WA)
9. The Sundowner Club, Adelaide, South Australia (ECH Incorporated in partnership with Eldercare Incorporated).

Service delivery context

Projects have targeted people with very high care needs. Eligibility for Pilot services requires Aged Care Assessment Team (ACAT) approval for residential aged care and, in all but one project, approval for high level residential care was required.

The average age of clients during the evaluation was 81 years and one in three clients was aged 85 years or over. The average Mini-Mental State Examination (MMSE) score, a measure of cognitive function, on entry to a project was 15 points out of 30. A score of 16 on the MMSE has been reported to be a key transition point that often marks the onset of rapid functional decline in activities of daily living (Feldman et al. 2005). Scores below 12 points are used in practice to indicate severe cognitive impairment (see for example Holmes & Lovestone 2003; Huusko et al. 2000). Severe cognitive impairment was indicated at entry to a project for 26% of care recipients for whom a baseline MMSE score was recorded.

Cognitive impairment contributed to the observed high levels of impairment in activities of daily living and social functioning. Most care recipients had experienced significant loss of function in the instrumental activities of daily living (IADL include housework, shopping, meal preparation, travelling away from home, medication use, and managing personal finances). In addition, 95% of care recipients had lost a degree of self-care and/or mobility function, including 80% with moderate or severe impairment in activities of daily living (ADL) involving self-care and mobility. Over 60% of care recipients were reported to be experiencing severe behavioural and psychological symptoms associated with dementia.

Support arrangements before joining a project varied across the group. Care from family was the main source of assistance for the majority of clients before and during the Pilot. Ninety-one per cent (91%) of community-based clients in the evaluation had a carer (88% of all clients, including those who usually reside in an aged care facility). Counting all reported sources of ongoing assistance to community-based clients before the Pilot, 53% were receiving assistance from a primary family carer as well as from government-funded formal services; 38% were receiving assistance from a primary carer without additional assistance from government-funded services; 4% were receiving assistance from government-funded services only (no family carer) and 4% recorded no previous sources of ongoing assistance (Table A3.1). Previous formal support arrangements are unknown for 1% of care recipients in the evaluation.

Carer availability was a prerequisite for entry in a number of projects; even when not specifically required, it was found that most people referred to the projects were receiving assistance at home from a primary carer. Participating carers comprised a mix of co-resident and non-resident carers, with a high representation of sons, daughters and sons- and daughters-in-law (45% of all carers). Men made up 41% of primary carers across the projects. One in four primary carers were not living with the care recipient.

Around 75% of carers who completed the Caregiver Strain Index (CSI) recorded high carer strain, confirming reports from all project coordinators of the very high levels of carer strain evident among family carers. A statistically significant positive correlation was found between levels of carer strain and psychological symptoms in carers including anxiety, insomnia and somatic symptoms. Projects have had to provide high level support to both care recipients and family carers.

Thus, the evaluation found multiple indicators of high risk of entry to residential aged care among the 249 care recipients:

- 240 had ACAT approval for high level residential care
- all 249 care recipients showed significant ADL impairment
- a high proportion of clients experienced moderate to severe behavioural and psychological disturbances and their carers reported experiencing distress as a result of these symptoms
- very high levels of carer strain and associated psychological symptoms.

Only 21% of care recipients were receiving a care package before joining a pilot project.

The Innovative Pool Dementia Pilot and national evaluation occurred prior to the announcement in the 2005 Federal Budget of Extended Aged Care at Home Dementia Program (EACH Dementia), which is part of the initiative *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*.

Do the pilot services offer new care choices which meet the needs of older Australians?

In short, the answer to the first evaluation question is 'yes, in all cases', but it is important to appreciate the different approaches that pilot services have taken to offering new care choices for older people with dementia. Reports in Part B detail the operation of each project and the key outcomes achieved (these are also summarised in Chapter 3 of Part A).

Each pilot project has offered a new care choice to referred clients with dementia-related high care needs and their carers. The Pilot is notable for the range of care models that have emerged. Three short-term intervention projects have a strong clinical focus with multidisciplinary input, two of which have addressed some important challenges in delivering services to people in regional, rural and remote areas. These projects have aimed to provide effective and timely specialist intervention at key milestones on the care continuum. Six other projects in the evaluation have offered an EACH-level service with a dementia specific focus.

The unique features of Innovative Pool Dementia Pilot projects are described below.

Projects with a clinical focus operating at the interface of health and aged care services:

- DBAMS is a specialist service for people with severe behavioural and psychological symptoms of dementia. There are three arms to the project: outreach, intermediate care, and education. The DBAMS outreach service is like a 'fly in' squad. A nurse with psycho-geriatric training (clinical nurse consultant or registered nurse) goes to the client, either in a home in the community or in an aged care facility, to complete a detailed assessment of behaviour and develop a behaviour management plan. If the client cannot be managed in the usual care environment and/or needs specialist medical assessment, for example, full medication review and observation, they are admitted to Yathong Lodge, the DBAMS intermediate care facility, for intensive clinical work-up and observation.

  The DBAMS outreach model has addressed significant unmet need for psycho-geriatric specialists in regional and rural communities of southern New South Wales. DBAMS has increased the capacity of aged care services in the region to provide specialist support to people with high and specific dementia-related needs. The establishment of a specialist team of clinicians provides valuable professional support to the few psycho-geriatric nurses who travel thousands of kilometres each week to perform client assessments.

  In its first year of operation, the DBAMS education program delivered education to over 1,000 people across 19 locations in southern New South Wales, including care professionals and family carers of people with dementia.

- DRAH is a model of high level case management in an Aged Care Assessment Team (ACAT). A shortage of geriatricians and psycho-geriatric specialists (nurses and medical practitioners) in the Northern Rivers area of NSW means that people with dementia can find it difficult to obtain an accurate diagnosis of dementia and dementia-related or exacerbated conditions. These difficulties often lead to complications in the provision of care at home by family and delays in accessing formal assistance. DRAH enables the North Coast ACAT to provide an intensive case management service, facilitating access to medical specialists via the use of telehealth technology, when required for diagnostic purposes, right through to linking care recipients and their family carers into the system of formal services through a partnership with Clarence Valley Council Community Services. DRAH is one of the first formal collaborations between health and community services in the region. Through DRAH, ACAT involvement continues beyond the usual period of ACAT assessment to ensure that medical diagnosis is achieved and appropriate services are established.

- NEDID operates within Austin Health, a large provider of health and aged care services in metropolitan Melbourne. Austin Health had previously run a *Trial at Home* project, which demonstrated that a high proportion of dementia patients in Austin Health hospital wards, who would ordinarily be given no option other than residential aged care following hospitalisation, could in fact return home with an appropriate level of support. NEDID accepts clients from Austin Health facilities and from the wider community. The project ensures that people referred from hospital wards receive all necessary physiotherapy and occupational therapy assessments prior to discharge and that in-home services are in place by the time the client arrives home. NEDID is able to help people with dementia avoid hospitalisation through its placement within a health service. NEDID has made a concerted effort to educate acute care staff that residential care is not the only option for high care dementia patients following hospitalisation.

  The multidisciplinary team conducts weekly case conferences to monitor client progress. NEDID clients and their family carers receive a high level of support from the team. This project services a region with a high culturally and linguistically diverse population and provides an interpreter/translation service to assist culturally and linguistically diverse clients.

An important finding in relation to specialist behaviour assessment and management for people with dementia is that people who might be precluded from accessing a care package because of severe behavioural and psychological symptoms are more likely to be able to remain at home through package care if they are also able to access a specialist behaviour management service if and when required. The same is true of the potential for this type of specialist intervention to reduce the impact of these symptoms of dementia on levels of care required in aged care homes.

Care packages as a means of helping members of the Pilot target group to avoid a change in care setting are likely to be most effective if recipients are able to access psycho-geriatric services for specialist diagnosis, medication review and behaviour management intervention. Widespread availability of specialist services would benefit both people with dementia living in the community and those living in aged care homes with limited expertise in specialist dementia care. Priority attention should be given to expanding this type of service provision in locations where specialist services are presently difficult to access.

Care package projects with a non-clinical, high care focus:

One short-term intervention project, Flexible Care Service, and four long-term care projects (RSL Care Pilot, Ozcare Packages, South Brisbane and Gold Coast Pilot, and Dementia Care in Alternative Settings) offered a level of package care that was not widely available at the time the Pilot was established. The focus of these services was ongoing intensive case management, high and flexible respite care, high weekly hours of care, high level carer support (education, counselling and referral) and a dementia-specific focus to service delivery. Dementia-specific care requires rostering flexibility with experienced care workers who are able to manage resistant, sometimes unpredictable clients and provide appropriate support to family members. These features plus high hours of care not widely available through mainstream care packages.

Individually, the projects differ in their targeting or in specific aspects of service delivery:

- South Brisbane and Gold Coast Pilot exclusively targets people from culturally and linguistically diverse communities, providing bilingual care workers, two care workers for respite periods (one worker stays with the client while the other provides bilingual support to the carer for times away from home, for example, for shopping and medical appointments). The project matches care workers to the cultural background of the client and offers culturally-specific fresh food services. Twenty-four hour emergency assistance is another important feature of this project that is in limited supply from mainstream services.
- RSL Care Dementia Care Pilot (RSL Care) and Dementia Care in Alternative Settings (DCAS) operate in metropolitan areas. These projects are able to offer more hours of care per week than an average Community Aged Care Packages (CACP) service and a dementia-specific service. RSL Care Pilot offers bilingual support to culturally and linguistically diverse clients but targets people with dementia high care needs of all backgrounds. High level respite care is available. In the reporting period 40% of project expenditure was recorded against respite services. DCAS offers up to 24.5 hours of care per week, which is in excess of a standard EACH package. DCAS offers the most comprehensive range of respite care services seen in the Pilot. DCAS respite offerings are designed to meet the differing needs of different groups of primary carers and this is achieved through a combination of in-home, special-purpose day unit respite and overnight respite.
- Ozcare Packages services a large regional and rural area of southern Queensland. The cost of transport to service high needs clients in these communities would normally preclude the delivery of high hours of direct care from a CACP service. Through flexible funding, Ozcare is able to guarantee higher hours of care while absorbing the high transport costs and other associated costs of staffing a service that operates across a large geographic area. High respite care provision is a main focus of the project: delivery of respite care consumed 47% of project expenditure in the reporting period.
- Flexible Care Service (FCS) is also a dementia-specific comprehensive case management and care package service. This project was originally proposed as a long-term care intervention but was implemented as a short-term intervention at the request of the Department of Health and Ageing. People referred to FCS, like the client groups in long-term package projects, have almost always reached a crisis in care, through death or sudden illness of a primary carer or carer burnout. FCS case managers are social workers who provide high level support to families in difficult circumstances to help stabilise the care environment and introduce required support services. High and flexible respite care is an important tool in this process. *annecto*, the service provider, operates a 24-hour rapid response system (Emergency After Hours Response Service). FCS clients are introduced to this system so that after the period of FCS service they continue to be able to access emergency assistance.

  FCS, like other short-term care projects, has faced considerable difficulty in discharging clients to an appropriate level of support. Administration of the project required close to 100% occupancy and this added further pressure, proving difficult to achieve in a flow-through pilot for high needs clients (this level of occupancy monitoring also caused difficulties for the other project in Victoria, NEDID). FCS was not designed with a clinical or transitional care focus. The service model more resembles that of the long-term care package projects in all respects except that the planned duration of care demands that discharge planning starts within a month of client commencement. The need to discharge clients to other services after establishing a rapport and building confidence is clearly problematic for care recipients, family members and the service provider.

The most compelling evidence that pilot services offer new care choices is found in responses to the Care Experience Survey. The following vignette, one of a number in this report, came from a relative of a client writing of their experiences before and during the Pilot. Before starting with a project the client was receiving formal care from two service providers in addition to care from family but needed 'more hours and therefore more active assistance with bathing, toileting, dressing, medication, meal preparation and at night, changing into sleepwear and getting to bed'.

This was the family's description of previous care:

> Fragmented service shared between two providers. Too few hours to be effective and to get all chores done. Gaps in service, for instance: no shopping, meal preparation, zero continence management. Found the locus of responsibility of getting help very difficult to identify. Too many players—GP, ACAT, Vet's Affairs, hospital social workers—but no-one taking ultimate responsibility to assess, plan and monitor delivery. 'The system' is terribly confusing and difficult to access. You find out about entitlements by accident, not by design.

The Dementia Pilot long-term care package offered the client a higher level of service with greater care coordination:

> The stability of having one service provider and a single point of contact for family members.
>
> The greater number of hours has been a godsend. Mum's condition has improved markedly—no longer depressed, feels more in control because the carers 'lead from behind'—that is, they help but in a way that Mum thinks she is doing it herself.
>
> Staff seem carefully selected for aptitude and well trained. Also, they are very well presented and handle liaison with family very tactfully.

The family particularly liked:

> Having one provider in total control. The provider's regular reassessments to check on Mum's dementia and other aspects and adjust service delivery accordingly.

Projects with innovative respite services:

Two new choices in respite care provision have emerged from the Pilot. One is The Sundowner Club, a project in Adelaide, South Australia, designed to meet the special needs of clients who experience sundowning behaviour. 'Sundowning' is used to describe symptoms experienced by some people with dementia that tend to manifest in the late afternoon and early evening, such as an increased tendency to wander or become agitated. Sundowning behaviours typically occur outside usual business hours and cause distress for carers and others concerned for the safety and wellbeing of the person with dementia.

The Sundowner Club is an evening meal and socialisation program. Clients are collected at their home address and transported to The Sundowner Club by bus where they help prepare a home cooked meal and dine with other members of the club in a small group supported setting (maximum eight clients). An activity program is available during these sessions, from 3.00 pm to 8.00 pm Monday to Friday. This project has proved popular with people who had become socially withdrawn due to dementia and provides a valuable opportunity for family carers to pursue their own interests, uninterrupted, of an evening.

The other innovative respite service is part of the DCAS long-term care project in Perth. Southern Cross Care WA, the approved provider, contributed two retirement village units for the project to operate a day respite service. Small numbers of clients can attend at any one time and benefit from the homelike setting with self-directed activities that cater to individual interests. Volunteers from the retirement village socialise with the clients and assist respite care workers.

Below is a tabular summary of the main features of the projects. A tick against an aspect of service delivery indicates that this has been a main focus for a project and that the project appeared to be successfully achieving its objectives in this area. 'P' indicates that a project has obvious additional potential, even though the particular aspect of service delivery indicated was not an intended focus or was not relevant to the group targeted during the Pilot.

In time, the new care choices seen in the Innovative Pool Dementia Pilot might come to be viewed as forerunners to EACH Dementia packages. The new EACH Dementia Program is aimed at those at the highest end of the community care continuum. Packages will provide the same full range of services that 'general purpose' EACH packages provide. However, additional specific services and approaches related to the special needs of care recipients with dementia will be considered.

	Short-term care projects				Long-term care projects				
	DBAMS NSW	DRAH NSW	FCS Vic	NEDID Vic	RSL Care Pilot Qld	South Brisbane & Gold Coast Qld	Ozcare Packages Qld	DCAS WA	The Sundowner Club SA
Dementia-specific client care									
High level case management and coordination	✓	✓	✓	✓	✓	✓	✓	✓	
ADL/IADL with social support		✓	✓	✓	✓	✓	✓	✓	
New socialisation programs									✓
Culturally sensitive care					P	✓			
Client advocacy	✓	✓	✓	✓	✓	✓	✓	✓	
Support in transitioning between care settings	✓	✓		✓					
Out-of-hours support and/or 24-hour response	✓		✓	✓	✓	✓	✓	✓	✓
Carer support with a dementia focus									
Flexible respite		✓	✓	✓	✓	✓	✓	✓	✓
New respite care models								✓	✓
Education programs for carers and relatives	✓	✓							
Social work/counselling	✓	✓	✓	✓	✓	✓	✓	✓	
Improved access to geriatric and psycho-geriatric services									
Establish early accurate diagnosis	P	✓							
Specialist diagnosis and management of BPSD and co-morbidities	✓	✓		✓					
Build capacity among dementia care professionals	✓	✓		✓					
Service regional, rural and remote regions	✓	✓					✓		

Do the pilot services enable clients to either re-join or live longer in the community?

The evaluation tracked the status of consenting clients who were accepted into short-term care projects from June to October 2004 and consenting clients who were already in or who were accepted into long-term care projects in the same period. Nine DCAS clients had ACAT approval for low level residential care; all other clients had ACAT approval for high level residential care. In addition to the results of ACAT assessments, there is evidence in the evaluation data that people accepted into the projects were at risk of imminent admission to residential care but for the availability of Pilot services.

Responses to the Care Experience Survey articulate the strong desire to continue with care at home. However, the strain on carers from long periods of caring with inadequate support, often combined with full-time employment, is also telling in the responses. This report presents some of those responses and reports on the support needs profiles of clients to demonstrate the tension that exists between desire of, and for, a care recipient to remain at home and the practical issues involved in making that possible.

The evaluation concluded that pilot services do enable clients to live longer in the community and the evidence is summarised below. Two factors have limited the influence of projects on long-term care outcomes:

1. Late referral for formal service intervention in many cases—41% of care recipients had care needs equivalent to high level residential care but had not received assistance from government community care programs prior to referral to a pilot project.
2. Short-term care projects have been unable to source sufficient numbers of high care packages for post-discharge ongoing support of clients.

Recorded accommodation outcomes need to be viewed in this context.

Short-term care projects — 56.5% of clients still living at home

More than half of the community-based clients of short-term care projects were still living at home when contacted for follow-up in the first half of 2005. Forty-eight of the 85 community–based clients in short-term care projects (56.5% of this group) were still living at home in the community and 26 clients (30.6%) had entered permanent residential care (7.1% deceased). Nine of the admissions to residential care were admissions to low-level residential care, indicating that some clients had reduced care needs at time of entry to a facility compared to their level of assessed need at time of entry to the Pilot. A mean of 231 days had elapsed between date of initial needs assessment for Pilot services and date of follow-up for clients who were at home (range 78 to 336 days), which is the average number of days that each of the 48 clients had so far avoided high-level residential care. Living alone was found to be the only client characteristic to be significantly correlated with discharge outcome, that is, residential status immediately upon discharge from a project (Chapter 4).

Past clients of short-term care projects (community-based during the Pilot) who were found to be still living at home were being supported by a variety of community care programs including EACH packages (eight), CACP (six), Home and Community Care Program (HACC) or Veterans' Home Care (12), and multiple programs (13). The evaluation found indications that clients discharged from pilot short-term care interventions to a HACC or similar service were less likely to be still living at home when contacted for follow-up than clients discharged to a care package. The program sources of funding (for example, CACP, HACC, EACH or National Respite for Carers Program etc) for ongoing support of community-based clients were commonly found to have changed between discharge from the Pilot and follow-up in 2005. The observed patterns of admission to residential aged care according to discharge community support arrangements and fluidity of formal care sources of funding in the post-discharge period indicates that a straightforward examination of discharge outcomes is unlikely to give a reliable picture of longer term accommodation outcomes and cost savings from short-term care interventions.

DRAH and DBAMS help clients to avoid hospitalisation for dementia, delirium and other mental and behavioural disturbances associated with or complicated by dementia by providing a complete alternative to assessment and treatment in hospital. It is estimated that DBAMS (16 packages) produces an annual saving of 230 hospital patient days through hospital avoidance; DRAH (15 packages) produces an annual saving of around 200 hospital patient days through hospital avoidance and early supported discharge.

NEDID supports clients in the transition from hospital to home; without this service all clients who have been referred to NEDID by acute care facilities would have needed to transfer to residential care.

All short-term care projects reported difficulties in discharging clients to appropriate long-term support programs. The use of multiple support programs may not provide an ideal solution to a shortage of high care packages if it results in multiple service providers and poor care coordination. Data collected for the evaluation show that clients with high levels of ADL and cognitive impairment were discharged to HACC and CACP services, presumably to receive a lower level of service than was available from pilot projects. Measures of client need dispel any notion that lower levels of service upon discharge were associated with reduced need for assistance.

Suboptimal discharge support arrangements may have resulted in more people entering residential care between date of discharge and date of follow-up than if more high care packages had been available for ongoing care.

Long-term care projects — 53.2% of clients still living at home

Likewise, over half (53.2%) of evaluation clients in long-term care projects were still living at home when contacted for follow-up in 2005 and 71 of these 75 clients were continuing with a pilot project. Approximately 30% of the group had entered permanent residential care (27% high level care and 3% low level care), on average 101 days after date of entry to a project.

The long-term care package projects were established over a number of months and this limits the usefulness of between-project comparisons of average duration of service and proportions of clients who entered residential care. Average durations of service calculated from the data (an average of the number of days between service commencement and date of discharge or date of follow-up of individual clients) are minimum estimates because follow-up truncated the service episodes of continuing clients. By completion of follow-up in April to June 2005, average per client days of service ranged from 257 to 349 days, by project. The longest recorded service period was 397 days, for a client who was continuing in a pilot project at time of follow-up.

There is strong evidence in the recorded accommodation outcomes of care recipients who participated in the evaluation that the long-term care package services enable people to live at home in the community for longer than would otherwise be possible. We base this conclusion on an assumption that clients were at imminent risk of entry to permanent residential care when referred to pilot services—a fair assumption given the levels of impairment and self-reports of carer strain. It is acknowledged that some differences in the needs profiles of the client groups have come about by different targeting strategies.

Further evidence was found in the indicators of carer wellbeing collected and analysed for the evaluation. A key question is how so many clients with severe cognitive and ADL impairment were still at home at the time of referral for pilot services. This of course has to do with the support available from families, and primary carers continued to play a major role in the provision of care during the Pilot. In many cases the crisis that triggered a referral to a pilot project involved carer strain and consequent breakdown in the provision of care at home.

Service activity and expenditure profiles of the projects show a high component of respite care and other forms of carer support. Repeated measures of carer strain and carer psychological wellbeing from the Caregiver Strain Index and General Health Questionnaire respectively showed significant overall reductions in levels of carer strain over time and improved self-reports of well-being (52% of carers reported reduced carer strain; 58% reported improved psychological wellbeing). Although it is not possible to attribute all reported improvements to project interventions, many carers used the Care Experience Survey to directly attribute their sense of improved wellbeing to pilot services and this is likely to have been a key factor in helping many clients to stay at home.

All project coordinators suggested that the ideal form of ongoing community care for members of the target group is a dementia-specific EACH package. Short-term care projects identified an EACH package as the ideal outcome for most discharged clients. EACH packages were either in very limited supply or were not available at all in the projects' service areas at the time of the evaluation.

AIHW discussions with service providers for the Pilot predated the announcement of the Extended Aged Care at Home Dementia (EACH Dementia) program in the 2005 Federal Budget (part of the initiative *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*). The new program consists of 2,000 new flexible care places allocated over three years:

- 667 packages to be released in 2005–06
- 667 packages to be released in 2006–07 (indicative releases)
- 666 packages to be released in 2007–08 (indicative releases).

What is the cost of the services per client per day?

Flexible care subsidy paid to care package projects ranged from $79.82 to $106.83 per allocated place day. These prices reflect the cost to the Australian Government for purchase of services on behalf of clients.

Long-term care package projects charged client co-payments of up to $7.00 per day in line with community care policy guidelines. Many clients received a discount or fee waiver due to financial hardship. DRAH and FCS short-term care projects did not charge client fees. FCS indicated that the overhead of administering client co-payments was unsustainable for short service periods and this led to the decision to forgo income from co-payments.

In comparison, the basic residential care subsidy payable by the Australian Government for care of a person in an aged care facility at Resident Classification Scale (RCS) level 2 was between $107.10 and $109.25 per day on 1 July 2004, depending on state/territory location of a residential service. The range of supplementary subsidies for residential care is not considered here but could apply to members of the target group. People who live in residential care facilities contribute towards the cost of accommodation in amounts negotiated between provider and client.

Projects with a clinical focus such as DBAMS and DRAH short-term care interventions provide a service that brings people with dementia into contact with specialist medical services. Thus, in these projects part of the service episode would otherwise be performed in a hospital or through outpatient visits to clinics and medical specialists, incurring out–of-pocket expenses and costs to Medicare and/or state health budgets. Care in a hospital setting would cost between $500 and $750 per day but hospital care is not considered equivalent to the care provided by DBAMS and DRAH since the pilot services allow people to be assessed and assisted in their home environment. This avoids the disruption of transfer to hospital and the negative effects of hospital environments for people with dementia.

Arguably, these short-term clinical interventions are best delivered in a community setting if possible. Assessment and diagnosis in the context of dementia care encompasses social and medical considerations and requires a high level of input from carers, ideally with advocacy. In the hospital setting it is often difficult for family members to be present when treating physicians are available on their rounds and there is no automatic day-to-day advocacy to assist carers in their interactions with specialists. The pilot projects have demonstrated that this interaction can be critical to achieving the best possible outcomes for patient and carer.

Other available service options such as those that many clients were discharged to on leaving a short-term care project, or which clients were accessing before joining a pilot project, include CACP and HACC services. The cost of these services to government is lower than the rates of flexible care subsidy for pilot services, for example, CACP subsidy at 1 July 2004 was $32.04 per day. However, these types of services would not meet the needs of most people in the Pilot; evidence of this is in the support needs profiles of clients, the fact that a high proportion of clients discharged from pilot projects onto HACC or CACP were discharged onto multiple support programs (hence, the cost is higher than the CACP subsidy rate in many cases), and in reports from family members that multiple service providers, less than 10 hours of formal assistance per week, or poor or no service coordination all contribute to decisions in favour of residential aged care over community care.

A more relevant question would appear to be what price we expect to pay to help people with dementia to live at home when home care is the preference of many families. The subsidy rate for an EACH package may not result in a saving to the public purse compared to residential care subsidy (during the evaluation levels of expenditure in the short-term care projects reached or exceeded EACH-level subsidy). Thus, an important issue highlighted by the Pilot is consumer preference and quality of life through quality dementia care. Less expensive, more readily available forms of community care naturally result in higher short-term savings but are unlikely to produce long-term savings or the best possible outcomes for clients because family members would continue to bear an unsustainably high share of the real cost of care.

Pilot strengths and weaknesses

Through the Innovative Pool Dementia Pilot new and innovative specialist services have been developed to meet the diagnosis and specialist assessment and management needs of people with dementia in regional and rural areas. These services have been trialled in areas that ordinarily have limited access to geriatric and psycho-geriatric expertise. The three types of short-term intervention—dementia-specific case management capacity in an Aged Care Assessment Team, outreach service for behaviour management in dementia care, and transition care packages—show considerable potential to operate alongside ongoing care packages of in-home ADL and carer support.

It was found that flow-through models of 8–12 weeks duration are well suited to highly specific, targeted interventions such as specialist assessment or transitioning between care settings. These interventions have a well-defined goal that is usually achievable within a time-limited period. The Pilot has not provided strong evidence that the care needs of people in the target groups are relenting to the point that discharge to low level community care would be an expected outcome following a short-term intervention. Flow-through services should ideally operate alongside a supply of ongoing high care packages to maximise the long-term benefits of short-term interventions by ensuring care continuity and consistent levels of service for care recipients and family carers.

Occupancy targets of over 90% that some short-term care projects were subject to are difficult for a provider to achieve in a flow-through service for the target group. Pilot service providers reported having to increase the number of experienced case managers to cope with the unanticipated demand for case management and it is unlikely that they would be able to continue to deliver the high level support over the longer term unless appropriate discharge support arrangements can be more readily sourced. Based on the experiences of short-term care projects, 'high level case management and coordination' equates to a one case manager per 8–10 clients (lower staff to client ratios might be manageable for an established and ongoing client group).

A higher than anticipated case management effort in short-term care projects was largely related to discharge planning. The optimal exit strategy for clients discharged to the community from these projects was most often an EACH package but these were hard to source. Changes in formal care arrangements and program sources of funding, typically involving multiple aged care funding programs, in the period between discharge from a Pilot project and follow-up in mid-2005 were commonly observed among people discharged from short-term care packages. Some family carers continued to seek the involvement of project coordinators in the months following discharge of their care recipient. This tended to occur when ongoing community support arrangements were not providing the same high level case management service delivered by the Pilot.

Projects that operate in rural and remote areas face high travel costs for staff. For example, Ozcare estimated that in the service region for Ozcare Dementia Packages, staff travel time runs to 1 hour per 7 hours of delivered client care (Ozcare covers the cost of staff travel time and encourages the use of fleet vehicles). Pilot funding has allowed a number of projects to absorb high travel costs while still delivering high hours of assistance to care recipients. Escalating fuel costs have a significant impact on take-home pay for workers and community care workers need protection of real wages if the workforce is to meet growing demand for services.

Respite care has emerged as a central tenet of service delivery in most projects and two innovative respite care models were demonstrated. The Sundowner Club offers a social outing for clients at a time of day that respite is generally unavailable. A day respite unit operating from a Southern Cross Care WA retirement village in the Dementia Care in Alternative Settings caters to small groups of clients in a home-like setting, an ideal model for clients with primary carers in paid employment and clients who may not adjust well to large groups or residential settings. All projects that delivered comprehensive in-home support used respite care to introduce formal services to care recipients new to community care and to diffuse difficult home situations at point of referral. Projects demonstrated flexibility in the provision of respite care by offering a range of respite settings to meet individual client and carer needs.

The Pilot has offered service providers greater scope to address the special needs of people from culturally and linguistically diverse backgrounds through the provision of interpreters and translators and bilingual care workers. South Brisbane and Gold Coast Innovative Dementia Care Pilot has been able to double the rostering of carer workers to provide assistance to a primary carer with English as a second language for appointments and shopping in parallel with in-home respite care, culturally specific food services, and a matching of care workers to the language and cultural background of clients.

Project coordinators and care managers have paid close attention to limiting the number of carer workers who attend each client to no more than three and more ideally to one or two people. Judging from responses to the Care Experience Survey, most arrangements were satisfactory for the care recipient and family carer(s). Some relatives said that too many people were involved in service delivery and that this caused anxiety and fear in the person with dementia especially if they were alone during the day when workers called. One family requested that the evaluation highlight the need for care workers to be clearly identified through visual means such as photo identification, uniform, or company logo, so that the person with dementia can feel confident about allowing callers to enter the home.

It is not always possible to keep the number of care workers to the desired minimum because of staff leave and other complications especially in services that operate across large areas and involve high staff travel time. The inevitability of staffing difficulties that arise from time to time and the fact that enough survey respondents mentioned the number of care workers suggests that identification of workers in dementia care, and community care for older people more generally, is an important quality and safety issue.

The Pilot has highlighted workforce issues in servicing the needs of the target group. There is a need for higher levels of training—several projects reported that the basic level of training from a Certificate III qualification may not adequately equip staff to work with clients who have high dementia-related needs, unless staff have previous, extensive experience in the field. Access to dementia-specific training for staff in regional and remote areas is a significant issue and as rising fuel costs increase the cost of travel, professional development opportunities are likely to be limited even further.

The message in responses to the Care Experience Survey is clear. Families have confirmed that by providing more hours of assistance, coordination from one point of contact, and specialist help for diagnosis and behaviour management, the projects have helped to improve the longer term outlook and quality of life for Pilot participants with dementia and their carers.

Part A

Main report

1 Introduction

A significant increase in the prevalence of dementia is acknowledged as a major health, social and economic impact for ageing populations worldwide. The World Health Organization places dementia in the top 20 causes of disability in the world and estimates that its already 'massive' social cost will rise rapidly over the next 20 years (WHO 2001). It is estimated that currently around 200,000 people in Australia have dementia and that, in 2005 alone, 52,000 people would have been newly diagnosed (Access Economics 2005). There is thus a pressing need to build capacity within health and aged care systems to support people with dementia and their care providers. A Dementia Pilot established under the Aged Care Innovative Pool is one element of a national response to this widely recognised need (the Innovative Pool was established in the financial year 2001–02 to target older people with rehabilitation needs and other high and special needs groups through a national pool of flexible care places outside of annual Aged Care Approvals Rounds). In 2005 dementia was named a National Health Priority.

This report presents the findings of an evaluation of Innovative Pool initiatives in dementia care. Pilot services within the 'High and Specific Need' stream of the Innovative Pool were established to explore approaches to service delivery that go beyond the boundaries of mainstream residential and community aged care programs. Throughout 2003–04, the Innovative Pool Dementia Pilot became operational across Australia as a set of projects under the administration of the Australian Government Department of Health and Ageing. Projects variously represent partnerships between levels of government, the community care sector, health and aged care services. Clients, their carers and families enter into the Pilot as partners in care under the provisions of the *Aged Care Act 1997* and Flexible Care Subsidy Principles.

This report presents the findings of an evaluation of nine projects in five mainland states—two in New South Wales, two in Victoria, three in Queensland and one each in South Australia and Western Australia. The national evaluation was completed by the Australian Institute of Health and Welfare (AIHW) under a Schedule to the Memorandum of Understanding between the AIHW and the Department of Health and Ageing. Evaluation results are to inform the Department's broader review of the Innovative Pool Dementia Pilot. The Hammond Care Group commissioned its own evaluation of the Short Term Intensive Community Care Service and the report is available upon request from The Hammond Care Group.

1.1 Purpose of the national evaluation

The purpose of the national evaluation of the Innovative Pool Dementia Pilot was to assess the effectiveness and efficiency of pilot services (projects) in meeting the aims and objectives of the Aged Care Innovative Pool as articulated in three evaluation questions:

1. Do the pilot services offer new care choices which meet the needs of older Australians?
2. Do the pilot services enable clients to either re-join or live longer in the community (defined as long-term living arrangements other than residential aged care and hospitals)?

   This question may not be relevant in the case of those Innovative Pool services which aim to provide more appropriate residential aged care services for people with dementia.
3. What is the cost of the services per client per day (both in absolute terms and relative to other service options available to clients)?

The evaluation was further required to identify the innovative elements of services and assess the quality of care they provide. A number of other issues were raised by service providers and families during the course of the evaluation and these are canvassed in this report to draw fully on the Pilot experience.

Pilot services were established prior to evaluation so that the range of innovative models was known in advance. The AIHW was briefed to develop a framework that would enable a consistent approach to evaluating different models of care. Differences between care models can be in the form of targeting differences—a project may target people who need a particular type of assistance, or who live in a certain type of locality, for example—and implementation differences, whereby a project develops a novel way to deliver services or enhances an existing form of service that is broadly applicable across the target group. Through evaluation, recognition would be given to local service objectives to the extent of their consistency with the overarching objectives of the Innovative Pool.

1.2 Overview of Dementia Pilot projects

The Department of Health and Ageing called for proposals to address a particular identified need for dementia care through ongoing residential places or through flexible places for care in alternative settings under either of two categories: ‘Dementia-related high needs or challenging behaviours’ and ‘Dementia care in alternative settings’ (Box 1.1).

Box 1.1: Two categories of Innovative Pool Dementia Pilot proposal

Dementia care for people with high care need and/or challenging behaviour

This category of proposal is designed to address the provision of appropriate high care residential services for people with dementia-related high care needs who are not being catered for through the normal allocation of aged care places. Proposals may be for an area where no dementia care is available or situations where an identified group of people require a particular type of service that is not available. Where these proposals would provide only aged care services, a funding contribution from the state or territory government is not mandatory.

Allocations of permanent residential aged care places through the Innovative Pool will be considered where a proposal demonstrates that the dementia care need cannot be addressed through the normal allocation processes.

Target group

The target group for this type of proposal is people with an ACAT assessment for high level residential care and relating specifically to their need for dementia care. They are unable to access suitable care in the aged care services available and are in danger of being inappropriately placed either in a service that cannot adequately meet their needs or in a service a considerable distance from their preferred location. A sufficient number of people in the target group will need to be identified to justify the size and scope of the proposed aged care service.

Eligibility is based on a current ACAT assessment for high level residential care and an assessment that the person is able to benefit from the type of dementia care that can be provided by the new service. The person should live or choose to live within the catchment of the area of the new service.

Dementia care in alternative settings through flexible places

This category of proposal is available to consider a range of different projects addressing dementia care issues in flexible ways. While the approaches may be different, the key outcome for each will be an improved range of service options for people with dementia who are not well catered for through the available aged care services.

The allocation of flexible care places to these projects will be on the basis that the identified need cannot be met through an allocation of residential or community care places. All such allocations will be time-limited and projects will agree to participate in a national evaluation.

Proposals should not be based upon the withdrawal of any existing services and should include support and a contribution of funding from state/territory government where any of the proposed services would otherwise have been funded by that government. Proposals should demonstrate relationships with any other dementia-related initiatives, including support and education for carers that may be available in the area.

Target group

The target group for this type of project is people with a dementia-related ACAT assessment for high level residential care who would benefit from an alternative approach to their care needs. This may be through short-term intensive interventions or any other approach that is different to mainstream residential or community care.

Eligibility

The precise eligibility requirements will depend upon the nature of the proposal and the specific group of people being targeted. Criteria should address the particular people within the broader target group who would be most likely to benefit from the proposed service and cannot access the care they require through other appropriate means. As the projects will be evaluated, it is important that the eligibility criteria are closely related to the aims of the project.

Source: Aged Care Innovative Pool 2002–03 Guidelines, July 2002, Australian Government Department of Health and Ageing.

Projects in the national evaluation have primarily focused on community-based care or community outreach and covered a range of metropolitan, regional and rural locations (Tables A1.1 and A1.2). Projects in New South Wales and Victoria have provided intensive short-term intervention to eligible recipients of 8 to 12 weeks duration. Projects in other states were designed to offer a longer duration of service to each client that could extend for the lifetime of the project or until a client can no longer benefit from the service offered. Throughout this report the distinction between these two types of project is made by reference to 'short-term care projects' and 'long term care projects', where the implied meaning of short- and long- term care is intended only in this context.

Client eligibility is based on completion of an Aged Care Client Record. A person needs Aged Care Assessment Team (ACAT) approval for residential care to be considered for pilot services and dementia-related high care needs must be demonstrated. Projects make a further assessment of commitment to receiving care at home and the appropriateness of community care on a case-by-case basis. Additional criteria may be enacted locally as stated in the agreement between the approved provider and the Department of Health and Ageing. Project objectives and policies consistent with the agreement were developed by project steering committees. Tables A1.1 and A1.2 summarise providers and objectives of short- and long-term projects, and Table A1.3 lists some key eligibility criteria for each project.

A client, or advocate, is appraised of their rights under the *Aged Care Act 1997* and of the time-limited nature of the Pilot. Projects were required to develop an exit strategy to address the ongoing needs of participants at the end of the pilot phase, for example, by outlining the process of transfer of clients to alternative services.

Part B of this report dedicates a chapter to each project from information gathered in the course of the evaluation. The remainder of Part A aligns project descriptions with the key evaluation questions—choice and care outcomes for older people with dementia. Chapter 2 examines how each project offers new care choices and Chapter 3 considers evidence on whether and how these choices enable people with dementia to remain longer in the community. Before addressing these questions, it is necessary to consider some important issues that impact on care outcomes for people with dementia because the national evaluation was designed within this context. We briefly mention the issues taken into account in the development of an evaluation framework and outline the methods, strengths and weaknesses of the national evaluation.

Table A1.1: Innovative Pool Dementia Pilot short-term care projects, service area, auspice and key local objectives

Project name (abbreviation)	Service area	Approved provider(s)	Type of auspice body	Key local objectives
Dementia Behaviour Assessment and Management Service (DBAMS) New South Wales	Northern and southern regions of Greater Murray Area	Southern Area Health Service (New South Wales Health)	New South Wales Government Health Service	Assess the effectiveness of outreach and intermediate care for people with BPSD in reducing the severity of BPSD and increasing confidence and competence among family carers and care professionals in managing behavioural symptoms. Identify underlying causes of BPSD with a view to resolving problems to facilitate a return to usual care or appropriate placement.
Dementia Rehabilitation at Home (DRAH) New South Wales	Northern Rivers region	North Coast Area Health Service (New South Wales Health)	New South Wales Government Health Service (ACAT)	Achieve a firm diagnosis where dementia is suspected but not diagnosed or where a person with dementia experiences other undiagnosed symptoms that complicate the provision of care. Link client and family to appropriate medical specialists and community service agencies for ongoing medical supervision and client and carer support. Build and strengthen working relationships between health and community services in the provision of care for people with dementia on the New South Wales Far North Coast.
Flexible Care Service (FCS) Victoria	Eastern metropolitan Melbourne	*Annecto—the people network* (formerly WiN Support Services)	Community service NGO	Assist clients and families in times of crisis. Provide respite to carers to help sustain the caring role. Establish in-home services where services may not have previously been in place/match level of service to care needs. Provide assistance to source appropriate form of ongoing formal care.
North East Dementia Innovations Demonstration (NEDID) Victoria	Northern and eastern metropolitan Melbourne	Austin Health, Heidelberg	Health service	Provide transition care (between hospital and home) to people with dementia following an acute or sub-acute episode at Austin Health. A proportion of NEDID clients are interim care-type clients. The aim for this group is to offer a possibly last chance to return/remain at home after other unsuccessful attempts.

Table A1.2: Innovative Pool Dementia Pilot long-term care projects, service area, auspice and key local objectives

Project name (abbreviation)	Service area	Approved provider(s)	Type of auspice body	Key local objectives
RSL Care Innovative Dementia Care Pilot (RSL Care) Queensland	Brisbane North and South	RSL (Queensland) War Veterans' Homes Limited	Community service NGO	Offer an opportunity for people with dementia-related high care needs to live at home through the provision of high level dementia-specific community care and intensive case management. Carer support focus, in particular the delivery of flexible respite care service.
South Brisbane and Gold Coast Innovative Dementia Care Pilot Queensland	Brisbane South and Gold Coast	Islamic Women's Association of Brisbane Multicultural Communities Council Gold Coast Queensland Transcultural Mental Health Centre	Community service NGO and health service partnership	Provide culturally appropriate dementia-specific services. Cater to the diverse needs of people from a range of cultural and linguistic backgrounds. Service delivery by bilingual, cross-cultural care workers. Increase access to medical services for people with dementia through transport assistance and accompaniment to appointments plus translation/interpreting support.
Ozcare Innovative Dementia Care Packages (Ozcare) Queensland	Rockhampton/ Gladstone and Bundaberg	Ozcare (formerly St Vincent's Community Services)	Community service NGO	Offer an opportunity for people with dementia-related high care needs to live at home through the provision of high level dementia-specific community care and intensive case management. Carer support focus, in particular the delivery of flexible respite care service.
Dementia Care in Alternative Settings (DCAS) Western Australia	Perth	Southern Cross Care (WA)	Community service NGO	Deliver flexible dementia-specific care to a level rarely possible through mainstream community care programs, of up to 24 hours per week. Provide flexible respite care through an offering of in-home and special-purpose day centre services.
The Sundowner Club South Australia	Southern and eastern metropolitan Adelaide	ECH Incorporated	Community service NGO	Offer a new type of service that operates outside 'standard' service hours when people who exhibit sundowning behaviours and their families often require additional support. Provide people with dementia an opportunity for socialisation in the form of an evening meal program in a supported, congregate setting. Encourage motivation and sound nutrition for people at risk of neglecting their self-care needs. Link people with dementia who have little or no experience of formal service into a formal support network.

Table A1.3: Innovative Pool Dementia Pilot projects, place allocations, funding periods and key eligibility criteria

Project	Places	Planned pilot duration	Eligibility criteria: ACAT approval	Eligibility criteria: Other key criteria	Intended average episode of care
Short-term care projects					
DBAMS, New South Wales	16	24 months	High level residential care	People with dementia/BPSD who would benefit from the provision of specialised assessment and behaviour management	8–12 weeks
DRAH, New South Wales	15	24 months	High level residential care	Dementia/BPSD	8 weeks
FCS, Victoria	20	24 months	High level residential care	Potential to benefit from a short-term program of dementia/BPSD care Primary carer involved on a daily basis	12 weeks
NEDID, Victoria	10	24 months	High level residential care, later extended to allow one concurrent low care client	Mild to moderate dementia	10 weeks
Long-term care projects					
RSL Care Pilot, Queensland	45	36 months	High level residential care	Primary diagnosis of dementia	Maximum 3 years
South Brisbane & Gold Coast Pilot	20	36 months	High level residential care	Primary diagnosis of dementia	Maximum 3 years
Ozcare Packages, Queensland	30	36 months	High level residential care	Dementia-related high care needs	Maximum 3 years
DCAS, Western Australia	35	24 months	Low or high level residential care; care needs in excess of CACP level of service	Moderate to severe dementia and/or BPSD	Maximum 2 years
The Sundowner Club, South Australia	15	24 months	High level residential care	Diagnosis of dementia and physical capability to leave the home environment	Maximum 2 years
Total	**206**				

Table A1.4: Innovative Pool Dementia Pilot projects, place allocation and number of evaluation participants by project and usual accommodation

Project	Place allocation	Evaluation participation		
		Community-based	Residential-based	Total
Short-term care projects				
DBAMS, New South Wales	16	16	23	39
DRAH, New South Wales	15	31	—	31
FCS, Victoria	20	24	—	24
NEDID, Victoria	10	14	—	14
Total short-term care clients	*61*	*85*	*23*	*108*
Long-term care projects				
RSL Care Pilot, Queensland	45	32	—	32
South Brisbane & Gold Coast Pilot	20	26	—	26
Ozcare Packages, Queensland	30	35	—	35
DCAS, Western Australia	35	33	—	33
The Sundowner Club, South Australia	15	15	—	15
Total long-term care clients	*145*	*141*	—	*141*
Total	**206**	**226**	**23**	**249**

— Nil.

1.3 Context for an evaluation of dementia care

A diagnosis of dementia has major long-term implications for the individual and the people who care for them. Dementia syndrome is characterised by a progressive and irreversible loss of cognitive function. Over time a person with dementia experiences memory loss and impaired comprehension, judgment, perception and learning which lead to severe disturbances in activities of daily living and social functioning. Dementia involves significant measurable and unmeasurable costs to individuals, families and society.

The care needs of a person with dementia vary markedly in relation to the severity of cognitive impairment; however, approximately 96% of older Australians who reported having dementia also experience severe or complete limitation in the core activities of daily living and therefore require the assistance of others on a regular and ongoing basis (AIHW 2004a). Dementia is a leading cause of admission to aged care facilities and presents a major challenge for the provision of care to many older people across a range of care settings. A person with dementia who lives alone in the community with limited social resources will typically face increasing difficulty as the dementia increases in severity. For a person who lives at home with the support of relatives and friends, increasing severity of dementia places higher demands on the support network and there can be high personal costs for carers. The care continuum of mainly informal care, to informal care supplemented by formal services, and finally to mainly institutional care is a commonly observed dementia care pathway. Recipients of formal care through the Community Aged Care Packages (CACP) program with access to informal assistance from a primary carer are more likely than those without a primary carer to have been diagnosed with dementia, consistent with the theory of supplementation to achieve higher total hours of care (AIHW 2004b; Schneider et al. 2003; Edelbrock et al. 2003; Edelman & Hughes 1990). As a group, people with dementia in aged care homes have been found to have higher care needs than residents without dementia (AIHW 2004a).

There is a strong association between dementia and rate of functional decline in activities of daily living (ADL) in old age. Dementia is often diagnosed when deterioration in cognitive function is sufficient to cause ADL impairment (WHO 2001). ADL have been defined as the most basic competencies in gerontology and 'central to stability of residence' at older ages (Lawton 1983, Gill et al. 1996, and Miller et al. 1999 cited in Lichtenberg et al. 2000). Derouesne et al. (2002) reported that people with early stage dementia in Alzheimer's disease are likely to first experience reduced social and leisure participation and then a reduced ability to manage finances and shop. People with severe dementia show more marked loss of ADL function that over a 12-month period is estimated to involve family caregivers in an average of 14 additional hours of ADL assistance per fortnight (in addition to an established level of ADL assistance plus supervision and help with other tasks and demands).

Caro et al. (2002) also associated relatively small degrees of measured cognitive decline with significantly higher odds of requiring more than 12 hours of supervision and active care each day, hence a greatly elevated risk of being unable to live independently. People with mild to moderate Alzheimer's disease were found to require an average of 14 hours of supervision each day; 15% of dementia patients required 24-hour supervision and 67% required more than 12 hours of daily supervision.

Since most people with dementia receive care at home from relatives, the care needs associated with progressive functional decline place heavy demands on the primary caregiver and members of the wider support network. Increased carer strain is correlated with increasing caregiving involvement (see for example Desai & Grossberg 2005 and Andrieu et al. 2003) but aspects other than time spent caring also play a role in the impact of dementia care on carers. Incontinence in the person with dementia, for instance, may cause an altering of the relationship between care recipient and primary carer that precipitates residential placement (Mittelman et al. 1993). Nocturnal activity and other behavioural and psychological symptoms of dementia—memory loss, wandering, intrusive and verbally disruptive behaviours, physical aggression and risk of harm to self or others, emotional symptoms—cause distress to carers and are associated with a high risk of institutionalisation for the person with dementia. Schofield et al. (1998) reported that carers of people with intellectual or cognitive impairment are more likely to experience overload, resentment, conflict and anger than carers of people with physical frailty alone. Another Australian study showed that cognitive impairment is the most important predictor of institutionalisation for older people at home with a primary carer (LoGiudice et al. 1997).

However, the relationship between care recipient symptoms, carer strain and long-term accommodation outcomes is neither automatic nor straightforward. Banerjee et al. (2003), for instance, showed that both severe behavioural problems in the person with dementia and the psychological domain of the carer were significant predictors of transition into residential care. The same study reported a 20-fold protective effect against institutionalisation for a person with dementia in having a co-resident carer. Personality traits influence how a carer perceives their situation and their receipt and perception of social support (Vernooij-Dassen et al. 1996; Morris et al. in Henderson & Jorm, 1998).

Treatment of dementia focuses on establishing an early, accurate diagnosis, early institution of recommended pharmacological and non-pharmacological interventions, treatment of medical and psychological co-morbidities, provision of appropriate formal services and addressing the wellbeing of carers (Desai & Grossberg 2005). Accurate diagnosis involves eliminating reversible causes of dementia including, for example, neurosurgical causes, post-surgical delirium, certain nutritional deficiencies, drug and alcohol toxicity, psychiatric illness, infection and sleep disorders. Early diagnosis opens doors to a range of support mechanisms that help to improve quality of life and increase the capacity for care at home. These range from pharmacological treatments to exercise training and behavioural management techniques that improve physical and mental health of people with dementia and instrumental in-home support. Family intervention in the form of short-term intensive counselling has been found to have long-lasting benefits for carer well-being and may help to delay long-term care placement (Desai & Grossberg 2005).

Despite evidence for the importance of early support, it appears that formal service intervention often occurs relatively late. A study in the United States estimated that only 60% of people with Alzheimer's disease, the most common cause of dementia in old age, are correctly diagnosed and only 50% of those people receive treatment at any stage (Mintzer cited in Desai & Grossberg 2005). In Australia, care for people living with dementia has been described as crisis driven, and this has been attributed to poor communication between general practitioners and carers, untimely referral for community care, and practical difficulties in accessing support services (Bruce et al. 2002; Bruce & Paterson 2000). Cultural factors also have a role to play. Kosloski et al. (1999) contend that an individual's estimate of need and perception of the usefulness of support services are culturally influenced. Differences between cultural groups including food preferences, gender roles, language and custom may lead to a perceived limited benefit of services that are established without regard for these and other important aspects of service delivery.

In summary, there is evidence that care outcomes for people with dementia are influenced by a number of interrelated factors:

- achieving a timely, accurate medical diagnosis
- provision of support in activities of daily living and social participation
- maximising sense of competency and coping among primary care providers
- management of behavioural and psychological symptoms of dementia
- management of physical health and wellbeing
- treatment and care that focuses on the circumstances and needs of the individual (so-called 'client-centred care').

Innovative services will aim to address the central tenets of dementia care in ways that might be otherwise impossible or infeasible. This provides a rationale for assessing the effectiveness of services in helping people with dementia to achieve the best possible outcomes in care. It is recognised that the human outcomes of dementia care come about through the interplay of many factors, some modifiable, others immutable.

1.4 Evaluation methods, strengths and limitations

An evaluation framework was developed to produce a snapshot of projects, covering multiple measurement domains but with an awareness of the complexity of outcome measurement in this field (AIHW 2003). The framework, including a proposed client consent and data collection protocol, was released for consultation in December 2003. Following minor refinement the protocol was submitted for ethics approval.

Ethics approval

AIHW Ethics Committee approval for the evaluation of the Innovative Pool Dementia Pilot was received on 3 March 2004 (Register Number EC 353). The Department of Health and Ageing Human Research Ethics Committee approved a separate application for the evaluation.

The AIHW Ethics Committee conducted annual reviews of the project which required notification of any breach of the approved protocol.

Timeframe and conduct of the evaluation

Evaluation guidelines based on the agreed framework were issued to projects in May 2004. Data collection started on 14 June 2004 and the recording of client-level data continued to 29 November 2004. Recruitment of evaluation clients and the procedure for obtaining informed consent was managed entirely by project coordinators using documents and forms supplied by the AIHW. The AIHW evaluation team did not have direct contact with clients and projects were instructed not to disclose the identity of evaluation clients in material sent to the AIHW.

The evaluation team met with project coordinators and staff throughout June and July 2004 to learn about local objectives, approaches to care, client groups and service environments. AIHW staff offered guidance on the collection and recording of evaluation data at these meetings. The evaluation team was able to attend some project steering committee meetings to gain the perspective of a wider group of stakeholders and interested parties, including family carers who volunteered to talk about their experience in the Pilot. Records of these discussions are the basis for project narratives in Part B of this report.

Any care recipient who was active on 14 June 2004 or who commenced services with a project between 14 June 2004 and late-October 2004 was invited to participate in the evaluation. Short-term care projects enrolled only commencing care recipients into the evaluation, that is, care recipients in a short-term care project who were already receiving services by 14 June did not participate. Care recipient participation was subject to full disclosure of the evaluation protocol and receipt of a signed consent form by a project coordinator. Forms, indicating consent or withholding of consent, were retained by the projects. Projects supplied de-identified evaluation data to the AIHW for consenting care recipients. Care recipients and their advocates were informed that they could withdraw from the evaluation at any point and that it was possible to decline to take part in specific parts of the evaluation should they wish.

The collection of client service activity and functional outcome measures was completed by 29 November 2004. The evaluation snapshot window extended to 31 December 2005 for the collection of financial results (the September and December 2004 quarters were separately reported). Financial results cover all of a project's care recipients, not just those participating in the evaluation.

During the data collection period, project coordinators issued a Care Experience Survey questionnaire to participating care recipients and carers. Participants returned forms direct to the AIHW by pre-paid post.

Guidelines issued to the projects specified key milestone dates (Table A1.5). Most projects supplied interim data soon after 30 September 2004 and the AIHW liaised with coordinators in the ensuing weeks on data quality and completeness. Final client-level data were required by 20 December 2004 and December quarter financial results by 14 February 2005. These targets were not met in all cases. The AIHW worked with project coordinators throughout the first half of 2005 to clean the data and complete a follow-up of evaluation participants.

The AIHW released draft reports on individual projects to project coordinators in July 2005.

Table A1.5: Milestone dates for the evaluation of Innovative Pool Dementia Pilot projects

Target date	Milestone
4 June 2004	Evaluation packs dispatched to projects
14 June 2004	Formal evaluation period starts
30 September 2004	Projects send data collected to date to AIHW
11–25 October 2004	AIHW and projects liaise on data quality
29 October 2004	Recommended last date for enrolling clients in the evaluation
1 November 2004	September quarter financial and occupancy reports due
20 December 2004	Projects send final database (except for remaining follow-up) and Client Profile and Assessment Forms to AIHW
31 December 2004	Formal evaluation period ends
17–28 January 2005	AIHW and projects liaise on data quality
14 February 2005	December 2004 quarter financial and occupancy reports due
29 April 2005	End of client follow-up period
9 May 2005	Closing date for submission of follow-up data to AIHW
July 2005	Draft report of results from individual dementia projects sent to projects for comment

Data storage and analysis

Projects transmitted de-identified unit record data to the AIHW electronically with password protection. Supplied data is stored at the AIHW secure facility in Fernhill Park, Bruce, ACT, where it will be retained for 5 years.

Statistical analysis was performed using the Statistical Analysis System (SAS) Version 8.2 and SPSS for Windows Version 13.0.

Methods

Evaluation of the Innovative Pool Dementia Pilot has involved quantitative and qualitative methods to reflect the Pilot experience of care recipients, family carers and service providers. This is a descriptive study of pilot projects in action. It was conducted *post hoc* in the sense that projects were established without influence from the evaluation.

The approach to answering each of the evaluation questions is outlined below.

Do pilot services offer new care choices to meet the needs of older Australians?

Semi-structured interviews with service providers during site visits and responses to the Care Experience Survey of care recipients and family carers are the source of information to the question of new care choices and meeting the needs of older Australians. Providers' descriptions of their services give an insight into project-specific objectives and innovation which can be related to the objectives of the Innovative Pool.

Interviews covered, but were not limited to, the following topics:

- innovative features of the service
- local service environment characteristics and areas of unmet need for people living with dementia
- care management and service delivery model
- unique characteristics of the project's target group
- criteria and processes for accepting referrals
- experience of setting up an innovative care service—staffing, linkages, etc.
- strategies for transferring care recipients to other programs or services, where applicable
- practical constraints to delivering innovative care
- factors that have or might prevent the service from continuing to provide care for an individual care recipient
- unintended or unexpected outcomes.

Interviews also provided an opportunity for project coordinators to identify any additional data collected locally that could be used to supplement standard evaluation data. Projects were invited to compile case study reports to illustrate the experience and outcomes of individual care recipients. Most have taken up this opportunity and the case studies are included in project reports in Part B.

The evaluation team interviewed referring Aged Care Assessment Teams to gain another perspective on how each service offered care choices not available through mainstream programs.

The Care Experience Survey was designed to obtain a consumer perspective on choices and needs. Respondents (care recipient or carer/advocate) were asked to identify their most pressing age related needs, areas of previously unmet need, and to compare their Innovative Pool service to previous care arrangements. They were further asked to assess whether, in their view, the new service adequately met their care needs and whether it might continue to provide adequate care for the foreseeable future.

Consumer feedback was sought on specific aspects of service delivery including care planning and coordination, level of consumer involvement, continuity of care, the range and availability of services, convenience, privacy and security. Respondents were asked to indicate if a questionnaire was completed with staff assistance.

A further assessment of increased care choices was made possible through the recording of services received by care recipients.

Do pilot services enable clients to either re-join or live longer in the community?

This question is an important focus of policy makers and planners and refers to one of the main objectives of the Innovative Pool: to test models of service delivery for their effectiveness in helping frail older people to age in place.

Qualitative data collected for the evaluation provide one source of information with which to address the second evaluation question. Supporting evidence comes from responses to relevant questions in the Care Experience Survey (Box 1.2) and case studies of real-life situations and outcomes.

Box 1.2: Care Experience Survey questions on perceived improved ability for clients to age in place.

1. *Before entering the pilot program, were you receiving enough help in each of the following areas…?*
2. *Overall, is the pilot program helping to address previously unmet needs?*
3. *Would the pilot program be an appropriate form of long-term assistance to you and your relative or friend with dementia?*

Quantitative data provide another source of information about care recipients: accommodation setting at referral, entry and exit; primary health condition; specific risk factors such as falls, sensory impairment and polypharmacy; recent history of hospitalisation; and measures of cognitive function and functioning in activities of daily living (ADL) at date of entry to a project. This information establishes and describes entry levels of risk to ageing in place within client groups (a care recipient could have completed an ACAT assessment some months before commencing in a project). Key functional outcomes for individuals captured in the evaluation are:

- cognitive function at entry and change over time
- entry level functioning in ADL and IADL (instrumental ADL) and change over time
- extent of behavioural and psychological symptoms at entry and change over time (behaviour management clients)
- level of carer reaction to care recipient behaviours (carers of behaviour management clients)
- carer strain and carer psychological wellbeing and change over time.

Instruments used to measure functional outcomes and the course of administration during the reporting period are listed in Table A1.6. Widely used functional outcome measures were chosen to avoid duplication of data collection as far as possible. Projects were asked to incorporate assessments for the evaluation into routine timetables for client reviews so that assessment for the evaluation would have minimal impact. Thus, projects exercised discretion over the administration of functional assessment tools within broad guidelines developed by the AIHW and this has meant that assessments for the evaluation were not always equally spaced for an individual or across individuals. The objective was to capture a set of baseline functional measures for each individual and a set of repeat measures during the evaluation so that the data might include a measure close to the time of discharge in cases where a care recipient left a project. Experience has shown that it is not always possible to record these data at point of discharge due to the difficult circumstances that often surround discharge.

Entry levels of functioning for established clients in long-term care projects were in most cases reconstructed from the Aged Care Client Record and project records of referral and initial needs assessment. If it was not possible to reconstruct entry levels of carer function and wellbeing from records, carer assessments were commenced around the start date of the evaluation. Dates of client and carer assessments were recorded separately.

The selected functional measures proved relevant and informative. Care managers were able to reconstruct baseline data where necessary and there were no reports of difficulty in adopting the measures or adapting existing data collection procedures to incorporate measures for the evaluation. Use of the MMSE proved problematic in some cases, for example, with clients who had low English proficiency or who were resistant or otherwise hard to assess with this instrument. IADL measures can be problematic for some clients because some domains such as domestic functioning are not always relevant to the lifestyle of the person being assessed, for example, because of cultural or gender role differentiation, although this did not cause major difficulties for the evaluation.

Behavioural and psychological symptoms of dementia (BPSD) were measured using relevant items from the Resident Classification Scale because it was thought that this scale would be familiar to service providers, whereas there would be varying levels of experience with more specialised behaviour assessment tools. Data recorded using the RCS items are mostly complete and consistent, although they did present some analytical difficulties. The RCS data are multidimensional and are not readily reducible to an overall measure of symptom severity. The AIHW found a conceptual model of hierarchy of BPSD proposed by Brodaty et al. (2003) to be useful here. We would also recommend that a measure of nocturnal disturbance be considered for any comprehensive measure of BPSD—this is not specifically included in the RCS scale. For this evaluation, carer reactions to care recipient BPSD were recorded and these have proved informative in assessing the real impact of BPSD on provision of care. The data show that symptoms such as memory loss and emotional and psychological disturbance (personality change) are highly distressing for family carers, often no less so than verbal and physical aggression.

Care recipient accommodation status was tracked over periods of up to 12 months from the start of the evaluation. While the evaluation timeframe is too short to assess the impact of innovative services on long-term utilisation of residential services, it offers some insight into rates of admission over time. Longer term follow-up of clients would be ideal, but there is a recognised imperative for timely information that can help to inform aged care policy.

Table A1.6: Methods of functional assessment of participating clients and family carers.

Functional domain	Instrument	Scale	Key indicator values	Recommended timing of administration
ADL	Modified Barthel Index (MBI), 20-point Collin scoring (Mahoney et al. 1958; Collin et al. 1988)	0…20 (complete impairment… no impairment)	Score of 12 marks a threshold between marked dependence and independence; scores of 8 or below indicate diminished likelihood of living in the community (see McDowell & Newell 2001:57).	1. Participating clients in short-term care projects: entry and discharge. 2. Participating clients in long-term care projects: entry, interim and final measures approximately 8 weeks apart.
IADL	Older American Resources and Services (OARS) IADL scale (Fillenbaum 1988)	0…14 (complete impairment… no impairment)	The loss of 3 or IADL is widely reported to indicate significant loss in this domain, corresponding to OARS IADL scores of 8 points or lower.	As above.
Cognition	Mini-Mental State Examination (MMSE) (Folstein 1975; see also Suh et al. 2004)	0…30 (complete impairment/unable to complete… no impairment)	17 points or lower indicates diminished likelihood of being able to live alone (Folstein 1975). 16 points marks a 'key transition point' in Alzheimer's disease signalling the rapid loss of ADL function over a 12-month period (Feldman et al. 2005).	Participating clients at entry and discharge, as applicable.
Behavioural and psychological symptoms of dementia (BPSD)	Resident Classification Scale BPSD items	0…3 (symptom absent… extensive monitoring required) 7 subscales		1. Behaviour management clients in short-term care projects: Entry and discharge. 2. Behaviour management clients in long-term care projects: Entry, interim and final measures approximately 8 weeks apart.
Carer reaction to BPSD	Adapted from Revised Memory and Behavior Problems Checklist (Teri et al. 1992; Neville & Burn 2001)	0…4 (not distressing… extremely distressing) 7 subscales		As above to coincide with client BPSD measures.
Carer strain	Caregiver Strain Index (CSI) (Robinson 1983)	0…13	Score of 7 or higher indicates significant strain associated with a caring role (Robinson 1983).	1. Participating carers in short-term care projects: at entry and discharge. 2. Participating carers in long-term care projects: at entry or start of evaluation, as applicable, interim and final measures to coincide with client functional assessments.
Carer psychological wellbeing	General Health Questionnaire 28-item version (GHQ-28) (Goldberg 1972)	Total score: 0…84 4 subscale scores: 0…21 Higher scores indicate significant recent decline in wellbeing	A subscale score of 12 points or higher indicates the individual has experienced recent marked decline in wellbeing in at least 3 symptomatically related areas of psychological wellbeing.	As above.

The evaluation followed a two-pronged approach in which important risk factors for entry to residential aged care were recorded over time and clients were followed up within the timeframe available to determine actual accommodation outcomes. This report covers both intermediate and final outcomes. Final outcomes are the care transitions that took place during the reporting period. Intermediate outcomes are the changes in the risk profile of client groups: levels of cognitive impairment, ADL decline, behavioural and psychological symptoms that complicate care, and caregiver strain.

In this way the evaluation was designed to identify:

- the proportion of care recipients at imminent risk of entry to residential aged care and the level of care required
- any factors that appear to limit the capacity for innovative services to help people avoid entry to residential care
- any risk factor patterns among care recipients who enter residential care that might suggest long-term outcomes for the wider target population
- the proportion of care recipients who are able to avoid entry to residential aged care in the context of level of risk at outset and/or likelihood of continued functional decline
- the respective average time periods for which these groups of care recipients are able to remain in their familiar home environment with support from pilot services and other sources of assistance.

An attempt was made to establish a valid comparison group for an impact evaluation of pilot services on accommodation outcomes. This planned study was the subject of a separate submission to the AIHW Ethics Committee (Register Number EC 354). To be successful, the study required conditions that would result in a waiting list for pilot services through normal referral and assessment processes (people on a waiting list would receive ‘usual care’ through other available programs and services as determined by ACAT and without influence of the evaluation). The Dementia Care in Alternative Settings project in Perth and a referring ACAT agreed to collaborate on the recording of waiting list information. Relevant data were collected but proved unusable because of the short periods of follow-up (the data are summarised in Chapter 8 of Part B). This has meant that an assessment of the impact of pilot services relies on collateral sources of information about Pilot participants only.

What is the cost of the services per client day (both in absolute terms and relative to other service options available to clients)?

The evaluation has recorded relevant components of the financial cost of Innovative Pool services:

- cost to care recipients in the form of co-payments
- cost to Australian Government in the form of flexible care subsidy
- cost to approved providers, that is, project expenditures
- cost to other parties, for example, state government, in the form of agreed contributions to pilot services.

Average cost to government per service day is compared with the corresponding cost to deliver high care through Extended Aged Care at Home and Residential Aged Care at the levels that would be required by care recipients in the Pilot.

Strengths and limitations of the national evaluation

The descriptive nature of the evaluation is both a strength and limitation. This section briefly describes how this is so and some of the implications for interpretation of results.

Design strengths and limitations

One limitation of 'action research' is that it generally provides no mechanism for attributing outcomes to interventions. In an experimental scenario the attribution of outcomes to interventions is achieved through randomisation and blinding, methods that often cannot be used in evaluations of aged care service delivery. In this evaluation it is possible to speculate on the impact of innovative dementia care on care recipients' ability to age in place. This is considered a minor limitation because (a) ACAT assessment for high level residential care forms the basis of eligibility assessment; (b) the evaluation collected collateral information to support the assumption that the risk of entry to residential aged care for most care recipients was indeed imminent; and (c) through the anonymous Care Experience Survey, family carers attributed improvements in their wellbeing and that of their care recipients to pilot interventions.

As described by the project teams, many carers and care recipients had persisted with care at home despite major difficulties. While aversion to residential care is a factor in long-term care decisions, the 'dynamics of aversion' under various conditions are not well understood and it is possible that aversion would have continued to influence people's decisions had pilot services not been available. The critical issue highlighted in project coordinators' accounts and case studies for the evaluation is that most care recipients had reached a point of exhausting all available sources of assistance in the community and this situation triggered referral to a pilot service. It is therefore reasonable to assume that the ability of many care recipients to remain at home following ACAT approval for residential care is an outcome of pilot services working with family carers and indeed this assumption is supported by responses to the Care Experience Survey. However, the evaluation is unable to link outcomes with specific aspects of a service—this is an evaluation of care packages/services in their entirety.

In keeping with the action research focus, a major strength of the evaluation is that it has collected a comprehensive set of data and information with minimal interruption to services and intrusion on clients. The result is an evaluation with much greater scope to explain the 'how' and 'why' than would be possible with a narrowly defined attribution design.

Perhaps a more serious limitation is the lack of independence between service provider and the measurement and recording of evaluation data. The AIHW has conducted the evaluation at arm's length in the interests of the privacy and comfort of care recipients. Responsibility for data collection, using AIHW developed tools, rested entirely with the project coordinators. Assessments of client ADL function were performed or arranged by the coordinators. Where possible, these assessments were designed to supply data for the evaluation with minimal disruption to the schedule of home visits by incorporating them into routine care planning and review. Baseline ADL measures were reconstructed from the client file (from the Aged Care Client Record in cases where a client was already established in a project by the time the evaluation started). The AIHW emphasised to projects that the purpose was not to measure project effectiveness on the basis of change in ADL measures but to use these measures to report on level and type of need in client populations, to help explain discharge outcomes, and to explore possible associations between outcomes and functioning in ADL.

The available timeframe for evaluation provided limited scope for longitudinal study and detailed description of the circumstances of large numbers of care recipients. The service episodes of almost half of the care recipients were truncated by the date of follow-up and completion of the evaluation, that is, they are 'censored' observations.

Data strengths and limitations

An informative set of data has been recorded for the evaluation but several limitations of the collection need to be acknowledged. The capacity of projects to record accurate, complete data varied considerably, particularly in relation to service activity and the attribution of expenditure to different service categories.

No attempt was made to record time series service data because this would have been a high impost on projects over the number of weeks involved and under the conditions in which project coordinators/care managers were operating. Therefore, the quantum of service units consumed during the evaluation, by service category, was recorded for each participating care recipient (and carer, where applicable) and there is no information about how the service utilisation of an individual varied over time within that period. It is thought that more detailed tracking of service delivery would require a dedicated administration role in each project team.

Home-based care settings present some practical difficulties in deciding how to code service events and the AIHW recommended that coordinators follow a pragmatic approach. For example, in one session a care worker might deliver both personal assistance and respite care. Projects have recorded service units according to the main purpose of staff attendance and have ensured as far as possible that personal and domestic assistance were recorded even where that primary purpose doubles as a form of respite care. In-home respite care was recorded when the primary purpose of staff attendance was to provide respite. The AIHW is confident that obvious inconsistencies and errors in the services data have been identified and corrected, but notes that there will always be grey areas in the measurement of in-home service delivery. In addition, the evaluation has relied on projects to capture the requested service activity data, allowing for varying degrees of sophistication in projects' information processes and systems.

Notwithstanding these caveats, the capture of detailed client-level service utilisation data is a major achievement of project coordinators and their support staff. A consistently defined, comprehensive picture of service delivery, taking in levels of need for assistance and amount and type of assistance received, in the community care sector is not often achieved on this scale. The challenge of gathering this type of information is defined not only in terms of the number of care recipients but in the variety of service auspice and objective. Flexible care adds a considerable overhead to the measurement of service utilisation as the pattern of service delivery to an individual care recipient can change considerably from week to week. Data recorded for the evaluation offer a tangible means of comparing the range of service models in the Innovative Pool Dementia Pilot.

For a variety of reasons it was not always possible for projects to collect a full set of repeated measures of client functioning and carer wellbeing. Entry or baseline functional assessment results were recorded for all participating care recipients but follow-up measures were not always taken or recorded (Table A1.7). In both the short-term care projects and long-term care projects, entry or baseline ADL scores (basic and advanced) were recorded for over 90% of participants who consented to functional assessments. Short-term care projects were asked to record entry and discharge ADL scores and this was achieved in almost 90% of cases. Long-term care projects were asked to record three repeat ADL measures and while this was achieved in approximately 60% of cases, over 80% of care recipients have at least two repeat measures recorded including an entry/baseline measure. The CSI data give good coverage of participating carers.

MMSE data are less complete than the ADL data but are sufficient to report on measured levels of cognitive function at entry within the project groups and across the Pilot. All projects were asked to record two MMSE scores: at entry and discharge (short-term care projects) or at entry and approximately 4 months later (long-term care projects). Records from a recent ACAT assessment were a common source of entry MMSE scores. It appears that short-term care projects operating from within a health service may have found it easier to repeat the MMSE on discharge or may have had access to ACAT reassessment at that time. Some ACATs did not release MMSE scores to projects, even on request, and in at least one case, staff in a community service agency felt insufficiently qualified to administer the MMSE.

Table A1.7: Completeness of functional assessment measures (per cent of participants who consented to assessments)

	ADL	IADL	MMSE	Caregiver Strain Index
	Short-term care projects (120 care recipients; 83 carers)			
Entry only	10.0	9.2	34.2	18.1
Complete set[(a)]	88.3	86.7	55.0	80.7
Discharge only	1.7	1.7	2.5	—
Missing	—	2.5	8.3	1.2
Total	**100.0**	**100.0**	**100.0**	**100.0**
	Long-term care projects (138 care recipients; 120 carers)			
Entry only[(b)]	13.8	13.8	36.2	30.0
Partial set including entry score	22.4	22.4	—	—
Complete set[(a)]	61.6	59.4	41.3	63.3
Final only	—	—	0.7	3.3
Missing	2.2	4.4	21.7	3.3
Total	**100.0**	**100.0**	**100.0**	**100.0**

(a) For clients in short-term care projects, a complete set comprises entry and discharge scores. For clients in long-term care projects, a complete set comprises entry, interim and final scores, except for Mini-Mental State Examination for which a complete set comprises entry and final scores.

(b) All but one project reconstructed care recipient functional measures as at date of entry from the Aged Care Client Record and other records. Ozcare Innovative Dementia Care Pilot, Queensland, recorded a 'baseline' score that reflected care recipient functional status close to the start of the evaluation.

— Nil.

The South Brisbane and Gold Coast Dementia Care Pilot expressed concern that the MMSE has not been validated on the range of culturally and linguistically diverse communities represented in that project. Provided there is bilingual support to enable administration of the MMSE, the main issue for its use with people of diverse backgrounds is the interpretation of results and not administration of the instrument. There is evidence that the MMSE is a useful screen for cognitive impairment in culturally diverse groups, although other tools may perform better for people with low levels of education and English literacy

(Borson et al. 2005). South Brisbane and Gold Coast Dementia Care Pilot made a good attempt to use the MMSE but it was necessary to exclude almost half the scores. Other projects reported MMSE scores of zero; zero scores for community-based clients were excluded from descriptive analyses and this reduced the number of MMSE scores available to report.

Finally, it has not always been possible for projects to report all of the costs associated with their operation, particularly in cases where a project has benefited from existing capital infrastructure and skilled workforce. For example, two projects in New South Wales (DBAMS and DRAH) were established with formal agreement between the Department of Health and Ageing and New South Wales Health for an amount of state contribution towards assessment and rehabilitation services. The financial contribution was recorded in one case but not in the other where the state made an in-kind contribution. Also, while the evaluation has not been able to determine exactly how state contributions have been used in a quantifiable sense it is clear that these two projects could not have operated without access to existing infrastructure and human capital. Some estimates of expenditure recorded for the evaluation are premised on a project's ability to draw on existing resources and are therefore underestimates of the true cost of operation and service delivery.

2 Target group profiles

This chapter summarises key socio-demographic, health and functional characteristics of evaluation participants, both care recipients and family carers. Descriptions of care recipients and family carers in this chapter lead into a discussion in Chapter 3 of how projects have offered new choices in dementia care. In this chapter we examine the support arrangements that care recipients had in place before the Pilot. These are considered in the context of measures of cognitive and ADL function of care recipients, the range and extent of behavioural and psychological symptoms of dementia, and indicators of the wellbeing of family carers (the main source of ongoing assistance for most members of the target group).

There is a high level of consistency between the data collected for evaluation and anecdotal reports from project coordinators. Both confirm the key role of family carers in helping to maintain people with dementia-related high care needs at home. Second, as support needs increase to the levels apparent at entry to the Pilot, some care recipients who were receiving assistance from formal services before the Pilot in addition to care from family were accessing multiple community care programs. The ability for a pseudo high-care package to be constructed in this way depends on the sources of funding available to a client's service provider; to be linked to a well-resourced service provider seems to be the exception rather than the rule. Other care recipients who were being maintained on a single support program before the Pilot had reached or exceeded the limit of assistance available and required a higher level of case management and service coordination than could be supported on their existing program. A further 40% of care recipients in the Pilot had been maintained solely with support from a primary carer, other relatives and friends.

Data and information gathered in the course of the evaluation suggest that most pre-existing support arrangements are unlikely to have been adequate given the high levels of need for assistance and complexities in delivering care described by project coordinators and care managers. The services delivered by projects reflect the level and type of prior unmet need in the target group. This chapter describes care recipients and carers and makes direct references to the implications of their attributes on the innovative dementia care seen in the Pilot.

De-identified unit record data on 249 care recipients were recorded for the evaluation, covering 108 care recipients in short-term care projects and 141 recipients in long-term care projects. A total of 219 relatives and friends who were providing care participated in the evaluation. Project-level data are reported in Part B.

All participating care recipients had been assessed by an Aged Care Assessment Team (ACAT) in the 12 months prior to joining the Pilot. Dementia, a dementia-related behavioural or memory disturbance, or delirium was reported as the primary health condition for 88% of clients in short-term care projects (95 clients) and 89% of clients in long-term care projects (126 clients). Other recorded primary health conditions include Parkinson's disease, transient cerebral ischaemic attack, neoplasm, osteoporosis and other diseases of the musculoskeletal system. ACAT assessment had determined eligibility for Pilot services based on cognitive impairment as a primary or secondary health condition that made a significant contribution to the need for care.

2.1 Key socio-demographic characteristics

At the start of the evaluation, care recipient ages ranged from 38 to 98 years (a case study report in Chapter 1 of Part B describes how a younger adult came to be accepted into the Pilot). Approximately 81% of care recipients in the evaluation were aged over 75 years and almost a third of care recipients were aged 85 years or over (Table A2.1). Long-term care projects recorded a slightly higher proportion (36%) of very old care recipients, defined as 85 years or over, compared with short-term care projects (25%). Women made up 62% of evaluation participants.

Government pensions and payments were the primary source of income for 91% of care recipients, primarily the Age Pension (78%), Department of Veterans' Affairs pensions (11%) and Disability Pension (2%) (Appendix Table A1).

Most care recipients were living in the community while receiving Pilot services, either in a private residence or in a retirement village (Table A2.2). All 23 care recipients who were living in an aged care home when they joined the Pilot were with the DBAMS project. DBAMS provides an outreach behaviour assessment and management service to people in the wider community and residential aged care, in combination with intermediate care if required. Other projects have exclusively targeted eligible people living in the community.

Table A2.1: Innovative Pool Dementia Pilot, number and per cent of clients by age group and sex

	Short-term care projects			Long-term care projects			All projects		
Age (years)	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**	**Males**	**Females**	**Persons**
					(number)				
Less than 65	4	—	4	1	4	5	5	4	9
65–74	14	7	21	6	12	18	20	19	39
75–84	21	35	56	26	41	67	47	76	123
85+	9	18	27	14	37	51	23	55	78
Total	**48**	**60**	**108**	**47**	**94**	**141**	**95**	**154**	**249**
					(per cent)				
Less than 65	3.7	—	3.7	0.7	2.8	3.5	2.0	1.6	3.6
65–74	13.0	6.5	19.4	4.3	8.5	12.8	8.0	7.6	15.7
75–84	19.4	32.4	51.9	18.4	29.1	47.5	18.9	30.5	49.4
85+	8.3	16.7	25.0	9.9	26.2	36.2	9.2	22.1	31.3
Total	**44.4**	**55.6**	**100.0**	**33.3**	**66.7**	**100.0**	**38.2**	**61.8**	**100.0**

— Nil.

Table A2.2: Innovative Pool Dementia Pilot, number and per cent of care recipients by usual accommodation setting

Usual accommodation setting	Number of clients	Per cent
Private residence	192	77.4
Retirement village — independent living unit	28	11.3
Retirement village — assisted living unit	1	0.4
Short-term crisis accommodation	1	0.4
Residential aged care — low care	11	4.4
Residential aged care — high care	12	4.8
Other	2	0.8
Not stated	2	0.8
Total	**249**	**100.0**

The majority of care recipients were living with family or others and 88% had a relative or friend providing ongoing care at home (Table A2.3). Only 7.6% of the group were living alone and did not have a primary carer. Some projects required care recipients to have a family carer who visited at least daily, hence carer availability in the Pilot partly reflects client selection policies. Carer availability was a prerequisite for entry to FCS and NEDID short-term care projects in Victoria. Three of the four care recipients in short-term projects who were living alone and did not have a family carer were in the DRAH project, in northern New South Wales. Fourteen DBAMS clients who were living in an aged care facility when they joined the project had a family carer during the DBAMS service episode. In some cases, this was a continuation of ongoing carer involvement, while in other cases a family member became actively involved in the processes of assessment and management of behavioural symptoms for the period of DBAMS service.

The long-term care project, Dementia Care in Alternative Settings (Southern Cross Care), also required care recipients to have access to care from a relative or friend. RSL Care Pilot and Ozcare Packages did not require a person to have a carer; however, all people in both projects were receiving assistance from family and friends and most had a primary carer. Most of the people in the long-term care projects who were living alone and who did not have a primary carer were in The Sundowner Club. Since the completion of the evaluation, The Sundowner Club profile has changed to include a much higher proportion of clients with a co-resident carer (refer Part B, Chapter 9).

Spouses and partners made up approximately 48% of participating family carers; sons and daughters (or sons- and daughters-in-law) comprised a further 45% of carers. Approximately 74% of family carers were living with the care recipient, although almost half of the people caring for a parent were not living in the same household (Table A2.4).

Table A2.3: Innovative Pool Dementia Pilot project clients, usual living arrangement by carer availability

	Short-term care projects			Long-term care projects			All projects		
Usual living arrangement	**No carer**	**Has a carer**	**Total**	**No carer**	**Has a carer**	**Total**	**No carer**	**Has a carer**	**Total**
					(number)				
Lives alone	4	12	16	15	28	43	19	40	59
Lives with family	2	64	66	—	95	95	2	159	161
Lives with others	9	17	26	—	2	2	9	19	28
Unknown	—	—	—	—	1	1	—	1	1
Total	**15**	**93**	**108**	**15**	**126**	**141**	**30**	**219**	**249**
					(per cent)				
Lives alone	3.7	11.1	14.8	10.6	19.9	30.5	7.6	16.1	23.7
Lives with family	1.9	59.3	61.1	—	67.4	67.4	0.8	63.9	64.7
Lives with others	8.3	15.7	24.1	—	1.4	1.4	3.6	7.6	11.2
Unknown	—	—	—	—	0.7	0.7	—	0.4	0.4
Total	**13.9**	**86.1**	**100.0**	**10.6**	**89.4**	**100.0**	**12.0**	**88.0**	**100.0**

— Nil.

Table A2.4: Innovative Pool Dementia Pilot, number of family/friend carers by carer relationship to care recipient and co-residency status

Relationship of carer to client	Short-term care projects			Long-term care projects				All projects			
	Non-resident	Co-resident	Total	Non-resident	Co-resident	Not stated	Total	Non-resident	Co-resident	Not stated	Total
						(number)					
Spouse/ partner	6	43	49	—	55	—	55	6	98	—	104
Son/daughter	12	19	31	28	31	1	60	40	50	1	91
Son/daughter in-law	1	3	4	2	2	—	4	3	5	—	8
Parent	—	1	1	—	—	—	—	—	1	—	1
Other relative	3	2	5	2	3	—	5	5	5	—	10
Friend/ neighbour	1	1	2	1	—	—	1	2	1	—	3
Not stated	1	—	1	—	1	—	1	1	1	—	2
Total	**24**	**69**	**93**	**33**	**92**	**1**	**126**	**58**	**160**	**1**	**219**
						(per cent)					
Spouse/ partner	6.5	46.2	52.7	—	43.7	—	43.7	2.7	44.7	—	47.5
Son/daughter	12.9	20.4	33.3	22.2	24.6	0.8	47.6	18.3	22.8	0.5	41.6
Son/daughter in-law	1.1	3.2	4.3	1.6	1.6	—	3.2	1.4	2.3	—	3.7
Parent	—	1.1	1.1	—	—	—	—	0.0	0.5	—	0.5
Other relative	3.2	2.2	5.4	1.6	2.4	—	4.0	2.3	2.3	—	4.6
Friend/ neighbour	1.1	1.1	2.2	0.8	—	—	0.8	0.9	0.5	—	1.4
Not stated	1.1	—	1.1	—	0.8	—	0.8	0.5	0.5	—	0.9
Total	**25.8**	**74.2**	**100.0**	**26.2**	**73.0**	**0.8**	**100.0**	**26.0**	**73.5**	**0.5**	**100.0**

— Nil.

Family members were the main source of ongoing assistance for most members of the target group and project staff confirmed that the wellbeing of family carers is a critical factor in maintaining members of the target group at home. This philosophy is reflected in project service activity profiles. The mix of co-resident and non-resident carers, older and younger carers has meant that projects have had to address the support needs of a diverse group of carers as well as care package recipients. All project teams emphasised the need for delivery of flexible respite care tailored to the needs of carers at different life stages. According to coordinators, at the time of entry to the Pilot most family carers showed a high level of strain associated with the caring role due to long periods of caring, often without adequate support. They stressed the importance of respite care in the first few weeks to help stabilise difficult home situations and to engage family carers in planning services for the care recipient. This means that 88% of the packages reported in the evaluation have been required to address the support needs of two people. Care managers remarked on their need to support families in coming to terms with a diagnosis of dementia and/or the changed circumstances of the person with dementia.

2.2 Targeting people with cognitive impairment

Mini-Mental State Examination (MMSE) scores were used to assess targeting in the Pilot. In most cases baseline MMSE scores were transcribed from Aged Care Client Records. Where this was not possible, care managers who felt competent to administer the MMSE did so for the evaluation. Seventy-one MMSE scores are missing, either because they were not available from the ACAT assessment and project staff did not feel sufficiently confident in using the MMSE, or because the care recipient was unable to complete the test and no score or a zero score was recorded (zero scores are considered missing values except for DBAMS residential aged care clients). In some cases the test could not be administered because of English language difficulties.

A score of 17 points or lower (out of 30) on the MMSE is a recognised indicator that an individual is unlikely to be able to live alone with safety (Folstein et al. cited in Angel et al. 2004). Feldman et al. (2005) reported that an MMSE score of 16 appears to be a key transition point at which most IADL function is lost and significant loss of ADL function begins to occur. An MMSE score of 10 points or less (out of 30) is often used to indicate severe cognitive impairment. A score of 23 points is generally used as the threshold value for probable cognitive impairment although 24 points is used for increased sensitivity to mild impairment (McDowell & Newell 1996). The MMSE is not always sensitive to mild cognitive impairment and early stage dementia, particularly in individuals with high levels of educational attainment, and the tool might not detect cognitive impairment associated with frontal lobe dementia. It is important to note that the MMSE is a screening tool and does not perform as a diagnostic tool in the absence of other clinical assessments. Notwithstanding these caveats, the MMSE is a widely used valid and reliable tool for the screening of cognitive impairment.

Baseline scores recorded for the evaluation have been used in two ways. First, the raw baseline scores were used to classify care recipients according to likely presence or absence of cognitive impairment with an adjustment for educational attainment using the method of Uhlmann & Larson (1991). After adjusting for years of formal education, 68 care recipients in short-term care projects recorded a baseline MMSE score indicative of cognitive impairment (74% of 92 valid scores; 16 missing values). In long-term care projects 91 recipients recorded a baseline score indicative of cognitive impairment after adjusting for educational attainment

(85% of 107 valid scores; 34 missing or invalid values). Project-level results and discussion are included in Part B.

The raw scores were then classified according to threshold values that broadly indicate level of impairment:

- severe cognitive impairment (10 points or less)
- moderate cognitive impairment below the transition value of 16 points
- moderate cognitive impairment at or around the transition value (16–18 points)
- mild cognitive impairment
- normal cognition range.

Based on this scheme, levels of cognitive impairment recorded in the evaluation range from mild to severe; 49% of recipients scored below the transition value of 16 points and a further 14% of recipients scored around the transition point at which more marked decline in activities of daily living as a result of cognitive impairment could be expected to occur (Table A2.5).

All projects appear to have targeted the intended group for delivery of Pilot services. Some of the care recipients who scored in the normal range of cognitive function at entry to the Pilot scored lower at a subsequent assessment. Projects working with clients in need of medical diagnosis, for example, suspected but unconfirmed dementia or delirium, have accepted some people who scored in the normal range and later recorded a lower score and in some cases delirium or temporary dementia was resolved through or during the period of intervention. At the time of the evaluation in 2004, The Sundowner Club was refining client selection processes to find a balance between clients with dementia-related high care needs (and carers in need of respite) and the requirement for clients to be physically able to leave their home to travel by bus to an evening meal and activity program. Re-evaluation of The Sundowner Club group in 2005 revealed a quite different profile to the group in 2004 in terms of levels of cognition and living arrangements.

Project reports in Part B discuss targeting issues in individual projects.

Table A2.5: Innovative Pool Dementia Pilot, number and per cent of clients by MMSE score at entry

	Short-term care projects		Long-term care projects		All projects	
MMSE score	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Valid zero[(a)]	6	6.5	. .	. .	6	3.4
1–10	23	25.0	18	20.9	41	23.0
11–15	14	15.2	27	31.4	41	23.0
16–18	12	13.0	12	14.0	24	13.5
19–24	27	29.3	23	26.7	50	28.1
25–30	10	10.9	6	7.0	16	9.0
Total valid	*92*	*100.0*	*86*	*100.0*	*178*	*100.0*
Missing	16		55		71	
Total	**108**	**100.0**	**141**	**100.0**	**249**	**100.0**

(a) MMSE scores of zero accepted where usual accommodation is residential aged care. All valid zeroes were recorded by DBAMS clients.

. . Not applicable.

2.3 Indicators of support need

Four sets of measures of care recipient support need were recorded for the evaluation.

One set comprises three ratings of core activity limitation of an individual at time of entry to a project: one rating for each of self-care, mobility and communication limitation (no limitation, mild, moderate, severe or profound). Equivalent measures are included in the Australian Bureau of Statistics national five-yearly Survey of Disability, Ageing and Carers and have been separately recorded in censuses of CACP and EACH recipients conducted by the AIHW. Thus, the core activity limitation data facilitate a comparison of evaluation participants with other groups of formal care recipients. For example, it has been found that 100% of EACH package recipients and around 80% of CACP recipients have a severe or profound activity limitation in self-care, mobility or communication (AIHW 2004c, 2004d).

A second set of measures of support need are levels of need for assistance in activities of daily living (self-care activities including eating, bathing, dressing, grooming, toilet use and continence, and activities involving mobility, that is, walking on a level surface and transfers) that produce a composite numeric score. The 20-item Modified Barthel Index (MBI) was used to measure ADL function. MBI scores have been used to cross-validate the more subjective ratings of core activity limitation and for comparisons of project groups.

The third set of measures comprises levels of need for assistance in instrumental activities of daily living that produce a composite numeric score. The Older American Resources and Services (OARS) IADL scale with seven items was selected for IADL measurement. This scale measures need for assistance across seven IADL domains: meal preparation; housework; travelling to places outside of walking distance (assuming that transport is available); shopping for food and clothes; taking medication; handling money; and telephone use.

A fourth set of measures pertains to the presence and severity of behavioural and psychological symptoms of dementia (BPSD), using relevant items from the Resident Classification Scale.

These ADL and BPSD measures were selected to enable care recipient groups receiving different types of assistance to be compared and to report outcomes for each project in the context of different levels and types of need within the groups.

Support need measures are summarised below.

2.3.1 Levels and areas of core activity limitation

Fifty-two per cent of care recipients in long-term care projects and 32% of recipients in short-term care projects were recorded as having a severe or profound core activity limitation at time of entry to a project (Table A2.6).

Table A2.6: Innovative Pool Dementia Pilot, number of care recipients with clients with severe or profound activity limitation in at least one core activity area

Severe or profound limitation?	Number	Per cent
Short-term care projects		
Yes	35	32.4
No	73	67.6
Total	*108*	*100*
Long-term care projects		
Yes	73	51.8
No	68	48.2
Total	*141*	*100*
All projects		
Yes	108	43.7
No	141	56.6
Total	**249**	**100.0**

Approximately 71% of care recipients experienced moderate, severe or profound self-care limitation on entry to the Pilot (Table A2.7). There was a relatively high proportion (40%) of people with moderate to profound limitation in communication (understanding others and making oneself understood) compared with the wider population of older people and other groups of older package care recipients, which is related to the targeting of people with dementia-related high care needs (AIHW 2004c, AIHW 2004d; ABS 2004). These baseline results are consistent with discussions between the AIHW and project teams. The target group includes frail, older people with dementia-related high care needs but also 'younger old' and older, more mobile people with dementia. Some members of the target group require very little or no mobility assistance and in a relative sense will not score poorly on a composite self-care and mobility scale such as the MBI. This type of care recipient generally scores poorly for IADL and may score high on a BPSD scale where those symptoms are present. Evaluation experience shows that multidimensional assessment and comparisons of support need are called for when working with and reporting on outcomes for this target group.

In all three areas of core activity—self-care, mobility and communication—a higher proportion of care recipients in long-term care projects compared to short-term care projects exhibited severe or profound core activity limitation (Table A2.7). Rates of severe or profound activity limitation are project specific. For instance, NEDID and FCS short-term care projects recorded care recipient groups more in line with the long-term care projects, with around 40% of clients having a severe or profound level of core activity limitation and commensurate high levels of ADL, IADL, and cognitive impairment. DBAMS and DRAH short-term care projects recorded lower proportions of care recipients with severe or profound core activity limitation, but for different reasons. DBAMS care recipients were more likely to register moderate than severe or profound self-care limitation and the primary area of support need in this project is management of behaviour and psychological symptoms. DRAH was supporting a more mixed group of care recipients covering the range of newly diagnosed people, people with delirium or other medical condition complicating their care, people with dementia who are just entering the formal care system and people with an established diagnosis of dementia who have reached a milestone on the care continuum.

Table A2.7: Innovative Pool Dementia Pilot, number and per cent of clients by level of core activity limitation, by project category

	Level of core activity limitation				
Core activity	**No limitation**	**Mild**	**Moderate**	**Severe or profound**	**Total**
			(number)		
Short-term projects					
Self-care	6	29	46	27	108
Mobility	28	44	21	15	108
Communication	16	56	23	13	108
Long-term projects					
Self-care	6	32	41	62	141
Mobility	22	46	39	34	141
Communication	36	42	21	42	141
All projects					
Self-care	12	61	87	89	249
Mobility	50	90	60	49	249
Communication	52	98	44	55	249
			(per cent)		
Short-term projects					
Self-care	5.6	26.8	42.6	25.0	100.0
Mobility	25.9	40.7	19.4	13.9	100.0
Communication	13.0	54.5	21.1	11.4	100.0
Long-term projects					
Self-care	4.3	22.7	29.1	44.0	100.0
Mobility	15.6	32.6	27.7	24.1	100.0
Communication	25.5	29.8	14.9	29.8	100.0
All projects					
Self-care	4.8	24.5	34.9	35.7	100.0
Mobility	20.1	36.1	24.1	19.7	100.0
Communication	20.9	39.4	17.7	22.1	100.0

2.3.2 Activities of daily living

Most clients required assistance in activities of daily living (ADL) and instrumental activities of daily living (IADL) when they entered the Pilot. The range of levels of functioning was similar across the short- and long-term care projects.

MBI scores at entry to a project ranged from zero to 20 out of a possible 20 points for recipients in long-term care projects and 1 to 20 for short-term care projects. Both groups produced a median baseline score of 12 points (Table A2.8). Ninety-five per cent of care recipients showed some level of dependency in activities of daily living when they entered the Pilot, and over 80% of clients showed moderate or severe dependency (Table A2.9). Sixteen clients were completely dependent in all activities of daily living. Patterns of dependency were similar in both the short- and long-term projects, though a higher percentage of the long-term care recipient group showed complete dependence in ADL (8% versus 5% of people in short-term care projects).

Table A2.8: Innovative Pool Dementia Pilot, summary of baseline ADL scores (Modified Barthel Index) for clients in short-term and long-term care projects

Baseline ADL	Number	Minimum	Median	Maximum	Mean	Std Dev
Short-term care projects	103	1	12	20	12.2	4.6
Long-term care projects	135	0	12	20	11.3	5.2

Notes

1. Baseline scores not recorded for five clients in short-term care projects.
2. Baseline scores not recorded for six clients in long-term care projects.

Table A2.9: Innovative Pool Dementia Pilot, number and per cent of care recipients by level of ADL dependency at entry

	Short-term projects		Long-term projects		All projects	
Level of ADL dependency[(a)]	**Number**	**Per cent (of valid scores)**	**Number**	**Per cent (of valid scores)**	**Number**	**Per cent (of valid scores)**
Independent	6	5.8	6	4.4	12	5.0
Slight	6	5.8	7	5.2	13	5.5
Moderate	34	33.0	45	33.6	79	33.2
Severe	52	50.5	66	48.9	118	49.6
Complete	5	4.9	11	8.1	16	6.7
Total valid scores	*103*	*100.0*	*135*	*100.0*	*238*	*100.0*
Not reported	5	. .	6	. .	11	. .
Total clients	**108**	**100.0**	**141**	**100.0**	**249**	**100.0**

. . Not applicable.

(a) ADL dependency category is based on MBI score out of 20: 20 points (independent); 19 points (slight dependency); 13–18 points (moderate dependency); 5–12 points (severe dependency); 0–4 points (complete dependency). Refer McDowell & Newell (1996).

Baseline IADL scores ranged from zero to 12 out of 14 points for the short-term care group and from zero to 10 points for the long-term care group, indicating that all care recipients had lost some IADL function and that a wide range of levels of need for assistance was observed (Table A2.10). Median scores of 3 points were recorded indicating low average levels of IADL function in both sets of projects which is consistent with the fact that IADL domains such as financial and household management involve executive functioning.

Table A2.10: Innovative Pool Dementia Pilot, summary of baseline IADL scores

Baseline IADL	Number	Minimum	Median	Maximum	Mean	Std dev.
Short-term care projects	100	0	3	12	7	2.6
Long-term care projects	132	0	3	10	3.7	2.7

Notes

1. Baseline scores not recorded for eight clients in short-term care projects.
2. Baseline scores not recorded for nine clients in long-term care projects.

Scatterplots of baseline IADL and ADL scores illustrate the patterns in individual projects (Figures A2.1 and A2.2). In the long-term care projects, Ozcare Packages, RSL Care Pilot and the South Brisbane and Gold Coast Pilot serviced care recipient groups with similar ADL profiles with most clients clustered in the middle range of ADL scores, very low to mid-range IADL scores, and smaller numbers of clients at the lower and upper ends of the ADL scale (Figure A2.1). One-third to one-half of clients in these projects exhibited very high dependency in ADL (some with almost complete dependency) and most clients scored 6 points or lower on the IADL scale, indicating total loss of function in two IADL and partial loss in others, or partial loss of function in most IADL. Dementia Care in Alternative Settings (WA) recorded proportionately more higher IADL scores and relatively few clients with very low MBI scores reflecting the intake of clients with ACAT approval for either high or low care. Scores for The Sundowner Club are clustered at the high end of both scales, reflecting the different type of service offered plus the fact that Sundowner Club clients at the time of the evaluation tended to be at higher levels of ADL function compared with The Sundowner Club group assessed a year later.

In the short-term care projects (Figure A2.2) NEDID and FCS serviced client groups with similar profiles of very low levels of IADL function and moderate to severe ADL impairment. The activity of daily living profiles of DBAMS and DRAH are more similar to each other than to NEDID and FCS.

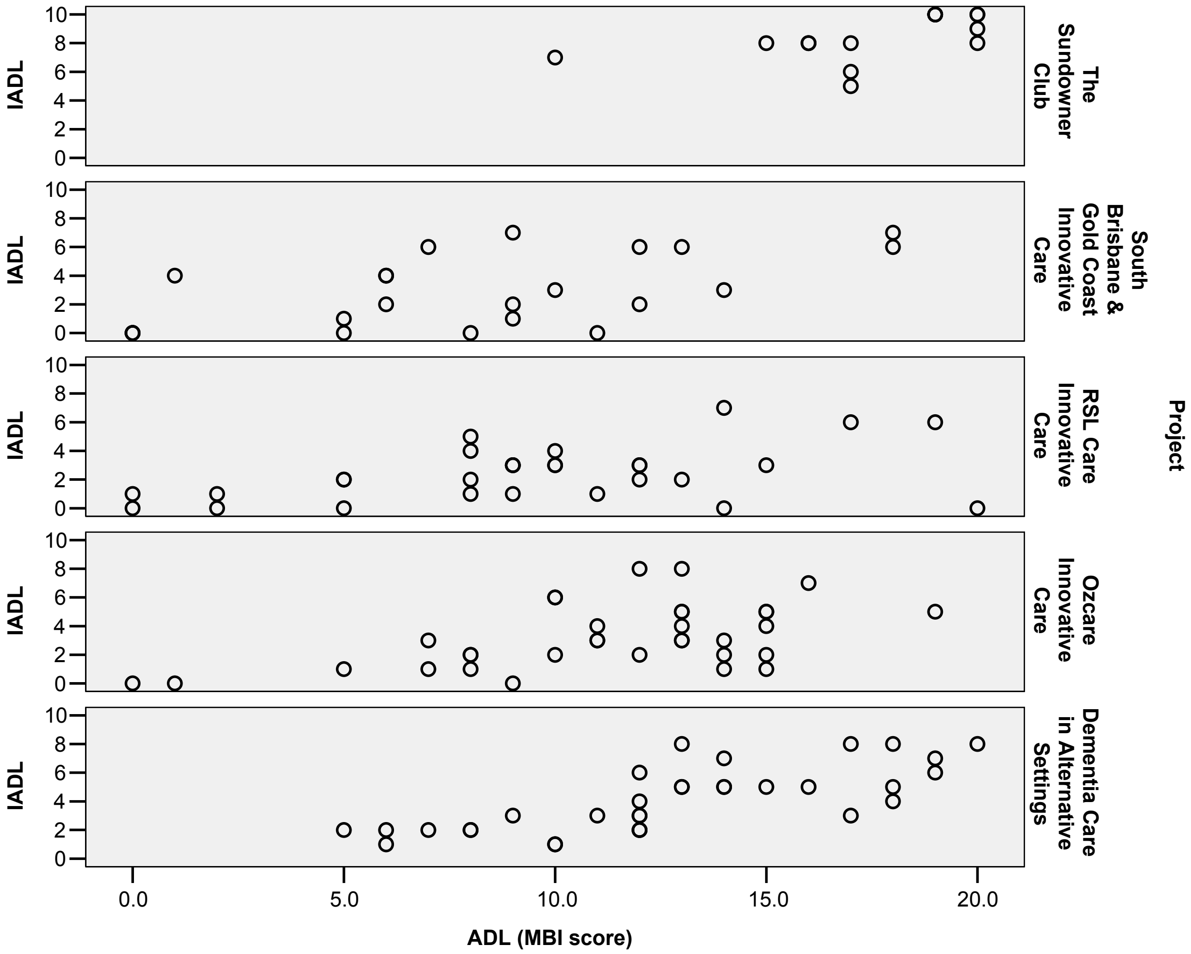


Figure A2.1: Innovative Pool Dementia Pilot, scatter plot of baseline IADL score by baseline ADL score for care recipients in long-term care projects, by project

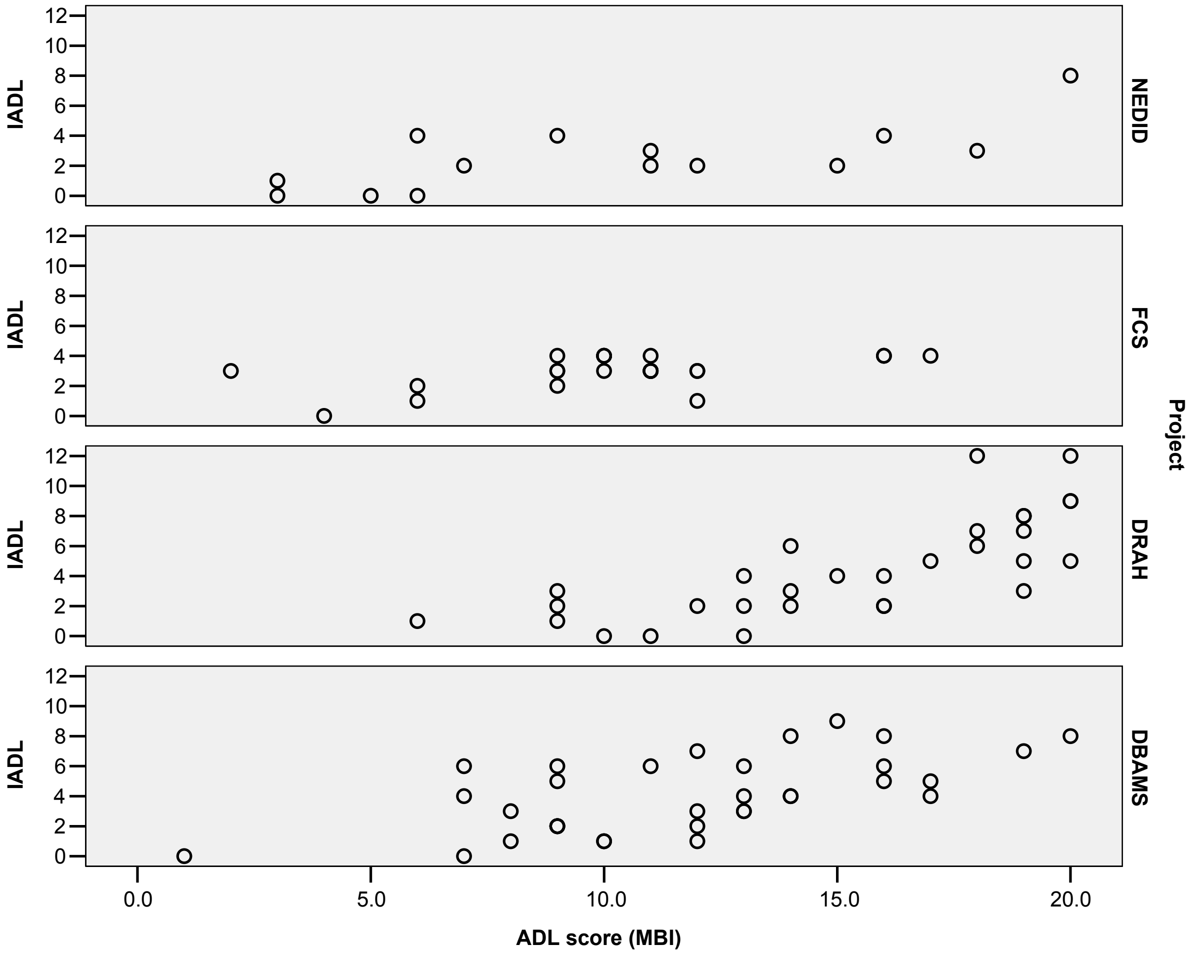


Figure A2.2: Innovative Pool Dementia Pilot, scatter plot of baseline IADL score by baseline ADL score for care recipients in short-term care projects, by project

Different patterns of reassessment occurred across the long-term care projects. Overall, 62% of clients in long-term care projects recorded a complete set of three ADL scores. For IADL, a complete set of scores was recorded for 59% of clients and a further 10% recorded just baseline and final measures. Only 41% of clients in long-term care projects recorded two MMSE scores. The average time between first and last assessments in long-term care projects was 166 days. Missing ADL, IADL and MMSE values are not random as they have tended to occur in relation to death or discharge of a client to hospital or residential care facility.

Reassessments were performed in short-term care projects on average 89 days after the entry assessment.

Patterns of both improvement and deterioration in ADL and IADL are evident in the data for care recipients in all projects (Tables A2.11 and A2.12). Median ADL and IADL change scores, calculated as the score at a final assessment minus the baseline score, are zero; however, the change scores range from high negatives, that is, lower functioning at the final assessment than on entry, to high positives, that is, improved functioning at the last assessment. Among 116 care recipients in long-term care projects for whom more than one MBI score was recorded (baseline score plus a score from one further assessment, at either interim or final assessment), 34% recorded decreased ADL function, 34% recorded no change and 32% recorded improved ADL function. Twenty-two people who recorded no change in ADL function recorded loss of IADL function. Of the 92 care recipients in short-term care projects for whom two ADL scores were recorded, 43% recorded a loss in ADL function, 24% recorded the same ADL score at baseline and final assessments and 33% showed improvement in ADL function based on a higher score at the final assessment.

Project reports in Part B contrast plots of ADL scores over time by accommodation outcome. These show no obvious pattern that suggests an association between level of ADL function at entry or change in ADL functioning over time with accommodation outcome. Care recipients with very low levels of function and decline in ADL functioning over the course of the evaluation are represented both among those who were still at home and among those who entered residential care.

Table A2.11: Innovative Pool Dementia Pilot long-term care projects, summary statistics for ADL and IADL scores at baseline and change in scores between baseline and final assessments

Variable	Number	Minimum	Median	Maximum	Mean	Std dev.
ADL (0 to 20)						
Baseline ADL	99	0	12	20	12.0	5.1
Change in ADL	99	–7	0	8	0.1	2.7
IADL (0 to 14)						
Baseline IADL	96	0	3	10	3.8	2.7
Change in IADL	96	–4	0	5	–0.1	1.6

Table A2.12: Innovative Pool Dementia Pilot short-term care projects, summary statistics for ADL and IADL scores at baseline and change in scores between baseline and final assessments

Variable	Number	Minimum	Median	Maximum	Mean	Std dev.
ADL (0 to 20)						
Baseline ADL	92	2	12	20	12.2	4.2
Change in ADL	92	–7	0	9	–0.3	3.2
IADL (0 to 14)						
Baseline IADL	90	0	3	12	3.7	2.5
Change in IADL	90	–7	0	5	–0.4	17

2.3.3 Behavioural and psychological symptoms of dementia

The frequency of behavioural and psychological symptoms of dementia (BPSD) exhibited in the week prior to the baseline assessment was recorded as another measure of support need that is not captured in ADL and IADL data. The RCS items cover seven types of BPSD as follows:

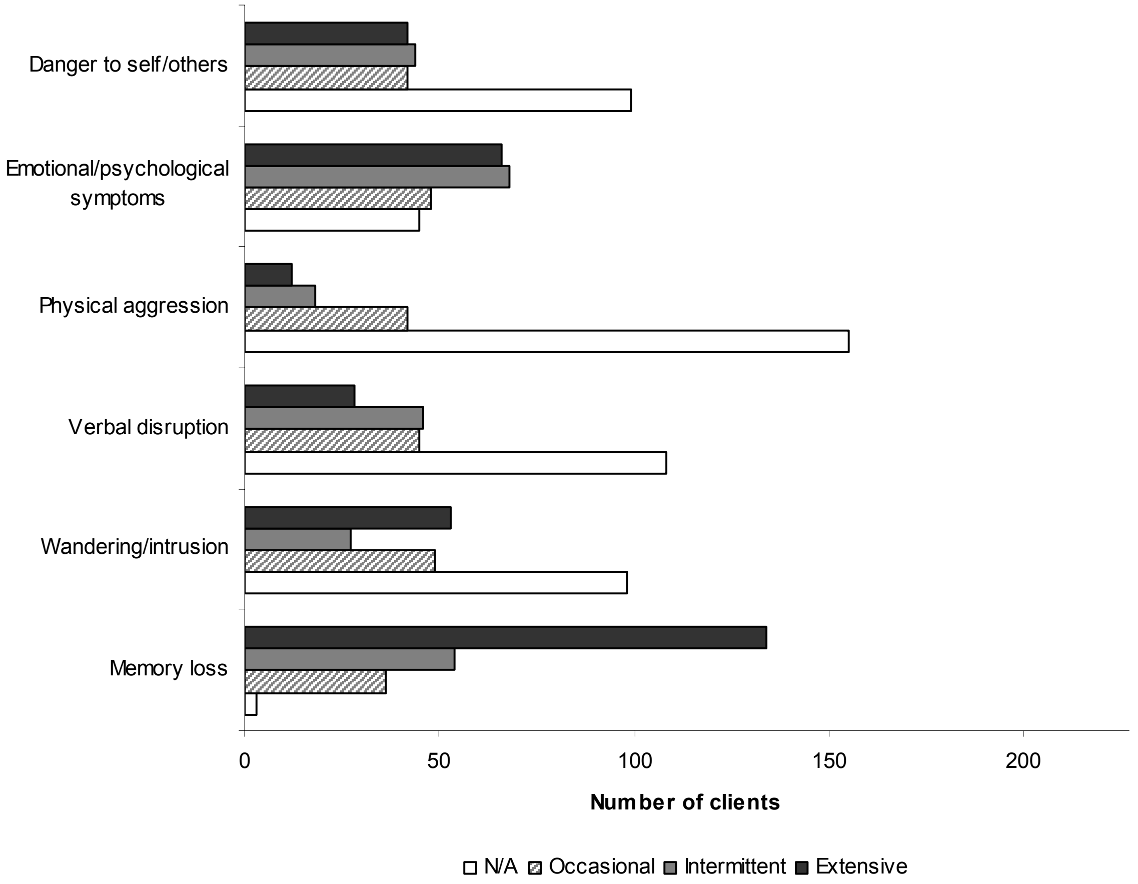
- Memory loss—relates to the care recipient forgetting information such as the names of family members, location of personal items, or recent activities.
- Problem wandering or intrusive behaviours—relates to the care recipient wandering, absconding, or interfering with other people or their belongings while wandering.
- Verbally disruptive or noisy behaviours—includes abusive language and verbalised threats directed at family members, visitors or care workers.
- Physically aggressive behaviour—includes any physical conduct that is threatening and has the potential to harm family members, visitors or care workers.
- Emotional or psychological symptoms—this item includes active and passive resistance (other than physical aggression), attention-seeking and manipulative behaviour, and depressive symptoms such as withdrawal and loss of sense of self.
- Danger to self or others—covers high risk behaviour requiring supervision or intervention and strategies to minimise the danger.
- Other behaviour—includes behaviour not covered in the above items which requires carers, family members or staff to spend time and effort in addition to support for daily activities.

Frequency of symptoms was rated using the four-point scale for RCS items:

- not applicable (does not require monitoring)
- occasional (requires monitoring but not regular supervision)
- intermittent (requires monitoring for recurrence and supervision on a less than daily basis)
- extensive (requires monitoring for recurrence and supervision on a daily basis).

Recording of BPSD measures was an optional component of the evaluation data collection. Project coordinators were encouraged to administer the tool to clients for whom behaviour management was an element of their care plan.

Virtually all care recipients for whom BPSD data were recorded exhibited memory loss, with emotional and psychological symptoms the next most prevalent class of symptom (Figure A2.3). Wandering or intrusive behaviour, verbally disruptive behaviour, presenting a danger to self or others, on at least an occasional basis, were recorded by at least half of the clients with BPSD.



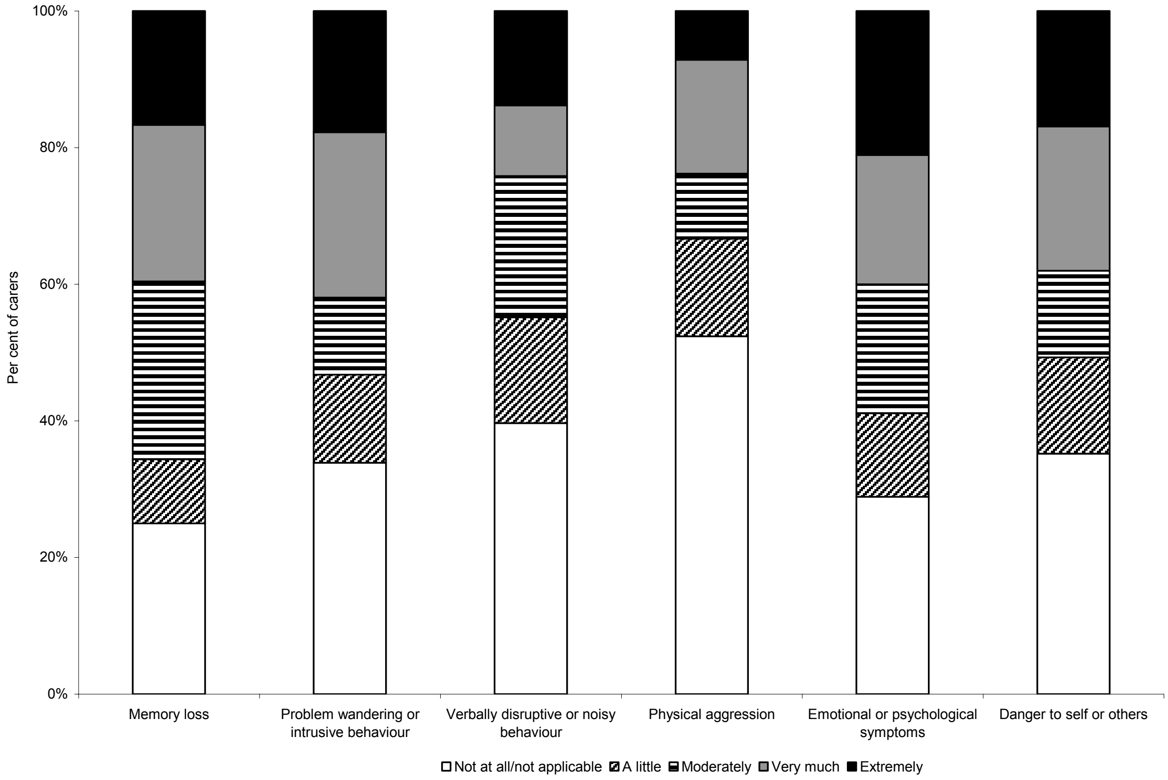
Source: Appendix Table A2.

Figure A2.3: Innovative Pool Dementia Pilot, total number of care recipients (short-term and long-term care projects) by type and frequency of behavioural and psychological symptoms of dementia at entry

Collectively, projects have targeted a group of care recipients with behavioural and psychological symptoms that create strain for family members and prove challenging to care providers. Providers reported that high flexibility is needed in service delivery because care recipients are not always amenable to receiving assistance or predictable in their response to it. Rosters often need to be altered at short notice. In starting with a new client, care workers usually need to make frequent visits to build rapport and periods of in-home respite are increased gradually to build confidence and establish a relationship with the person with dementia so that other and more frequent services can be introduced. Changes in the condition of the person with dementia can require continual rostering flexibility and ongoing high level case management plus staff skilled in this type of work. It was suggested that this is not an area for inexperienced care workers and that a care worker with only basic Certificate III training is likely to experience difficulties.

Evaluation measures of care recipient BPSD were supplemented by measures of carer reactions to each symptom exhibited by a care recipient. These data are self-reports from family carers on whether and to what extent each symptom causes distress.

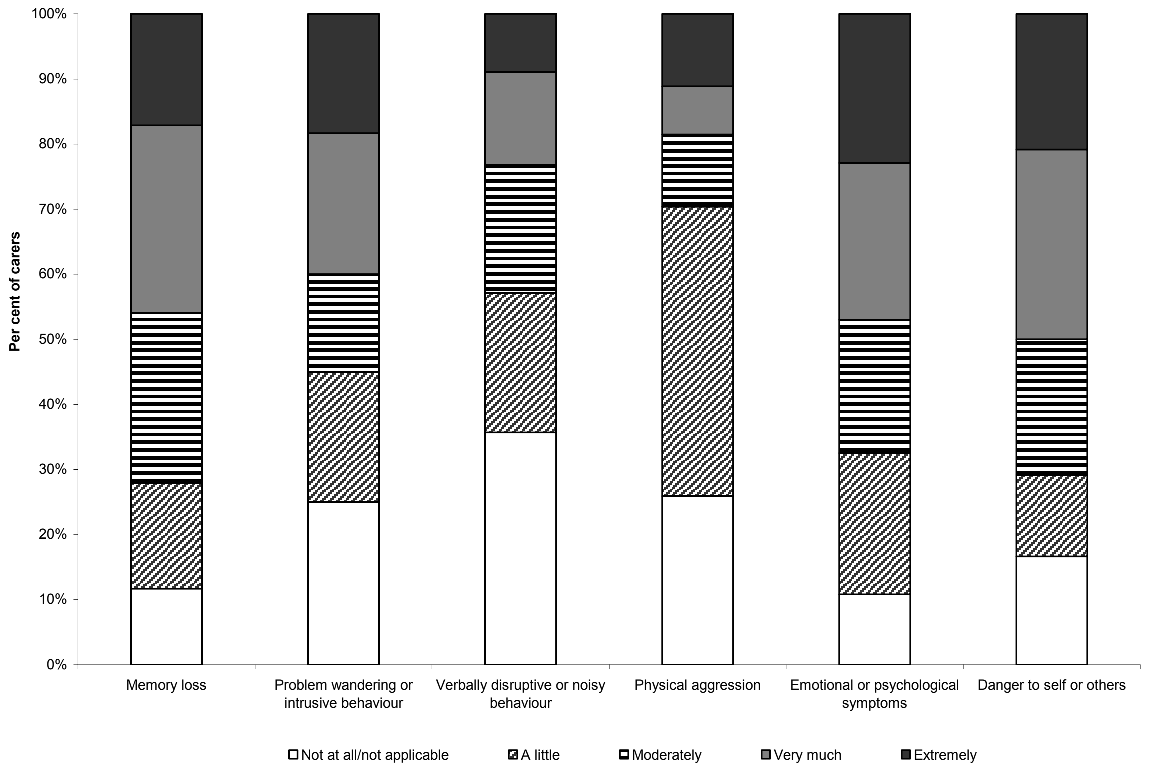
For each type of BPSD surveyed, at least 50% of carers reported some level of distress (Figures A2.4 and A2.5). Over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, and wandering or intrusive behaviour reported moderate to extreme distress as a result of these symptoms. Carers in long-term care projects were more likely to report higher levels of distress from BPSD than carers in the short-term care projects. These results confirm the role of BPSD in contributing to carer strain and of the consequent importance of carer support and behaviour management services.



Note: Per cent of carers is per cent of carers with a care recipient who was identified as displaying the symptom on an occasional, intermittent or extensive basis.

Source: Appendix Table A3.

Figure A2.4: Innovative Pool Dementia Pilot short-term care projects, per cent of carers by reported level of distress at care recipient behavioural and psychological symptoms



Note: Per cent of carers is per cent of carers with a care recipient who was identified as displaying the symptom on an occasional, intermittent or extensive basis.

Source: Appendix Table A4.

Figure A2.5: Innovative Pool Dementia Pilot long-term care projects: per cent of carers by reported level of distress at care recipient behavioural and psychological symptoms

Care recipients with repeated BPSD measures were classified according to changes in the frequency of symptoms exhibited around the time of the first and last assessments (in addition to these figures, the emergence of new symptoms was recorded for between five and 10 care recipients between first and final assessments). The picture that emerged is a reduction in the frequency of symptoms during the measurement period for approximately one half or more people in most symptom classes (Tables A2.13 and A2.14).

Table A2.13: Behaviour management clients in short-term care projects, number of clients by change in frequency of BPSD symptoms between baseline and final assessments, by symptom category

	Frequency of symptom over time			
Behaviour	**Decrease**	**No change**	**Increase**	**Total**
Problem wandering or intrusive behaviour	26	21	7	54
Verbal disruption/noisy behaviour	29	20	3	52
Physical aggression	25	9	2	36
Emotional or psychological symptoms	47	28	6	81
Danger to self or others	31	23	10	64

Table A2.14: Behaviour management clients in long-term care projects, number of clients by change in frequency of BPSD symptoms between baseline and final assessments, by symptom category

	Frequency of symptom over time			
Behaviour	**Decrease**	**No change**	**Increase**	**Total**
Problem wandering or intrusive behaviour	24	8	19	51
Verbal disruption/noisy behaviour	21	21	5	47
Physical aggression	5	13	1	19
Emotional or psychological symptoms	33	31	9	73
Danger to self or others	25	2	20	47

One difficulty in using data from the RCS behaviour items is that they do not give a summary measure of the severity of BPSD in a person with dementia. A model of service provision for dementia that refers specifically to BPSD developed by Brodaty et al. (2003) offers a useful way to reduce the RCS item data. This seven-tiered conceptual model is described in Box 2.1. The authors indicate the level of specialist intervention that is typically required at each level of severity of BPSD. For example, 'people in tier 5 may not be able to be managed within mainstream aged care services and may require tailored intervention programs administered by a specialist multidisciplinary team'. Data collected for the evaluation are informative up to tier 5. It is clear that some people accepted into services with a clinical focus on behaviour management could in fact present at a higher tier and only after assessment and intervention would the correct classification to tier 5 or 6 at entry to the Pilot be obvious.

Evaluation clients with baseline and final behaviour scale scores were classified according to the model with slight adaptation for its application to evaluation data:

- *Severe BPSD*: care recipients who were reported to be exhibiting one or more symptom on the behaviour items on an extensive basis *or* who exhibited physical aggression *or* who presented a danger to self or others, intermittently or extensively, were classified as having severe behavioural and psychological symptoms (equivalent to tier 5).

- *Moderate BPSD*: care recipients who do not satisfy the criteria for severe BPSD but who had one or more symptoms on an intermittent basis were classified as having moderate behavioural and psychological symptoms (equivalent to tier 4).
- *Mild BPSD*: care recipients who did not satisfy the criteria for severe or moderate BPSD but who displayed one or more symptoms occasionally were classified as having mild behavioural and psychological symptoms (equivalent to tier 3).
- *With dementia but no BPSD*: clients for whom 'not applicable' was recorded against all behaviour items were classified as not having behavioural and psychological symptoms of dementia (equivalent to tier 2).[1]

Following this scheme, the level of severity represents the minimum severity of BPSD based on available data.

Box 2.1: Summary of Brodaty, Draper and Low's (2003) seven-tiered model of service delivery for behavioural and psychological symptoms of dementia.

Tier 1	***No dementia.***
Tier 2	***Dementia with no behavioural and psychological symptoms.***
Tier 3	***Dementia with mild behavioural and psychological symptoms****, for example, apathy, mild depression, repetitive questioning and 'shadowing' (closely following other people). Symptoms may respond to distraction and reassurance or be ameliorated by altering interactions or the environment.*
Tier 4	***Dementia with moderate behavioural and psychological symptoms****, for example, major depression, verbal aggression, low-level (non-dangerous) physical aggression, psychosis, sexual disinhibition and wandering. Generally people in tier 4 require specialist consultation and specifically targeted interventions such as behaviour management programs.*
Tier 5	***Dementia with severe behavioural and psychological symptoms****, for example, severe depression, aggression and marked agitation. People in tier 5 may not be able to be managed within mainstream aged care services and may require tailored intervention programs administered by a specialist multidisciplinary team.*
Tier 6	***Dementia with very severe behavioural and psychological symptoms****, that is, people with severe behavioural disturbance complicating their dementia such as dangerous physical aggression which cannot be managed by family or residential care staff, even with the assistance of other specialist services. Such people require placement in special-care facilities, for example, psycho-geriatric or aged care neurobehavioural units.*
Tier 7	***Dementia with extreme behavioural and psychological symptoms****, that is, people who are so violent that they have harmed other residents or staff. Management in hospital or special-care facilities may be unsuccessful and a high-security specialist care unit is required.*

On classifying the data to these levels, it was found that over 64% of care recipients in the evaluation experienced severe BPSD and almost three-quarters experienced at least moderate BPSD (Figure A2.6). For 195 care recipients with complete sets of repeated BPSD measures, data for the first and last assessments were cast in a two-way table to examine patterns of change: 113 recipients (58%) remained at the same level of severity; 16% of

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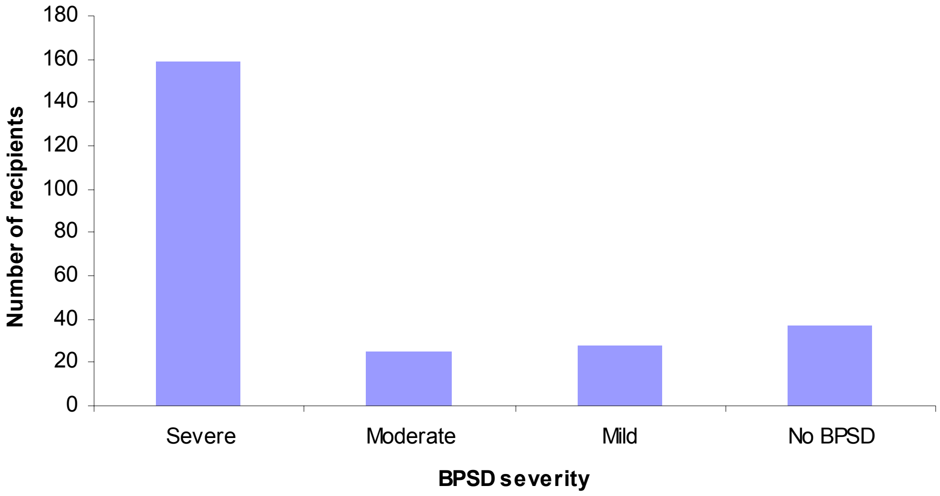
[1] For the purposes of this analysis it was assumed that all clients taking part in both short- and long-term projects have some form of dementia.

recipients recorded higher severity of symptoms at the final assessment compared to the first; and 26% of recipients recorded lower severity of symptoms at the final assessment.

All projects have accepted care recipients with moderate to severe BPSD. For most projects, however, a level of BPSD that poses a safety risk to staff would normally preclude a person from being accepted and would make formal assistance in a community setting virtually impossible. These higher levels of severity of BPSD are evident in the DBAMS short-term care project which is specifically designed to assess and manage behaviour and psychological symptoms through psycho-geriatric intervention and specialist medical review.



Source: Appendix Table A5.

Figure A2.6: Innovative Pool Dementia Pilot long-term care projects, per cent of care recipients by severity of behavioural and psychological symptoms classified to the Brodaty et al. (2003) model

Severity of BPSD in DBAMS clients is of particular interest from the perspective of how this type of specialist service can operate in parallel with other service models for people with dementia. At entry, 94% of DBAMS clients exhibited severe BPSD (3% moderate and 3% mild). At final assessment 26% of DBAMS clients were experiencing reduced symptoms to the extent that they had moved down a level of severity in BPSD; 74% were maintained at around the same level of severity but this proportion includes those clients who could have entered DBAMS at a higher level of severity than can be detected (available data do not allow a distinction between extreme BPSD and severe BPSD). Data for four DBAMS care recipients reveal reduced symptoms equivalent to moving down two or three levels of severity in the Brodaty et al. (2003) service delivery model, for example, from severe to mild or no BPSD.

The DBAMS team reported that medication review and/or specialist intervention can be highly effective in reducing the severity of BPSD in some clients, while in other cases the strategy is to increase understanding among primary care providers (family carers and aged care staff) of the causes and triggers for symptoms and to promote a sense of competency in the caregiver. The specific approach to be followed depends on the results of detailed investigation into the underlying causes of symptoms, which may be medical, historical (person's previous life experience), or related to/exacerbated by the current care environment.

An important finding in relation to specialist behaviour assessment and management for people with dementia is that people who might be precluded from package care in the community because of severe BPSD could be able to remain at home if they are able to access a specialist behaviour management service if and when required. The same is true of the potential for this type of specialist intervention to reduce the impact of BPSD on levels of care required in aged care homes.

Care packages as a means of helping members of the Pilot target group to avoid a change in care setting are likely to be most effective if recipients are able to access psycho-geriatric services for specialist diagnosis, medication review and behaviour management intervention. Widespread availability of specialist services would benefit both people with dementia living in the community and those living in aged care facilities where there is limited expertise in dementia care. Priority attention should be given to expanding this type of service provision in locations where specialist services are presently difficult to access.

2.4 Family carers

The evaluation collected information about family carers because it was assumed at the outset that the total package of care for a high proportion of care recipients in the Pilot would comprise care from family or significant others in addition to Pilot services. There is a great deal of evidence that the ability of a person with dementia-related high care needs to remain living in the community as the dementia progresses has much to do with the sense of wellbeing and competency of their primary carer. The success of formal services in helping people to achieve their preferred or best possible care outcomes will depend on the assistance provided to both care recipient and carer. Further, since family members are central care providers to so many people with dementia, any evaluation of services should consider the involvement of carers in care planning and decisions about long-term arrangements and take into account carers' perspectives on the appropriateness of pilot services.

All project coordinators emphasised the importance of engaging primary carers and other family members in care planning. They reported on the need to cater to the needs of different age and lifestyle groups of carers and reflected on how the characteristics of a carer can influence the level and type of their involvement in care planning and the type of carer support required. It was noted that younger carers are often more confident in negotiating the system and interacting with service providers in a care management partnership role. This can reduce the level of ongoing high level case management from the service provider. Employed younger carers for this target group may have a reduced need for social support compared to full-time carers or co-resident older carers. This group generally requires more flexible respite care than is offered by most mainstream services, to support carers' participation in paid employment. Older carers and socially isolated carers can benefit from social support and respite services that offer opportunity for social interaction. Examples of Innovative Pool respite services that meet the varied needs of carers include:

- The social support networks that have become established through the carer support and education program in Dementia Rehabilitation at Home continue to provide support beyond the period of project service.
- South Brisbane and Gold Coast Innovative Dementia Care Pilot respite care service provides a respite carer in the home and at the same time a bilingual support worker to accompany the family carer in the community for shopping and appointments; flexible timing of respite care covers weekends, evenings and periods of respite at short notice to allow the family carer to accept invitations for social outings and attend religious services, usually held on weekends.
- The Sundowner Club provides an out-of-home program for the care recipient that offers carers an opportunity of relief from the caring role to have an evening meal with family and friends or catch up with family members who work during the day, for example. This service is offered at a time of day when few other respite services operate.
- Dementia Care in Alternative Settings day respite care is ideally suited to people with an employed primary carer who can benefit from care in a small group, home-like setting.

Project coordinators and care managers have needed to assess care recipient and carer support needs on a case-by-case basis. They reported that the circumstances of individual carers mean that a 'one size fits all' philosophy to service provision will not achieve the best possible outcomes. A major objective and challenge for service providers working with people with dementia-related high care needs and their family carers is to deliver a package of services that suits the particular client rather than to offer a level and type of service that is more easily and routinely delivered to the services' wider client groups.

2.4.1 Carer profiles

Roughly equal proportions of participating carers were aged in each of the three age groups 45–64, 65–74 and 75 years or over (Table A2.15). Compared to the wider population of primary carers identified in the ABS Survey of Disability, Ageing and Carers, this group of carers comprises a high proportion of males (40%). Male carers were on average older than female carers—among the female carers were a high number of non-resident daughters providing care for a parent with dementia.

Carer relationship and co-residency are discussed in section 2.1 because of their relevance to the living and support arrangements of care recipients.

Table A2.15: Innovative Pool Dementia Pilot, number of family carers in long-term and short-term care projects, by age group and sex

Age (years)	Short-term projects			Long-term projects			All projects		
	Males	Females	Total	Males	Females	Total	Males	Females	Total
					(number)				
25–44	1	2	3	5	8	13	6	10	16
45–54	9	12	21	7	16	23	16	28	44
55–64	2	11	13	10	14	24	12	25	37
65–74	5	16	21	15	12	27	20	28	48
75–84	17	12	29	9	18	27	26	30	56
85+	2	2	4	4	—	4	6	2	8
Not stated	1	1	2	2	6	8	3	7	10
Total	**37**	**56**	**93**	**52**	**74**	**126**	**89**	**130**	**219**
					(per cent)				
25–44	1.1	2.2	3.2	4.0	6.3	10.3	2.7	4.6	7.3
45–54	9.7	12.9	22.6	5.6	12.7	18.3	7.3	12.8	20.1
55–64	2.2	11.8	14.0	7.9	11.1	19.0	5.5	11.4	16.9
65–74	5.4	17.2	22.6	11.9	9.5	21.4	9.1	12.8	21.9
75–84	18.3	12.9	31.2	7.1	14.3	21.4	11.9	13.7	25.6
85+	2.2	2.2	4.3	3.2	—	3.2	2.7	0.9	3.7
Not stated	1.1	1.1	2.2	1.6	4.8	6.3	1.4	3.2	4.6
Total	**39.8**	**60.2**	**100.0**	**41.3**	**58.7**	**100.0**	**40.6**	**59.4**	**100.0**

— Nil.

Indicators of carer wellbeing

Two scales were chosen to report on the wellbeing of participating carers since carer support is an important element of service delivery in the projects. Measures of carer strain and carer wellbeing were not collected out of academic interest—they are used to report how likely the support needs of care recipients are to impact on primary carers, as this helps to inform the level of assistance required to support a person with dementia at home.

Robinson’s (1983) 13-item Caregiver Strain Index (CSI) measures the level of strain that a person associates with being in a caring role. Scores can vary from zero to 13 points; a score of 7 or higher indicates high strain. A positive answer to any question may suggest that intervention is required in that area.

The 28-item General Health Questionnaire (GHQ-28) was used to measure carer psychological wellbeing at each assessment, relative to how they usually feel. The GHQ-28 includes four symptom subscales: anxiety, depression, somatic symptoms and social dysfunction, and generates a composite score ranging from zero to 84 points where 84 indicates feeling much worse than usual in all areas. A score of 14 points or higher on one sub-scale means that those symptoms (for example, anxiety) were worse or much worse than usual, at the time of completing the assessment.

CSI and GHQ-28 data were collected through self-report. Carers completed the assessments in writing.

The collected data confirm anecdotal reports from project coordinators and case managers that carers of people referred for pilot services typically present with high levels of carer strain. In some cases carer strain was reduced during the reporting period, but for other carers the level of strain remained high over time. Coordinators remarked that formal services would be able to achieve better long-term outcomes if referral for formal service intervention occurred earlier. It is thought that most carers had managed for too long without adequate support. More timely assessment and referral is a key to achieving good outcomes for people with dementia and their families.

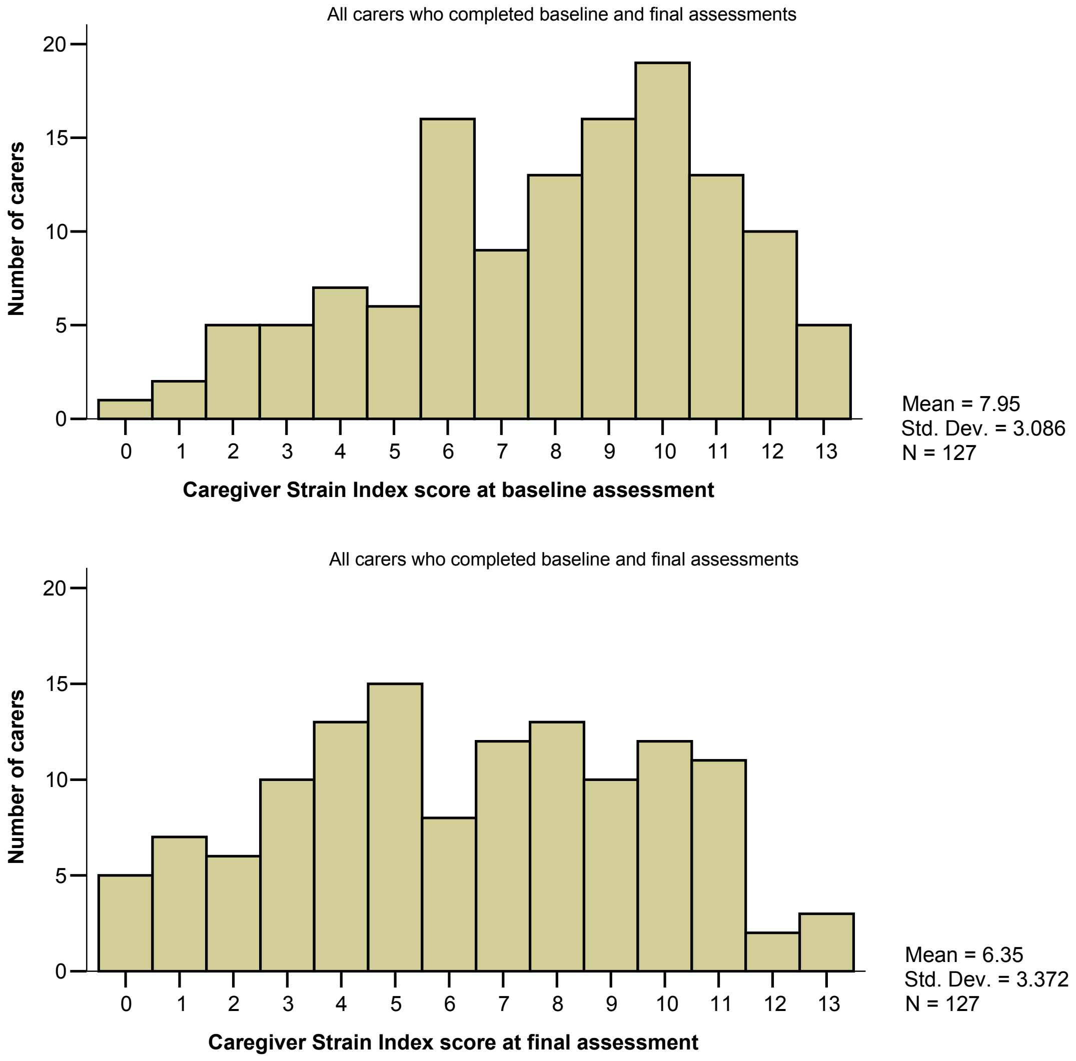
Carer strain (CSI) scores were recorded for 178 carers at the baseline assessment. Scores ranged from zero to 13 (Table A2.16). Almost three-quarters of carers scored above the threshold of high carer strain, revealing that projects have targeted clients whose conditions present significant challenges to people who provide ongoing daily assistance.

Table A2.16: Innovative Pool Dementia Pilot, summary statistics of self-reported Caregiver Strain Index scores at baseline, by project

Project	Count	Minimum	Median	Maximum
Short-term care projects				
DBAMS	15	2	7	13
DRAH	22	1	7.5	11
FCS	23	0	9	13
NEDID	14	5	10	13
Long-term care package projects				
RSL Care Pilot	28	4	9	13
South Brisbane & Gold Coast Pilot	14	3	10	13
Ozcare Packages	30	1	8	12
Dementia Care in Alternative Settings	32	2	8.5	12
All care package projects	**178**	**0**	**9**	**13**

Note: Does not include The Sundowner Club because it is not a care package service.

Carers who completed the CSI twice did the second assessment on average 115 days after the first. The spread of scores at first and second assessments is depicted in Figure A2.7 to show a general shift across the group towards lower carer strain scores, with fewer carers scoring higher than the threshold of 7 points at the second assessment compared to the first assessment.



Note: Excludes TheSundowner Club because it is not a care package service.

Figure A2.7: Distributions of Caregiver Strain Index scores at baseline and final assessments (all care package projects)

GHQ-28 self-report scores were reported for 60 carers of clients in short-term care projects and 101 carers of clients in long-term care projects (three of whom did not complete the depression sub-scale) (Table A2.17). DRAH elected to not administer the GHQ-28.

Anxiety and insomnia were the most frequently reported psychological symptoms. Around 20% of carers in short-term projects and just under 25% of carers in long-term projects who completed the GHQ-28 scored 14 points or higher on the anxiety sub-scale. Higher proportions of carers in long-term care projects scored above the threshold of 14 points on all sub-scales. Approximately 16% of carers in long-term care projects scored 14 points or higher for somatic symptoms and approximately 17% scored above the threshold for social dysfunction. Five carers in long-term projects scored above 13 points for severe depression, indicating significant personal risk for those people. Approximately 12% of carers in short-term care projects scored 14 points or higher on somatic symptoms, and 5% scored above the threshold for social dysfunction.

Table A2.17: Innovative Pool Dementia Pilot, summary statistics of General Health Questionnaire (GHQ-28) scores (carer self-reports) at baseline assessment

		Raw scores					Scores ≥ 14	
GHQ-28 subscales	Total responses	Minimum	Median	Maximum	Mean	Standard deviation	Number	Per cent
Short-term projects								
Somatic symptoms	60	0	7	20	6.9	4.8	7	11.7
Anxiety and insomnia	60	0	9	19	9.6	4.9	12	20.0
Social dysfunction	60	0	7.5	21	8.2	3.5	3	5.0
Severe depression	60	0	1	12	2.8	3.7	—	—
Long-term projects								
Somatic symptoms	101	0	5	21	6.6	5.2	16	15.8
Anxiety and insomnia	101	0	7	21	8.3	6.1	25	24.8
Social dysfunction	101	1	8	20	9.3	3.8	17	16.8
Severe depression	98	0	1	18	3.0	4.5	5	5.1

— Nil.

A statistically significant association was found between baseline measures of carer strain and GHQ-28 measures of psychological morbidity. Across the projects, 149 carers completed both the CSI and GHQ-28 at a baseline assessment (Table A2.18). The sample correlation coefficient is 0.52, which is significantly different to zero (prob < 0.0001; 5% level of significance). Thus, the data confirm that high levels of carer strain are associated with lower levels of psychological wellbeing among primary carers whose care recipients participated in the evaluation.

Table A2.18: Summary statistics for paired baseline measures of carer wellbeing

Measure	Number of records	Minimum	Mean	Maximum
Baseline CSI (0–13 points)	149	0	8.4	13
Baseline GHQ-28 (0–84 points)	149	6	27.6	71
Pearson's correlation coefficient: 0.52				

Forty-nine carers of clients in short-term care projects and 68 carers of clients in long-term care projects completed the GHQ-28 at a final assessment as well as a baseline assessment.

Comparison of baseline and final GHQ-28 scores for these clients indicates that, for the group as a whole, psychological symptoms relating to recent events and recently changed circumstances had reduced by the final assessment. The average change in scores on each of the sub-scales was negative (overall reduction in negative impact of caring) in both long-term and short-term care projects. The highest average reduction in symptoms was recorded on the anxiety and insomnia sub-scale (average decrease of 2.5 points in long-term projects and 1.8 points in short-term projects). The proportion of carers who scored 14 points or higher was reduced on all sub-scales.

A range of experiences is evident in measures of the CSI and GHQ-28 recorded for individual carers over time. Some carers reported an increase in carer strain (16%) and reduced overall wellbeing (22%); others registered no change in carer strain (32%) or psychological wellbeing (20%). However, higher proportions of carers reported reduced carer strain (52%) and improved psychological wellbeing (58%). Decreases in CSI scores tended to be greater in absolute value than reported increases. Paired *t*-tests were used to test the significance of differences between the paired first and final scores on the CSI and GHQ-28 for individuals (5% level of significance). The mean changes between first and final scores on each measure were found to be significantly different to zero, indicating significant change in the direction of reduced carer strain and improved psychological wellbeing across the group of carers during the period of observation (CSI: mean change = –1.6 points, $t = -5.67$, prob <0.0001; GHQ-28: mean change = –5.6 points, $t = -4.00$, prob <0.0001).

It is noteworthy that a major element of risk of entry to residential care for care recipients—high levels of strain and associated psychological symptoms in primary carers—was observed to have reduced in many cases. Although it is not possible to attribute all instances of reduced strain to the pilot interventions, many carers did attribute their sense of improved wellbeing and coping to the formal support received. A selection of responses to open-ended questions in the Care Experience Survey from carers whose CSI and GHQ-28 scores indicate reduced carer strain and improved psychological wellbeing demonstrate their attribution of the effect:

- 'NEDID have been marvellous with every need. The pilot program has certainly made my life much easier. Having 3 showers a week and 6 hours respite broken in 2 stages. Also supplying much needed continence undies.'
- 'I found the staff was very good and helpful and I don't know how I would have cope [sic] without their advise [sic] and assistance.' Asked what the carer particularly liked about the pilot program: 'Relief of family burden, see letter…' [the evaluation team received a handwritten letter of gratitude for the support received from the pilot project]
- 'The responsibility for finding staff is now taken off my shoulders. The coming and going of different staff I have found to be very supportive and I don't feel so lonely.'
- *Describe your situation before the Pilot:*
  Response: 'DID NOT HAVE HELP BUT I REALLY NEEDED IT' [emphasis original].
  What did the client need help with the most?
  Response: 'The carer (me) needed to know that she is not alone and there is help available. My husband does not like to leave home but now enjoys a day at Home Club. He also was very unsteady walking, but now he has a frame to help him get around and shower seat and rails on bath.'

  Any comment about how the pilot program helps or fails to help meet client needs?
  Response: 'I have to give it [the pilot program] the highest praise as it has made my life so much easier…everyone who works for the program are truly caring for carer and client, there is not one thing I could complain about. Everyone seems to be dedicated to help both client and carer.'

3 New choices in dementia care

Each project in the Innovative Pool Dementia Pilot has offered a type or level of dementia care that was previously unavailable or difficult to access because of limited availability in the catchment area. Detailed descriptions of the projects are contained in Part B. This chapter outlines the main sources of assistance to care recipients before the Pilot to provide a basis for comparing the type of care received from Pilot projects to care recipients' prior care arrangements. Following this is a description of the new care choices. The chapter concludes with a summary of the key features of each project as observed and reported during the evaluation and relates these to aspects of best practice in care for people with dementia that are identified in the literature. This summary highlights the similarities and differences between projects to enable a comparison of the range of care choices that have emerged in the Pilot. The reader is referred to Part B for case study reports that illustrate how the care models have operated for individual care recipients and their carers.

3.1 Sources of assistance before the Pilot

Care from family was the main source of assistance for the majority of clients before and during the Pilot. Ninety-one per cent of community-based clients in the evaluation had a carer (88% of all clients, including those who usually reside in an aged care facility). Counting all reported sources of ongoing assistance to community-based clients before the Pilot, 53% were receiving assistance from a family (primary) carer as well as from government-funded formal services; 38% were receiving assistance from a primary carer without additional assistance from government-funded services; 4% were receiving assistance from government-funded services only (no family carer) and 4% recorded no previous sources of ongoing assistance (Table A3.1). Previous formal support arrangements are unknown for 1% of care recipients.

A high rate of carer availability among Pilot clients compared to mainstream package clients is partly related to client selection criteria in a number of projects that require a person referred for pilot services to have a relative or friend providing ongoing care at home. In most cases it was not necessary for a carer to be living in the same household but someone needed to visit the home daily, be able to provide out-of-hours assistance if required, and be willing to participate in care planning. Besides intake policies that required carer availability, the high needs characteristics of the target group have meant that the availability of care from family was the primary enabler for most clients to be living at home prior to referral to the Pilot.

The key role of family carers which is reflected in the client intake policies of pilot projects is also highlighted by an OECD report on long-term care for older people: 'It has also become generally accepted that once an older person has significant disabilities, the contribution of a family carer or carers will be key to maintaining that older person at home' (OECD 2005:40). According to the report, it has been the experience in many OECD countries that schemes which aim to support more severely disabled older people rely heavily on informal carers and that there is a higher probability of success if a family carer is available. This has prompted a rethink of approaches that target mainly people who live alone and leave large numbers of primary carers to cope without adequate support.

Table A3.1: Innovative Pool Dementia Pilot community-based clients[(a)], number and per cent of clients by main sources of assistance before the Pilot

Type of previous government program support	Short-term care projects			Long-term care projects			All projects		
	No carer	Has a carer	Total	No carer	Has a carer	Total	No carer	Has a carer	Total
				(number)					
No program support	3	48	51	5	37	42	8	85	93
Care package[(b)]	—	2	2	3	42	45	3	44	47
Other program/s	3	29	32	4	47	51	7	76	83
Unknown	—	—	—	2	1	3	2	1	3
Total	**6**	**79**	**85**	**14**	**127**	**141**	**20**	**206**	**226**
				(per cent)					
No program support	3.5	56.5	60.0	3.5	26.2	29.8	3.5	37.6	41.2
Care package[(b)]	—	2.4	2.4	2.1	29.8	31.9	1.3	19.5	20.8
Other program/s	3.5	34.1	37.6	2.8	33.3	36.2	3.1	33.6	36.7
Unknown	0.0	0.0	0.0	1.4	0.7	2.1	0.9	0.4	1.3
Total	**7.1**	**92.9**	**100.0**	**9.9**	**90.1**	**100.0**	**8.8**	**91.2**	**100.0**

(a) Excludes 23 DBAMS clients who resided in an aged care facility on joining the Pilot.

(b) CACP or EACH.

— Nil.

Approximately 41% of community-based care recipients in the evaluation had not been receiving assistance from community care programs before the Pilot (Table A3.2). Forty-seven per cent had been receiving assistance through one program, most often HACC or CACP, and a further 8% had been receiving assistance through multiple programs. One in five care recipients were on a CACP, which typically provides up to 7 hours of care per week. Almost 25% of people who were on a CACP were also receiving assistance from other programs, for example, Day Therapy Centre, HACC, Veterans' Home Care services, or HACC supplemented with brokered services through the National Respite for Carers Program (NRCP). Service providers with access to National Respite for Carers Program funding value the ability to broker supplementary services for high care CACP clients. In the mainstream service context, multiple sources of funding are used to boost weekly care hours and provide a more comprehensive package of services for high care dementia clients than would be available through a single program. This is reliant on the client's major service provider having access to other programs and the case management capacity to arrange a 'pseudo-package'.

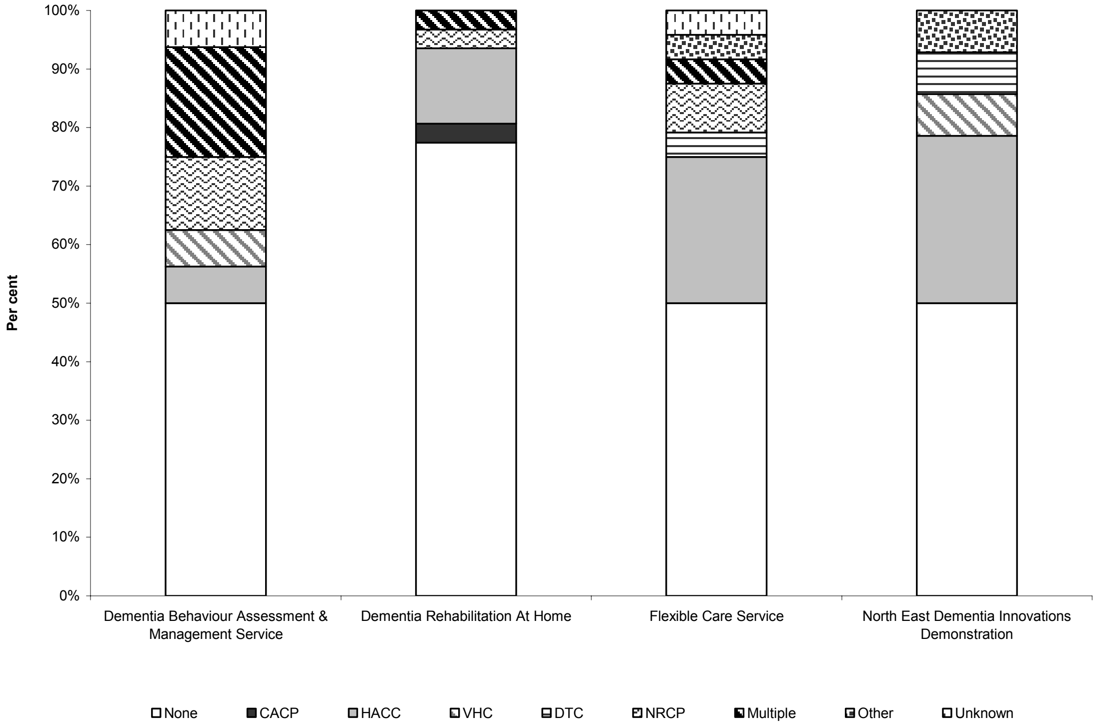
Table A3.2: Innovative Pool Dementia Pilot, number and per cent of community-based care recipients by previous formal assistance through government support programs, by program

	Short-term care		Long-term care		All projects	
Previous government support program	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
No previous Government program support	51	60.0	42	29.8	93	41.2
Single program						
HACC	16	18.8	18	12.8	34	15.0
Veterans' Home Care	2	2.4	4	2.8	6	2.7
National Respite for Carers Program	5	5.9	22	15.6	27	11.9
Day Therapy Centre	2	2.4	1	0.7	3	1.3
CACP	1	1.2	34	24.1	35	15.5
EACH	—	—	1	0.7	1	0.4
Total single program support	*26*	*30.6*	*80*	*56.7*	*106*	*46.9*
Multiple programs						
HACC & National Respite for Carers Program	3	3.5	2	1.4	5	2.2
Day Therapy Centre & National Respite for Carers Program	1	1.2	2	1.4	3	1.3
CACP & Day Therapy Centre	—	—	7	5.0	7	3.1
CACP & HACC	—	—	1	0.7	1	0.4
CACP & Veterans' Home Care	—	—	1	0.7	1	0.4
CACP & National Respite for Carers Program	1	1.2	—	—	1	0.4
CACP, HACC & Day Therapy Centre	—	—	1	0.7	1	0.4
Total multiple program support	*5*	*5.9*	*14*	*9.9*	*19*	*8.4*
Other/unknown program	3	3.5	2	1.4	5	2.2
Not stated	—	—	3	2.1	3	1.3
Total	**85**	**100.0**	**141**	**100.0**	**226**	**100.0**

— Nil. *Note:* Excludes 23 DBAMS clients who were living in residential aged care on referral to the project.

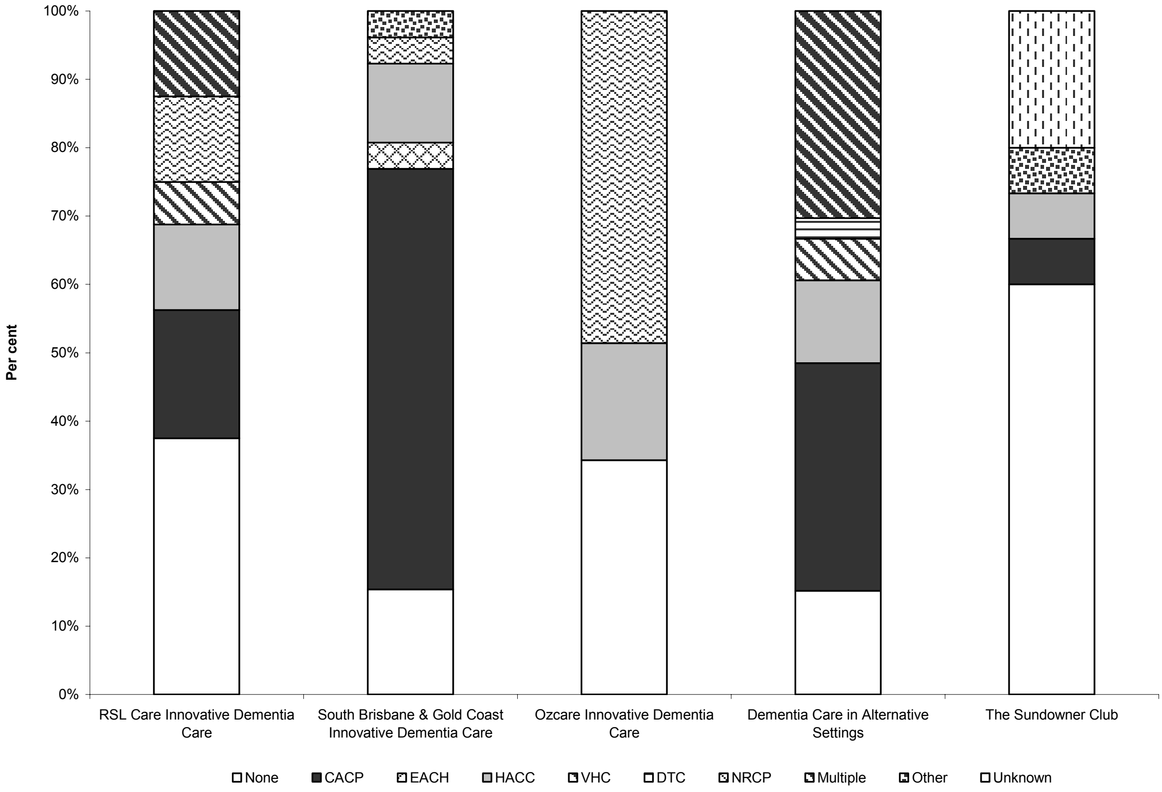
The Pilot has enabled some care recipients previously being supported on multiple programs to transfer to a comprehensive and high care package while maintaining continuity of care.

Care recipients in long-term care projects were more likely to have been receiving assistance through government programs before the Pilot than care recipients in short-term care projects (approximately 70% versus 40% of community-based recipients respectively; Table A3.2, Figures A3.1 and A3.2). Prospective clients for long-term care projects are often identified from within the service provider's existing client base. Recipients in long-term care projects were also more likely to have had a care package (as distinct from non-package formal services) prior to the Pilot. Dementia Rehabilitation At Home, a short-term care project in New South Wales, recorded almost 80% of clients who were new to government program support. This project targets people in need of a diagnosis, which explains the comparatively higher proportion of clients with no history of government program support.



Source: Part B, Chapters 1 to 4.

Figure A3.1: Innovative Pool Dementia Pilot, proportion of community-based clients in short-term care projects by previous government support program, by project



Source: Part B, Chapters 5 to 9.

Figure A3.2: Innovative Pool Dementia Pilot, proportion of community-based clients in long-term care projects by previous government support program, by project

Overall, 22% of clients were known to be on a waiting list for residential aged care when they entered the Pilot.

The Care Experience Survey gave an opportunity for clients and carers to comment on the adequacy of assistance received before the Pilot. Respondents could indicate in which areas the client had prior unmet need, taking into account all previously available sources of assistance. Survey respondents are a subgroup of the evaluation group. Approximately 28% of respondents said that the client had not been receiving assistance—formal or informal care—in the 6 months prior to joining a project (refer Table A6.3). The most common source of assistance with everyday activities was family, friends and/or neighbours. Around 57% of respondents reported that the client had been receiving assistance from a community organisation (refer Table A6.4). The most frequently cited areas of unmet need for assistance before joining a project include domestic assistance, social support and nursing care at home. Assistance to manage the behavioural and psychological symptoms of dementia stood out as the most frequently mentioned area of unmet need—67% of respondents indicated that they needed help but were not receiving any assistance in this area prior to the Pilot (refer Table A6.5).

3.2 New care choices

This section gives a brief synopsis of projects in the national evaluation drawing on project reports in Part B.

Short-term care projects mostly focus on aspects of dementia care that require specialist intervention and high-level support at major milestones on the care continuum. This set of projects shows greater variation in objectives and service models than the long-term care projects. Each short-term intervention model is unique in terms of target group and care type, although there is a degree of overlap. Dementia Behaviour Assessment and Management Service (NSW Health), Dementia Rehabilitation at Home (NSW Health), Flexible Care Service (*annecto – the people network*, Victoria), and North East Dementia Innovations Demonstration (Austin Health, Victoria) all offer intensive care over a period of 8 to 12 weeks to address high level and specific dementia-related needs.

Four long-term care projects deliver care packages of high level case management and coordination, flexible respite care, high hours of care and flexible service delivery. The two features of these packages that distinguish them from mainstream care packages are the total hours of service that can be provided and a dementia-specific focus. Projects in Queensland (RSL Care, Ozcare and South Brisbane and Gold Coast Innovative Dementia Care pilots) and Western Australia (Dementia Care in Alternative Settings) offer comprehensive packages of dementia-specific in-home ADL and social support, flexible respite care, community access, and support for carers and relatives. Staff rosters in these projects need to be managed with high flexibility and responsiveness to deliver client-centred care. The South Brisbane and Gold Coast project was established to target culturally and linguistically diverse communities. Ozcare Packages services regional and rural/remote locations. The fifth project which we loosely group with the above as a long-term care project is unlike the other four because it is not a care package/case management service. The Sundowner Club in South Australia is an evening meal and activity program that serves dual purposes of innovative respite care and socialisation for people with dementia.

The projects are described in more detail below.

3.2.1 Models of short-term intervention

Dementia Behaviour Assessment and Management Service

Dementia Behaviour Assessment and Management Service (DBAMS) is a specialist consultancy service for people with BPSD living at home in the community or in an aged care home. DBAMS services regional, rural and remote communities in southern New South Wales covering a region of approximately 114,000 square kilometres. Prior to DBAMS, access to psycho-geriatric medical and nursing care in the region was limited and specialist intervention for people with severe BPSD would typically involve lengthy delays. Without timely intervention, people with BPSD face an increased risk of changes to their care arrangements. Family carers and relatives often become unable to cope and actively seek residential aged care placement. Few nurses in general aged care homes have the training in psycho-geriatrics to enable them to effectively manage clients with severe BPSD without specialist support. Compounding the problem is a shortage of dementia-specific beds in the region. A lack of adequate specialist support can lead to occupational health and safety risks for staff with obvious workforce implications.

DBAMS is the type of specialist service referred to in tier 5 of the Brodaty et al. (2003) model of service delivery for people with dementia. DBAMS offers an outreach service to care providers and primary carers at home to help reduce symptoms through investigation of triggers (for example, care environment) and diagnosis of medical or pharmacological causes of BPSD. The project helps care providers cope with and manage symptoms in the usual home environment. Community outreach is supported by a 16-bed intermediate care unit that is used if DBAMS staff assesses that a client needs specialist medical observation and treatment. Among 39 evaluation clients, 20 received outreach services without needing intermediate care, 15 clients received intermediate care and community outreach and four clients received intermediate care only.

The DBAMS multidisciplinary team comprises a geriatrician, two visiting psycho-geriatricians, a psycho-geriatric nursing team headed by a clinical nurse consultant, social worker, and diversional therapist. Other allied health professionals are subcontracted from the base hospital or local Aged Care Assessment Service. Carers are supported by a social worker, psychologist, counsellor and dementia support worker.

Community outreach

The DBAMS psycho-geriatric nursing team assesses clients at home to determine if possible the underlying causes of BPSD and develop a behaviour management plan. Particular attention is paid to medications, significant past events, current living arrangements and environment. Often the investigation will delve into a client's earlier life experiences in search of possible triggers. Where possible, a behaviour management plan is developed for implementation at home by family carers and/or aged care staff with ongoing guidance and support from DBAMS. Carers and care providers have 24-hour access to DBAMS via a telephone hotline.

DBAMS provides consultancy services for staff in residential facilities. Staff can access specialist geriatric and nursing expertise by telephone or organise outreach workers to visit the facility.

Intermediate care

If a client cannot be managed at home or if initial assessment identifies a need for specialist medical assessment the client can be admitted to Yathong Lodge, the DBAMS 16-bed intermediate care unit. Medication review and management are key interventions for most clients at Yathong Lodge. While there, a client may receive allied health care and have the opportunity to participate in the 'Sunshine Club', a program of small group activities for people with common interests and level of functioning developed to encourage social interaction and participation. Under the supervision of a diversional therapist, clients are able to participate in music therapy, aromatherapy and similar activities.

A client may be admitted to Yathong Lodge on multiple occasions as symptoms change or resurface. Case study reports included in the DBAMS project report in Chapter 1 of Part B illustrate how a client can access behaviour assessment and management through a combination of community outreach and intermediate care.

The DBAMS clinical team meets regularly to prioritise admissions to Yathong Lodge and organise rapid, appropriate placement when this is required. Discharge case conferencing and behaviour management meetings also play a central role in the multidisciplinary coordination of access to intermediate care and outreach services.

Dementia education

DBAMS delivers dementia-specific education programs to aged care professionals, carers and interested members of the public throughout the service region. The project has supplied to the evaluation the learning objectives for the *Introduction to Dementia and Communication with People with Dementia* training sessions, education program survey tools and education program evaluation results (see DBAMS education attachment, Part B Chapter 1).

Client profiles

The DBAMS client group included 23 clients living in residential aged care and 16 in private residences or retirement villages at time of referral to DBAMS. Most clients were ambulatory but showed moderate to profound self-care limitation. A MMSE score of zero was recorded for eight clients; non-zero scores ranged from 1 to 28 points with a mean of 15.5. Twenty-four of the 39 clients scored below the key transition score of 16 points.

As a group, DBAMS clients displayed the highest prevalence and frequency of psychological and behavioural symptoms of dementia of any client group in the Pilot. Fourteen community-based clients presented a danger to self or others at least occasionally. One was reported to be physically aggressive most of the time and another six clients were physically aggressive on an intermittent basis. Fourteen community-based clients exhibited four or more psychological and behavioural symptoms on an intermittent or extensive basis, 11 of whom exhibited two or more symptoms on an extensive basis. All 12 residential high care clients exhibited three or more behaviours on an intermittent or extensive basis, and 10 exhibited two or more psychological and behavioural symptoms on an extensive basis. Among residential low care clients, six clients exhibited physical aggression on an intermittent or extensive basis. All clients in residential low care exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, and nine clients exhibited two or more psychological and behavioural symptoms on an extensive basis.

Thirty-six clients exhibited at least moderate ADL dependency, including 22 clients with severe or complete dependency.

Key outcomes

DBAMS is a point of referral for rapid access to psycho-geriatric expertise for people with BPSD in southern New South Wales. When DBAMS was first established, all 16 intermediate care beds were occupied and a waiting list had grown to six or seven potential admissions. Demand for intermediate care slowed as community outreach became established: during 2005 bed occupancy averaged 12 inpatients with a maximum of one name on the waiting list at any one time. Reduced demand for intermediate care illustrates the success of an outreach model in providing effective in-place supports to clients with behaviour management needs. Very few calls have been made to the telephone hot line, a further indication that the project has been able to reach people in need of specialist intervention and put in place appropriate management strategies. According to the supervising geriatrician, use of psychotropic medications among DBAMS clients has been almost completely eliminated through specialist assessment, medication review and behavioural intervention.

An estimated 94% of clients accepted into DBAMS during the evaluation showed severe BPSD. Reassessment at the end of the DBAMS episode indicated that at least 26% of clients experienced a significant reduction in the severity of symptoms.

Between October 2003 and December 2004, 1,058 people attended DBAMS dementia-specific training sessions in 19 locations across the catchment area. Directors of aged care homes in the region with staff who have participated in the education program reported to the evaluation team that sessions have improved staff understanding of dementia and associated behavioural symptoms and provided them with practical ideas to assist in the management of residents with special needs. Participants value the opportunity to access training from DBAMS specialists in the workplace (or at least in their home towns), as this means more staff members can participate at a reduced cost. Travel time and staff release costs make conventional training for people living and working in rural and remote locations hard to arrange and expensive.

Directors also remarked that nursing staff are drifting back to community nursing because of high levels of occupational stress. They believe that DBAMS has made inroads to reducing staff burnout by providing staff with strategies for the effective management of clients and by offering an immediate solution in situations where a client needs specialist diagnosis and management.

DBAMS was launched into an environment of long-term unmet need among clients with behaviour management needs. Referrals for people with very severe BPSD received priority and accommodation outcomes for community-based clients during the reporting period reflect this high level of need. Among 15 evaluation clients referred to DBAMS from the community who were still alive at follow-up, two were at home in the community, 10 had entered residential care, and three clients remained in the DBAMS intermediate care unit. Seven of the 10 clients who entered residential care entered at low care level despite having been assessed by ACAT as requiring high level residential care. In the group who were in residential low care at referral to DBAMS, three had moved to a high care facility and the others were either still in DBAMS intermediate care or had remained/returned to their low care facility. DBAMS has helped a considerable number of clients avoid a change from low to high care. The project reported that a shortage of dementia-specific beds in the region presents a major challenge to discharging some clients from DBAMS.

DBAMS has played an important role in: (a) facilitating appropriate placement for clients who are difficult to place because of BPSD and a shortage of dementia-specific beds; (b) in helping staff in aged care homes to manage clients and avoid the need for transfer to hospital or another facility; and (c) assisting a proportion of clients to avoid premature placement or transition to higher level care. Given the role that BPSD play in precipitating care transitions for people with dementia, the model of outreach and intermediate care piloted by DBAMS shows enormous potential for reducing hospitalisation and high care placement among people with dementia.

The DBAMS coordinator remarked that it would be ideal for people to be referred to the service earlier. Earlier intervention is likely to increase the prospects of a person with BPSD remaining in the community or avoiding a move to high level residential care. It is clear that the DBAMS model could also be extended or adapted to offer an effective early referral service for people seeking medical diagnosis of dementia and other types of clinical assessment and management in early stage dementia. There is considerable potential to expand this model of community outreach with intermediate care to increase access to specialist dementia care in regional, rural and remote areas and we see a possibility for the model to be applied to early diagnosis.

Dementia Rehabilitation at Home

Dementia Rehabilitation at Home (DRAH) has a strong clinical focus with two primary aims: to assist people to achieve medical diagnosis of dementia, dementia-related symptoms and medical co-morbidities, and to link clients and carers into a formal support network. DRAH operates under the auspice of the ACAT in Grafton, in partnership with Clarence Valley Council Community Services to service the needs of people with dementia in the Clarence Valley, northern New South Wales. This project models high level case management capacity (including coordination of specialist medical services) within an ACAT.

The service environment of the Valley was characterised as relatively low level service provision with poor access to medical specialists and mental health services and limited support for carers of people with dementia. Older people in the region find it difficult to access specialist geriatric and psycho-geriatric services. At the time that DRAH was establishing in 2003, the geriatrician in Richmond had a 4-month waiting list and the geriatrician in Coffs Harbour was situated in a different area health service. There was no psycho-geriatric support, only a clinical nurse consultant appointed to the ACAT in 2002 and a visiting psycho-geriatrician. Dementia Outreach Service visited Clarence Valley only three days per month.

At the commencement of DRAH it was identified that a large number of people being assessed for DRAH had no formal diagnosis of dementia. The family and carers were in crisis, and often the client would not accept help. The Telehealth Service commenced at the same time as DRAH and although Telehealth was not originally conceived of as a key feature of DRAH, it became an integral part of the project. Through Telehealth, DRAH clients are able to access medical specialists including a geriatrician (two hours per fortnight) and psycho-geriatrician (up to four hours per fortnight). DRAH also assists clients who need to travel to Coffs Harbour or Lismore for specialist consultation.

Clients and carers are assisted to identify up to 16 rehabilitation goals to facilitate successful transition through a milestone point on their care continuum. In this context, ‘transition’ might be the passing from an unawareness or uncertainty of the presence of dementia to accurate clinical diagnosis with education and counselling. Or it could involve a client’s progression from an unstable care situation due to social isolation or BPSD to a more managed environment through the diagnosis and treatment of behavioural symptoms and establishment of in-home services.

DRAH integrates intensive clinical assessment and work-up with community based, in-home services delivered by Clarence Valley Council Community Services. The ACAT is responsible for case management and overall direction for the project, covering clinical client management and oversight of community service.

The DRAH multi-disciplinary team comprises a gero-psychologist, specialist nurses, social worker, occupational therapist and physiotherapist. Care plans are developed and reviewed in weekly case conferences to prioritise and manage clinical input and contribute to the planning of community-based client services. Geriatric and dementia specialist services in Sydney are accessed via Telehealth. Two geriatricians in the region also consult with DRAH clients. A person accepted into the project who needs confirmation of dementia, medication review or other type of clinical investigation or gero-psychiatric examination will typically undergo a period of intensive clinical work-up that may involve medical specialists, a clinical nurse consultant, and allied health professionals.

Community service for DRAH clients is based on a philosophy of client-centred care and carer support. Care packages are designed to meet individual needs and cover ADL support, social support and community participation, and flexible respite care. DRAH contracts with

Community Programs Incorporated to deliver a five-week dementia-specific education program for carers and other family members.

Client profiles

DRAH supplied information about 31 clients for the evaluation. Prior to DRAH, 26 of these clients had not accessed government-funded community aged care.

Mini-Mental State Examination scores recorded at entry to DRAH for 30 clients show that during the evaluation DRAH targeted clients with a range of levels of cognitive impairment. MMSE scores for DRAH clients reflect that the project accepts a relatively high proportion of cases of suspected, but unconfirmed, dementia that is consistent with the aim of helping clients to achieve early and accurate diagnosis. Note that the MMSE is not always effective at detecting mild cognitive impairment—people in early-stage dementia can score within the normal range of 24 to 30 points. Entry MMSE scores of DRAH clients ranged from 6 to 28 points and averaged 19.9 points.

Two-thirds of DRAH clients showed at least moderate dependency in ADL when they entered the project. The remaining clients were slightly dependent or independent in ADL but all had experienced considerable loss of IADL function prior to joining DRAH.

A relatively high proportion of DRAH clients experienced behavioural and psychological symptoms of dementia. Seventeen clients exhibited emotional or psychological symptoms of dementia and seven clients were physically aggressive at times. Four clients wandered or displayed intrusive behaviour and nine were verbally disruptive on an intermittent or extensive basis. Eleven clients presented a danger to themselves or others either intermittently or extensively. Four clients exhibited three or more psychological and behavioural symptoms on an extensive basis.

At entry to DRAH, 12 carers, or around half of the carers participating in the evaluation, recorded a Caregiver Strain Index score that was above the threshold for high carer strain.

Key outcomes

Beneficial outcomes for clients include:

- Firm diagnosis and identification of the kind of dementing disorder, for example, Alzheimer's, vascular, fronto-temporal (accurate diagnosis assists with formulating a care plan for the appropriate management of BPSD and can be passed on if the client later enters an aged care facility).
- Advice to clients and family on planning, for example, wills, enduring guardianship.
- Driving issues are discussed for safety reasons and cancellation of licence may occur.
- Medication review, reducing inappropriate medications, recommendations for more appropriate medication use.
- Advice on anti-cholinesterase medication (unavailable if there is no diagnosis) is given by specialist geriatrician, psycho-geriatrician, psychiatrist or neurologist.
- Guardianship support and advice from aged care specialist.
- Carers are able to attend consultations and talk with specialists who offer support and advice on continuing the caring role.
- General practitioners (GPs) are supported and refer directly to the project—recommendations sent back to the referring GP are extensive and seen as assisting with education. The strengthening of relationships between ACAT, GPs and community

services is an important positive outcome given the key role that GPs can play in timely referral.

- Hospitals are able to formulate better discharge plans and involve the carer when all the relevant clinical information is compiled.

Not all clients are referred for diagnosis because of the time and effort involved; consequently clients are screened according to urgency of the situation at home (delirium, self-neglect, medication issues, carer/family stress, etc.).

Among 31 DRAH evaluation clients, 13 had an existing diagnosis of dementia when referred to DRAH and 15 people were newly diagnosed with dementia during their DRAH episode. Two clients with an existing diagnosis were assisted to consult with a geriatrician in Coffs Harbour or Lismore to confirm/review their diagnosis. Telehealth was used to confirm or review the dementia diagnosis or behavioural symptoms in four clients with an established diagnosis. Dementia and type of dementia was diagnosed in 15 cases. No diagnosis was made in three cases (delirium sometimes resolves before specialist consultation occurs). Seven clients were diagnosed with delirium superimposed on dementia. In total, Telehealth was used to facilitate medical diagnosis and review for 18 clients in the reporting period.

In its first 6 months of operation DRAH discharged 21 out of a total 25 clients to remain at home with support services. The project reported acute care savings and a high rate of goal attainment. DRAH estimates that 97 hospital patient days were saved through early supported discharge in the first 6 months. In addition, eight people received DRAH services as a complete alternative to hospital. The 25 care recipients who were discharged in the first 6 months collectively identified 88 rehabilitation goals, of which 64 goals were fully achieved, 15 partially achieved and eight goals were not achieved during the DRAH period of care.

The project's 12-monthly report indicates that of the 58 clients who completed their program of care in the first year of operation, only seven had entered permanent residential care. Key achievements in the second six months included:

- an estimated saving of 204 acute care patient days per year through supported early discharge and hospital avoidance
- the training of 16 carers in brain and behaviour, nutrition, self-care strategies, the importance of touch, and community service awareness
- review of the carer program and launch of a new education program in February 2004
- the training of 14 care workers from Clarence Valley Council in the management of dementia and dementia-related behavioural symptoms.

Among the 31 clients who participated in the national evaluation, 26 remained at home with support services and three clients entered residential high care by completion of follow-up (one client was deceased and one client was not located). DRAH experienced difficulty in discharging some clients and compromises were necessary in making discharge support arrangements due to a shortage of high care packages in the region. DRAH recorded actual and optimal ongoing community support arrangements for evaluation clients. In 17 out of 22 discharges, the project identified an EACH or dementia-specific EACH package as the optimal ongoing support arrangement (refer to Chapter 2 in Part B).

Flexible Care Service

Flexible Care Service (FCS) offers short-term intensive support for people with dementia-related high care needs. FCS was established at a time when EACH packages were not available in the northern and eastern suburbs of Melbourne. Referring Aged Care Assessment Services[2] (ACAS) reported that FCS has accepted ACAS clients who previously would have been referred to service agencies as 'urgent CACP' because there are rarely vacant Linkages packages in the service region (prior to the availability of EACH packages in the region, 'Linkages' packages funded under the HACC program were the only community care equivalent of high level residential care). For this type of client, ACAS often takes on a case management role that is beyond the scope of its brief. ACAS observed that some community service providers 'give up' on high care clients with complex needs, leaving ACAS to pick up the pieces. Thus, FCS presented a new referral option for ACAS to place high care dementia clients.

The service operated as a full brokerage model under the auspice of *annecto – the people network* (formerly WiN Support Services), an established community service agency. FCS offers each client a tailored comprehensive care package for a period of 8–12 weeks which comprises intensive case management by experienced social workers, service coordination, high and flexible ADL and social support, respite care, and carer support and education. Project coordinators see respite care as a core component of the service because it assists in reducing carer strain to more manageable levels so that carers are able to contribute to long-term care planning. In addition, many clients and carers have not used respite care before coming into the project and FCS offers an opportunity to introduce respite care services to help sustain caring within families over the longer term.

Care recipients have access to the *annecto*-operated Emergency After Hours Response Service (EARS). EARS was unique in Victoria and at the time was available to clients of all *annecto* programs as well as being brokered by other agencies. FCS clients and carers may not need to access EARS during their time in the project but knowing it is available increases confidence that support can be accessed at any time in the future.

FCS was in fact proposed as a long-term care project but was established as a short-term care project at the request of the Department of Health and Ageing. *annecto* had envisaged that the project would target people with dementia-related high care needs who had not previously used formal services so as to link more people in need of formal care into a support network. Identifying people with no or minimal established services had proved difficult and the majority of people accepted into FCS have been using at least Council HACC services plus high levels of informal care. To be accepted into FCS a person must have a family carer who visits at least daily.

A typical person referred to FCS has experienced a crisis in care, often due to the death of a primary carer, carer illness or burnout. Clients have had moderate to severe dementia at time of referral and have been at the point of no longer having access to care at home. FCS serviced a very high needs group during the evaluation—75% of care recipients required personal care for continence management. BPSD and resistance to formal services are common in the FCS client group. Any formal service arrangements in place prior to referral to FCS proved inadequate under the condition of breakdown in informal care. Whenever possible, FCS ensures continuity of care by brokering to existing service providers and injecting additional brokered services plus high level case management and social work from the FCS team.

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[2] Equivalent of ACAT in other jurisdictions.

Client profiles

During the evaluation, FCS serviced a group of people with some of the highest levels of need for ADL support and carer support observed in the Pilot.

MMSE scores recorded at entry to the project ranged from 2 to 24 points with a median of just 10 points (n = 16; mean 11.8 points). Around half of FCS care recipients had severe dementia and 75% scored below the 'transition value' of 16 points on the MMSE that is associated with the onset of marked decline in ADL function.

Most clients either needed assistance or were completely dependent in tasks involving self-care when they commenced with FCS. MBI scores at entry range from 2 to 17 out of 20 points, indicating that all clients had lost a degree of ADL function in addition to significant loss of IADL function. The mean entry MBI score (9.7 points) indicates that the middle of the MBI distribution for FCS clients was in the range of severe dependency in ADL.

Fifteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, two of whom exhibited two or more symptoms extensively.

Nineteen carers registered very high levels of carer strain.

Key outcomes

FCS assisted 50% of the evaluation clients to remain at home despite a very high and imminent risk of admission to high level residential care. Among 24 evaluation clients, 12 were still at home some 8 to 12 months after acceptance into the Pilot (eight were deceased and eight were in high level residential aged care).

Levels of carer strain were observed to decrease or remain stable for a high proportion of family carers. Eight carers recorded a reduction in carer strain during the FCS service episode and 10 carers remained at the level recorded at their first assessment. Five clients experienced a reduction in symptoms from above to below the threshold for high carer strain.

These positive client and carer outcomes have been achieved in the face of significant challenges for FCS staff. A second case manager was appointed because the intensive level of assessment, case management and service coordination in a short-term care pilot could not be sustained by one experienced case manager. This experience suggests that one case manager per eight to 10 clients is required to meet the case management needs of people in the target group in a flow-through (short-term intervention) project. The project team described its role as 'crisis management' because in a flow-through pilot there is so little time to establish services for a client with complex care needs and their carer before it is time to start discharge planning. Discharge planning is usually a complicated exercise in these circumstances. It is rarely possible to reach a stage of stabilised care needs within 8 weeks, yet this is necessary in order to reliably assess maintenance of effort prior to discharge.

Discharge planning in FCS was further complicated by the limited range of suitable discharge options. FCS coordinators see Extended Aged Care at Home (EACH) and HACC-funded Linkages packages as the best forms of ongoing support for most clients. However, people with a valid ACAT approval for an EACH package at the time of referral to FCS were specifically excluded at the request of the Department's Victoria Office because of a guideline which states 'criteria should address the particular people within the broader target group who would be most likely to benefit from the proposed service and cannot access the care they require through other appropriate means' (Innovative Pool Guidelines 2002–03).

It is perhaps overly optimistic to equate eligibility to mainstream high level community-based aged care with timely access in areas where prevailing demand for such services exceeds supply. Further, it seems illogical that a care recipient and their carer would enrol in an 8–12 week service if they were hopeful of being able to access an EACH package. Lengthy waiting times for EACH packages have ruled out one appropriate discharge option for many FCS clients. Linkages packages (HACC-funded services for people with complex care need who require case management and coordination) were also said to be in short supply. The result is often a long waiting period to obtain the ideal discharge outcome. Clients who were unable to access a high care equivalent package on discharge from FCS were assisted by the project team to source ongoing service through multiple programs, often involving multiple service providers, and with no overall case management, while they await an EACH or Linkages package.

Limited access to respite care in the region presented another major problem because respite is critically important in reducing high levels of carer strain evident at time of referral.

All of these factors need to be taken into account when assessing client accommodation outcomes. There is evidence, albeit from a small number of clients, that longer term accommodation outcomes depend on the type of formal support arrangement put in place at time of discharge from FCS. Between 30 November 2004 and 3 June 2005, six of the FCS evaluation clients discharged to the community entered high level residential care. Three of these clients were initially discharged from FCS to HACC services, two were receiving services from multiple programs, and one client had had a CACP after FCS. The three clients who were discharged from FCS onto an EACH package continued to be maintained on this program at follow-up. Ongoing high level case management and high hours of care to support the needs of the client with dementia and their carer are critical to maintaining people with dementia-related high care needs at home.

The FCS team concluded that the short-term intervention model of FCS does not lend itself to mainstreaming. FCS targets a group that, at the time the project was established, was not adequately serviced by any other community service in the Eastern Metropolitan Region. Standard EACH is viewed as perhaps not providing for the required level of carer support. Advanced dementia requires a unique support service that incorporates a level of expertise and flexibility that is not normally available through general package offerings (these observations were made prior to the announcement of dementia-specific EACH packages in mid-2005).

The service provided by FCS is equivalent to the type and level of assistance that families in crisis might receive in the first months of one of the Dementia Pilot long-term care package projects. All of the issues described by the FCS coordinators are held in common with the long-term care package services, described below. Unlike the long-term care projects, the short-term nature of FCS demanded a hand-over of clients and carers within a 12-week period. In addition to the difficulty of discharging clients when limited suitable discharge options are available, it is not ideal for care recipients and carers to have to separate from a service after trust, rapport and reliance are established.

Possibly the best application for a short-term care intervention such as FCS is to provide an appropriate level of support for people who are waiting for an EACH package. A lengthy wait for flexible care in the community incurs a high risk that the person with dementia will be placed in permanent residential care. A short-term package with high social work input such as FCS provides one means of reducing this risk, addressing the social factors that contribute to a need for high care, and providing advocacy that many carers need when seeking an EACH package. Ultimately, the availability of a flexible care package for ongoing care determines whether a person with dementia-related high care needs is able to avoid or delay residential placement.

North East Dementia Innovations Demonstration

Austin Health in Melbourne applied for Innovative Pool funding on the strength of the success of its Trial at Home pilot. For a number of years, Austin Health had experienced a steady increase in demand for hospital-based care for older people who no longer required acute medical care but who were unable to return home without case management and community supports. The Trial at Home pilot was one of a number of initiatives in response to this demand. It demonstrated that 85% of participants continued to live at home successfully 10 months after its introduction. Client feedback was positive and participants were observed to benefit from improved health and functional capacity during their time on the pilot. More than half of the 17 Trial at Home participants suffered from dementia. Funding for Trial at Home was not assured beyond June 2003.

The Austin Health proposal for NEDID highlighted an undersupply of dementia-specific residential and community services in Melbourne's north-east at the time. Long waiting lists existed for dementia-specific beds, there were no community care options targeted to people with high care needs associated with dementia, and only minimal day care services that offered dementia-focused programs.

NEDID was designed to address five specific areas of unmet need in the provision of community services for people with dementia living in the catchment area:

1. Need for immediate brokered service provision to support dementia clients with high care needs who wish to stay at home. Prior to NEDID only one program with this level of brokerage existed.
2. Very limited immediate access to case management programs in the area, with long waiting lists. Northern Community Options had a waiting list of 84 names in mid-2004. There were no Extended Aged Care at Home (EACH) packages in the region at that time.
3. Limited training among service providers for working with the target group. For example, service provision for clients who require hoist transfer or PEG feeding can be difficult to source.
4. Few culturally specific agencies to cater for a high level of cultural diversity in the catchment area.
5. Availability of residential respite care—NEDID is able to make residential respite care more readily available for dementia clients with high care needs by supplementing the care in facilities, for example, by providing additional personal care, or an overnight carer. These clients would previously not have been able to use residential respite because of their behavioural symptoms and high care needs.

Through a period of specialist assessment, review and transition care, NEDID aims to enable Austin Health clients to remain at home wherever possible, or to enter residential aged care from the project with a higher level of functioning and independence than they would have otherwise. NEDID is a multidisciplinary team comprising a nurse case manager, social worker and neuropsychologist. A geriatrician is available for assessment, behaviour management requiring medical intervention and to provide consultancy to the general practitioner and the NEDID staff.

NEDID offers a flexible model for an innovative dementia care service in the community setting. NEDID provides a strong focus on case management, individual needs assessment, counselling and education, and a tailored package of community services that can comprise nursing care, allied health, personal and domestic assistance, home respite, equipment hire, planned activity group programs, carer support and education, a brokered after-hours response service, and access to a specialist Dementia Care Team.

Innovative features of the service include:

- intensive case management using a team approach, with a strong focus on input from hospital social work and neuropsychology departments
- flexibility around exit times, as determined by the individual care plan
- dementia education tailored to client need by a neuropsychologist or care manager, depending on the type of dementia and behaviours exhibited
- definitive selection process
- weekly case conference for community care clients.

Client profiles

Patterns of referral reflect NEDID's capacity to provide transitional care in addition to high level care for community clients. Most evaluation clients were referred to NEDID by Austin Health services. In a larger group of 35 NEDID clients 40% of referrals were from hospitals, 48% came from an Aged Care Assessment Service (Heidelberg or Bundoora) and 11% came from the community.

Ten national languages have been represented in the wider NEDID client intake (five in the evaluation group), reflecting the demographic diversity of the north-eastern metropolitan region of Melbourne.

In most cases, NEDID required that a care recipient had support from family carers and 12 of the 14 evaluation clients were living with family during their time in NEDID.

MMSE scores were recorded for 10 clients at entry to NEDID; four missing values were recorded for clients with no or little ability to communicate in English. Recorded scores range from 4 to 24 points with a median of 13 points, indicating that all assessed clients screened positive for cognitive impairment. The median score falls in the range of moderate to severe dementia.

The ADL assessment was completed for all clients. The median score of 10 points indicates that the middle of distribution of ADL scores of NEDID clients was in the range of severe dependency in ADL. Two clients exhibited total dependency in self-care and mobility; eight clients exhibited severe dependency; and three clients exhibited moderate dependency.

Eleven NEDID clients presented a danger to themselves or others at least occasionally. One client was reported to be physically aggressive most of the time. All clients exhibited two or more psychological or behavioural symptoms on an intermittent or extensive basis and 12 clients exhibited two or more symptoms on an extensive basis.

Eleven of the 14 carers recorded scores above the threshold for high carer strain as assessed by the CSI, two of whom scored the maximum possible score.

Key outcomes

NEDID achieved considerable success in working at the interface of hospital and community services. This required a persistent and concerted effort to educate hospital staff on the objectives of the project and appropriate referral practice. Inroads were made into dispelling a common belief among hospital staff that people in the target group are not able to be supported in the community. NEDID presents a referral alternative to residential care.

Much of the success is attributed to the high skill levels of the multidisciplinary team and the level of case management that facilitates a holistic approach to addressing the needs of both client and carer. NEDID has accepted clients on the verge of admission to residential aged care, but has been able to stabilise care needs and modify behaviours, enabling the client to remain at home for a period of time while helping to significantly reduce carer strain. NEDID reported that in situations where a client has entered an aged care home, the NEDID experience has helped to make the placement decision an informed one. In some cases, a new Aged Care Client Record has been required to reflect the improvements that have occurred.

NEDID has been instrumental in assisting over half of the clients to return home from hospital or remain at home, with formal services supplementing a high level of care from family. Carer commitment to providing care at home and a sustainable care plan with options for easily accessible appropriate continuing care at the conclusion of NEDID services are said to be the most important selection criteria for this type of program. Eight out of 14 evaluation clients (57%) who started with NEDID between June and October 2004 were still living in the community in June 2005. These clients were receiving assistance from various programs in addition to care from family: EACH package (two); multiple programs including EACH plus other program (one), HACC plus other program (one), Veterans' Home Care plus other program (one); other unspecified program support (two); and ongoing NEDID service (one). Clients in care at follow-up included residential high (three) and low (two) care clients, and one in hospital.

Two carers reported a marked reduction in carer strain during their time with NEDID; five others were still experiencing a high level of strain associated with the caring role at the time of their final assessment.

The case management load was perhaps underestimated at the outset and project coordination time had to be increased from 0.8 to 1.0 full-time equivalent to manage client throughput for a pool of 10 places. While clients accepted into NEDID have been of the type originally anticipated, the complexity of some clients' needs exceeded expectation.

Discharge planning presented a major challenge for NEDID due to a lack of suitable options for ongoing high care in the community. This has led to the development of the Step-Down program to offer reactive case management and limited respite care for clients who are awaiting a long-term community case management program. The aim is to maintain throughput in NEDID by offering a reduced level of transitional support to exiting clients, similar to that which is available through mainstream services. One client was still on NEDID at the end of May 2005 as the case manager was unable to place them in an appropriate program. This client had been in NEDID for approximately 10 months. One of the clients discharged to another program received services from Step-Down. This client had also been difficult to place and had spent 7 months on NEDID. Two other clients who were discharged to EACH and multiple programs had been in the project for 6–7 months, far exceeding the planned duration of care.

From the NEDID experience, occupancy monitoring for a program of time-limited care intervention, particularly in the context of a small number of packages, would prove a critical issue for mainstreaming this type of program. The level of program occupancy monitoring applied to NEDID (100%) is considered unsustainable over the longer term. It was suggested that funding based on 90% occupancy might be a more viable proposition for a short-term intervention targeting this client group.

3.2.2 Models of long-term intervention

Three Innovative Pool projects in Queensland (RSL Care Innovative Dementia Care Pilot, Ozcare Innovative Dementia Care Packages, and the South Brisbane and Gold Coast Innovative Dementia Pilot) and one in Western Australia (Dementia Care in Alternative Settings) offered packages of dementia-specific care and case management as an alternative to high level residential care. The establishment of these pilot services predated the announcement of the EACH Dementia Program. All of the approved providers of long-term care packages are experienced care package providers and deliver a range of other government programs, including HACC and Veterans' Home Care. Compared to the short-term care projects, these projects recorded high rates of transfer from mainstream care programs, mainly CACP. All providers indicated that high care packages were in extremely short supply in the catchment areas.

High level case management, flexible respite care and carer support are key features of these services. Differences between the services relate mainly to location (metropolitan versus regional and rural/remote) and target group for example, culturally and linguistically diverse communities, or the acceptance of clients with ACAT approval for low care or high care, versus high care only.

Coordinators said that community service agencies maintain many people on low care packages for too long because of a lack of any suitable alternative. Providers with access to multiple sources of funding may be able to maintain high care clients through complex budgeting arrangements. Thus, while the Innovative Pool-funded packages may resemble the type of care that providers are sometimes able to deliver, the Dementia Pilot has enabled this level of service delivery without the overhead of managing multiple sources of funding and potentially, multiple service agencies. This capability is highly valued and is said to produce a superior distribution of resources between low and high care community clients.

The Sundowner Club, Adelaide, implements a different model to the other long-term care projects. This project offers a new type of respite care and socialisation service at a time of day when formal services do not usually operate.

Long-term care projects are described in more detail below.

RSL Care Innovative Dementia Care Pilot

RSL Care Innovative Dementia Care Pilot is one of the larger projects (45 flexible care places), which serviced eligible residents of Brisbane North, Brisbane South and the district of Ipswich/West Moreton. RSL Care is an established provider of residential and community aged care. Major sources of government funding for community care include the Community Aged Care Packages, Home and Community Care, Veterans' Home Care and Day Therapy Centre programs. RSL Care services are available to veterans and other members of the community.

The project was designed to deliver genuinely individualised packages of care with a level of allied health, registered nursing and carer support that is not normally available through mainstream packages. Respite services are tailored to individual needs and preferences. Diversional therapy, behaviour management, alternative therapies, carer mentoring and education were cited as specific focuses of a multidisciplinary approach to service delivery and client care.

The objectives of the RSL Care Pilot were to:

- provide a comprehensive approach to dementia services for people with behaviours that normally would be difficult to manage in the community or residential setting
- provide a service that focuses on sustaining the relationship of client and carer and maintaining their social capacity
- increase support to carers of people with dementia and associated challenging behaviours living in the community through delivery of flexible service options such as residential respite, weekend and evening respite and emergency in-home respite
- reduce premature admission of clients to residential care.

The project aimed to cater to the needs of people from culturally and linguistically diverse backgrounds and reported an increasing number of referrals from this special needs group. RSL Care brokers bilingual and culturally specific staff as necessary and has sourced services from service providers who specialise in service provision to culturally diverse groups.

Flexible respite care was identified as a critical factor for maintaining high care clients with dementia at home and is a primary focus of the project. It was suggested that many relatives and carers of older people with dementia do not receive adequate respite from the caring role due to the inflexibility of mainstream services. Carers need respite care that fits into their lifestyles and the routines of care recipients, yet many respite services are designed more with the availability of care workers in mind, leaving little flexibility for consumer choice to be exercised. RSL Care reported a very high level of unmet need for emergency respite care in the service area. People often experience difficulty locating emergency respite services in times of crisis and do not always meet with a quick response. RSL Care reported that responsiveness of respite care services in times of family crisis is a major issue.

A dementia-specific focus allows for high level carer support and close monitoring and therapy for the care recipient with behavioural and psychological symptoms. Referrals to the project were made mainly on the basis of behaviour management need rather than ADL limitations. Higher hours of care are related to the dementia specificity of the project and not merely the fact that the project is servicing a high needs group. Dementia care can place heavy demands on family carers and this requires a higher level of coordination and flexibility to reduce carer strain. The care workers require support, education and coaching and skills to communicate effectively with the person with dementia to provide support with activities of daily living.

Packages delivered high level coordination and management, and a multidisciplinary approach to assessment which is not generally available in mainstream low care packages.

Prior to establishment of the Innovative Dementia Care Pilot, RSL Care clients with dementia were being supported through CACP with supplementation from dementia-specific respite care services, often funded by the National Respite for Carers Program. RSL Care reported that the Pilot enabled more efficient and longer term support of high care clients than a set of services designed for low care clients cobbled together under different funding arrangements. The ability to address the needs of care recipient and carer under the one funding arrangement is seen as a major benefit of the Pilot. It was suggested that innovative funding arrangements should be geared to more proactive care management for the target group. A widespread gap in service knowledge among older people and the confusion caused by different eligibility and funding requirements add to confusion about what is the most appropriate service for a client. RSL Care recommends flexible service delivery at an earlier stage of the care continuum for people with dementia so that supports are in place to avoid crisis situations from developing.

Initial estimates of the resources needed for assessment and care coordination for Pilot clients were too low. Coordinators reported on the lengthy time that is required to establish rapport, build confidence and understand family dynamics impacting on the circumstances of carers and clients. In many cases, clients and carers either have not received services before, or have become disenchanted. Considerable ground may need to be recovered before a coordinator can establish a comprehensive care plan for the client. This can take several visits over a number of weeks. Early respite care assists greatly to ease the client and carer into acceptance of formal assistance. The early phase must be managed carefully to avoid further 'service disappointment'.

In terms of weekly hours, once a care plan is established, Pilot experience suggests that a minimum of 10 hours per week is required to support a client and carer. Case management load varies depending on the geographical distribution of care recipients. As an indication, Brisbane North had two case managers for 10 packages; Brisbane South had two case managers for 20 packages; and Ipswich/West Moreton had one case manager for 15 packages. All case managers were employed full-time. Each client was said to have received continuous interaction from one case manager.

Client profiles

All RSL Care Innovative Dementia Care clients have a relative or friend providing care at home and most were co-resident carers. Just under two-thirds of clients transferred to the Pilot from mainstream program delivery that included CACP, HACC, Veterans' Home Care, National Respite for Carers Program, and service provision through multiple programs.

Most RSL Care evaluation clients were reported to experience severe to profound core activity limitation in self-care and moderate to profound mobility limitation.

Non-zero MMSE scores at entry to the project ranged from 3 to 18 out of 30 points (median 14), indicating moderate to severe levels of cognitive impairment.

At time of entry to the project, five clients were completely dependent in self-care and mobility, 19 clients exhibited severe dependency, six clients exhibited moderate dependency and one client displayed slight dependency. One client was independent in self-care and mobility, but showed high dependency in IADL.

Behavioural and psychological symptoms data were reported for 21 clients. All exhibited memory loss, 12 clients exhibited symptoms at least occasionally and one client exhibited physical aggression frequently. Ten clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis.

Twenty-eight carers completed the CSI; 24 carers recorded scores above the threshold of high carer strain.

Key outcomes

Overall, the project's client base was younger than expected and more clients than initially anticipated were independently mobile. The very high needs clients tended to be younger, ambulant, and with behaviour management needs; whereas at the outset it was expected that high care needs would be associated with age-related frailty and dementia. Behaviour management needs resulted in a higher than expected demand for training and support for care workers and family members. Levels of case management needed to support a client and carer were much higher than anticipated, mainly because referrals were generally for people who had reached crisis point.

RSL Care project coordinators reported that the Pilot funding model provides greater scope to balance the case management load of people entering the project often at a time of very difficult home circumstances, with the ongoing case management and coordination needs of established clients whose care needs can change unexpectedly. Case management involves not just client care, but interaction with family members who are experiencing conflict and anxiety.

Fifty per cent of RSL Care evaluation clients were found to be still living in the community at time of follow-up, most of whom were continuing in the project. Nine clients (28% of the group) had entered high level residential care.

South Brisbane and Gold Coast Innovative Dementia Pilot

The Islamic Women's Association of Queensland and Multicultural Communities Council of the Gold Coast, with support from the Queensland Transcultural Mental Health Centre, established a pilot project in Brisbane and on the Gold Coast to target the needs of people with dementia from culturally diverse backgrounds. The aim was to offer an alternative to mainstream care services for cultural-specific care in a community-based setting. An important characteristic of the targeted client communities is a strong desire to maintain family members with age-related frailty or disability at home.

The partner organisations bring experience in HACC, CACP and respite care delivery to the pilot in addition to specialising in service delivery to culturally and linguistically diverse communities. Close ties to community groups facilitates ready access to a pool of bilingual support workers who provide not only communication support to clients, but an awareness of cultural preference and observance. Building on this existing experience and infrastructure, the project has extended an existing model of service delivery to meet the needs of high care clients, many of whom had been maintained on packages better suited to low care clients.

The Islamic Women's Association and Multicultural Communities Council of the Gold Coast operate CACP services that deliver 6 to 8 hours of care per week, although both organisations have in the past delivered up to 12 hours per week to very high needs CACP clients through goodwill. Funding for mainstream community care packages has been found to be insufficient to support a high-needs dementia client and the family carer for an extended period of time.

Needs in the project's target group reflect both cultural and linguistic diversity and a range of psychosocial factors associated with separation, resettlement and in some cases, the aftermath of war and persecution. After people immigrate to Australia, many strive to maintain their cultural practices. Continuity in language, food and meal patterns, religious observation, family roles, and living at home is central to being able to maintain cultural identity. For many such older people a move away from the family home to a setting that is not sympathetic to language and cultural observance entails both a loss of home and of identity. Language barriers in institutional settings impact on socialisation and more fundamental functioning such as food and fluid intake and psychological wellbeing. Providing access to a bilingual care worker means that the client is more likely to eat well and medicate safely. It may be equally difficult for many members of the target group to accept help from outsiders, particularly in the presence of language barriers and lack of cultural and experiential awareness.

Project coordinators remarked on the scarcity of culturally-specific care services for older people. A small number of residential facilities cater to the needs of people from culturally and linguistically backgrounds but they generally service a limited geographic area. Culturally-specific community care is very hard to access. The Gold Coast was said to have had no multicultural aged care services at the time apart from the South Brisbane and Gold Coast Dementia Pilot.

Typically, the family carer pays the price for a lack of formal support. Given the culturally related reluctance to use residential care even when needs are at an extremely high level, carers struggle on to their detriment. Any sign of not coping is perceived as failing the care recipient and failing the community. Carers in culturally and linguistically diverse communities who have not had access to services become used to not seeking help. In most cases, the caring role falls to wives and daughters. It can be a long process to bring a carer to the point of willingness to accept help. Carer support is thus an important aspect of providing a culturally sensitive service to high needs clients.

The project offers comprehensive packages of care to people who require bilingual support and a culturally sensitive approach to care. Whenever possible, clients are matched with care workers from their own cultural and language group. This means care workers are able to communicate with clients in their first language, and understand and support clients' social, cultural, religious and culinary needs and preferences, which is particularly important in light of evidence that dementia can cause asymmetrical language loss in bilingual people and has the greatest effect on a person's more recently acquired language (Mendez et al. 1999), meaning that English language skills may be impaired even for clients who were previously fluent in English as a second or third language.

Following referral of a client to the project coordinators, if confirmation of dementia is required the Queensland Transcultural Mental Health Centre is able to provide a bilingual mental health consultant from the same cultural background as the client.

Client profiles

The interpretation of MMSE scores for people from culturally and linguistically diverse backgrounds is problematic and it is apparent in data recorded for the evaluation that difficulties were experienced in assessing some clients' level of cognition. A primary health condition of dementia was recorded for most evaluation clients (22 out of 26) as per the Aged Care Client Record.

Most South Brisbane and Gold Coast Innovative Dementia Care Pilot evaluation clients experienced severe to profound activity limitation in all three core activity areas—self-care, mobility and communication. All had lost some ADL function and a median score of 11 points on the MBI indicates that approximately half of the clients were severely dependent in self-care and/or mobility when they entered the project.

A range of behavioural and psychological symptoms were evident in the client group. At entry to the project, 13 clients showed intermittent or extensive signs of emotional or psychological symptoms of dementia. One client was reported to be physically aggressive most of the time, and eight others displayed intermittent or occasional physical aggression. Seven clients wandered or displayed intrusive behaviour on an intermittent or extensive basis. Six clients presented a danger to self or others.

All but one carer who completed the CSI recorded a score above the threshold for high carer strain.

Key outcomes

South Brisbane and Gold Coast Innovative Dementia Care Pilot made considerable progress in assisting family carers to look after themselves and in reducing carer strain and social isolation. Bilingual support for care recipients facilitated the introduction of formal assistance or increased assistance from outsiders. This eases pressure on family carers.

The project worked collaboratively with ACAT assessors on approaches to the assessment of people from culturally and linguistically diverse backgrounds, for example, to promote an understanding that it may be inappropriate for a male ACAT member to assess a female client, or that the shame associated with letting a visitor see an untidy house or with 'failing' in the culturally assigned role of caring for a relative can lead carers and families to go to extreme lengths to maintain the impression that they are coping despite high strain.

The AIHW was made aware that the project encountered delays in obtaining response from ACATs in its early days, stemming from the fact that ACATs were not familiar with the new service. At that stage, care recipients were commencing services prior to completion of ACAT assessment. Some clients were said to be transferring from a CACP, having received ACAT approval some time ago. It is not clear that these approvals would have been for high care in all cases, or that each ACAT approval for CACP clients was current at the time of transfer. However, the evaluation data reflect mostly sound referral and assessment patterns, with only one client recording an ACAT approval dated more than 12 months before the client commenced in the service.

As at June 2005, 14 of the 26 evaluation clients were still at home receiving Pilot services; in total 18 evaluation clients were still living at home with Pilot services or another source of formal care (69%).

Ozcare Innovative Dementia Care Packages

The Ozcare Innovative Dementia Care Packages pilot serviced the Queensland cities of Bundaberg, Rockhampton and Gladstone and their surrounding regions, a catchment area that extends approximately 350 km from Ridgelands, north-west of Rockhampton, south to Bundaberg, and approximately 100 km inland from Bundaberg to Mt Perry. Service was coordinated from centres in Bundaberg and Rockhampton.

Ozcare is a large, established provider of community and residential aged care services in Queensland. The organisation delivers HACC, CACP, EACH, Veterans' Home Care, and National Respite for Carers Program services from over 20 locations around Queensland in addition to a range of other services for special needs groups. The pilot provided an opportunity for Ozcare to develop and implement a dementia-specific service for people in regional and rural areas where a high level of unmet need for such services existed.

The target group was people with a primary diagnosis of dementia who wish to remain living in the community and who have a current ACAT approval for high level residential aged care. The project proposal was developed with an expectation of targeting a mix of older frail people and younger ambulatory clients with advanced dementia, with or without a family carer. Most people accepted into the project had access to assistance from family or friends.

Ozcare reported on past experience in servicing high care community clients with dementia. A typical pattern would involve referral of a person with ACAT approval for high level residential care who is already on waiting lists at aged care homes. Many family carers would prefer their partner or parent to remain living (with them) in the community, however, limited hours of care and limited access to respite care can leave the carer believing there is no alternative but to actively pursue permanent placement, particularly when faced with increasing difficulties in managing behavioural symptoms. Thus, the primary area of unmet need in the target group was access to high hours of care with flexible delivery and in this respect, the project was not a major departure from Ozcare's existing service model. Rather, the Pilot enabled Ozcare to deliver a higher level of service to an existing client base more effectively and efficiently through flexible funding.

On the question of specific issues that impact on older people with dementia-related high care needs, Ozcare made a number of observations:

1. People can experience great difficulty in obtaining a medical diagnosis of dementia and this limits their timely access to appropriate community services. For example, at the time of reporting, people in the region had no access to a geriatrician; a neurologist visited Rockhampton once a month; Bundaberg had no visiting neurologist. By the time services receive a referral, more than likely the care recipient is exhibiting advanced behavioural symptoms.
2. Many people with dementia and their families and carers would benefit from earlier introduction to formal services through National Respite for Carers Program together with a CACP or HACC service. Diagnosis and medical management are critical to implementing appropriate care pathways.
3. There is a lack of access to memory clinics in the region.
4. Family members and carers are generally reluctant to use advisory services that are located in the south, for example, a Dementia Advisory Service call centre that operates from South Australia.
5. Carers can be reluctant to use residential respite services because of the minimum periods that are often imposed. Many residential respite services offer care for a minimum of 7 days and many care recipients do not respond well to a prolonged period away from home and familiar faces. Day respite centres offer a viable alternative but are not available in all areas and travel time to regional centres can be prohibitive.

The spread of resources over a large geographic region which involves high travel costs to rural and remote areas has a considerable impact on service delivery in the region, reducing the level of direct care to care recipients for each dollar spent.

Ozcare Innovative Dementia Care Packages provide ongoing comprehensive dementia-specific care under a single package of care rather than via multiple funding categories or multiple service providers. Simplified funding for high level care improves continuity of care and case management. The service adopted a multifaceted approach to care planning with an emphasis on carer involvement, carer support and respite services. In particular the project aimed to fill identified gaps for dementia-specific respite care services (residential and in-home) and transport services.

The range of services available to approved recipients included but was not limited to: case management and coordination, personal care, nursing and allied health care, respite care (including block respite and overnight care), domestic assistance, meal preparation and nutrition management, assistance with minor home modifications and access to aids and equipment, transport, emergency medical alarm and carer education.

Needs assessment and care planning is performed by a project coordinator and specialist assessments are brokered to appropriate services, for example, for occupational therapist or social worker involvement on a case-by-case basis. Initial needs assessment typically takes 1.5 to 2 hours in the home. Record keeping, obtaining informed consent, care planning and scheduling following an initial assessment can take up to an additional 2 hours. This activity often extends to organising enduring power of attorney and referrals to outside providers for additional services (for example, medication management, meals on wheels, home nursing).

Care plans are reviewed one month after commencement and then every two to three months.

Key factors that distinguish Ozcare Innovative Dementia Care Packages from mainstream service models for the target group include attention to dementia-specific aspects of service delivery through knowledge and understanding of the needs of people with dementia, their carers and families; skills in assessment and care planning; maintaining the group as a service target group to prevent care recipients from being relegated to the 'too hard' category; and access to staff training for specialised areas of care.

Client profiles

MMSE scores were recorded for 26 clients at first assessments which occurred at the start of the evaluation. Non-zero scores ranged from 1 to 26 points out of 30 points, revealing a range of levels of functioning from mild to advanced dementia (all clients have a primary health condition of dementia). A median score of 16 points reveals that half of Ozcare clients had reached the point of marked decline in ADL function that is associated with an MMSE score of around 16 points.

At the first ADL assessment two clients showed complete dependency in self-care and mobility, 16 clients exhibited severe dependency and 15 clients exhibited moderate dependency. This project recorded a high proportion of clients with continence management needs.

Wandering or intrusive behaviour were present in half of the clients. Seventeen clients showed signs of emotional or psychological symptoms at least occasionally. Fourteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, six of whom exhibited two or more symptoms on an extensive basis.

Key outcomes

The Ozcare Innovative Dementia Care Packages pilot demonstrated that it is possible to maintain high care clients with dementia at home with a comprehensive care package and care provision with a dementia-specific focus. Notable successes include two clients who returned home from residential aged care to take up a package and another client who received a package at a time of crisis in care (while waiting for residential placement) and decided to continue with the package rather than take a residential place when one became available. Families of clients who have died or entered residential care stated that, were it not for the care package, the care recipient was likely to have died in hospital or entered into care via hospital. Many package clients have accessed residential respite care in the past but families have expressed much higher satisfaction with a care package at home. Such examples demonstrate a strong preference for high level care at home, provided appropriate formal supports are in place.

Sixteen evaluation clients (46%) were still at home receiving service from the project at time of follow-up. Thirteen clients had entered residential high care and four clients were deceased (the status and whereabouts of two clients was unknown).

Ozcare identified late referral and intervention as a major challenge to assisting people in the target group. At the start of the evaluation 19 out of 30 family carers (63%) recorded high levels of carer strain. At their final assessment, 11 out of 21 carers (52%) scored above the threshold for high carer strain. Although the average measured level of carer strain in the group decreased over the assessment period and some carers showed marked reductions, a high proportion continued to report negative effects of their caring role, providing evidence of the ongoing high level of support that family carers need if informal care is to be sustained. Project coordinators remarked that in too many cases this was because formal assistance was sought and received too late. Many people reach crisis point by the time of their first ACAT assessment, so that it can be difficult or impossible for the families to consider community-based care. Alternatively, a package may be accepted as a perceived solution to the waiting period for residential care placement. Many people in this situation expect that residential care is the only viable long-term care option.

Approximately half of the people accepted into the project had had a nursing assessment for continence management. The 'retraining' approach to continence management (regular toileting without the use of continence aids) creates a number of issues for services and family carers. Multiple home visits per day are usually required, with carer assistance on each occasion. Skilled continence nurses should attend for training purposes. Ozcare remarked that some family carers reject intensive approaches to continence management.

Overall, the service model has developed in line with Ozcare expectations. Social support and community access components were expanded in response to needs within the target group. The client base was much as expected by Ozcare through previous experience of operating dementia-specific services for the National Respite for Carers Program and Community Aged Care Packages. It was noted that limited access to aids and equipment and high hours for care coordination present two practical difficulties for flexible service delivery.

Distance is another challenge in rural and remote regions. Lack of access to allied health and specialist medical services, vehicle availability, and limited public transport all contribute to the tyranny of distance. Staff travel in the course of service delivery is expensive and time consuming. Ozcare estimates one hour of staff travelling time is required for every 7.2 hours of care service delivery.

The project highlighted workforce issues in servicing the needs of the target group. There is a need for higher levels of training—a Certificate III is a very basic qualification and may not adequately equip staff to work with clients who have high dementia-related needs. In order for Ozcare Innovative Dementia Care Packages to operate effectively, staff numbers had to increase to ensure that several workers became sufficiently familiar with each client for continuity of care. Flexibility was built into the staff roster to allow for after-hours service and overnight care.

Dementia Care in Alternative Settings

Dementia Care in Alternative Settings is a pilot of 35 flexible care places for eligible residents of the southern suburbs of Perth, Western Australia. This project was an initiative of Southern Cross Care Western Australia Incorporated, a not-for-profit provider of residential and community aged care services.

Dementia care is part of the organisation's existing core service delivery programs. For over 6 years, Southern Cross Care WA has delivered community care programs including adult mental health (low level support), HACC services, CACP services, and HACC-funded dementia-specific day centres in Bunbury and Broome. Southern Cross Care WA provides consultancy services, employing a dementia consultant, clinical nurse consultant, occupational therapy consultant, registered mental health nurse and occupational health and safety consultant to work with clients across the full range of programs.

The objective of Dementia Care in Alternative Settings was to provide additional care options to members of an existing Southern Cross Care client base who were previously being supported on a high number of hours through the CACP service and to expand services to new clients in the community. The DCAS team suggested that the constrained level of service provision from more widely available mainstream care packages—limited hours of in-home care and lack of flexibility in respite care delivery—contributes to people with moderate to severe dementia entering residential care prematurely despite a strong preference of many for care at home.

There are programs that support individuals who are at an equivalent level of hostel care and need approximately 4–8 hours per week of service delivery, for example, CACP. Programs that provide an equivalent level of nursing home care and provide approximately 12–17 hours are limited in their geographical allocation and number of places, for example, EACH. Flexible respite is an area of high unmet need, according to Southern Cross Care. Community respite services tend to offer respite for short periods of time, typically just a few hours, or for longer periods in bursts of two to three days. Either model may not adequately assist a carer with other high time demands such as paid employment or other caring responsibilities, or a carer who needs longer periods of respite over a sustained period to help them cope with the demands of dementia care. Residential respite can be hard to access at short notice and is not the preferred respite service for many care recipients and their carers.

DCAS trialled a service model designed to deliver up to 24.5 hours per week to meet the higher needs of the target group. The project targets older people with moderate to severe dementia who wish to remain living in their own homes and who are not actively seeking residential care placement. Participation in DCAS requires that the client and his/her family are committed to the client receiving care at home. ACAT approval for low or high level residential care is required and assessment processes must demonstrate that a client has moderate to severe dementia and/or behavioural symptoms of dementia.

DCAS comprehensive care packages provide for service on seven days per week and up to 3.5 hours per day. Services are tailored to individual client needs and may include personal care, medication management, meal preparation and assistance with feeding, domestic assistance, escorting for shopping and appointments, social support, respite care, therapy and behaviour management, continence management and carer support services.

The high number of hours and flexible rostering of DCAS to ensure a minimum number of staff delivering services to a client are key innovative features of the project.

DCAS established a new respite care facility to offer day centre and emergency overnight respite care to complement the in-home respite service. Southern Cross Care contributed two adjoining units in a Southern Cross Care retirement village and uses project funding to operate the service. Day respite is available four days per week with two staff in attendance each day. DCAS respite clients normally spend 5 to 7.5 hours at the centre on each day of attendance. Residents in the retirement village assist staff on a volunteer basis and appear to enjoy the opportunity to contribute, while respite care clients benefit from the social atmosphere of the centre. Activities and lunch are included and transport to the centre can be arranged. The service allowed DCAS to provide quality dementia-specific day respite services on an efficient basis. The provision of respite care in alternative settings provides for maximum flexibility which met with high acceptance from care recipients and carers.

Client profiles

Nine evaluation clients had ACAT approval for residential low care and 24 were approved for residential high care.

MMSE scores were recorded for 28 clients when they entered the project. Non-zero scores range from 4 to 24 points out of 30 indicating that all assessed clients screened positive or on the threshold of cognitive impairment. Levels of cognitive impairment ranged from mild to severe.

Over half of DCAS evaluation clients measured severe dependency in self-care and mobility at time of entry. One client who was independent in ADL needed assistance in all but one IADL. On average, DCAS clients were completely dependent in three out of seven IADL at the time of entry.

DCAS recorded a relatively high proportion of clients with personal care needs related to continence management and almost all clients were unable to bathe/shower or use the toilet without assistance.

Behavioural and psychological symptoms were evident in most DCAS clients when they started with the project. Most clients (82%) exhibited emotional or psychological symptoms of dementia on an intermittent or extensive basis and a similarly high proportion (79%) were reported to be a danger to themselves or others. Twenty-four clients (73%) exhibited two or more psychological and behavioural symptoms on an extensive basis.

During the evaluation all clients had a family carer. Around half of carers were living with the care recipient. Twenty-four carers recorded scores above the threshold of high strain on the CSI, and five others scored just one point below the threshold.

Key outcomes

Recording of client ADL measures and carer strain scores is routine practice in needs assessment and review of clients across Southern Cross Care community care programs. This assisted with the incorporation of evaluation protocols into established DCAS procedures and enabled the project to report levels of carer strain on or around date of entry to the project.

DCAS targeted people with very high care needs, clearly in excess of a CACP level of service, and whose family carers reported high levels of strain. Support for carers placed heavy demands on the project coordinator and support workers. It was observed that in many cases, carers have managed without an adequate level of support from formal services so that by the time a client is accepted into DCAS, the carer can be experiencing severe strain. Twenty-four carers recorded scores above the threshold of high strain on the CSI, and five others scored just one point below the threshold. During the evaluation, repeated CSI measures revealed that many carers experienced a decrease in carer strain after their care recipient joined DCAS and this was reflected in a group median decrease of 3 points on the CSI. Twenty-one of the 27 carers who completed baseline and final assessments registered a reduction in carer strain.

The project team observed that earlier intervention may help to avoid some of the difficulties that DCAS encountered in introducing higher levels of support in circumstances that can involve high carer strain and family conflict.

The innovative day respite centre has been a major success for the project. Clients respond well to respite care in a small group, home-like setting where their individual needs and preferences are catered for. This model of respite is particularly well suited to clients who have an employed primary carer and those who can benefit from a more social form of respite care in a homely environment. DCAS offered different forms of respite care (in-home, overnight and day centre) to meet the needs of carers in a range of different life circumstances: older people providing care for a husband or wife (seven carers), employed, non-resident daughters, sons and in-laws (24 carers), other relatives and friends (two carers).

New and different models of respite care in DCAS recognise that clients have different needs too.

Seventeen clients, or approximately 52% of the evaluation group were still living at home at follow-up in June 2005, including 12 clients with ACAT approval for high level residential care. In total 16 clients were still with DCAS. Fourteen clients had entered residential care (12 high care) and two clients were deceased. One client who was on DCAS at follow-up had been discharged from the project in December 2004 to enter high level residential aged care. This person chose to return home, and recommenced with DCAS in January 2005. This is a prime example that DCAS, as a model of high level dementia-specific community care, offers a real alternative to residential care.

The Sundowner Club

The Sundowner Club is a new model of evening respite and socialisation for people with dementia who have been approved for residential care placement but who remain living in the community. The service was designed and established by ECH Incorporated in partnership with Eldercare Incorporated.

ECH is a large not-for-profit provider of residential aged care and retirement village accommodation in South Australia. ECH is an approved provider for the CACP program, is a collaborative partner within regional HACC programs and operates community Day Therapy Centre services. ECH also offers a range of food services to its own clients and those of other aged care providers. Eldercare Incorporated is a large provider of residential aged care including high and low level residential aged care services and dementia-specific services. Retirement living is the other major area of business for ECH and Eldercare. Both ECH and Eldercare operate secure dementia units within their residential care services.

The Sundowner Club was initially intended to provide services to existing ECH and Eldercare independent living unit residents with dementia who were at risk of placement into residential care, with a view to extending the service to community clients according to program capacity. Entry criteria specified by the Department of Health and Ageing include a diagnosis of dementia and approval for residential care placement. Initially targeting people who had been approved for high level care, the entry criteria were broadened to include low care approvals following negotiations between ECH and the Department in mid-2004. In addition, clients were required to need supervision in the early evening and to be physically able to leave their home safely.

The rationale for The Sundowner Club was to address a gap in mainstream service provision for people with dementia who have specific ‘after hours’ care needs, and those who find it difficult to access, or are reluctant to, use traditional forms of respite care. People who live alone, for example, may be excluded from respite services by virtue of not having a co-resident carer, adult day care programs are frequently rejected as ‘childish’ or as providing inappropriate activities by the intended service recipients, and men and younger people with dementia are observed to resist the idea of joining day programs where the ‘very old’ comprise the majority of participants (Sundowner Club Pilot Proposal, ECH Incorporated and Eldercare Incorporated).

Over time, ECH Support Services Coordinators in each of the three metropolitan service regions had become increasingly aware that people in the target group may be placed in residential care as a result of frequent complaints from neighbours and others about sundowner behaviour (‘sundowning’ refers to behavioural symptoms associated with dementia that tend to manifest more intensely in the late afternoon and early evening, often causing distress to carers and families and risk of harm to the person with dementia). Yet, it was also apparent that most people in this situation are able to manage at other times of the day with appropriate formal and informal supports. The Sundowner Club was thus conceived as a means to overcome a general lack of formal support services that extend into evening hours.

Clients of The Sundowner Club attend an evening meal and activity program in a communal setting. The Sundowner Club provides return transportation from home to the venue. Up to eight clients attend on any given night. A client is able to attend on more than one evening per week.

The Sundowner Club was designed to achieve the following primary outcomes:

- respite for carers
- supervision of clients with dementia
- improved quality of life for clients and carers
- extended periods of independent living and thus delayed entry to residential care, especially by supporting carers
- improved management of client behaviours on participating nights
- education for carers and significant others on successful ways of managing behaviours associated with dementia.

The Sundowner Club is unique among the Innovative Pool Dementia Pilot long-term care projects in that it is a stand-alone evening meal and socialisation program rather than a comprehensive care package service. Clients are expected to continue in any pre-existing formal support arrangements, with The Sundowner Club providing a supplementary, innovative service. Around 80% of Sundowner Club clients receive assistance from other community care services and continue to do so while taking part in the program. Clients who require ongoing case management will access that support through another service since The Sundowner Club does not operate a case management model. These clients usually have a primary case manager, either through a CACP, ECH Support Coordination Service, or a HACC-funded service. Sundowner Club staff liaise with the primary care manager to address changes in client needs or status. While The Sundowner Club program was not intended to replace case management or care package services, ECH reported that it has been effective in supporting clients and carers by providing regular respite which is valued by the client and carer.

Service delivery commenced in April 2004, operating five nights per week based at two locations in metropolitan Adelaide. Issues encountered during the establishment of The Sundowner Club included recruitment of suitably experienced/qualified staff willing to work regular evening hours; education of referral sources to make appropriate referrals to the program (both within ECH/Eldercare and other service providers, ACAT, GPs, etc); and waiting time for ACAT assessments (at the time that the program commenced operating some clients waited a number of months after referral to ACAT before being assessed by ACAT).

Client profiles

Changes in the profile of Sundowner Club clients were observed in the course of the evaluation. Data collection for the national evaluation commenced shortly after The Sundowner Club was established. During this phase the new program was promoted among community service agencies in the area to establish sources of referral and client selection processes were refined in line with operational experience. The profile of clients in the formative program from June to September 2004, and in the more mature program of September 2005 were recorded for the evaluation.

Initially, the evaluation tracked the progress of 15 clients most of whom were referred by ECH and Eldercare. A number of this initial group scored relatively high on the MMSE, in the range of mild cognitive impairment or no discernible cognitive impairment. By September 2005, seven members of the initial group were still attending The Sundowner Club. All of these clients recorded MMSE scores indicative of cognitive impairment.

In September 2005, most of the 21 clients attending The Sundowner Club had been referred from the broader community by service providers other than ECH or Eldercare. Seven were residents within ECH independent living units, of whom six clients were living alone with varying levels of support from family members. The larger group included:

- 17 clients with a family carer (12 co-resident) and four clients without a carer
- 14 clients with a primary diagnosis of dementia
- 14 clients who were able to be assessed recorded a current MMSE score indicative of cognitive impairment ranging from mild to severe. Scores range from 7 to 23 points out of 30, median 15.5. Seven clients could not be assessed because of difficulties in interpreting English instructions or responding in English but it was reported that most of these clients would show moderate to severe cognitive impairment had they been assessed in their own language
- seven male clients (two from culturally and linguistically diverse backgrounds): six were living with a spouse or family member and one was living alone in an ECH independent living unit
- six clients from culturally and linguistically diverse backgrounds including Latvian, Serbian and Italian nationalities. One client was living alone in an independent living unit (non-resident family carer) and the remaining clients were living with family carers (either partners or sons/daughters). Generally, clients from culturally and linguistically diverse backgrounds demonstrate more confused behaviours including frequent wandering, higher levels of agitation, and repetitive speech (often in a mixture of English and first language). Four of the clients required extensive staff assistance for basic personal care tasks including eating and toileting.

Clients in the mature program are more likely to come from a culturally and linguistically diverse background, more likely to live in the community with a co-resident carer, and more likely to score poorly on the MMSE or to be unable to be assessed than the initial group.

Key outcomes

The Sundowner Club is a highly innovative respite program that caters to people with or without a carer. It operates as an adjunct program to case management/package services which rely heavily on the continuing involvement of informal carers to provide ongoing support to clients with dementia. Discharge outcomes do not provide a valid measure of project effectiveness because discharge from The Sundowner Club will almost always be due to factors outside of the realm of a respite service and often associated with the availability of high care package support.

The Sundowner Club provides regular respite at a time of day when few other services are readily available to assist carers, to maintain the client's involvement in socially appropriate activities outside the home, to monitor clients who live alone for changes in self-care or health status, and to provide supervision for clients with 'sundowning' behaviours such as wandering and agitation. This project highlights the positive features of a small group model in supporting community living clients with advanced dementia.

The importance to carers of receiving out-of-home respite for the person with dementia has been emphasised repeatedly by carers in feedback to Sundowner Club staff throughout the program and during the follow-up evaluation in September 2005. Carers reported that being able to have regular time to themselves at home has been an important factor in enabling them to provide ongoing care. They emphasised the importance of feeling that the person with dementia is enjoying the experience and several carers reported that they would feel intensely guilty about receiving respite and less likely to continue with a service if they felt that the person with dementia was unhappy or was not enjoying the program. A social outing in a non-confronting supported environment is an important outcome for clients. The ability to spend time at home in the confidence that the person with dementia is enjoying a social outing is an important outcome for their carers.

Carers described how The Sundowner Club has reduced the isolating effects of Alzheimer's disease for both the person with dementia and their relatives. One woman described her husband's experience as 'the slow torment of losing his mind' which she felt was particularly difficult for a man who had previously been extremely successful in business and a gifted artist and musician. One client and his wife reported their ongoing sense of loss and grief at his diagnosis. His ability to be insightful fluctuates, however he was very aware that his illness was affecting his wife too. He was also able to clearly describe his loneliness and frustration, including his word-finding difficulty that slows his participation in social situations. He commented repeatedly on the importance of The Sundowner Club to him, stating 'I would certainly miss not having some contact with people'. His wife reported that he had been referred to other community-based groups, however participation was short-lived because he was frustrated by the activities offered, which he felt were inappropriate and patronising, and by his difficulty in coping with larger groups of people. This carer said that the small number of clients attending The Sundowner Club played a major part in her husband's willingness to attend, along with the activities offered, which he enjoyed. While The Sundowner Club offered the carer some respite, it was thought to be of greater importance to her husband because it enabled him to retain a valued social role with other people. Prior to attending The Sundowner Club, he had become increasingly withdrawn.

Another carer reported that 'a carer goes through more hell than the patient' because the carer has to cope with their own sense of grief and their partner's fluctuating insight and loss of function. She reported that she most missed being able to have a meaningful conversation with her husband and her difficulty coping with her husband's increasing egocentricity, especially during a recent period of illness when she needed support and he was unable to respond to her needs and placed extra demands on her. She talked of the importance of The Sundowner Club to her: 'the beauty of it (the Sundowner Club) is that he leaves here and comes back' (door-to-door transport is provided) and 'I get about 5 precious hours to myself —I can watch the news without him constantly interrupting me because he can't follow what is happening on the TV anymore'. She feared that his mobility would deteriorate to the point that he would become unable to board the Sundowner bus and that this would mean that he was no longer able to attend the evening. She also talked of the importance of the evening to her husband: '(he) gets bored at home with me' and 'he really enjoys the music. He has always loved music and singing, and (the coordinator) is able to bring out the best in him because she can just pick up a tune and play it on the piano while he sings. He gets a great deal of enjoyment from singing, but even that is slipping and her skill is that she can work out what he is singing so he still feels that he is doing well'. This carer feels that her husband's participation in The Sundowner Club has been valuable for him by enabling him to continue to participate in activities that he previously enjoyed while also providing her with invaluable respite enabling her to pursue her own interests.

Carers of Sundowner Club clients spoke of the importance to them of feeling that they could get out of the house on their own and resume their interests. For example, one used the time to have coffee with daughters, and more recently has joined an adult French language class for mental stimulation. Another carer enjoyed being able to phone her adult children who live interstate without constant interruptions from her husband with dementia. She reported that her children are a major source of support to her but that she can rarely speak to them freely with her husband present. She also watched the evening news uninterrupted, which she said 'on the surface is a small thing, but it means a lot to me because I am so isolated in the house with (her husband) and I need to know what is going on in the world or I feel even more isolated'.

A daughter reported to staff that her mother (who has advanced dementia and is no longer able to speak English and only speaks in single words in her first language) came home with a smile on her face for the first time in months after her first visit to The Sundowner Club. Similarly, the daughter reported to staff that her mother was 'happy all the next day even though she can't remember going to the Club, she is still happy' and that her mother was once able to tell her daughter 'I had a good time'. One wife spoke of her difficulty in finding activities that her husband would enjoy at home, stating that he got bored at home and needed his own 'normal' social outlet despite the extent of his dementia.

Interviews with the carers have highlighted the following issues and strengths of the small group model utilised by The Sundowner Club, including:

- their experiences of increasing social isolation, loss of meaningful social contacts and infrequent participation in valued community activities due to their responsibilities as a carer
- carers' desires to regain intellectual stimulation and social activities to replace the interaction with their partners that their partners are no longer able to sustain
- increasing social isolation for the person with dementia despite a strong desire to maintain social contact
- the importance of supporting the individual with dementia to retain their own valued social roles
- the difficulty experienced by people with dementia in coping in large group settings where they are overwhelmed by and unable to cope with or participate in multiple conversations and stimuli
- the importance of a small group model in enabling the client to participate and interact to the best of their abilities
- the importance to the client with dementia of being able to participate in a program that offers socially and developmentally appropriate activities and interaction
- the frustration experienced by clients with dementia of being expected to participate in programs which they perceive to be demeaning or infantile, resulting in reluctance to attend and/or service refusal
- the importance of staff being able to be respectful, flexible and responsive to individual needs in a group setting, adapting and changing activities to maximise each individual's participation.

The key issues affecting placement for those Sundowner Club clients who subsequently moved into residential aged care appear to be the lack of available high care or dementia-specific case management services, lengthy waiting lists for CACP services, the lack of other community programs able to support clients with dementia and challenging behaviours on an ongoing basis, and the withdrawal of informal carer support (either spouse, family or friends). In many cases carers had been actively seeking placement prior to the client commencing with The Sundowner Club and most clients remained living in the community for some months after commencing with The Sundowner Club program.

Lack of care packages or informal care for ongoing primary care of clients is reflected in Sundowner Club patterns of discharge. Of the initial evaluation group of 15 clients, seven clients were still living at home and attending The Sundowner Club in September 2005. One client had been discharged to a HACC service. The remaining seven clients had entered permanent care: low care, including low care secure placement (two); high care (four); unknown level (one).

3.3 Condensed summary of project objectives and operational focus

The domains of each project's operation as highlighted through the evaluation and described above are summarised in Table A3.3. A tick indicates that a project set out to address a particular aspect of dementia care and was seen to be achieving its objectives in that area. 'P' indicates that a project showed potential to expand or extend into an area but that during the evaluation either the clients were such that the project did not function in this way or that the particular aspect of care was not a stated project objective. Based on the experiences of short-term care projects, 'high level case management and coordination' equates to a one case manager per eight to 10 clients, although lower staff to client ratios may be manageable for an established and ongoing group.

Long-term care projects concentrated their activities in dementia-specific ADL and carer support. Apart from The Sundowner Club, all of the long-term care projects delivered the type of care that is the provider's core business for CACP clients but service to Pilot clients was delivered with a dementia-specific focus that demands skilled staff, high rostering flexibility and generally higher hours of service per week. All of the long-term care package projects focused on client-centred respite care to deliver more flexible respite than is more generally available. The Sundowner Club and Dementia Care in Alternative Settings have demonstrated novel forms of respite care.

Two of the short-term care projects, DBAMS and DRAH, showed a specialist diagnosis and behaviour management focus. These projects aim to address the medical and behavioural needs of clients at a key transition point on the care continuum. DBAMS and DRAH have addressed the difficulty in accessing specialist services in rural and remote areas, each by a different means—Telehealth in DRAH and mobile response with intermediate care back-up in DBAMS. NEDID played a transitional care role for patients with dementia in Austin Health facilities but also received community referrals.

It can be seen in Table A3.3 that FCS aligns closely with the long-term care projects in terms of objective and service model. Originally designed as a long-term project, the short-term nature of FCS presents special problems in relation to discharge. The rationale for offering high level ADL support and case management to people with dementia-related high care needs for just 12 weeks is somewhat elusive. Whereas the other short-term care projects have a very specific purpose of specialist diagnosis or transition care, the focus of FCS is intensive case management, social work, in-home ADL support, flexible respite care and 24-hour rapid response. These are the domains of ongoing dementia care. Respondents to the Care Experience Survey were unanimous in their praise of the service and all wanted it to continue.

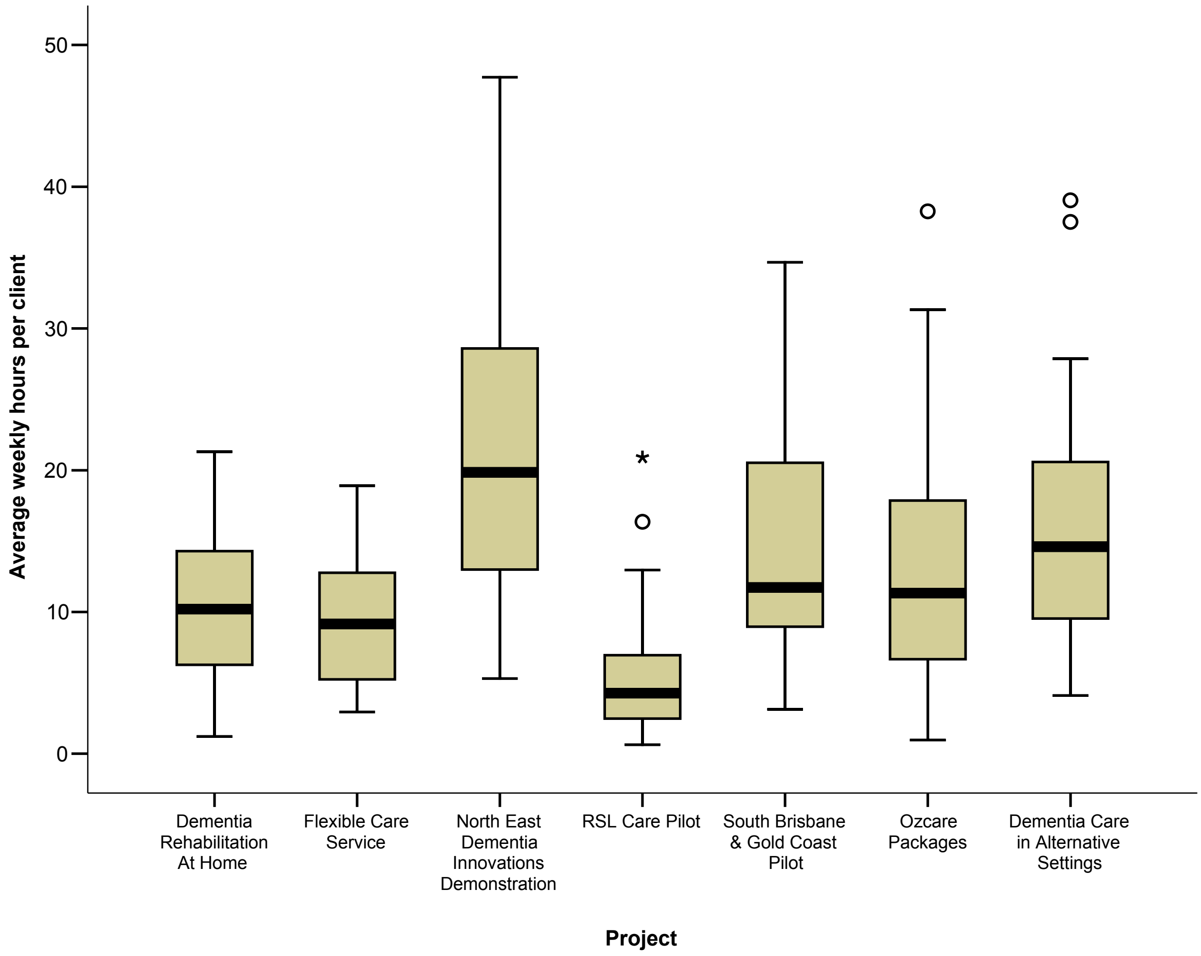
The flow-through concept whereby clients receive a short-term intervention is best suited to specialist interventions or transitioning between care settings. There is little evidence in this evaluation that many people in the target group would experience a reduction in care needs over a period of 8 to 12 weeks to allow a discharge to a lower level of care.

Many clients received very high hours of care each week. Figure A3.3 shows the distribution of weekly hours of service per client by project, averaged over the evaluation period, including personal assistance, nursing and allied health care, domestic assistance, social support and respite care (in-home and day centre). Each boxplot represents the middle 50% of client average weekly hours in a project—the lower edge aligns with the 25th percentile of weekly hours in the project and the upper edge aligns with the 75th percentile weekly hours. The heavy line that bisects a box is the median, or 50th percentile of average weekly hours per client. Low and high outliers are marked with a circle and extreme values are indicated by an asterisk. For example, the distribution of average weekly service hours per client in the RSL Care Pilot at the time of the evaluation has a 25th percentile of 2.3 hours, a median of 4.3 hours, and a 75th percentile of 7.1 hours. This means that 25% of clients were receiving up to 2.3 hours of services per week; 50% were receiving up to 4.3 hours per week; and 75% of clients were receiving up to 7.1 hours per week of instrumental assistance on average. Two clients were receiving markedly higher average hours of assistance: one received around 15 hours on average per week (circle in Figure A3.3) and another client received around 20 hours on average per week during the measurement period (asterisk in Figure A3.3).

The data represented in Figure A3.3 do not include case management and ancillary services such as delivered meals and transport, which were not recorded in time units. These other types of service were delivered at different levels by the projects. For instance, in DRAH, case conferencing of the multidisciplinary clinical team involved multiple team members in 2 to 3 hours of client review per week for almost all clients and Telehealth services for communication between interstate specialists, clients and case managers are not counted in these figures. Ozcare Packages serviced a large rural and remote region and staff travel time was not included in these figures of direct client care. Short-term care projects, Flexible Care Service, North East Dementia Innovations and Dementia Rehabilitation At Home, had the added case management component of discharge planning that starts around 4 weeks after client commencement. Thus, the plots represent the distribution of *minimum* average weekly hours of service per client in the reporting period. DBAMS and The Sundowner Club are not included because these projects are not in-home ADL support services.

Table A3.3: Assessment of demonstration of main innovation objectives, by project

	Short-term care projects					Long-term care projects				
	DBAMS NSW	DRAH NSW	FCS Vic	NEDID Vic		RSL Care Qld	Ozcare Qld	SB&GC Qld	Sundowner Club SA	DCAS WA
Dementia-specific client care										
High level case management and coordination	✓	✓	✓	✓		✓	✓	✓		✓
ADL/IADL with social support		✓	✓	✓		✓	✓	✓		✓
New socialisation programs									✓	
Culturally sensitive care						P		✓		
Client advocacy	✓	✓	✓	✓		✓	✓	✓		✓
Support in transitioning between care settings	✓	✓		✓						
Out-of-hours support and/or 24-hour response	✓		✓	✓		✓	✓	✓	✓	✓
Carer support with a dementia focus										
Flexible respite		✓	✓	✓		✓	✓	✓	✓	✓
New respite care models									✓	✓
Education programs for carers and relatives	✓	✓								
Social work/counselling	✓	✓	✓	✓		✓	✓	✓		✓
Improved access to geriatric and psycho-geriatric services										
Establish early accurate diagnosis	P	✓								
Specialist diagnosis and management of BPSD and co-morbidities	✓	✓		✓						
Build capacity among dementia care professionals	✓	✓		✓						
Service regional, rural and remote regions	✓	✓					✓			

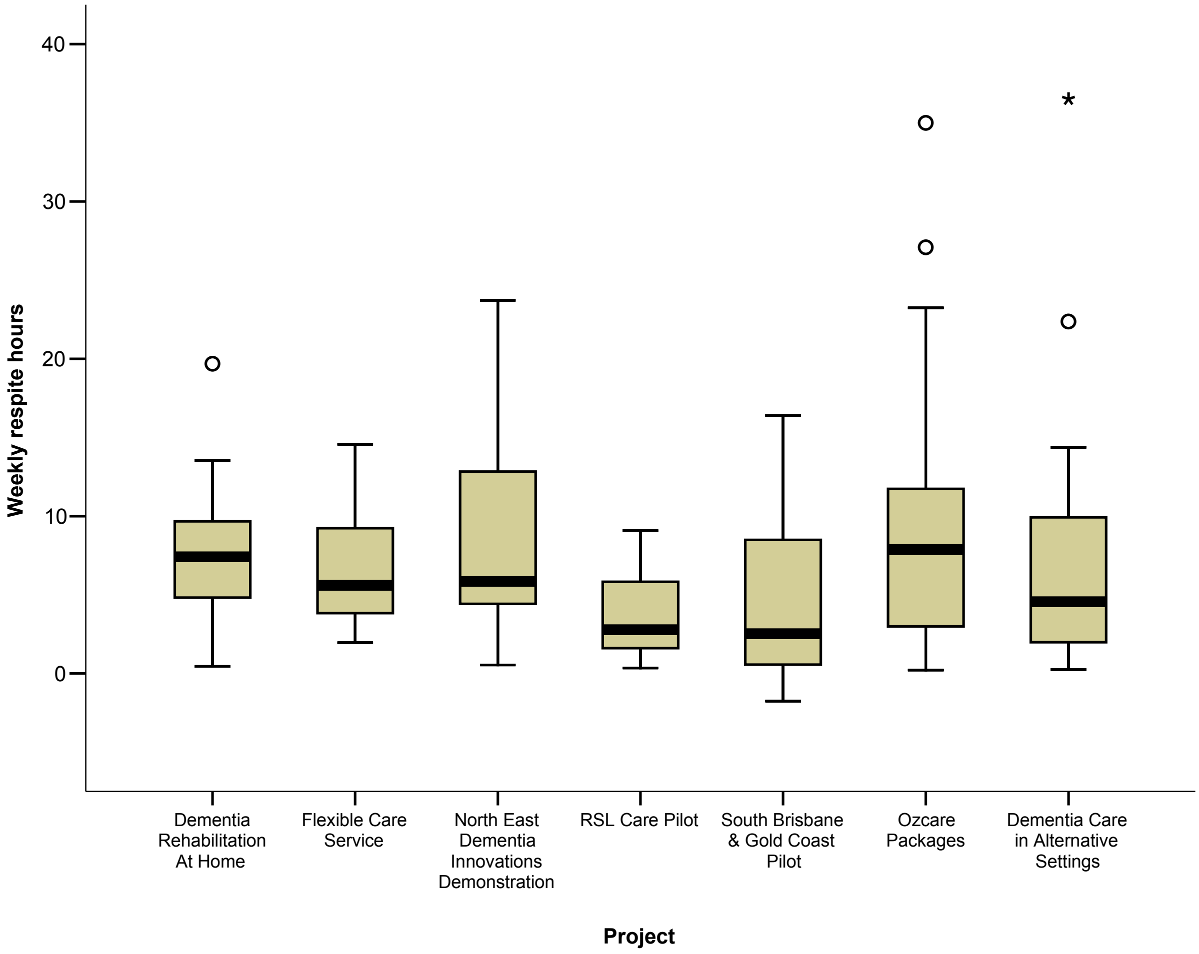


Source: Appendix Table A10.

Figure A3.3: Distribution of minimum average weekly hours of service per client during the evaluation, by project

Median per client weekly hours of direct care in most projects was around 10 hours per week, excluding case management and ancillary services. 75th percentiles of care hours in the projects mostly lie between 15 and 20 hours per week. In other words, at least 25% of clients in most projects received a minimum of 15 hours of assistance per week. Very high service users are seen in all projects.

Respite care was a large component of service delivery in terms of both the proportion of weekly care hours and proportion of service expenditure. Figure 3.4 shows the distribution of average weekly hours of respite care per client for each project during the reporting period. Projects that delivered day centre respite services recorded some very high respite care users, that is, in situations where a client attended a day respite centre on multiple days per week for 5–6 hours per day. In a number of projects 50% or more clients received an average of more than typical CACP hours (6–7 hours per week) in respite care alone, in addition to any other services received. Project coordinators emphasised the importance of high respite care in the weeks immediately after a client is accepted into a project to help stabilise the home situation and provide relief to family carers so that they are better able to contribute towards the planning of other services.



Source: Appendix Table A11.

Figure A3.4: Distribution of average weekly hours of respite care per client (in-home and day centre respite) during the evaluation, by project

The proportion of service expenditure used for the delivery of respite care is reflected in expenditure pie charts in Part B of the report for those projects that submitted financial results. The short-term comprehensive care package services (NEDID, FCS and DRAH) reported between 17% and 29% of service expenditure on respite care delivery. RSL Care and Ozcare reported approximately 40% and 47% of service expenditure respectively for respite.

Average levels of service (hours or number of events) for the range of service types offered by each project are given in the project reports in Part B.

3.4 Consumer perspectives

The above discussion and summary has drawn on information from interviews with the Dementia Pilot service providers and project steering committees, and from service activity data collected for the evaluation. The most compelling evidence that pilot services have offered new choices in dementia care comes from a reading of answers to the Care Experience Survey, mostly from carers and relatives writing on behalf of clients but in some cases from clients themselves, in relation to the following questions:

1. At the outset, what did you hope or expect the pilot program would deliver?
2. Overall, is the pilot program helping to address previously unmet needs?
3. What do you particularly like about the pilot program?
4. Are there any aspects of the pilot program that you do NOT like?
5. Carers: please comment on your previous experience (before the pilot program) of seeking help to care for your family member/friend with dementia.
6. Would the pilot program be an appropriate form of long-term assistance to you and your family member (or friend) with dementia?

Over the following pages vignettes taken from completed questionnaires are presented. These responses describe how projects have achieved their stated objectives in practical terms.

Flexible Care Service, Victoria (*annecto*—the people network)

Older couple living at home:

Client's most pressing needs: allied health, aids, social participation. Client had one hip replaced and had been on a waiting list for a second hip replacement for over 12 months. Client and carer had not been out of the home for social outings for over 5 years. The client's husband had been providing care for over 50 years since the client's first mental breakdown. Client had been hospitalised on multiple occasions and had a complex medication regime. Client has extremely limited mobility and high personal care and continence management needs. Local council had been providing twice weekly personal assistance (approximately 2 hours per week).

Hopes and expectations: 'Physio treatment. Help with equipment – wheelchair, toilet seat, respite in home, outings to clubs, home help.'

Benefits of FCS: The project delivered aids and equipment and facilitated social participation to an elderly and isolated couple. The client's husband summarised the experience: 'I have found care manager,[name], very caring and helpful on many occasions both with equipment, finding respite care in home, and out.' Carer indicated that Flexible Care Service would be an appropriate form of long-term care at home.

Older client who previously received help from younger family members only:

Client's most pressing needs: daily personal care, including help with medication use, and domestic assistance in the home. Family had been providing all personal assistance, domestic assistance, help to keep medical appointments, help with medication use, domestic assistance, gardening and home maintenance and accompaniment.

Hopes and expectations: 'Day to day assistance so client could continue living in own home for as long as possible and give some respite to family members.'

Experience before FCS: 'Nobody was able to provide me with direct contact details of necessary assistance. There was no progress in getting assistance.'

Benefits of FCS: 'Within a week of first meeting with pilot program all assistance was in place and have been provided with further information for future requirements if and when required. Client is now receiving personal care assistance and attending day centre twice weekly.'

Older couple living at home:

Client's most pressing needs: 'Bathing and dressing – but evening "sitting" a close second.'

Before FCS: 'My friends helped with 'sitting' so I could go out occasionally and my daughter moved back here to help day to day.'

Hopes and expectations: 'I didn't know pilot programmes existed but gardening, cleaning, gutters and heavy work were the things I worried about. As my husband's [condition] got worse bathing etc. became an issue.'

Benefits of FCS: FCS delivered personal assistance, home maintenance and gardening and day centre respite care. 'Great! The showering help is marvellous and 4 hours a month gardening is proving a great help. The help that has been offered is practical and pleasantly delivered.'

Older couple living at home:

Client's most pressing needs: continence management; showering.

Carer's hopes and expectations: 'Respite at home to allow me to do tasks outside of the home, for example, shopping etc.'

Benefits of FCS: FCS delivered personal assistance, continence management, domestic assistance and home modifications. Services were rated as good to very good, although showering assistance was withdrawn on request because of client's resistance. Weekend and evening emergency service was rated very good. The carer found FCS to be 'a great help to know I can rely on the mental help…I can get support if I need it and this takes a lot off my mind.'

Dementia Behaviour and Management Service, New South Wales (Southern Area Aged Care Service)

Older couple living at home:

On entering DBAMS, the client' most pressing needs were restlessness at night and need for help with behavioural and psychological symptoms. It had become difficult for the family carer to shower and dress the client.

Hopes and expectations: 'I thought the program would be able to offer additional professional services to assist both client and carer within the home so that daily living would be happy and manageable'.

Benefits of DBAMS: Carer indicated that DBAMS met the client's and carer's needs and rated as good to very good the personal assistance, continence management, assessment and management of behavioural and psychological symptoms, and help with medications. She remarked: 'If this [modifying client's behavioural symptoms to make care at home more manageable] could not be achieved within the home then a careful explanation was given to me to show how the program could unfold. I have the utmost respect for the gentle and helpful manner of all who contributed in the care of my husband through this program'. The carer particularly liked 'the caring approach to assessing the situation of client and carer in order to obtain the maximum assistance to each person'.

An older client receiving care from younger family members:

'For some reason we were not aware of our mother's demented state until it became very acute and violent and with the benefit of hindsight it has become very obvious that she showed many signs of mental deterioration up to two years before dementia being diagnosed. Had we educated ourselves re the signs of early dementia we may have been able to help her.'

Benefits of DBAMS: Good to very good assessment of needs, involvement of family and selection of services to meet needs. 'Excellent [care] at Yathong Lodge.'

An older client receiving care from younger family members:

The client's most pressing needs were 'getting meals and drinks, having showers; total deafness makes communicating really hard; dressing sensibly'.

Hopes and expectations: 'Help understand dementia'.

Experience before DBAMS: 'The family doctor not taking us seriously when asking for help, making us feel that we just wanted to push my mother into a home and not realising how hard it is to cope with the situation'.

Benefits of DBAMS: This carer rated as good to very good all aspects of DBAMS service, including assessment of client needs and suitability of care plan, involvement of family and friends in decisions about client care and services and selection of services to meet client needs, and indicated that DBAMS would provide an appropriate ongoing referral service for the client

Dementia Rehabilitation At Home, New South Wales (North Coast ACAT & Clarence Valley Council)

Older couple living at home:

Client's most pressing needs before the project included accurate medical diagnosis (confused state) and 'organising all medical treatment, medications, hearing aids, organising bathing and clothes, social activities'.

Hopes and expectations (written by wife to describe her husband's, the client's, circumstances): 'I was receiving no help, no care except that from my wife. I hoped the program would be able to get me out to do and see different things and give my wife some time out. We needed to get into the 'system' of care for example, podiatry, district nursing, etc. – as we had no information on where to go. Through the team organising these things for me I was able to get help.'

On previous experience (before DRAH): 'Bloody hopeless!! Three local doctors – no help!!! One said "nothing wrong with your husband – you spoil him rotten and he's lazy". I changed doctors. But this one did give me a referral to a physician. I didn't want a physician, I wanted a geriatrician – that deals with dementia. I was told I couldn't, I had to go through the 'process'! The physician did the 'test' – no word of Alzheimer's dementia just, 'Oh a bit short of memory'. X-rays taken, return to physician: 'normal ageing'. So he just gave me a script for a fairly new dementia drug; still the word dementia wasn't mentioned. Nothing. I left hoping these tablets would reverse what I new was wrong'.

Benefits of DRAH: 'Then he (my husband) went on this program. He was correctly diagnosed by a psychogeriatrician, diabetic clinic, dietician, podiatry, the ongoing treatment he needs. The Pilot program opened doors for me to know where to go and get help. Before the program I was at the end of my endurance, without hope. I don't need sympathy (it's nice) or [to be] loaded with guilt – I need sound day by day help and that's what the program gave me'.

Client with husband as primary carer:

'Before the Pilot Program I had my wife assessed by her local GP. He did not think there was a real problem. My daughter was not satisfied with that and contacted the Dr for another appointment and she came along with me to the surgery; she was able to ask more relevant questions than I. The Dr finished by apologising for not being more attentive to my wife's needs. After the appointment my daughter then contacted the local community centre. They put my wife into this pilot program and arranged a video consultation with a specialist at Concord Hospital. The specialist diagnosed by wife as having Alzheimer's disease'.

Client with employed family carer:

Client's most pressing needs: 'Meal preparation, cleaning house, organising all aspects of living at home, laundering clothing, paying accounts, etc., remembering to stay positive'.

Carer's hopes and expectations: 'Care for client when I was at work. A sense of not being alone during carer's absence from home. Stimulation for client's mind'.

Experience before DRAH: Care 'difficult to obtain, expensive. People employed to assist were not familiar with the needs of age, poor health and dementia'.

Benefits of DRAH: 'The staff have been excellent at all times. They are flexible, understanding and caring. The daily (five times per week) visits of the care worker; the assistance given by the care worker in the home; the social activity provided each week for the client; the availability of the care worker to take the client to the doctor, hairdresser, etc. while I am at work'. Carer also mentioned that she liked the availability of a holiday program for carers even though she was not able to avail herself of it because of work.

North East Dementia Innovations Demonstration, Victoria (Austin Health)

An older couple, wife providing care at home:

The client's most pressing needs on entering NEDID were 'dressing, personal grooming – showering, putting on shoes and socks. Dressing for the weather. Remembering [the] day – time – any appointments. Can't understand bills, instructions'. The couple had received no formal assistance prior to NEDID.

Hopes and expectations: 'I was hoping to understand what was happening to my husband mentally. I asked for respite care because I was becoming angry and frustrated by his behaviour and he, in turn, was becoming upset. I needed to try to fix our daily help for each other so it was more peaceful. I had heard of respite care and thought it would help me to help my husband'.

Before NEDID: 'I didn't realise my husband had dementia, I put it down to just getting old and cranky and to his other medical condition.'

Benefits of NEDID: NEDID has provided home maintenance, minor home modifications, aids and equipment, physiotherapy and occupational therapy, and day centre programs for the client, all rated good to very good services by the carer. The carer was very happy with the assessment, her involvement in care planning and service selection and the support provided to her as a carer. 'It is helping me understand how my husband's mind is failing to grasp reality and how he must feel. I feel more confident now to be of more help to him and not to shun any help for me as well. It is lovely to know we are not alone, there are friends to help…our personal carer who comes to fix up my husband is a lovely, caring young man. He is a credit to his job and I hope he stays with us. The other staff are kind, competent, and friendly, making our learning much easier. They show a personal interest in each of the [family] carers and make us very comfortable. ' The client's wife particularly liked aspects of carer education in NEDID: 'The way things are explained in simple terms and the instructor doesn't talk down to us. It helps us understand what is going on in our partners' heads. I hope it will continue to be here for us after the time is up. It's a great comfort.'

Older client with a younger family carer:

Client's most pressing needs: 'Finances and meals.'

Hopes and expectations: 'To give carer a break and to help encourage with general living.'

Before NEDID: 'The support just didn't seem to be there when it was needed for a long time'.

Benefits of NEDID: This client received help with medication use, aids and equipment, management of behavioural and psychological symptoms and physiotherapy/occupational therapy. 'The program has helped my father immensely and I am very grateful for all their help and time. I could not have asked for nicer people in helping us'. The carer particularly liked the helpfulness and efficiency of NEDID staff.

Older client with a younger family carer:

Client needed extensive help across a broad range of ADLs and before NEDID all help came from the client's daughter who hoped NEDID would provide 'daily carer support to daughter who is primary carer – who works fulltime and is not in good health. Client lives alone in own home and for 2 months daughter was required to move in with father to nurse him and manage acute pain and medication'. Before NEDID the client had received support and assistance from the Aged Care Assessment Team, physiotherapist and occupational therapist at Austin Health; their assistance was highly valued: 'The Aged Care Assessment Team (A.K.) was very professional and respectful in her contact with client and family. The occupational therapist (A.S.) was of invaluable assistance in her professional approach and respect for client and primary carer.'

Benefits of NEDID: NEDID delivered personal assistance, continence management and nursing care lifting some of the burden of care from the primary carer. 'Daily carer [care worker] contact with client has had a very positive impact on his general psychological and social outlook.'

Dementia Care in Alternative Settings, Western Australia (Southern Cross Care WA)

Client was an existing CACP client of Southern Cross Care WA with a non-resident family member providing support:

Client' most pressing needs: 'Making meals and drinks, shopping, medication, household cleaning/washing, companionship and entertainment and activities, feeding dogs, behavioural and psychological help.' The client was receiving assistance with nutrition, shopping and medication use but more hours were required for more assistance with household cleaning and laundry, companionship and help with activities such as sewing and baking ('which client used to enjoy but no longer can do without supervision'), and social events.

Before DCAS: 'I was ignorant as to what services/help was available for elderly people and those people with dementia. I also did not understand the effects of dementia on the person's skills, behaviour and on their family/friends. Three factors were crucial in improving the situation for both the client and myself: (1) the ACAT were vital and excellent with assessment of the client, informing me of services available and providing contact with community organisations to deliver that care; (2) Alzheimer's Australia provided excellent education and insight to me through their 'carer's course', counselling services and advice; (3) the community organisation providing care for the client simultaneously informed me of the pilot program. Without that organisation's input, I would not have known about the program nor been able to obtain access to it for the client.'

Benefits of DCAS: 'Has objectively greatly reduced loneliness and has provided stimulating activity for the client. Has helped the client with household chores and has provided initiative and supervision with activities – often the client can't do things by herself but can do them very well with minor help/stimulation. The client is objectively more content but subjectively no happier. The family member is very happy with the pilot program. The client's psychological profile hinders her from adapting to her changed circumstances [widowhood] and resents others helping her, believing she needs no help.'

Older client with younger family carers:

Prior to DCAS, client was receiving help from family members only. More assistance was needed for medication use, household chores, home maintenance, transport and accompaniment, physiotherapy and occupational therapy.

Client's most pressing needs: 'Medication prompts, meal preparation, companionship. Some activities client more willing to accept help from "outsider" than family. Laundry and home help.'

Benefits of DCAS: 'Creative problem solving of staff has problems solved in areas beyond family abilities, for example, client disoriented each Friday early evening (result of attending day centre). Availability of program ensures companion is present when client returns home and therefore prevents distress and possible wandering'. Family carers particularly liked 'the fact that it [DCAS] permits our mother to remain in her own home as is her wish. Professionalism and creative support that gives family confidence. Reliable interaction between carer support staff, coordinator and family'.

Older client with younger family carers who previously used a respite care service:

Client's most pressing needs: social skills, meals, household cleaning, shopping, 'one on one support'.

Family hopes and expectations: 'Continuity of carers with minimal changes. Help with washing, cleaning, etc., social activities, medication supervision, assistance with meal preparation'.

Before DCAS: 'Insufficient hours available in [previous service]. Many changes in carers [care workers], some not well trained and therefore didn't always understand client's needs.'

Benefits of DCAS: 'Continuity has given a sense of security to a lonely and fearful lady'. The family particularly liked 'careful selection of carers and minimal disruption by carers leaving. Obvious affection between carer [care worker] and client'.

Ozcare Innovative Dementia Care Packages, Queensland

An older couple living at home, wife is primary carer:

Client's most pressing needs: personal assistance, physiotherapy and occupational therapy, help with the behavioural and psychological symptoms of dementia.

Hopes and expectations: More social contact and activities, relief for carer.

Before Ozcare: 'My husband's doctor did not ever have him assessed for any respite or help services and did not even like me going in with him on doctor's visits which really concerned me as my husband was often confused and would always say he was doing well. When admitted to hospital the doctor was never available to give me any reports of [my husband's] condition and I took him to another much more caring Dr. A friend told me to contact ACAT myself and since then to the Carer Respite Centre and also to Day Respite Centre. Before we had help from all these wonderful organisations (only since January 2004) my husband relied on me for everything. He has had [named medical condition] for 17 years and the past 3 years have been frustrating for him and a nightmare for me. We have no family living in the same town. I have asthma, high blood pressure, take nexium for stomach problems but still very active at 72 years of age. I would suggest doctors should advise patients of help available to them as my husband's doctor for 5 years considered only his medication but his new doctor is much more helpful.'

Benefits of Ozcare Packages: Provided mobility assistance, domestic assistance, social support and day centre programs for the client. The carer rated standard of service and staffing arrangements as good to very good in all areas and particularly valued 'the help and friendship given'.

Client with a daughter who is primary carer:

Client's most pressing needs: 'Bathing, toileting, eating, dressing, outside contact.'

Family hopes and expectations: 'I am a widow and working full time as this is necessary for my family. I am an only child. I hope to keep my parents at home as long as it is possible. They would be so stressed out of their home environment. I go around at least once a day. As I am the only daughter (child) and working full-time I seemed to be on the go every minute of the day (every day).'

Benefits of Ozcare Packages: 'This is a wonderful program. Ozcare are exceptional and they have made a great deal of difference to my parents' life and mine…[staffing arrangements rated good to very good]… I am able to know this by seeing the positive outcome of my mother with Ozcare visits…that I am able to keep my mother in her own home environment which is what she wants – to stay in her home.'

Family members commenting on the experience of their elderly parents:

'We wanted permanency – to know that the assistance would not be withdrawn. Prior to the [pilot] program hours of support were not assured. Agencies did their best to provide whatever hours they could, but we get very insecure. At any time the hours could be allocated to someone else.'

Benefits of Ozcare Packages: 'We now receive exactly the same hours as before, but these are allocated hours and secure.'

To the question of the Pilot as a long-term option: 'More hours would be needed – we understand this is unlikely and appreciate what our family receives. There could never be as many hours that are genuinely needed to make this situation sustainable. Dad's whole life is devoted to keeping Mum at home and meeting her needs. He manages to do this with the help of the program, but there are never hours left for him to rest and rejuvenate.'

South Brisbane & Gold Coast Innovative Dementia Care Pilot, Islamic Women's Association of Queensland

An existing client with a younger family member as primary carer:

Client's most pressing needs: personal care and exercise. The client was on a CACP before the Dementia Care Pilot but needed higher hours of formal assistance per week in addition to care from family.

Hopes and expectations: 'Hours of care – increase; exercise.'

Benefits of South Brisbane & Gold Coast Pilot: 'Culturally appropriate to live at home – programme very helpful. All staff excellent.' Family member particularly likes 'Daily care for Dad and support for Mum. Respite care means Mum always has time to go out.'

A new client who previously used respite care only from another provider; wife as primary carer:

Client's most pressing needs: 'Personal care/all ADLs; nutritional needs, continence aids, mobility aid.'

Hopes and expectations: 'Personal care, respite, transport, nursing support.'

Benefits of South Brisbane & Gold Coast Pilot: 'Allows wife respite; attends to [client] needs and organises medical aids. Male workers for personal care. Female worker to support wife. Collaboration by nurse with GP'.

An existing CACP client who transferred to a Pilot package:

Client's most pressing needs: Client was on a CACP but needed more hours of personal care; attention to safety issues; mobility assistance; meal preparation and feeding. More hours per day, 7 days a week and more respite for wife.

Benefits of South Brisbane & Gold Coast Pilot: 'Visits by RN but need more hours (at the moment 16 hours per week not including respite). The workers speak the same language. Trained in the area of our needs'. The primary carer particularly likes the 'respite at home in the hours I needed most; speak the language Mum speaks.'

An existing CACP client who transferred to a Pilot package:

Client's most pressing needs: 'In-home respite; help to understand and manage behavioural and psychological symptoms of dementia; social support at home and in the community; every day to have fresh cooked food.'

Hopes and expectations: 'More social support; more service to fulfil my needs; more day respite/respite at home; interpreting at regular appointments; more nursing at home and help with medications.'

Benefits of South Brisbane & Gold Coast Pilot: 'All staff are very friendly, on time in my place. I had enough help from all of them. The pilot program is addressing and fulfilling my needs. More understanding of present problem of loss of memory; more service for me. Fresh food every day is [sic] been cooked. All appointments to the doctor and interpreting is done on time. '

RSL Care Innovative Dementia Care Pilot

An older couple, husband is primary carer:

Client's most pressing needs: more personal care assistance, continence management, mobility assistance, accompaniment, physiotherapy and occupational therapy, and respite for primary carer

Before RSL Care Innovative Care Pilot the couple had been using a respite care service.

Carer's hopes and expectations: 'Relieve me (husband/carer) of the showering and dressing of my wife. Give me additional respite each week in addition to DVA respite of 3.75 hours pere week.'

Benefits of RSL Care Pilot: 'Gives me time to rest and take a deep breath. Extremely helpful to me in organising my life as after 6 years of caring I was coming to the stage when I thought my wife would have to go into a nursing home which I wanted to avoid at all costs. Now I feel confident I can continue to care for her. Signed Husband.'

The client, an existing RSL Care client, has a younger family member as primary carer:

Client's most pressing needs: 'Bathing, dressing and toileting. Also meal preparation. [Client] does not instigate any activity.'

Carer's hopes and expectations: 'More social interaction for Mum as I work fulltime and she is alone for a large percentage of the day. Also an increase in her self-sufficiency by having someone here to encourage her to do things herself.'

Benefits of RSL Care Pilot: 'I am extremely blessed to have the carer who looks after Mum. She is an absolute gem and keeps an eye on me too which is lovely. Mum is getting extra hours which should help with her social interaction.'

A client with spouse as primary carer:

Client's most pressing needs: showering, dressing, help at breakfast time, toilet needs. Client completely unable to care for self, perform housework or shop. Client and carer had unmet need for assistance in all areas of domestic and social functioning and client needed full personal assistance, continence management, nursing care and management of behavioural symptoms of dementia.

Before RSL Care Innovative Care Pilot the carer provided all assistance 7 days per week without outside help.

Carer's hopes and expectations: 'There are 7 x 24 = 168 hours in a week. I'm left on my own. To my way of life the early morning time and dinner/bed times would seem to be the highest need for help. Perhaps efforts to those two periods of each day could be looked at. I accept staff can't be everywhere at the same time of morning of each day and I understand that other people are worse off than my wife.'

Benefits of RSL Care Pilot: The project delivered the only regular and ongoing assistance received by the couple, amounting to 12 hours per week. Carer rated personal assistance from RSL Care Pilots as very good: ' It's very good when you are able to get someone, but staff can't all be with someone at the same time' and found the monitoring of client's behavioural and psychological symptoms to be also very helpful'. Quality of respite care: 'excellent'.

The carer said that the project would be an appropriate form of long-term assistance but 'would be much better if more than 12 hours a week was available. It's very hard to try and help someone at home 7 x 24, doing everything by yourself with only 12 hours a week help.'

The Sundowner Club, South Australia (ECH Incorporated)

A summary of client and family hopes and expectations of service from Sundowner Club:

'Opportunity to meet people, have dinner and do activities.'

'Company of other people and meals being prepared for me.'

'Interaction with others.'

'A meal, conversation, meeting and talking [to] people.'

'To be able to socialise with people, have a cooked dinner twice a week. Join in with different activities that the program offers.'

'Company of other people. Able to socialise more with people with the same health issues.'

'Had no idea what to expect.'

And benefits of Sundowner Club to clients:

'Getting out of the house and doing something a bit different.'

'The chance to socialise with other people with the same problems as me. Having a home-cooked meal.'

'Getting out [and] interacting with others.'

'Staff have been very good to me. Very happy with the care and support of me. Enjoy being picked [up] by the bus and taken back home. If the transport was not available I would not be able [to] attend.'

'Staff are very caring people and willing to do anything to improve my quality of life. Being able to socialise with people. Having dinner cooked for me. Being picked up by the bus and taken home again. Joining in all the activities being done during the night.'

'Like seeing the different people. Beginning to come out of my shell—start talking to different ones. Listen more than anything else.'

'Program helpful in the way it helps me to communicate with others and getting me out of the house.'

The following detailed answer from a person with a relative in a long-term care project sums up the difficulties that people with dementia and their carers have in accessing assistance through mainstream services and contrasts this with their experience in a pilot project:

The client had identified unmet needs in all areas before entering the Pilot service:

> 'More hours and therefore more active assistance with bathing, toileting, dressing, medication, meal preparation and at night, changing into sleepwear and getting to bed.'

Before the Pilot the client was serviced by two providers:

> 'Fragmented service shared between two providers. Too few hours to be effective and to get all chores done. Gaps in service, for instance: no shopping, meal preparation, zero continence management. Found the locus of responsibility of getting help very difficult to identify. Too many players—GP, ACAT, Vet's Affairs, hospital social workers—but no-one taking ultimate responsibility to assess, plan and monitor delivery. "The system" is terribly confusing and difficult to access. You find out about entitlements by accident, not by design.'

And the Innovative Pool Dementia Pilot delivered a new care experience in the following ways:

> 'The stability of having one service provider and a single point of contact for family members.'

> 'The greater number of hours has been a godsend. Mum's condition has improved markedly—no longer depressed, feels more in control because the carers "lead from behind" —that is, they help but in a way that Mum thinks she is doing it herself. '
>
> 'Staff seem carefully selected for aptitude and well trained. Also, they are very well presented and handle liaison with family very tactfully.'

Family particularly liked:

> 'Having one provider in total control. The provider's regular reassessments to check on Mum's dementia and other aspects and adjust service delivery accordingly.'

In summary, clients and carers responded very favourably to new models of care that provide a single point of entry to a range of service types, where that single contact, the case manager/project coordinator, takes full and ongoing responsibility for service coordination while encouraging input from clients and family carers. Projects focused on delivering higher hours of care and service that is delivered at a time and in a form to suit individual needs. The major problems in accessing assistance from mainstream services that were raised by many respondents to the survey are:

- People with dementia and their carers are not accessing timely assistance and a major contributing factor is poor communication with general practitioners.
- Carers reported that family doctors often tend to a patient's physical needs, for example, medications, but ignore the caring and social needs which means that timely referrals to ACAT and community services are not forthcoming. Over time this contributes to high carer strain because practical assistance is not available when it is needed.
- CACP hours of assistance and the level of case management that is economically feasible to provide within CACP funding limits are insufficient to address the range of needs of most people in the Dementia Pilot target group.
- People who experience behavioural and psychological symptoms of dementia and their carers need assistance from highly adaptable services that employ staff skilled in creative problem solving. Many carers like staff to encourage the person with dementia to engage in activities and to be encouraged to do things for themselves. Servicing the Dementia Pilot target group is the domain of skilled and experienced care workers.
- Dementia may cause a person to lose the ability to do their favourite activities or go out socially but this does not mean that the person loses their desire for activity and social interaction. Pilot projects have placed an emphasis on increased participation in addition to ADL assistance. In other programs with more limited hours of care available, the ADL and respite needs are more likely to be attended to first, leaving little or no capacity to address the person's social participation needs. For some people with dementia this has dire consequences for their sense of wellbeing, hence psychological state and quality of life.
- Prior to the Pilot, many participating carers were providing a level of care to keep their relative at home which they indicated would be unsustainable over the longer term due to the carer's own age and health issues and/or full-time paid employment necessary to support the carer's own family. Policy decisions for future community care for people with dementia-related high care needs will have major implications for the ability of families to provide the level of support that is required to growing numbers of people with dementia in the community and for workforce participation.

Innovative Pool projects have variously addressed these issues and in so doing, they provide options for high level dementia care at home that were previously unavailable or in such limited supply as to be effectively unavailable.

Minor criticisms were levelled but respondents emphasised that these would in no way influence them to terminate a service. In some cases the difficulties encountered were resolved over a period of time. For example, a number of carers reported that there were too many care workers attending the client at first, but that this was resolved to the family's satisfaction and the client became settled with one or two workers making home visits; or services were initially offered at an unsuitable time of day but after discussions with family the project coordinator made more acceptable arrangements. Specific issues are mentioned below as a possible guide for service improvement. Carers have made constructive suggestions that may help inform the implementation of existing and future dementia care programs.

Several carers with a relative receiving a long-term care package said that hours of assistance were capped at around 10–12 hours per week, or that they were not receiving more hours than before but that their pilot project was able to guarantee the level of assistance received. While expressing gratitude for the assistance received, these carers indicated that more was needed. Service providers have had to manage project budgets to meet the needs of as many care recipients and carers referred for service as possible and to prioritise levels of service delivery for a group of care recipients. The main points to highlight are that most people in the target group can be expected to require more than 10–12 hours of assistance per week and that, based on the financial results submitted by two projects, there was capacity for projects to deliver higher levels of service in the reporting period.

Access to aids and equipment and weekend and evening emergency assistance have been issues for a number of care recipients in long-term care projects.

Family carers also used the Care Experience Survey to highlight the need for responsive communication between project coordinators and clients and relatives, for example, the returning of telephone calls and advice in advance of altered service arrangements. In more than one long-term care package project the number of care workers attending clients was at times too high for some clients (this does not seem to have occurred across the board). Too many faces arriving at the door can cause confusion and fear in the person with dementia. This is particularly an issue for those clients who do not have a co-resident carer to vet callers. One relative made the following request:

> 'One, or at most two, carers being allocated to each client would be beneficial. The client's short-term memory problems make it difficult for the client to cope with multiple carers—client still does not know four regular carers after 6+ months. By the time changes for holiday/sick leave are included, the client is very distressed at all the people who she does not know, coming in and out of her house. She does not know who to let in the front door. Having a business type card with name, photograph and organisation name on it which relief carers (that is, not the regular carers) can give to the client to keep each time the relief carer comes to the client's door may help reduce stress and confusion and uncertainty.
>
> I realise that funding is a major factor in staffing and, on the other hand, I consider that when clients have dementia, they would greatly benefit by having a consistent carer.
>
> **Please could this be considered in the evaluation of the pilot program by the Department.'** [emphasis original]

Ensuring staff continuity is not always an easy task in community care. Difficulties can arise when clients are spread over a large geographic area and there are only a handful of clients in any one 'pocket' who can be serviced by one or two workers while also providing each worker with enough hours of employment per week within the area in which they are prepared to travel. High travel costs associated with the escalating cost of fuel impact on the amount of travel time that workers are prepared to build into paid hours. Thus, number of packages and travel distances come into play besides staff sickness and holiday leave. Staff working for Ozcare Innovative Dementia Care Packages in Queensland are paid for travel time and are encouraged to use fleet vehicles, demonstrating one provider's initiative in minimising the impact of travel on take-home pay.

3.5 Main findings

This chapter describes the key features of Innovative Pool Dementia Pilot projects and highlights the important outcomes for clients and carers. Projects have variously tackled different aspects of dementia care—diagnosis, high level ADL support with high and flexible respite care, BPSD diagnosis and management, and social support.

Care choices that have emerged or are highlighted by the Dementia Pilot include:

- intensive case management that involves the coordination of in-home services and the accessing of and interaction with specialist services
- care packages that offer dementia-specific ADL support and respite care at a much higher level than is widely available through mainstream care packages
- specialist multidisciplinary interventions for diagnosis and management of dementia, dementia-related conditions, and conditions that often occur in people with dementia and which complicate the provision of care
- culturally specific care
- a 24-hour emergency and rapid response system
- innovative approaches to respite care and socialisation for people with dementia.

The projects in each category (short-term care and long-term care) should not be viewed as necessarily offering the same types of care or as operating under similar conditions. Project coordinators in the long-term care package projects all suggested that the service they offered could be described as a dementia-specific EACH package, however they have operated in different service environments, that is, servicing metropolitan or regional and rural communities, and some have targeted people from culturally and linguistically diverse backgrounds.

Specialist and transitional short-term interventions such as DBAMS, DRAH and NEDID help to 'catch' people at a point where without specialist support they are likely to face permanent residential care placement but with that support have a good chance of being able to remain in their familiar home environment. These types of services are needed to operate alongside long-term care packages for without them, it is likely that ADL support and respite care will at some point prove an incomplete solution to ageing in place for a person with dementia-related high care needs.

4 Accommodation and support outcomes

Chapter 4 examines the accommodation status of evaluation clients and consumer feedback on the issue of pilot services as long-term care options to address the evaluation question: *Do the pilot services enable clients to either re-join or live longer in the community (defined as long-term living arrangements other than residential aged care and hospitals)?*

Apart from nine people who had ACAT approval for low care, all care recipients who participated in the national evaluation had been approved by an ACAT for high level residential care. Chapter 2 presented functional profiles and characteristics of the care recipient group as further evidence of the overall high level of support need. Medium-term accommodation outcomes in projects should be compared in the context of differences between the support needs profiles of project care recipient groups.

4.1 Accommodation outcomes for clients in short-term care projects

By completion of follow-up in mid-2005, all clients who participated in the evaluation had been discharged from the short-term care projects, although four continued to be supported on a maintenance of effort basis, including 3 clients who remained in the DBAMS intermediate care unit. This section summarises length of stay and accommodation status of the 85 clients who were living in the community when they joined a short-term care project, all of whom commenced with the projects during the evaluation.

Average length of stay across the projects, including any leave days, was 86 days (range 15 to 212 days). Clients who were discharged and remained at home in the community were in a project for an average of 89 days.

Forty-eight of the 85 clients (56%) were living at home in the community when contacted for follow-up (Table A4.1). A mean of 231 days had elapsed between date of initial needs assessment for Pilot services and date of follow-up for clients who were at home (range 78 to 336 days), which represents the average number of days that each of the 48 clients had so far avoided high level residential care.

Clients contacted at home were found to be receiving formal services through various government programs. Most of the 14 clients who were not receiving government program support or who were receiving assistance from HACC only (with or without informal care) had been in the DRAH project. These follow-up outcomes are consistent with the lower needs profiles of a proportion of DRAH evaluation clients, as described in Chapter 2.

All projects reported that program support arrangements for clients following discharge were not always optimal given clients' support needs at time of discharge, but that the arrangements were the best that coordinators were able to make given what was available. DRAH recorded both actual and optimal discharge support arrangements to illustrate the disparity between availability and what was assessed to be an appropriate level of ongoing support (Chapter 2 in Part B). To summarise, an EACH package was the preferred discharge option for 17 DRAH clients but no EACH packages were operational in the project's catchment area at the time. Instead of the preferred discharge support arrangement the following outcomes were recorded for these 17 clients:

- four clients were discharged home with no formal support or with unspecified services;
- seven clients were discharged onto HACC or VHC services (with or without Day Therapy Centre services)
- four clients received a CACP
- one client was discharged to residential aged care
- one client was unable to be discharged from the project.

The most common ongoing support arrangements for community-based past clients in the other short-term care projects were found to be CACP, EACH and multiple program support (which may include a CACP or EACH package). Follow-up summaries in the project reports in Part B provide information about multiple program support arrangements.

Twenty-six clients or 30.6% of the group were in permanent residential care when located for follow-up, nine of whom were in a low care facility.

Two main points to emerge from follow-up of clients have implications for comparisons of the projects and assumptions about long-term savings that arise from short-term care interventions:

- 17 clients were discharged from projects directly to residential aged care. Another 9 clients were discharged from projects and remained at home for a period before entering residential aged care at a later date. One of these clients was on an EACH package and one was on a CACP package before entering residential care; the others were on HACC or HACC plus other programs. Exact dates of admission to residential care for these clients were not recorded but admission occurred within 6 months of discharge from a project in all cases.
- Support programs being used by clients discharged to the community often change over the short term. Thirty-five of the clients who were discharged from projects and who were still in the community at follow-up had changed their formal support arrangements between discharge and follow-up. Examples of changes in program support include clients who were discharged to a HACC service and were found to be on a CACP or HACC plus other program such as National Respite for Carers Program or another unspecified program, for example, a state government program; clients discharged to an EACH package were found to be later receiving EACH plus National Respite for Carers Program plus other unspecified program support; other clients discharged to an EACH package were later found to be on HACC plus National Respite for Carers Program instead of EACH; some clients discharged to a CACP were later on a CACP with additional HACC service; and so on.

Table A4.1: Short-term care projects community-based clients, number of clients by residential status and government program support at completion of follow-up in 2005

	DBAMS	DRAH	FCS	NEDID	Total
Discharged, at home					
Without government program support	—	3	—	—	3
Home and Community Care	—	10	1	—	11
Veterans' Home Care	—	1	—	—	1
National Respite for Carers Program	1	—	—	—	1
Community Aged Care Packages	1	6	1	—	8
Extended Aged Care at Home	—	—	4	2	6
Multiple programs (includes any of above)	—	5	5	3	13
Pilot program maintenance support	—	—	—	1	1
Other, unspecified program, e.g. state government	—	—	—	2	2
Not stated	—	1	1	—	2
Total clients at home	*2*	*26*	*12*	*8*	*48*
Discharged, in care					
Permanent residential care— high	3	3	8	3	17
Permanent residential care— low	7	—	—	2	9
Total permanent residential aged care	*10*	*3*	*8*	*5*	*26*
Intermediate care (pilot program)	3	—	—	—	3
Hospital	—	—	—	1	1
Total discharged and in care	*13*	*3*	*8*	*6*	*30*
Deceased	1	1	4	—	6
Unknown status/support arrangement	—	1	—	—	1
Total	**16**	**31**	**24**	**14**	**85**

Notes

1. Excludes 23 DBAMS clients living in an aged care facility on entry to DBAMS.
2. Clients discharged to multiple government support included those on CACP plus HACC; EACH plus NRCP and other unspecified services; HACC plus Day Therapy Centre services; HACC plus NRCP; Veterans' Home Care plus Day Therapy Centre services; Veterans' Home Care plus National Respite for Carers Program and other services.

— Nil.

The availability of care packages for discharged clients is influenced by supply and demand conditions that are likely to be different across the projects' service areas. Together with the observed instability of support arrangements over time for many community-based clients, this suggests that (a) it is difficult to assess or compare the effectiveness of projects on the basis of accommodation outcomes at either discharge or follow-up and (b) cost savings in terms of the number of clients who remain at home in the community cannot be reliably calculated on the basis of support arrangements at time of discharge.

It is not known if the availability of care packages has impacted on the number of clients who were discharged directly from short-term care projects into residential care, or the extent to which the supply of residential care beds might have impacted on clients discharged to home to wait for placement. The accommodation outcomes of clients who were discharged to community care programs or who remained at home without formal support is of special interest given the reported discharge planning difficulties. Outcomes for 51 clients in this situation who were contacted at follow-up are presented in Table A4.2 along with summary statistics for entry and discharge MBI and entry MMSE scores.

4.1.1 Client ADL levels by program support on discharge

One possibility is that the type of program support received on discharge from a short-term care project is related to level of client ADL impairment. Discharge data were examined to see whether this appears to be the case. Three clients who remained at home without program support after their service episode were people who did not have a carer, whereas the other 48 clients all had a co-resident carer during their service episode. Discharge summaries for the 48 clients with a carer were used to explore patterns of ongoing support program and ADL functioning.

The mean MBI scores at entry and on discharge for clients who received an EACH package appear to be lower than for the other program support groups (Table A4.2). The difference between the mean MBI scores for the EACH discharge group and the CACP, HACC/VHC, and multiple programs discharge groups was indeed found to be statistically significant at the 5% level of significance in a one-way analysis of variance. That is, clients who received an EACH package scored significantly lower on the MBI, indicating significantly higher ADL impairment on average than clients who received other types of program support. No significant differences in the mean MBI scores (entry or discharge) were found between the CACP, HACC/VHC and multiple programs discharge groups.

Projects appear to have prioritised clients with higher levels of ADL impairment for EACH packages.

4.1.2 Client residential outcomes at follow-up by program support on discharge

Higher proportions of clients who were discharged to HACC/VHC (24%) or HACC/VHC (17%) with other programs were found to be in high level residential care at follow-up, compared with clients who received a CACP (10%) or EACH (11%). Differences between the proportions cannot be tested due to the small sample sizes. The data raise a question about the importance of ongoing case management and high level care for people with dementia following short-term interventions. While case management can be accessed in some HACC Community Options services (for example, Linkages in Victoria), none of the discharged Dementia Pilot clients received this type of HACC service when project services ceased. The other issue is the very low functional levels of some clients discharged from a flexible care service onto HACC or Veterans' Home Care.

Table A4.2: Innovative Pool Dementia Pilot short-term care clients who were living in the community on discharge from a project, summary statistics for ADL and MMSE scores and residential accommodation outcome at follow-up

Program support on discharge	Number of clients	Functional measures summary statistics						Residential-care at follow-up	
		Measure	Valid observations	Minimum	Median	Maximum	Mean	Number	Per cent
None	3	Entry MBI	3	6	18	19	14.3	—	—
		Discharge MBI	3	5	17	18	13.3		
		Entry MMSE	3	12	12	19	14.3		
HACC/VHC/other	17	Entry MBI	17	3	14	20	13.9	4	23.5
		Discharge MBI	15	2	13	19	13.1		
		Entry MMSE	15	4	17	28	17.8		
Multiple program support[(a)]	12	Entry MBI	12	6	11.5	20	12.6	2	16.7
		Discharge MBI	12	5	14	20	12.6		
		Entry MMSE	11	3	17	23	14.4		
CACP	10	Entry MBI	10	9	16.5	19	14.3	1	10.0
		Discharge MBI	10	9	17.5	20	16.3		
		Entry MMSE	9	2	23	26	18.8		
EACH	9	Entry MBI	8	3	9	12	8.3	1	11.1
		Discharge MBI	8	2	7.5	11	7.4		
		Entry MMSE	4	8	15.5	24	15.8		
Total	**51**							**8**	**15.7**

(a) Includes HACC or Veterans' Home Care with Day Therapy Centre and/or National Respite for Carers Program.

— Nil.

4.1.3 Associations between client characteristics and accommodation setting on discharge

Due to the possible impact of discharge support arrangements on longer term accommodation outcomes, variables that might be associated with accommodation outcomes could be investigated only in terms of clients' accommodation settings immediately after discharge from a project, that is, not at follow-up. This leaves just 65 records for clients who received short-term care interventions who were living in the community at entry to a project and who were discharged either to remain at home or to enter residential aged care (with a known date of discharge). Clients discharged to hospital who were later found to have entered residential care were included in the analysis; those whose location at follow-up after hospital was not ascertained were excluded.

Logistic regression analysis was performed with the dependent, or outcome, variable coded as 'at home' or 'in care' and stepwise selection was used to test the significance of a range of potential correlates with accommodation outcome at discharge (using PROC LOGISTIC in SAS Version 8.2). Testing was performed at the 5% level of significance. Independent variables included in the analysis were age, living arrangement (alone or with others), unplanned or urgent hospitalisation just prior to referral to a project, entry and discharge MBI scores, IADL score at entry and discharge, and severity of behavioural and psychological symptoms derived from the RCS item scores (severe or not severe). Inclusion of MMSE scores would have reduced the available sample; it is considered that any impact of cognitive function on accommodation outcome is expressed in the included ADL and BPSD measures.

Living arrangement was the only variable to show a significant association with client accommodation status at time of discharge (X^2 on 1 degree of freedom: 5.74; prob = 0.0166). The sample comprised data on 10 clients who were living alone while receiving Pilot services and 55 clients who were living with family. Half of those living alone were discharged directly to residential care, compared with 14.5% of clients living with family. Living arrangement is bound up with carer availability since 53 of the 55 clients who were living with family had a co-resident primary carer. Based on the analysis results, the odds of a person who lives alone entering residential aged care on discharge from a Dementia Pilot short-term care project are estimated to be 5.8 times higher than for a person who lives with others. A 95% confidence interval for the odds ratio is estimated at between 1.4 and 25.0. The width of the confidence interval is due to the error of estimation in a small sample.

The evaluation found no evidence that age, level of ADL functioning or severity of BPSD at entry are significant predictors of a person being able to remain in the community after completing a short-term care intervention of the types offered in the Pilot. This is not to suggest that functional measures at entry are uncorrelated with short-term accommodation changes in the absence of the type of interventions available through the pilot services. It is also important to note that the finding is specific to the clients accepted into Dementia Pilot short-term care projects—the screening effects of ACAT assessment together with client intake policies are relevant. The client group represents a narrower range of functional levels than the general ACAT population.

It is concluded that the short-term care projects have been successful in assisting more than half of their clients to remain at home in the community, for an average of 231 days when follow-up was completed. Functional status at entry does not appear to have been an indicator of accommodation outcome on completion of a short-term intervention. This suggests that a person with dementia-related high care needs who has been assessed as eligible for residential high care has the potential to avoid placement in the short to medium term, even if severe cognitive and ADL impairment is present. The importance of family carers in assisting people with dementia-related high care needs to remain at home for as long as possible is implicated in the results. All short-term intervention projects were found to be addressing the needs of carers through respite care, counselling, education, advice and referral and seeking to identify and address specific causes of carer strain and have therefore provided the type of assistance that is required to help maintain people with high care needs at home.

It is speculated that more clients would have been living at home at time of follow-up had projects been able to source more care packages, particularly high care packages, for ongoing care. Access to suitable discharge options would be key requirements for the success of mainstreamed short-term intensive intervention.

4.2 Accommodation outcomes for clients in long-term care projects

Long-term care projects made efforts to contact clients who had been discharged since the start of the evaluation. Follow-up was completed by the first week of June 2005 and the status of 133 of the 141 clients (94% of the group) was ascertained (Table A4.3). Approximately 53% of clients who participated in the evaluation were living at home when contacted for follow-up and 30% of clients had entered residential aged care, in most cases high level care. Accommodation status and government program support was not determined for eight clients who had left projects during the reporting period or between the end of the evaluation and completion of follow-up. Failure to locate clients was usually because the clients had left their projects through a move out of the area or an admission to hospital without resuming project services.

Client accommodation profiles by project need to be examined in view of when clients commenced services and this is related to project establishment dates. For long-term care projects the evaluation was a snapshot of clients during a short time interval. Projects were asked to invite established clients at the start of the evaluation in addition to any clients accepted into the projects during the evaluation up to mid-October 2004. The DCAS and Ozcare projects became operational in October 2003; the South Brisbane/Gold Coast project commenced a month later in November 2003; RSL Care Pilot became operational in January 2004. The Sundowner Club commenced operations in April 2004, just 2 months before the beginning of data collection for evaluation. Hence, client commencements in the evaluation data are weighted in the later quarters for the RSL Care and Sundowner Club projects, while South Brisbane and Gold Coast, Ozcare and DCAS recruited proportionately more clients with early start dates (Figure A4.1).

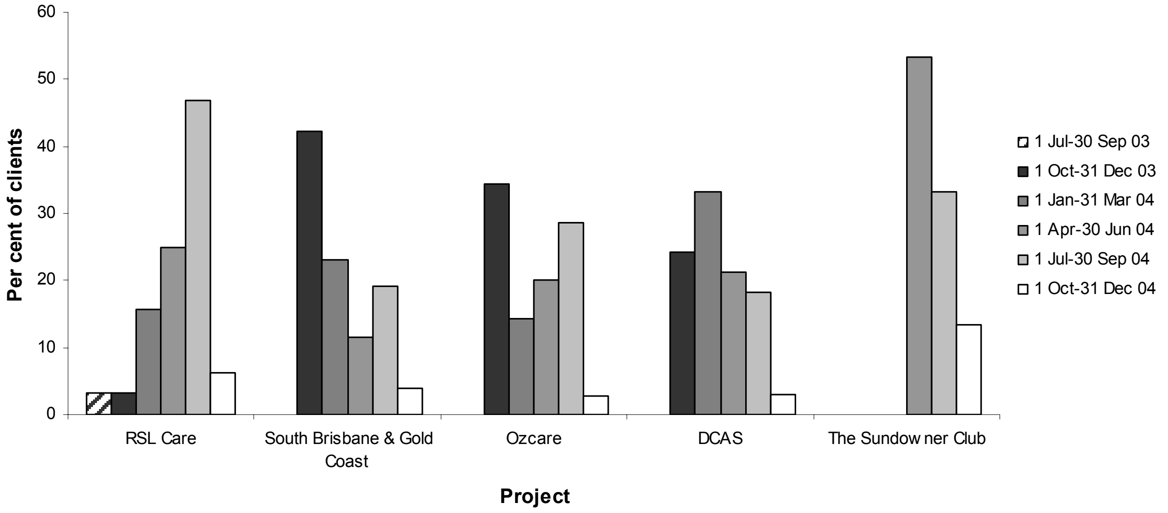
Table A4.3: Long-term care projects, number and per cent of clients by accommodation status and program support at follow-up

	At home					Residential aged care					
Project	**Continuing client**	**No program support**	**HACC**	**CACP**	**Total at home**	**RAC: low**	**RAC: high**	**Total in care**	**Deceased**	**Not located at follow-up**	**Total**
						(number)					
RSL Care, Qld	15	1	—	—	*16*	—	9	*9*	5	2	32
South Brisbane/Gold Coast, Qld	14	—	1	1	*16*	—	1	*1*	5	4	26
Ozcare, Qld	16	—	—	—	*16*	—	13	*13*	4	2	35
DCAS, WA	16	—	1	—	*17*	2	12	14	2	—	33
Care package clients	*61*	*1*	*2*	*1*	*65*	*2*	*35*	*37*	*16*	*8*	*126*
Sundowner Club(a), SA	10	—	—	(a)	*10*	2	3	*5*	—	—	15
Total	**71**	**1**	**2**	**1**	**75**	**4**	**38**	**42**	**16**	**8**	**141**
						(per cent)					
RSL Care, Qld	46.9	3.1	—	—	*50.0*	—	28.1	*28.1*	15.6	6.3	100.0
South Brisbane/Gold Coast, Qld	53.8	—	3.8	3.8	*61.5*	—	3.8	*3.8*	19.2	15.4	100.0
Ozcare, Qld	45.7	—	—	—	*45.7*	—	37.1	*37.1*	11.4	5.7	100.0
DCAS, WA	48.5	—	3.0	—	*51.5*	6.1	36.4	*42.4*	6.1	—	100.0
Care package clients	*48.4*	*0.8*	*1.6*	*0.8*	*51.6*	*1.6*	*27.8*	*29.4*	*12.7*	*6.3*	*100.0*
Sundowner Club(a), SA	66.7	—	—	(a)	*66.7*	13.3	20.0	*33.3*	—	—	100.0
Total	**50.4**	**0.7**	**1.4**	**0.7**	**53.2**	**2.8**	**27.0**	**29.8**	**11.3**	**5.7**	**100.0**

(a) Four Sundowner Club clients were receiving other program support concurrently with The Sundowner Club including CACP (three clients), and one client who also attended a Day Therapy Centre; six clients were attending The Sundowner Club without other program support.

Note: No clients were found to be in hospital when contacted for follow-up; however, a number of clients had been discharged from projects to hospital and had either returned home or entered residential care after hospitalisation.

— Nil.



Source: Appendix Table A12.

Figure A4.1: Long-term care projects, per cent of clients by quarter in which services were commenced, by project

Accommodation outcomes of clients who attended The Sundowner Club are influenced by their other main support arrangements since the project is not a case management/care package service.

South Brisbane and Gold Coast Innovative Dementia Care Pilot recorded a lower rate of transfer to residential aged care even though this was one of the longer established client groups. Contributing factors possibly include the relatively high proportion of clients not located for follow-up (four out of 26); a higher death rate, that is, the project was able to support clients at end of life; and the fact that members of the targeted culturally and linguistically diverse communities are highly averse to residential placement owing to cultural preference and a scarcity of culturally specific aged care homes.

The other three care package projects—RSL Care Innovative Dementia Pilot and Ozcare Innovative Dementia Care Packages in Queensland and Dementia Care in Alternative Settings, Western Australia—recorded more similar client accommodation outcome profiles. Dementia Care in Alternative Settings (DCAS) was the only project to report admissions to low level residential care—this was the only project in the Pilot to accept clients with ACAT approval for low care. Both DCAS admissions to low level residential care were clients with approval for residential low care.

Average length of stay calculated across all clients is not a meaningful metric because of the different establishment dates, hence differences in the maturity of client groups. Further, since 50% of clients had not completed their episodes of care, a longer timeframe is needed to estimate the average length of time that projects are able to help maintain high care dementia clients at home. Considering just the 76 clients who were accepted into projects after 30 April 2004, by which date all projects were up and running, 23 clients (30.3%) had entered permanent residential care by completion of follow-up approximately 12 months later. Thus, among clients accepted into pilot projects over a 6-month period, an estimated

70% can be expected to be still with their projects for between 6 and 12 months after service commencement, at a minimum.

By completion of follow-up, lengths of stay of up to 397 days were recorded for package care clients:

- 397 days in South Brisbane and Gold Coast Innovative Dementia Pilot
- 393 days in Ozcare Innovative Dementia Care Packages
- 377 days in Dementia Care in Alternative Settings
- 344 days in RSL Care Innovative Dementia Care Pilot.

The median length of stay of clients who entered residential care with a known project discharge date was 101 days (range 7 to 362 days; Table A4.4). This is a small sample median but the range of experiences of clients is evident in the data—some clients who ultimately entered residential care were supported at home for between 6 months and a year with assistance from a pilot project.

Table A4.4: Long-term care projects, summary statistics for clients accepted into projects from 1 May 2004 and who were discharged to enter permanent residential care (with known date of discharge)

Project	Number	Minimum days	Median days	Maximum days
RSL Care Innovative Dementia Care	4	54	80	119
South Brisbane & Gold Coast Pilot	—	. .	. .	. .
Ozcare Innovative Dementia Care	5	7	169	362
Dementia Care in Alternative Settings	5	87	111	214
The Sundowner Club	5	12	89	145
Total	**19**	**7**	**101**	**362**

Note: Discharge date is not available for four clients who entered residential care.

. . Not applicable.
—Nil.

4.3 Reduced use of hospital services

Fifty-four per cent of clients in short-term care projects had used hospital services in the 6 months before joining a Dementia Pilot project. Known details of recent hospital admissions were reported for 45 clients (42%) of the evaluation group who had been admitted to hospital. The number of urgent or unplanned admissions for these clients in the six months prior to joining a Dementia Pilot project ranged from one to four per client. All four short-term care projects provided a level of monitoring and support in medication use and nutrition management that would assist clients to avoid hospitalisation for conditions that can be managed appropriately at home. Three projects stand out as having high potential to reduce the need for hospital services in the target group through supported discharge or helping clients to avoid admission for dementia-related reasons.

NEDID, based within Austin Health, accepted four out of 14 evaluation clients from hospital wards and facilitated smooth transitions from hospital to home, ensuring that clients' occupational needs were assessed and met prior to discharge. NEDID was established following the discontinuation of a Trial at Home pilot and in the same vein as Trial at Home, NEDID has accepted hospital patients with dementia who would otherwise have entered residential aged care directly from hospital.

DBAMS, the specialist behaviour management service for people with severe behavioural and psychological symptoms of dementia provides a complete alternative to hospital care for people with dementia who cannot be managed in their usual care environment. Transfer to hospital often is not an ideal solution for people in this situation and the unfamiliar, clinical hospital environment can exacerbate behavioural symptoms. Moreover, the specialist assistance required for members of the DBAMS target group may not always be available in the region's hospitals. Acute care settings are not the best environments for an investigation of the range of possible causes for BPSD.

Ten of the 39 DBAMS clients had been admitted to hospital in the 6 months before joining DBAMS for dementia, delirium, psychosis or depression. On average, each patient had spent 11.6 days in acute care for these dementia-related or BPSD-exacerbating conditions. During the evaluation only one dementia-related hospital admission was recorded among DBAMS clients. For people with severe BPSD, living in the community or in residential aged care, hospital would be an automatic option when a breakdown in usual care occurs. DBAMS offers an alternative and superior means of assessing and managing BPSD. Based on the before and after reports of hospitalisation of DBAMS clients, it is estimated that the 16 DBAMS packages result in a saving of around 230 acute care days per annum by avoiding hospitalisation when the reason for admission is dementia, delirium, depression or other mental or behavioural disturbance.

By the time the evaluation commenced, the DRAH project in northern New South Wales based in the North Coast Area Health Service had established strong links with local general practitioners and hospital emergency departments and was receiving referrals from these sources. A high proportion of people being referred to DRAH would otherwise have been admitted to hospital for diagnosis and management. DRAH facilitates specialist medical diagnosis and clinical work-up within the community, helping people with dementia to avoid hospitalisation and to access specialist services.

Flexible Care Service, Victoria, and Ozcare Innovative Dementia Care Packages, Queensland, both established profiles in local hospitals. Clients have been discharged home from hospital with hospital discharge planners contacting these projects to arrange in-home support. This forging of relationships between health care and community services helps to avoid patient readmission by ensuring adequate support to patients in the recovery period.

Referrals to community service agencies from hospital staff provide evidence that projects are working effectively to reduce avoidable admissions to residential aged care direct from hospitals. The evaluation found that projects have provided and promoted in-home care as an alternative referral option for hospital staff who make or influence decisions on the care of people with dementia-related high care needs following discharge from hospital.

4.4 Consumer feedback on projects as long-term care options

Clients and carers were surveyed to find out how they viewed Pilot services in enabling clients to remain at home. Extracts from the survey summary in Chapter 6 relevant to the question of long-term care are reported below. Most responses came from family carers.

The majority of respondents (81%) believed that their project had fully addressed previously unmet needs of the client. Ninety-six respondents to the survey (81%) believed the Innovative Pool Dementia Pilot had delivered a level and type of service that would help to support their relative or friend for the foreseeable future. Eight respondents (7%) in four projects stated that the project would be an unsuitable form of longer term care. Nine respondents (8%) in six projects were unsure about the suitability of the project as a longer term care option.

The survey asked respondents to specify aspects of service delivery that they particularly liked, and these answers refer to both tangible and intangible benefits and enhanced service delivery. Open-ended responses mention intangible benefits, with increased participation and confidence/reassurance the most frequent of these. Most responses relate to specific types of assistance, most commonly respite care, carer support, and domestic assistance (10 responses each). In addition, around one-quarter of respondents referred to service quality and value, with enhanced service cited most often (see Table A6.12).

Carers and family members were asked about the information and support provided to them by the project:

- 80 respondents (68%) said that being involved with the project had increased their understanding of dementia (23 respondents did not believe that their understanding of dementia had been improved; 13 undecided)
- 101 respondents (86%) reported that the project had increased their awareness of the support services available to them (11 did not believe that the project had improved their awareness; four undecided)
- 94 respondents (80%) believed that the project provided enough help to support them in their caring role (10 indicated insufficient support; two undecided)
- 81 (69%) believed the respite care options provided by the project were suitable and all respondents rated the quality of respite care provided as satisfactory or good to very good.

Comments from carers and family members highlight the aspects of services that they value and help to illustrate the depth of gratitude for the assistance received in a way that service level measures cannot describe:

> 'As soon as my husband started the program, life changed for us.'
>
> 'Somebody can speak the language and understand our culture. My husband doesn't want to go to residential care.'
>
> 'This is a wonderful program. [The provider] is exceptional and they have made a great difference to my parents' life and mine.'
>
> 'Pilot program has been the best thing for [client] in years. Program workers get 100% mark from me as family member/carer.'
>
> 'Program has given me peace of mind.'
>
> 'The program has reduced the "frazzled" element for me by about 90%.'
>
> 'Excellent.'

To the question of pilot as a long-term care choice:

> 'Yes please! Could not get by without it. '
>
> 'It has been of great help.' [emphasis original]
>
> 'My family was very deprived we don't have any idea of service. This pilot project changed our lives.'
>
> 'Help received [through a CACP] only 10 hours [per week], which is too little, but now [things are] better.'
>
> 'We needed to get into the "system" of care… as we had no information on where to go. Through the team organising these things for me I was able to get help.'

> 'The pilot program opened doors for me to know where to get help. Before the program I was at the end of my endurance, without hope. I don't need sympathy (it's nice) or to be loaded with guilt—need sound day-by-day help and that's what the program gave me.'

When carers expressed doubts over whether pilot projects could provide support over the longer term, they mostly referred to high carer strain, need for supervision or higher level care than a project could provide, or concerns about whether project services would be sufficient to cope with needs that would likely increase in the future. For example:

> 'However just recently my mother's condition has deteriorated to the point where home care would no longer be suitable. I have found the responsiveness and flexibility of the coordinator to meet my mother's changing needs wonderful. It would be great to have this program continue. Had Mum's condition not changed so much we would have been very happy to have the program and staff continue for long term. I have nothing but praise and appreciation for this program. Thank you.'
>
> 'Certainly the program is of great value as a long-term solution. However once [client] becomes bed-ridden the program would be of little use as [client] would need nursing home care.'
>
> 'But would be much better if more than 12 hours a week was available. It's very hard to try and help someone at home 7 x 24 [sic], doing everything by yourself with only 12 hours a week help.' [emphasis original]
>
> 'No, if he was home I would have found it too hard to manage I myself 73 years old all day [sic]. Waiting for knee reconstruction also have diabetes (33 years on insulin).'
>
> '[Client] wants to stay in her home for as long as possible but needs all the care and help she can get. [My husband] and I are unable to give this kind of care as I have high blood pressure and he has to do the things I can't do in our own home.'
>
> 'If the dementia and health of my mother worsened, she would require more care, possibly the presence of someone in the house the whole time. I (the carer) am at work. This would equate to approximately eight hours per day on those days I am casual teaching.'
>
> 'The client's specific psychological difficulties in conjunction with the client's circumstances are the reason for the "no" answer rather than any aspects of the pilot program.
> (1) Client lives alone, since husband died on isolated, large rural property. I think the pilot would provide appropriate long-term assistance for people who live with another person in urban accommodation. (2) For the program to work long term, the client needs insight into his/her difficulties and a willingness to accept help. The client resents help from carers, can act with much resistance, is suspicious, blames others and can be verbally abusive. The client is unhappy and does not consider companionship from carers to be appropriate. However, as the client's only child I have found the program extremely valuable to me. I could not have coped as long as I have without it, and in my objective opinion the client was more unhappy before the program started. It has been of great short-term (about 9 months so far) assistance to me and my wife.' [emphasis original]
>
> 'Having been the main carer for 7 to 8 years, feel unable to continue indefinitely.'
>
> 'Unsure of the future.'

Projects have assisted people with dementia-related high care needs to remain at home for as long as possible. The projects have delivered instrumental assistance and valued carer support and have helped to increase service knowledge among the many carers who had not previously used community services.

5 Service costs and residential care savings

Chapter 5 addresses the evaluation question on the cost of services per client per day in terms of the price paid and the cost of delivery.

Service providers were asked to provide financial reports covering all project activity from 1 July to 31 December 2004. Income and expenditure associated with evaluation clients constitutes a proportion of total income and expenditure since not all active care recipients during the two quarters participated in the evaluation. Financial reports were not supplied by two projects: South Brisbane and Gold Coast Innovative Dementia Care Pilot (Islamic Women's Association of Queensland) and Dementia Care in Alternative Settings (Southern Cross Care, Western Australia).

5.1 Cost of services to government and consumers

The main sources of income to projects is Australian Government flexible care subsidy payments and client co-payments; daily rates are shown in Table A5.1.

Operational Guidelines for the Innovative Pool indicate the Australian Government's preference for projects to put in place arrangements for client co-payments, following the same principles as for community care more generally:

(a) If the care recipient's income is less than or equates to the amount of the maximum basic rate of pension, the fee must not exceed 17.5% of the amount of the maximum basic rate of pension.

(b) Where the care recipient's income is greater than the maximum basic rate of pension, the fee must not exceed 17.5% of the amount of the maximum basic rate of pension plus 50% of the income in excess of the maximum basic rate of pension.

Accordingly, co-payment amounts vary across the projects and between clients in a project and most projects offered discounted fees to a proportion of clients.

The daily cost to the Australian Government of comprehensive care packages in the Pilot lies between $79.82 and $106.83. All clients with ACAT approval for high care who entered an aged care facility entered at high care level. The effective subsidy levels for residential high care (RCS levels 1 to 4) on 1 July 2004 ranged from $65.22 (RCS 4) to $120.65 (RCS 1), with slight variations across the states and territories. The RCS levels on admission of clients who entered residential care are not known; however, given the levels of need for assistance recorded at entry to pilot projects, a minimum of RCS 3 ($92.27 to $94.07 as at 1 July 2004) and average of RCS 2 ($107.10–$109.25 as at 1 July 2004) is assumed to have applied for these admissions. The cost to Government of care packages is between $2 and $27 per client per day less than residential care subsidies, depending on the project. Clients pay between nil and $7 per day for care packages, representing a significant saving compared to accommodation payments for residing in an aged care facility, which are negotiated between residential care providers and clients on an individual basis.

Table A5.1: Innovative Pool Dementia projects: location, date of service commencement, number of packages and per package average daily income

Project	Daily payments Flexible care subsidy[(a)]	Client co-payment min–max (mean)	Average combined per person payment[(c)]
Short-term care packages			
Dementia Behaviour Assessment and Management Service (DBAMS)	$92.46	Nil (community) $37.00 (intermediate care)[(b)]	$92.46 (community) $129.46 (residential)
Dementia Rehabilitation At Home (DRAH)	$83.47	Nil	$83.47
Flexible Care Service (FCS)	$97.45	Nil	$97.45
North East Dementia Innovations Demonstration (NEDID)	$106.83	Nil or $5.80	$112.63
Long-term care packages			
RSL Care Innovative Dementia Care Pilot (RSL Care)	$86.17	Nil–$6.00 ($5.20)	$91.37
South Brisbane & Gold Coast Innovative Dementia Care Pilot (SBGC)	$79.82	Nil–$7.00 ($3.30)	$83.12
Ozcare Innovative Dementia Care Packages (Ozcare)	$80.89	$1.00–$6.00 ($4.91)	$85.80
Dementia Care in Alternative Settings (DCAS)	$94.00	$1.43–$5.57 ($4.71)	$98.71
Respite and socialisation program			
The Sundowner Club	$30.73	$1.50	$32.23

(a) Based on a mix of clients at RCS Levels 2, 3 and 4.

(b) Clients who stay in the intermediate care facility pay $37 towards accommodation costs for each day in the facility. No co-payment for outreach.

(c) Sum of Australian Government average per package daily subsidy and standard client fee. Where client fees vary between a minimum and maximum amount, the mean is used to calculate average combined daily payment.

Source: Memoranda of Understanding between approved provider and Australian Government (flexible care subsidy rates); evaluation database (client co-payment rates).

Residential care does not necessarily substitute for care packages with a high clinical component such as DBAMS and DRAH. In these projects, the cost of service delivery includes the cost of specialist services that would otherwise be provided on a private consulting basis or in hospitals incurring out-of-pocket medical expenses to clients and charges to Medicare and state health budgets (depending on whether clinical work-up and treatment is done on an admitted patient or outpatient basis).

5.2 Cost of service delivery

Table A5.2 contains a summary of income and expenditure reported by the projects.

- Short-term care projects reported a carry-over of funds from the September 2004 quarter into the December 2004 quarter, highlighting operating surplus as source of funds during the reporting period in addition to flexible care subsidy and client co-payments.
- NSW Health contributed to the operation of Dementia Behaviour Assessment and Management Service (DBAMS) and Dementia Rehabilitation at Home (DRAH). Agreements between the state and Australian Governments for these projects included New South Wales Government contributions of $200,000 per annum to DRAH and $776,991 per annum to DBAMS in rehabilitation and care coordination support. DBAMS reported part of this contribution in the two financial quarters of the evaluation; in the reporting period DRAH received in-kind contribution from NSW Health in the form of assessment and clinical support but this is not reflected in DRAH financial reports for the evaluation.
- DRAH did not report state government payments and nor are costs covered by state contributions reported in the project's statement of expenditure; therefore, the financial reports for DRAH provide a balanced picture of income and expenditure although they do not reflect the total cost of delivering the service. State contributions have been in the form of access to existing Area Health Service infrastructure provided free of charge to the project.
- DBAMS reported state government contributions in the reporting period and there was an anticipation that part of the expenditure on the intermediate care facility, Yathong Lodge, in the reporting period would be covered by future State contributions. DBAMS clients admitted to the intermediate care facility pay $37 per day of inpatient care towards accommodation costs, which contributed to the $65,683 the project collected in client co-payments in the reporting period. DBAMS reported a deficit of $130,856 at the end of December 2004. This resulted from costs associated with a formal review of Yathong Lodge, including consultancy costs, payments to staff stood down during the review period, and the additional costs for bringing in additional staff and management to cover nursing shifts, manage the unit and implement the review recommendations. During the reporting period, repair and maintenance costs were also incurred, associated with repainting the unit. The project coordinator reported that the Area Health Service would fund the shortfall, but at the time of reporting no budget adjustment had been made.
- Expenditure reported in quarterly financial reports to the evaluation does not reflect the true cost of service delivery in projects with a high clinical component/multidisciplinary team environment due to the in-kind contributions from health services (DBAMS, DRAH and NEDID).

Table A5.2: Innovative Pool Dementia Pilot projects, available funds and expenditure by project (nearest whole dollar), 1 July to 31 December 2004

	Income								
Project	**Aust Govt subsidy income**	**State govt payments**	**Client co-payments**	**Other income**	**Total new income**	**Funds carried forward[(a)]**	**Total available funds**	**Total expenditure**	**Surplus/ deficit[(b)]**
Short-term care packages									
DBAMS	269,984	388,496	65,683	—	724,163	827	724,990	855,846	–130,856
DRAH	228,499	—	239	1,970	230,708	43,500	274,208	274,207	—
FCS	355,692	—	—	—	355,692	78,000	433,692	415,500	18,192
NEDID	194,965	—	6,628	—	201,592	40,186	241,778	201,378	40,400
Long-term care packages									
RSL Care	592,839	—	20,487	—	613,326	—	613,326	354,135	259,191
SBGC	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Ozcare	442,873	—	21,870	—	464,743	—	464,743	318,319	146,424
DCAS	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.	n.r.
Respite and socialisation program									
The Sundowner Club	81,776	—	647	—	82,422	—	82,422	71,707	10,715

(a) Surplus/deficit reported as carried forward from the June 2004 financial quarter into the September 2004 financial quarter.

(b) Surplus/deficit remaining at the end of the December 2004 financial quarter.

n.r. Not reported.

— Nil.

Source: Project quarterly financial reports.

Using the data provided in financial reports, project expenditure per client service day was calculated by dividing total expenditure by the number of client service days reported in occupancy reports (Table A5.3). Short-term care projects were able to expend in excess of new income by drawing on surplus funds from previous quarters. The high rate of expenditure reported by DBAMS has to do with capital expenditure at Yathong Lodge in the period, as mentioned earlier. The two long-term care package projects that provided financial results reported expenditure well below income per client service day, in excess of CACP subsidy ($32.04 at 1 July 2004) but well below EACH-level subsidy. DCAS did not supply financial results but judging by the figures provided by Ozcare and RSL Care and considering the service activity profiles of all of the long-term care package projects, it is not immediately obvious that acceptance of clients with ACAT approval for low care into DCAS is a good use of this level of funding and service delivery.

Table A5.3: Innovative Pool care package projects (short-term and long-term), number of client service days, total expenditure and expenditure per client service day by project, 1 July to 31 December 2004

Project	Client service days	Total expenditure ($)	Average expenditure per client service day ($)
Short-term care packages			
DBAMS	2,938	855,846	291
DRAH	2,660[(a)]	274,207	103
FCS	3,680	415,500	113
NEDID	1,691	201,378	119
Long-term care packages			
RSL Care	6,538	354,135	54
SBG	n.r.	n.r.	n.r.
Ozcare	5,032	318,319	63
DCAS	n.r.	n.r.	n.r.

(a) DRAH client service days include 627 ‘maintenance days’ (extended length of stay due to discharge difficulties), as reported by the project.

. . Not reported

Source: Project quarterly financial reports.

The Sundowner Club reported total expenditure in the two quarters of $71,707 for the delivery of 673 attendances, working out at approximately $106.55 per client attendance. The project operated at 75% of capacity (a maximum of eight clients can attend per session and there are five sessions per week) which affects the level of expenditure per client service day. The Sundowner Club has high fixed costs—approximately 80% of total expenditure comprises staff salaries and related costs plus operation of a bus service—that apply regardless of the number of clients attending.

A breakdown of direct care expenditure by service category is reported in each of the project reports in Part B. Due to the very different models of service delivery in the short-term projects an aggregate breakdown of service expenditure across the projects is not particularly informative. Only two long-term care package projects reported financial results so no attempt has been made to aggregate those figures in an overall picture of service expenditure across the long-term care projects.

5.3 Estimated savings to residential care system

Savings to the residential aged care system accrue as long as the cost of innovative care packages is less than residential care subsidy and continues to accrue for the period that residential care is avoided. An attempt was made to estimate savings in residential care subsidy payments based on actual client outcomes for the people who participated in the evaluation.

For short-term projects the estimation involved calculating the savings that accrued over the time that a care recipient spent in a project (number of days between discharge date and commencement date) and any savings that accrued after discharge given the type of government program support that was known to have taken effect after discharge, for example, a CACP or HACC service, or home without government program support. When discharge occurred because a client died or entered residential care the saving is calculated over the number of days in a pilot project.

For this exercise, it is assumed that admissions to high level residential care would attract a residential care subsidy payment for RCS 2. Savings per day are calculated as the difference between the RCS level 2 subsidy and the current (at the time) rate of prevailing type of care, flexible care subsidy for days in a project and rates of subsidy for other types of care for days in the community following discharge. It was necessary to estimate the cost of HACC service at the CACP subsidy rate, as the true cost is not known.

Results of this type of analysis need to be interpreted with caution for a number of reasons:

- Chapter 4 reported that short-term care projects experienced difficulty in finding suitable ongoing care arrangements for discharged clients. The type of government program support recorded between discharge and follow-up in many cases is a compromise on a more ideal, but unavailable and more costly, form of community care. Projects that were less able to source EACH packages, for example due to limited supply in their service region, inevitably report higher cost savings because clients had to be discharged onto less expensive forms of ongoing support. These short-term cost savings do not necessarily produce higher long-term savings or preferred outcomes for clients.
- A proportion of clients in short-term care projects were discharged to multiple support programs and many clients had a change in ongoing support arrangements between discharge from a project and follow-up. There are no reliable estimates of the financial cost of multiple program assistance. Moreover, it cannot be assumed that the support arrangement on discharge will last indefinitely or even for a few months and it is not possible to factor in the changes to daily savings as community care arrangements change.
- Some projects did not follow up all clients, requiring an assumption that discharge support arrangement continued until date of follow-up.
- A few dates of entry to residential care were not recorded where the client was discharged from a project, remained at home for a period and later entered residential aged care. In these cases date of entry to residential care was estimated as the midpoint between date of discharge and date of follow-up.
- Results are subject to error of estimation, which is higher in smaller projects that have relatively fewer client outcome records for use in calculations. Client outcomes are highly individual.

- Dates of follow-up varied and this could have a minor impact on the results.
- Estimated savings for an individual represent savings that accrued between two fixed dates—date of client commencement and date of follow-up. Averaged over all the person days of observation, average aggregate savings are estimates of the savings that had accrued by completion of follow-up for these particular client groups and are truncated by the date of follow-up. Past clients of short-term projects who were still at home at follow-up could remain living at home for a longer period than was observed and would therefore accrue higher long-term savings in avoided residential care. The results thus apply to the particular client groups observed at a particular point in time and are used only to provide broad-brush estimates based on observed outcomes.

The total saving in avoided residential care subsidy at RCS level 2 for each client was averaged over the number of days of observation of the client and the mean per day saving across all observed clients was calculated along with the standard error of the mean to reflect the degree of variation in project estimates (Table A5.4). Mean daily savings multiplied by 365 were rounded to the nearest $1,000 to produce estimated minimum per package annual savings based on the mix of client outcomes observed in the evaluation.

Using this method, minimum per package annual savings are estimated to lie between $5,000 and $18,000, depending on project. Two factors contribute to a lower estimated per packages saving in NEDID. First, NEDID receives a higher rate of flexible care subsidy compared to the other projects and this reduces the per day saving for every avoided day of residential care at RCS level 2 during the pilot project service episode. Second, NEDID was able to discharge proportionately more clients onto an EACH package and this reduces the savings that accrue post-discharge, though it can still be considered a positive outcome for clients.

DRAH is seen to produce relatively high per package annual savings, which is partly due to the different needs profile of a proportion of DRAH clients (with its focus on diagnosis of dementia and related conditions, DRAH has accepted a mix of clients at the low and high end of the care needs continuum) plus the fact that DRAH was in most cases unable to source required high care packages for discharged clients. The DRAH summary of actual versus optimal discharge arrangements shows that a high proportion of clients discharged to a CACP or HACC service would have been more ideally placed on an EACH package had one been available. Therefore, cost savings calculated in this type of exercise do not reflect the best outcomes for clients and may not lead to longer term cost savings if less than ideal discharge support arrangements lead to premature entry to residential care.

Table A5.4: Short-term care projects, estimated per package saving in residential care subsidy (RCS 2) averaged over all clients in the evaluation

State	Project	Flexible care subsidy rate	Number of records	Est. mean per client daily saving ($)	Standard error of mean ($)	Estimated minimum per package annual saving ($)
NSW	DBAMS[(a)]	92.46	16	22	3.1	8,000
	DRAH	83.47	30	49	2.9	18,000
Vic	FCS	97.45	23	28	4.3	10,000
	NEDID	106.83	14	13	5.1	5,000

(a) Refers only to DBAMS clients who were living at home in the community at time of entry to the project.

In the long-term care projects, around half of the evaluation clients were continuing with the services at time of follow-up, thus savings would continue to accrue for as long as those clients remain in the community. Taking into account the days of avoided high level residential care for discharged and ongoing clients up to dates of follow-up, estimates of the minimum number of residential care days avoided by evaluation clients in each project within the first 12 to 18 months of project operation were calculated (Table A5.5). These were calculated using records for clients with ACAT approval for high level residential care on referral to a project with known status at follow-up. They are minimum estimates because (a) the evaluation has no information about any early start clients (October 2003–May 2004) who were discharged before the evaluation commenced and (b) calculations use the number of days in a project for continuing clients that are truncated by the date of follow-up.

RSL Care Innovative Dementia Care Pilot commenced in January 2004, some 4–5 months after the other projects. Commencement dates of evaluation clients in the RSL Care Pilot are clustered towards the middle and end of the period of evaluation; therefore the group includes relatively fewer long-stay clients.

Table A5.5: Long-term care package projects, number of avoided days of high-level residential care among evaluation clients with ACAT approval for high level residential care and minimum estimates of average per client dollar savings in care subsidy at completion of follow-up

Project (start date)	Number of records analysed	Total days at home (all observed clients)	Average days at home (per client)	Difference between RCS 2 and flexible care subsidy ($)	Accrued total savings to date ($)	Average savings per client to date ($)
RSL Care Pilot (Jan. 2004)	31	7,961	257	20.93	166,624	5,375
South Brisbane & Gold Coast Pilot (Nov. 2003)	24	8,056	336	27.28	219,768	9,157
Ozcare Packages (Oct. 2003)	35	11,243	321	26.21	294,679	8,419
Dementia Care in Alternative Settings (Oct. 2003)	24	8,367	349	13.1	109,608	4,567

Based on these figures, indicative annual savings to government from a long-term care package service funded at the rate of $80 to $85 per place day can be expected to be between $8,000 and $10,000 per package through avoided residential care subsidy for each client with ACAT approval for high level residential care. The estimates assume that each care recipient in the evaluation would have entered high level residential aged care had they not been offered a place in the Dementia Pilot. While the period of observation extended beyond 12 months for some clients, the evaluation does not have access to information about clients discharged in the first few months of operation of the projects, during which time additional savings would have accrued for short-stay clients. This is taken into account by interpreting the above estimates as indicative annual per package savings for the mix of clients at the time of the evaluation.

5.4 Main findings

The cost to the Australian Government of short-term care interventions in the Innovative Pool Dementia Pilot varied across the projects, ranging from $83.47 to $106.83 per client per day. Clients in the short-term care projects had ACAT approval for high level residential care. Residential care at RCS level 2 would have cost $107.10 (New South Wales) or $109.25 (Victoria) in basic subsidy at the time of the evaluation (subsidy rates current 1 July 2004).

Two of the short-term care projects, DBAMS and DRAH, have offered a type of service that is not comparable to residential care. Indeed DBAMS accepted clients who could not be managed in residential care settings due to severe behavioural and psychological disturbance. These two projects are specialist services that assist in the medical diagnosis and ongoing care and management of dementia and dementia-related conditions. In addition, DRAH provides short-term ADL support prior to referral for ongoing ADL support. Flexible Care Service and NEDID provide short-term packages of in-home support that could be compared with residential care in terms of the type of instrumental assistance delivered. However, any such comparison is artificial, since it was the express wish of all care recipients to remain at home for as long as possible and the projects provided the support to family carers to maximise the chance of success.

Difficulties in discharging clients from short-term care projects to suitable levels of ongoing formal support limit the usefulness of estimated cost savings from these projects. The evaluation was informed that an EACH package was the most suitable long-term care option for most clients being discharged from short-term care projects but that few could be sourced. Savings that accrue as a result of clients being discharged to lower levels of service than delivered by the pilot projects, such as a CACP or HACC service, are considered to carry the risk of high personal cost to the care recipient and their family carers over the longer term and it is not obvious that over the medium to long term these lower levels of assistance would help maintain people with dementia-related high care needs in the community.

The real savings produced by the types of short-term interventions observed in the evaluation accrue over a much longer period: timely accurate diagnosis of dementia has significant long-term benefits by ensuring earlier intervention; management of severe behavioural symptoms of dementia improves the quality of life of the person with dementia and gives care providers effective strategies to reduce strain and burnout; high level case management and intensive respite offered to a carer in a time of crisis plus assistance to source more appropriate forms of ongoing support gives people with dementia the chance to stay at home when residential care would be the only other option.

Four long-term care package projects offer an alternative to high level residential care in the form of high average weekly hours of in-home services plus flexible respite care and other forms of carer support. Long-term care package projects in the Dementia Pilot received government funding of between $79.82 and $94.00 per client per day and client co-payments were levied according to standard community care guidelines (up to $7.00 per day but many clients received a discount or waiver). There are indications that the long-term care packages cost significantly less than these amounts to operate, which gives providers the potential to carry unfunded clients or to offer higher levels of assistance to clients than were observed in the evaluation. It is not clear why some clients in the RSL Care and Ozcare projects highlighted ongoing unmet needs (for example, more hours of assistance, aids and equipment), given that these projects reported large surpluses. South Brisbane and Gold Coast Pilot and Dementia Care in Alternative Settings declined to report financial results.

The Sundowner Club received a flexible care subsidy at a rate of $30.73 per client per day and client co-payments of $1.50 per day. Flexible care subsidy is paid on the basis of eight clients attending The Sundowner Club on five evenings per week. During the evaluation this project operated at 75% of capacity. This is reflected in total expenditure per client attendance (one evening meal and activity program) of $106.55. High fixed costs (staff salaries and transport) mean that costs are not avoided if fewer people attend a session. The Sundowner Club cannot be compared to residential care or to the long-term care package projects as it is not a case management service and does not provide in-home ADL support. The Sundowner Club is a valuable adjunct to a care package but in itself is unlikely to maintain a high care client at home if other formal and informal support is not available.

6 Care Experience Survey summary of results

6.1 Survey aims and methodology

The Care Experience Survey was designed to elicit client and family perspectives of:

- level and areas of need for assistance
- the extent to which needs were met before joining a pilot project
- project effectiveness in meeting previously unmet needs
- the standard of aspects of service delivery
- the suitability of projects for providing care at home over the longer term.

The survey questionnaire was designed according to the recommendations of Cooper and Jenkins (1998) to find out about positive and any negative aspects of service delivery. The questionnaire was reviewed by a clinical psychologist and was piloted among staff at the AIHW and their older relatives and a small number of early clients in the North East Dementia Innovations Demonstration project at Austin Health who did not take part in the evaluation. The draft questionnaire was sent to service providers in the Pilot for comment. Feedback from the review and piloting was used to fine tune the instrument.

Project coordinators in the Dementia Pilot issued the Care Experience Survey questionnaire to each participating client/carer, having allowed for a client to have been receiving services for at least 4 weeks. Respondents completed the questionnaire and mailed it to the AIHW evaluation team by reply paid post. The Survey was anonymous. While responses can be linked to client profile and assessment data using the unique client identification code recorded by the project coordinator on the front of each questionnaire before issue, names and addresses or other identifying information were not requested.

The questionnaire includes a combination of closed, limited response and open-ended questions. Respondents were asked to compare the care received from a project to the clients' 'usual care' (before the project) and to report on whether the project met or is meeting previously unmet need for assistance across a range of areas covering health care, social care and ADL support. Respondents were also able to comment on specific aspects of service delivery such as care planning and coordination; continuity of care; the range and availability of services; choice; convenience; privacy and security; and the physical environment. Carers and family members were asked to assess the support and assistance they receive to assist them in their caring role and whether they believe that the project provides a suitable long-term care option for the care recipient.

A copy of the questionnaire is available on request to the AIHW Ageing and Aged Care Unit.

Analysis of completed questionnaires received by 31 January 2005 is summarised below. The data were analysed with frequency and cross-tabulation procedures in the SPSS computer package.

6.2 Response rates

A total of 249 questionnaires were distributed and 135 questionnaires were returned by 31 January 2005 (Table A6.1). Response rates for individual projects range between 29% and 71%, with an overall response rate of 54%.

Table A6.1: Care Experience Survey, surveys distributed and received, and response rates by project

Project (approved provider)	Number of surveys distributed	Number of surveys received	Response rate (per cent)	Per cent of total response
Dementia Behaviour Assessment and Management Service (Southern Area Health Service, NSW Health, Wagga Wagga)	39	13	33.3	8.9
Dementia Rehabilitation at Home (North Coast Area Health Service, NSW Health, Northern Rivers)	31	21	67.7	14.4
Flexible Care Service (*annecto—the people network*, Melbourne)	24	7	29.2	4.8
North East Dementia Innovations Demonstration (Austin Health, Melbourne)	14	9	64.3	6.2
RSL Care Innovative Dementia Pilot (RSL Care Queensland, Brisbane)	32	14	43.8	9.6
South Brisbane & Gold Coast Pilot (Islamic Women's Association, Brisbane and Gold Coast)	26	16	61.5	11.0
Ozcare Innovative Dementia Care Packages (Ozcare, Rockhampton/Gladstone and Bundaberg)	35	25	71.4	17.1
Dementia Care in Alternative Settings (Southern Cross Care WA, Perth)	33	20	60.6	13.7
The Sundowner Club (ECH Incorporated, Adelaide)	15	10	66.7	6.8
Total	**249**	**135**	**54.2**	**100.0**

6.2.1 Respondent identity

Respondents were asked to indicate who completed the Care Experience Survey on the first page of the questionnaire. More than one respondent could be identified on each questionnaire, for example, where a carer assists the client to complete a questionnaire, both 'client' and 'carer' is recorded. Respondent identities varied across the projects (Table A6.2).

Table A6.2: Care Experience Survey, respondent identities by project

	Respondent identity					
Project	**Client**	**Carer**	**Other relative**	**Project coordinator**	**Other advocate**	**Total**
			(number)			
Dementia Behaviour Assessment and Management Service	2	9	2	—	3	16
Dementia Rehabilitation at Home	3	18	—	—	2	23
Flexible Care Service	1	7	2	—	—	10
North East Dementia Innovations Demonstration	—	9	1	—	—	10
RSL Care Dementia Pilot	3	14	3	—	—	20
South Brisbane & Gold Coast Pilot	4	8	1	5	6	24
Ozcare Innovative Dementia Pilot	5	21	3	—	1	30
Dementia Care in Alternative Settings	1	16	3	—	—	20
The Sundowner Club	8	3	—	1	—	12
Total	**27**	**105**	**15**	**6**	**12**	**165**
			(per cent)			
Dementia Behaviour Assessment and Management Service	12.5	56.3	12.5	—	18.8	100.0
Dementia Rehabilitation at Home	13.0	78.3	—	—	8.7	100.0
Flexible Care Service	10.0	70.0	20.0	—	—	100.0
North East Dementia Innovations Demonstration	—	90.0	10.0	—	—	100.0
RSL Care Innovative Dementia Care Pilot	15.0	70.0	15.0	—	—	100.0
South Brisbane & Gold Coast Pilot	16.7	33.3	4.2	20.8	25.0	100.0
Ozcare Innovative Dementia Care Packages	16.7	70.0	10.0	—	3.3	100.0
Dementia Care in Alternative Settings	5.0	80.0	15.0	—	—	100.0
The Sundowner Club	66.7	25.0	—	8.3	—	100.0

Note: Multiple responses permissible.

— Nil.

Twenty-seven questionnaires were completed with the involvement of clients and 120 with the input of carer and/or other family members. Respondent identity was not indicated on three questionnaires.

Project coordinators were asked to encourage completion of the questionnaire by each client with or without assistance from a carer or other involved family member, wherever possible. This was not always possible and five clients received assistance from project staff.

Circumstances that led to staff involvement included, for example, lack of a carer or other close relative or friend, poor eyesight, impaired fine motor skills, or difficulty with written English. As the purpose of the survey was to gather views of the projects from the point of view of clients and their families, surveys completed by project staff (seven forms) were excluded from analysis of questions directly relating to satisfaction with project implementation, for example, satisfaction with staffing arrangements, convenience of project services, and project planning and coordination.

6.3 Coding framework

The AIHW engaged a consultant to develop a coding framework for responses to open-ended questions and perform analysis of completed forms in their entirety.

Development of the coding framework was an iterative process. The consultant completed a thematic analysis of a selection of hand-written responses to five key open-ended questions. The first two of these questions focus on needs and expectations. Two initial lists of 20 to 30 recurring themes were constructed, one by the consultant and one by the AIHW evaluation team. A high level of agreement was apparent and the process of cross-referencing the two lists produced a set of core themes for the initial coding framework. This list was further expanded and refined to accommodate responses to three more open-ended questions on the adequacy and quality of the project services and staffing.

The AIHW evaluation team reviewed the resulting set of codes. A number of additional codes were subsequently added to the framework until it was shown that responses to the five key open-ended questions in 50 completed questionnaires could be coded satisfactorily. The final coding framework consists of:

- 30 core themes
- 10 themes specifically associated with how the projects meet or fail to meet client needs
- nine themes that deal specifically with staffing issues
- nine themes associated with aspects of the Pilot that attract positive feedback from respondents
- nine themes associated with aspects of the Pilot that attract negative feedback from respondents
- 15 themes to cover general comments, both positive and negative.

Over 80 themes were identified for the coding framework and used in the interim analysis. The framework has been designed so that specific themes can be combined into more general categories for reporting purposes.

Inter-rater reliability of coding according to the global coding framework and responses to the most commonly answered open-ended questions was tested on a random sample of 20 questionnaires. A total of 23 categories from the coding framework featured in this analysis. Ten categories had perfect agreement and a further eight categories only deviated very slightly. The intra-class correlation coefficient for agreement between independent raters was 0.967, indicating a very high level of inter-rater reliability.

6.4 Summary of results

The Care Experience Survey revealed that projects have targeted clients with a wide range of needs, most commonly in the areas of domestic assistance, personal assistance, behaviour management, community access and social support. Approximately 28% of clients who responded to the survey (or on whose behalf a response was submitted) are reported as not having received assistance, either formal or informal, in the 6 months prior to starting with a project (Table A6.3). The most common source of assistance with everyday activities was family, friends and/or neighbours. Around 57% of respondents reported receiving assistance from a community organisation prior to the pilot (Table A6.4).

The areas mentioned by most respondents in relation to prior unmet need include domestic assistance, social support and nursing care at home. Assistance to manage the behavioural and psychological symptoms of dementia stood out as the most common area of unmet need—67% of respondents indicated that they needed help but were not receiving any assistance in this area prior to the project (Table A6.5).

These results accord with results from the baseline assessment of clients, which show that many clients displayed behavioural and psychological symptoms of dementia, and that most clients were partially or wholly dependent on the assistance of others for self-care and domestic activities.

Negative comments about service delivery mostly related to communication between the project coordinator and clients/carers, for example, returning telephone calls and checking up on things; access to aids and equipment; and limited hours of assistance. The few criticisms made were levelled mainly at the long-term care package services. Better or more frequent communication was desired by some of the family carers in DCAS and RSL Care Pilot and several carers with a relative in the Ozcare Packages project mentioned limited availability of aids and equipment. Comments about insufficient hours of assistance indicated gratitude for the amount of assistance received but also highlighted that more assistance was often needed. Comments from some carers in the RSL Care Pilot suggest that assistance to their care recipients was capped at 10–12 hours per week, which they felt was insufficient to meet their needs.

Across all projects, respondents made many more positive comments than negative comments when asked about aspects of the project they particularly liked and disliked. The most common single service type most liked was services and support for carers, including respite care (22 responses), though the majority of positive comments related to intangible benefits of the projects (77 responses) (Table A6.12). The most common criticism on these items was a lack of information and communication from the project team (six responses) (Table A6.13).

Carers and family members report benefiting from the information and support services provided by the projects (67–85% of those who responded in each project). The majority of carers and family members who received respite were happy with the nature, amount and quality of respite service provided (approximately 60–70% of those who responded). The survey also identified gaps in the awareness of carers and family members of people with dementia relating to Australian Government support services available to them, with approximately 50-60% those who responded unaware of four key sources of information and support.

Ninety-one of the 110 carers and family members who completed section C (83%) believe the Innovative Pool Dementia Pilot project delivered a level of service that could be expected to support their relative or friend for the foreseeable future (Table A6.15). Eight respondents

(7%) across four projects stated that the project would be an unsuitable form of longer term care. Eight respondents (7%) across six projects were unsure about the suitability of the project as a longer term care option. Comments from carers and family members illustrate their gratitude for the assistance provided through the projects. Where carers and family members expressed doubts over whether the project would be suitable in the longer term, they generally cited high carer strain, need for supervision or higher level care than the project could provide, or concerns about whether project services would be sufficient to cope with needs which may increase in the future.

A sample of responses to selected open-ended questions, taken from several projects, follows.

To the question of client and family expectations of the projects:

'Personal care—emotional support, education about medication and dementia.'

'Same hours per day, seven days. More respite.'

'I am a widow and working fulltime as this is necessary for my family. I am an only child. I hope to keep my parents at home as long as possible. They would be so stressed out of their home environment. I go around at least once a day.'

'I was receiving no help, no care except that from my wife. I hoped the program would be able to get me out to do and see different things and give my wife some time out.'

'Assistance, support and respite in caring for my mother in my home.'

'I had no expectations of help, but am pleasantly surprised with the help and advice forthcoming.'

To the question of how the project helps or doesn't help to meet needs and aspects most liked, clients, carers and relatives say:

'As soon as my husband started the program, life changed for us.'

'Somebody can speak the language and understand our culture. My husband doesn't want [to go to] residential care.'

'I think the first weeks were great with two visits a day. The one hour a day has not been so good.'

'Respite at home in the house.'

'The staff carry out their tasks in a caring and professional manner.'

'The quality support that is provided for a person with dementia and cerebrovascular disease. The documented service delivery plan provided by the provider.'

'This is a wonderful program. [The provider] is exceptional and they have made a great difference to my parents' life and mine.'

'Pilot program has been the best thing for [client] in years. Program workers get 100% mark from me as family member/carer.'

'Program has given me peace of mind.'

'The program delivers in all areas but one. It is not possible to place Mum into a respite centre when I need a break, so it would be wonderful if in-house respite was available for the occasional weekend off.'

'The program has reduced the "frazzled" element for me by about 90%.'

'Excellent.'

‘It has been of great help.’ [emphasis original]

Comments on experience in accessing community care before the Innovative Pool Dementia pilot:

‘[client] had never received any help prior to this program except a man who came to mow the lawn.’

‘My family was very deprived we don’t have any idea of service. This pilot project changed our lives.’

‘Help received [through a CACP] only 10 hours [per week], which is too little, but now better.’

‘Before the program it was difficult to get help as family member was very uncooperative.’

‘We needed to get into the “system” of care…as we had no information on where to go. Through the team organising these things for me I was able to get help.’

‘Bloody hopeless!! Three local doctors—no help!!! One said “there’s nothing wrong with your husband — you spoil him and he’s lazy”.’

‘The pilot program opened doors for me to know where to get help. Before the program I was at the end of my endurance, without hope. I don’t need sympathy (it’s nice) or [to be] loaded with guilt—need sound day-by-day help and that’s what the program gave me.’

‘I felt lost. I didn’t know where to turn for help. I had Mum and Dad to look after, we lived on a farm and it took 1 hour to the nearest town for the doctors, and 2 ½ hours [to the specialist]…we had a lot on our plates with the drought also.’

‘ ”Commonwealth Carers Respite Centres” this is a JOKE!! It only caters for Emergency Respite to carers. It’s very misleading and incorrect.’ [emphasis original]

‘Didn’t like to overburden the family.’

6.5 Tabulated responses

6.5.1 Previous sources of assistance

Forty-one of the 135 respondents indicated that they had not been receiving assistance with everyday activities (personal care, meal preparation, taking medication, mobility, and transport) from any source in the 6 months prior to entering the project (Table A6.3). The most common source of assistance with everyday activities was family, friends and/or neighbours (77 respondents); 60 respondents reported that they were receiving assistance from either the organisation delivering the Innovative Pool services or another organisation.

Table A6.3: Care Experience Survey, sources of assistance prior to entering the pilot

Source of assistance	Responses	Per cent
No-one	41	30.4
Family, friends and/or neighbours	77	57.0
Organisation delivering the pilot	27	20.0
Another organisation	23	17.0
District nursing service	12	8.9
Home care service	7	5.2
Other	25	18.5

Note: Multiple responses permissible.

Around 47% of respondents reported not having received service or assistance from community organisations in the 12 months prior to entering the pilot (63 respondents) (Table A6.4). Domestic assistance (47 respondents), personal assistance (33 respondents), transport to appointments (29 respondents) and in-home respite care (26 respondents) were the most common types of assistance received from community organisations.

Table A6.4: Care Experience Survey, assistance received from community organisations prior to entering the pilot

Assistance type	Responses	Per cent
Not applicable/no previous assistance	63	46.7
Domestic assistance	47	34.8
Personal care	33	24.4
Transport to appointments	29	21.5
In-home respite care	26	19.3
Medication management	22	16.3
Advice to find required aids/equipment	20	14.8
Behaviour management	17	12.6
Day centre respite care	15	11.1
Respite care in a residential aged care facility	15	11.1
Home maintenance	11	8.1
Assistance with manual handling	10	7.4
Help managing financial affairs	10	7.4
Home nursing	8	5.9

Note: Multiple responses permissible.

6.5.2 Identified needs

Responses to question 3 give an indication of respondents' views of how well clients' needs in each of 13 areas were being met prior to entering the project.

The highest numbers of clients with any level of need for assistance (including unmet, partially met and fully met need) were in the areas of domestic assistance (102 respondents), personal assistance (93 respondents), behaviour management (92 respondents), and transport to appointments and social events (90 respondents) (Table A6.5).

The areas of need where respondents more frequently indicated adequate assistance was received prior to the project are: transport to appointments and social events (59% of clients with need were receiving adequate assistance prior to entering the Pilot), help to get to a doctor when needed (59% of clients with need were receiving adequate assistance), medication management (56% of clients with need were receiving adequate assistance). Forty-three clients were receiving some personal assistance, but not enough to meet their needs (46% of clients with identified need). Other common areas of need where assistance was being provided at inadequate levels include domestic assistance (37% of clients with identified need), and nursing care at home (35% of clients with identified need).

Behaviour management is the area with the highest level of identified previously unmet need—62 of the 92 clients (67%) with identified need for assistance with behavioural and psychological symptoms of dementia were not receiving any assistance in this area prior to the Pilot. Other areas where assistance was needed but was not being received prior to the Innovative Pool projects include physiotherapy (59% of clients with identified need), continence management (43% of clients with identified need) and nursing care at home (42% of clients with identified need). Across all areas, at least 20% of clients with identified need were not receiving any assistance prior to the Pilot.

'Not applicable' was most often recorded against mobility assistance (85 respondents), physiotherapy (79 respondents), continence management (70 respondents), and nursing care at home (70 respondents), though at least 65 clients identified a need in each of these areas.

These results accord with results from the baseline assessment of clients which show that many clients display behavioural and psychological symptoms of dementia, and that most clients were partially or wholly dependent on the assistance of others for self-care and domestic activities.

Table A6.5: Care Experience Survey, assessment of the adequacy of assistance received from all sources prior to the pilot

Assistance type	Had enough help	Had help, more needed	Did not have help, help needed	Number with identified need	Number reporting unmet need	Not applicable/ did not need help[(a)]	Total
				(number)			
Personal assistance	27	43	23	93	66	42	135
Continence management	16	21	28	65	49	70	135
Mobility assistance	21	16	13	50	29	85	135
Help to get to a doctor when necessary	51	14	22	87	36	48	135
Medication management	45	15	21	81	36	54	135
Domestic assistance	42	38	22	102	60	33	135
Home maintenance	34	16	22	72	38	63	135
Transport to appointments and social events	53	19	18	90	37	45	135
Assistance to source aids/equipment	31	14	25	70	39	65	135
Accompaniment at home	41	29	19	89	48	46	135
Nursing care at home	15	23	27	65	50	70	135
Physiotherapy	13	10	33	56	43	79	135
Behaviour management	10	20	62	92	82	43	135
				(per cent)[(b)]			
Personal assistance	29.0	46.2	24.7	. .	. .	. .	100.0
Continence management	24.6	32.3	43.1	. .	. .	. .	100.0
Mobility assistance	42.0	32.0	26.0	. .	. .	. .	100.0
Help to get to a doctor when necessary	58.6	16.1	25.3	. .	. .	. .	100.0
Medication management	55.6	18.5	25.9	. .	. .	. .	100.0
Domestic assistance	41.2	37.3	21.6	. .	. .	. .	100.0
Home maintenance	47.2	22.2	30.6	. .	. .	. .	100.0
Transport to appointments and social events	58.9	21.1	20.0	. .	. .	. .	100.0
Assistance to source aids/equipment	44.3	20.0	35.7	. .	. .	. .	100.0
Accompaniment at home	46.1	32.6	21.3	. .	. .	. .	100.0
Nursing care at home	23.1	35.4	41.5	. .	. .	. .	100.0
Physiotherapy	23.2	17.9	58.9	. .	. .	. .	100.0
Behaviour management	10.9	21.7	67.4	. .	. .	. .	100.0

(a) Includes missing values (assumed to be 'not applicable').

(b) Number of responses as a percentage of number of respondents who indicated the service was needed.

. . Not applicable.

6.5.3 Hopes and expectations on joining a project

- Thirty respondents either stated that they had no prior expectations of the project or were unsure of what to expect, or did not provide any comment (Table 6.6).
- Of the 153 statements of expectation related to specific areas of assistance, carer services and support was the most commonly cited service type (45 responses), followed by domestic assistance (42 responses).
- Seventy-five statements of expectation related to intangible benefits, with increased participation the most commonly cited (27 responses).
- Forty-two statements of expectation related to improved service quality and value, the most common of which was enhanced service (15 responses).

Table A6.6: Care Experience Survey, respondents' hopes and expectations of projects, analysis of open-ended responses

Theme	Responses
Specific instrumental assistance/services	
Carer services and support	
Respite care	28
Assistance for carer	17
Total carer services and support	*45*
Domestic assistance	
Domestic assistance	20
Assistance with meals	14
Assistance with shopping	8
Total domestic assistance	*42*
Personal assistance	25
Behaviour management	12
Nursing support	9
Transport	7
Continence management	5
Other specific instrumental assistance/services	8
Total specific instrumental assistance/services	*153*
Intangible benefits	
Participation	27
Safety	16
Confidence/reassurance	16
Independence	13
Other intangible benefit	3
Total intangible benefits	*75*

(continued)

Table A6.6 (continued): Care Experience Survey, respondents' hopes and expectations of projects, analysis of open-ended responses

Theme	Responses
Improved service quality/value	
Enhanced service	15
General positive	13
Enhanced quality of care	5
Other improved service quality/value	9
Total improved service quality/value	*42*
No expectations, unsure, no comment	30

Note: Multiple responses permissible.

6.5.4 Quality and appropriateness of services

The majority of respondents (84%) believed that their project had addressed or was addressing previously unmet needs (Table A6.7). Eighteen respondents across seven projects stated that their project was addressing some areas of unmet need, but not to the extent that they had hoped. Just one respondent indicated that the project was not addressing some important needs.

Table A6.7: Care Experience Survey, respondents' beliefs about whether the projects meet previously unmet needs, by project

Project	Yes	Partly	No	Missing	Total
			(number)		
Dementia Behaviour Assessment and Management Service	12	1	—	—	13
Dementia Rehabilitation at Home	19	1	—	1	21
Flexible Care Service	6	1	—	—	7
North East Dementia Innovations Demonstration	9	—	—	—	9
RSL Care Innovative Dementia Care Pilot	9	4	1	—	14
South Brisbane & Gold Coast Pilot	14	2	—	—	16
Ozcare Innovative Dementia Care Packages	21	3	—	1	25
Dementia Care in Alternative Settings	13	6	—	1	20
The Sundowner Club	10	—	—	—	10
Total	**113**	**18**	**1**	**3**	**135**

(continued)

Table A6.7 (continued): Care Experience Survey, respondents' beliefs about whether the projects meet previously unmet needs, by project

Project	Yes	Partly	No	Missing	Total
			(per cent)		
Dementia Behaviour Assessment and Management Service	92.3	7.7	—	—	100.0
Dementia Rehabilitation at Home	90.5	4.8	—	4.8	100.0
Flexible Care Service	85.7	14.3	—	—	100.0
North East Dementia Innovations Demonstration	100.0	—	—	—	100.0
RSL Care Innovative Dementia Care Pilot	64.3	28.6	7.1	—	100.0
South Brisbane & Gold Coast Pilot	87.5	12.5	—	—	100.0
Ozcare Innovative Dementia Care Packages	84.0	12.0	—	4.0	100.0
Dementia Care in Alternative Settings	65.0	30.0	—	5.0	100.0
The Sundowner Club	100.0	—	—	—	100.0
Total	**83.7**	**13.3**	**0.7**	**2.2**	**100.0**

Note: Excludes six surveys completed with the assistance of project coordinators.

— Nil.

Most respondents rated the quality of the health and personal care and the home and community care services delivered by their project as satisfactory or good to very good (Tables A6.8 and A6.9). Weekend and emergency assistance and home modifications were the areas of service delivery most often rated as unsatisfactory across the projects (six respondents each), followed by personal assistance and food services (five respondents each).

Table A6.8: Care Experience Survey, respondents' ratings of the quality of project health and personal care services

Service	Good to very good	Satisfactory	Less than satisfactory	Not applicable[(a)]	Total
			(number)		
Personal assistance	74	17	5	39	135
Continence management	37	21	2	75	135
Mobility assistance	37	20	3	75	135
Medication management	40	17	—	78	135
Weekend/evening emergency assistance	24	13	6	92	135
Provision of aids and equipment	37	8	4	86	135
Nursing care	22	9	—	104	135
Behaviour management	57	30	3	45	135
Physiotherapy and occupational therapy	19	12	1	103	135
			(per cent)		
Personal assistance	54.8	12.6	3.7	28.9	100.0
Continence management	27.4	15.6	1.5	55.6	100.0
Mobility assistance	27.4	14.8	2.2	55.6	100.0
Medication management	29.6	12.6	—	57.8	100.0
Weekend/evening emergency assistance	17.8	9.6	4.4	68.1	100.0
Provision of aids and equipment	27.4	5.9	3.0	63.7	100.0
Nursing care	16.3	6.7	—	77.0	100.0
Behaviour management	42.2	22.2	2.2	33.3	100.0
Physiotherapy and occupational therapy	14.1	8.9	0.7	76.3	100.0

(a) Includes missing values (assumed to be 'not applicable').

Note: Excludes six surveys completed with the assistance of project coordinators.

— Nil.

Table A6.9: Care Experience Survey, respondents' ratings of the quality of home and community services

Service	Good to very good	Satisfactory	Less than satisfactory	Not applicable[(a)]	Total
			(number)		
Domestic assistance	50	19	4	62	135
Food service	40	11	5	79	135
Home linen/laundry service	26	9	1	99	135
Home maintenance	11	3	4	117	135
Home modifications	22	14	6	93	135
Social support	44	9	2	80	135
Transport	41	13	1	80	135
Day centre programs	28	13	1	93	135
Interpreting service	17	3		115	135
			(per cent)		
Domestic assistance	37.0	14.1	3.0	45.9	100.0
Food service	29.6	8.1	3.7	58.5	100.0
Home linen/laundry service	19.3	6.7	0.7	73.3	100.0
Home maintenance	8.1	2.2	3.0	86.7	100.0
Home modifications	16.3	10.4	4.4	68.9	100.0
Social support	32.6	6.7	1.5	59.3	100.0
Transport	30.4	9.6	0.7	59.3	100.0
Day centre programs	20.7	9.6	0.7	68.9	100.0
Interpreting service	12.6	2.2	0.0	85.2	100.0

(a) Includes missing values (assumed to be 'not applicable').

Note: Excludes six surveys completed with the assistance of project coordinators.

— Nil.

At question 9 respondents were asked to list services they believed were unsatisfactory and to provide reasons that service delivery did not meet expectations. Across the projects, respondents identified a total of 34 services or aspects of projects as less than satisfactory (Table A6.10). Limited availability of service and unidentified 'other' factors were most commonly identified as the reasons services were less than satisfactory. Cost does not feature prominently as a reason for dissatisfaction; poor ratings are more likely to be related to limited availability or other unspecified factors.

Table A6.10: Care Experience Survey, aspects of project rated unsatisfactory and stated reasons

Service rated less than satisfactory	Responses	Reasons
Emergency assistance after hours and weekends	4	Limited availability Other factors
Personal assistance	4	Limited availability Problems with staff Other factors
Home modifications	3	Limited availability Other factors
Home maintenance	3	Problems with staff Other factors
Domestic assistance	3	Limited availability Other factors
Assistance with meals	3	Problems with staff Other factors
Provision of aids and equipment	2	Limited availability Too costly Other factors
Amount of assistance from the pilot inadequate	2	Limited availability
Day programs	1	Limited availability
Management of behavioural symptoms of dementia	1	Inconvenient
Medication management	1	Other factors
Mobility assistance	1	Problems with staff
Physiotherapy and occupational therapy	1	Limited availability Other factors
Assistance with shopping	1	Other factors
Social contact	1	Problems with staff
More mental stimulation needed	1	Other factors
Unspecified	1	Limited availability

Examples of written responses to question 9:

‘Bathroom needs modification, have yet to access this service.’

‘Meals on wheels meals not liked and a lot went to waste.’

‘More stimulation needed mentally.’

‘Personal care—Dad will not allow it.’

‘Looking into day programs but haven’t heard back yet.’

‘Showering—wife objects to service so I do it now.’

‘12 hours per week is too little.’

Over three-quarters of respondents rated the staffing arrangements of their project as good to very good (Table A6.11). Three respondents stated that staffing arrangements were unsatisfactory.

Table A6.11: Care Experience Survey, ratings of project staffing arrangements, by project

Project	Good to very good	Satisfactory	Less than satisfactory	Missing	Total
			(number)		
Dementia Behaviour Assessment and Management Service	10	—	—	3	13
Dementia Rehabilitation at Home	17	3	—	1	21
Flexible Care Service	6	1	—	—	7
North East Dementia Innovations Demonstration	7	2	—	—	9
RSL Care Innovative Dementia Care Pilot	9	5	—	—	14
South Brisbane & Gold Coast Pilot	16	—	—	—	16
Ozcare Innovative Dementia Care Packages	16	8	1	—	25
Dementia Care in Alternative Settings	14	4	2	—	20
The Sundowner Club	9	1	—	—	10
Total	**104**	**24**	**3**	**4**	**135**
			(per cent)		
Dementia Behaviour Assessment and Management Service	76.9	—	—	23.1	100.0
Dementia Rehabilitation at Home	81.0	14.3	—	4.8	100.0
Flexible Care Service	85.7	14.3	—	—	100.0
North East Dementia Innovations Demonstration	77.8	22.2	—	—	100.0
RSL Care Innovative Dementia Care Pilot	64.3	35.7	—	—	100.0
South Brisbane & Gold Coast Pilot	100.0	—	—	—	100.0
Ozcare Innovative Dementia Care Packages	64.0	32.0	4.0	—	100.0
Dementia Care in Alternative Settings	70.0	20.0	10.0	—	100.0
The Sundowner Club	90.0	10.0	—	—	100.0
Total	**77.0**	**17.8**	**2.2**	**3.0**	**100.0**

Note: Excludes six surveys completed with the assistance of project coordinators.

—- Nil.

Of the 135 respondents[3], 119 (88.1%) stated that project services are delivered in a manner that is always or mostly convenient, both in terms of getting to and from service locations, and having staff come to the home. Four respondents stated that service delivery is sometimes inconvenient, and one respondent reported that services are often inconvenient. A rating was not given by 11 respondents.

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[3] Excluding the six questionnaires completed with the assistance of project coordinators.

Question 13 asked respondents to specify aspects of their project which they particularly liked. Respondents provided a total of 223 positive comments, 77 of which mention intangible benefits, with increased participation (17 responses) and confidence/reassurance (16 responses) the most frequent (Table A6.12). Sixty-six responses relate to specific types of assistance, most commonly respite care (12 responses) and carer support and domestic assistance (10 responses each). Fifty-five comments relate to service quality and value, with enhanced service cited most often (12 responses).

Table A6.12: Care Experience Survey, aspects of service delivery viewed favourably by survey respondents

Theme	Responses
Intangible benefits	
Increased participation	17
Confidence/reassurance	16
Optimises/maintains wellbeing	12
Pilot helps— non-specific	10
Safety	8
Other intangible benefits	14
Total intangible benefits	*77*
Specific instrumental assistance/services	
Respite care	12
Carer support	10
Domestic assistance, meals and shopping	10
Personal assistance	9
Language/interpreter service	8
Other specific instrumental assistance/support	17
Total specific instrumental assistance/services	*66*
Improved service quality/value	
Enhanced service	12
Flexibility of project	8
Increased information	8
Enhanced quality of care	7
Project is culturally/traditionally aware	5
Other improved service quality/value	15
Total improved service quality/value	*55*

(continued)

Table A6.12 (continued): Care Experience Survey, aspects of service delivery viewed favourably by survey respondents

Theme	Responses
Staff characteristics	
Personal qualities	12
Work ethics	7
Other staff characteristics	5
Total staff characteristics	*25*
Total positive comments	**223**
Negative comments	2
No comment, unsure	18

Note: Multiple responses permissible.

Question 14 asked respondents to specify aspects of their project which they particularly disliked. Twenty-one negative comments related to eight aspects of service delivery (Table A6.13). The most common criticism is lack of communication and information about the project (six responses). Twenty-four (24) respondents specifically stated that there were no aspects of the project that they did not like, and another 94 did not respond to the question.

Table A6.13: Care Experience Survey, negative comments about service delivery: summary table of thematic analysis

Theme	Responses
Lack of information/communication needs improving	6
Understaffing issues	4
Inflexible service provision	3
Costs	3
No weekend/evening services	2
Fails to meet social needs	1
Limited hours/not enough time	1
Duty of care issues	1
Total negative comments	**21**
Positive comments	1
No, none at all	24
No comment/answer made	94

Note: Multiple responses permissible.

6.5.5 Information and support provided to carers and family members

The section of the questionnaire reserved for carers or other involved family members was completed by 118 respondents.

Carers and family members were asked about their awareness of a range of Australian Government carer support and information services:

- 70 (59.3%) had never heard of or contacted Commonwealth Carelink
- 65 (55.1%) had never heard of or contacted a Commonwealth Carer Resource Centre
- 58 (49.2%) had never heard of or contacted a Commonwealth Carer Respite Centre
- 69 (58.5%) had never heard of or contacted the Dementia Helpline.

The survey asked carers and family members to indicate who, prior to the Pilot, they had approached about getting help to care for their relative or friend. More than half the respondents nominated an Aged Care Assessment Team or general practitioners (Table A6.14). Twenty per cent said that they had not previously sought advice about getting assistance. Government departments and information services, community organisations and hospitals were also identified as organisations approached for advice on receiving assistance with the caring role.

Table A6.14: Care Experience Survey, persons and organisations previously approached for advice on obtaining assistance in providing care at home

Nominated source of advice or assistance	Number of responses	Per cent of responses
Aged Care Assessment Team	77	65.3
General practitioner	66	55.9
Family, friends	38	32.2
No-one	24	20.3
Government department	23	19.5
Community organisation	23	19.5
District nursing	19	16.1
Hospital emergency department	14	11.9
Government information service	11	9.3
Community health clinic	7	5.9
Total responses	**118**	**100.0**

Carers and family members were asked about the information and support provided to them by the project:

- 80 (67.8%) believed that being involved with the project had increased their understanding of dementia, 23 (19.5%) did not believe that their understanding of dementia had been improved, and 13 were undecided
- 101 (85.6%) reported that the project had increased their awareness of the support services available to them, 11 did not believe that the project had improved their awareness, and four were undecided

- 94 (79.7%) believed that the project provided enough help to support them in their caring role, 10 did not believe that the support provided by the project was sufficient, and two were undecided.

Carers and family members recorded their opinions of the respite services offered by Dementia Pilot projects:

- 81 (68.6%) believed the respite care options provided by the project were suitable, eight reported that the respite care options provided were not suitable, and 12 were undecided
- 71 (60.2%) judged the amount of respite care they received through the project to be adequate, 14 said that they were not receiving enough respite care, and 10 were undecided
- 74 (62.7%) rated the quality of the respite care provided by the project as good to very good, and 18 rated the quality of respite care as satisfactory. No carers or family members rated the quality of respite care as unsatisfactory.

Overall, carers and family members reported benefiting from the information and support services provided by the projects, and the majority of carers and family members who received respite were happy with the nature, amount and quality of respite service provided. The survey also identified gaps in the awareness of carers and family members of people with dementia relating to Australian Government support services available to them.

6.5.6 Innovative Pool model as a long-term care option

Carers and other relatives were asked to assess the suitability of their project as a long-term care option for the care recipient (Table A6.15). Overall, 91 respondents (82.7%) believed the project delivered a service that could be expected to support their relative or friend for the foreseeable future. Eight respondents (7.3%) across four projects stated that the project would be unsuitable as a form of longer term care.

Table A6.15: Care Experience Survey, carers' and other relatives' assessment of the project suitability as a long-term care option for the care recipient

Pilot project	Yes	No	Unsure	Not applicable[a]	Total
			(number)		
Dementia Behaviour Assessment and Management Service	9	—	1	1	11
Dementia Rehabilitation at Home	14	2	—	2	18
Flexible Care Service	6	—	1	—	7
North East Dementia Innovations Demonstration	8	—	—	1	9
RSL Care Innovative Dementia Care Pilot	12	—	2	—	14
South Brisbane & Gold Coast Pilot	8	—	—	—	8
Ozcare Innovative Dementia Care Packages	18	1	2	1	22
Dementia Care in Alternative Settings	13	3	2	—	18
The Sundowner Club	3	—	—	—	3
Total	**91**	**6**	**8**	**5**	**110**
			(per cent)		
Dementia Behaviour Assessment and Management Service	81.8	—	9.1	9.1	100.0
Dementia Rehabilitation at Home	77.8	11.1	—	11.1	100.0
Flexible Care Service	85.7	—	14.3	—	100.0
North East Dementia Innovations Demonstration	88.9	—	—	11.1	100.0
RSL Care Innovative Dementia Care Pilot	85.7	—	14.3	—	100.0
South Brisbane & Gold Coast Pilot	100.0	—	—	—	100.0
Ozcare Innovative Dementia Care Packages	81.8	4.5	9.1	4.5	100.0
Dementia Care in Alternative Settings	72.2	16.7	11.1	—	100.0
The Sundowner Club	100.0	—	—	—	100.0
Total	**82.7**	**5.5**	**7.3**	**4.5**	**100.0**

(a) Includes missing values (assumed to be 'not applicable').

— Nil.

Respondents who believe that the project is a suitable care option for the longer term commented:

'My wife is aged 81 years—she has had mental breakdowns for over 50 years since the birth of our first daughter. Over the years she had at least 20 breakdowns requiring hospital treatment (three in the last 4 years), her daily medication is 9 tablets per day plus her hip replacement and the other one not done, her mobility is very limited.'

'I would suggest that doctors should advise patients of help available to them, as my husband's doctor for 5 years considered only his medication but his new doctor is much more helpful.'

'Once again, we appreciate what we receive and it makes it possible for mum to stay at home. More hours would provide respite for Dad, but we understand that's unlikely.'

'Provided that service is adjusted to changing needs.'

'However just recently my mother's condition has deteriorated to the point where home care would no longer be suitable. I have found the responsiveness and flexibility of the coordinator to meet my mother's changing needs wonderful. It would be great to have this program continue. Had Mum's condition not changed so much we would have been very happy to have the program and staff continue for the long term. I have nothing but praise and appreciation for this program. Thank you.'

'Certainly the program is of great value as a long-term solution. However once [client] becomes bed-ridden the program would be of little use as [client] would need nursing home care.'

'Yes please! Could not get by without it.'

'But would be much better if more than 12 hours a week was available. It's very hard to try and help someone at home 7 x 24 [sic], doing everything by yourself with only 12 hours a week help.' [emphasis original]

Respondents who believe that the project is not a suitable care option in the longer term commented:

'No, if he was home I would have found it too hard to manage I myself 73 years old all day [sic]. Waiting for knee reconstruction also have diabetes (33 years on insulin).'

'[Client] wants to stay in her home for as long as possible but needs all the care and help she can get. [My husband] and I are unable to give this kind of care as I have high blood pressure and he has to do the things I can't do in our own home.'

'If the dementia and health of my mother worsened, she would require more care, possibly the presence of someone in the house the whole time. I (the carer) am at work. This would equate to approximately 8t hours per day on those days I am casual teaching.'

'They have been assessed as needing long-term residential care (Mum and Dad).'

'Client would need 24 hour 7 day a week care in the near future for her safety and that of carer.'

‘The client’s specific psychological difficulties in conjunction with the client’s circumstances are the reason for the “no” answer rather than any aspects of the pilot program.
(1) Client lives alone, since husband died on isolated, large rural property. I think the pilot would provide appropriate long-term assistance for people who live with another person in urban accommodation. (2) For the program to work long-term, the client needs insight into his/her difficulties and a willingness to accept help. The client resents help from carers, can act with much resistance, is suspicious, blames others and can be verbally abusive. The client is unhappy and does not consider companionship from carers to be appropriate. *However,* as the client’s only child I have found the program extremely valuable to me. I could not have coped as long as I have without it, and in my objective opinion the client was more unhappy before the program started. It has been of great short-term (about 9 months so far) assistance to me and my wife.’ [emphasis original]

‘With the client’s deteriorating condition it can be forseen that 24 hours care/supervision will become necessary before too long.’

‘Having been the main carer for 7 to 8 years, feel unable to continue indefinitely.’

Respondents who were unsure whether the project is a suitable care option in the longer term commented:

‘One option canvassed was for my sister to move permanently in with my wife and I at our home with continuing support (bathing etc.) from program. Whilst this may have worked successfully for a limited period, it was felt by all concerned to be impractical in the long term for following reasons: (1) stress in our home/relationship and extra workload on my wife. (2) distance travelled by program staff and friends.’

‘If more services were introduced it could be of long-term assistance.’

‘Unsure of the future.’

7 Conclusion

Innovative Pool Dementia Pilot projects were found to be targeting older people with very high dementia-related care needs. Over 80% of care recipients who participated in the national evaluation were aged 75 years and over and almost one-third were aged 85 years or over at the time. High levels of ADL and cognitive impairment recorded for the evaluation are consistent with the fact that most clients had ACAT approval for high level residential aged care by the time they started to receive Pilot services.

Care from relatives and friends was the main source of assistance for most clients and was the main reason that most Pilot recipients were still living at home before joining a project. Over 90% of community-based care recipients who participated in the evaluation were either living with a primary carer (most often a relative) or were receiving ongoing daily care from a relative or friend. Only 7% of the group were living alone and did not have a primary carer. Most projects required a person referred for services to have a carer calling in at least daily.

In addition to informal care, some care recipients were receiving formal services before joining the Pilot. Just over half the group (53%) had both a primary carer and assistance from government-funded community care services; 38% had a primary carer and were not receiving government-funded assistance; 4% received assistance from formal services only. The remaining 5% of community-based care recipients reported having had no previous sources of assistance (4%) or previous assistance is not known (1%). Approximately 21% of clients had been receiving a care package service before the Dementia Pilot, usually a CACP.

Assessment data recorded for the evaluation reveal concerning levels of carer strain and a statistically significant association was found between measures of carer strain and self-reports of psychological symptoms. Many carers reported strong negative reactions to the behavioural and psychological symptoms of dementia in their care recipient. These reports were not limited to what might be thought of as the more severe forms of behavioural disturbance, for example, aggression, but were also reported in connection with memory loss and emotional responses in the person with dementia—symptoms that typically emerge in the early stages of dementia.

The Dementia Pilot has offered a new choice to those people who had not formerly used government-funded services or any type of formal assistance by providing the opportunity for formal service intervention. Most of the 21% of community-based care recipients who had been receiving a care package before the Pilot were receiving CACP services (46 care recipients). Pilot providers noted that people had been transferred from a CACP to a Pilot package because a CACP is not usually adequate to support a high care dementia client. In addition, around 18% of care recipients who were previously receiving formal services had been accessing multiple aged care programs. Some service providers with access to multiple sources of funding use this as a way to increase service levels to high needs clients.

Areas of unmet need that have been targeted by Pilot projects include:

- limited access to high level community care—a CACP does not usually provide enough hours of care per week to adequately help family carers to maintain a person with high dementia-related needs at home

- a limited supply of community care with a dementia-specific focus—greater flexibility needs to be built into service delivery for staff to be able to respond to the needs of individual clients
- difficulty in achieving timely diagnosis of dementia and, hence, early intervention
- difficulty in obtaining and maintaining service for people with severe behavioural and psychological symptoms.

Three of the Pilot projects demonstrated a strong clinical component to service delivery in a short-term (8–12 weeks) intervention model. The Dementia Behaviour Advisory and Management Service addressed the problems of staff shortages in a large regional/rural area through an outreach behaviour assessment service that provides intensive clinical work-up in an intermediate care unit. This highly innovative service offered in-place behaviour management for care recipients living in the community and in residential aged care services. Dementia Rehabilitation At Home also addressed the challenges of regional and rural Australia for community care delivery, but via the use of Telehealth technology. This project has brought people with dementia into contact with clinical specialists for the purpose of diagnosis of dementia and co-morbidities and has linked people into the network of community services. Telehealth has been found both here and overseas to reliably assess dementia patients (Loh et al. 2005) and shows enormous potential for reducing the difficulties in accessing specialist services that are faced by people in rural and remote locations. A third short-term care project, North East Dementia Innovations Demonstration, provided an interface between hospital and home for patients at Austin Health in Melbourne and offered a new referral option for Aged Care Assessment Services in the region. The location of this service within a large acute and sub-acute care service maximises the chances for people with dementia to return and remain at home after a period in hospital.

One short-term care project, Flexible Care Service, is considered more similar to the long-term care projects on the basis of the type of assistance offered. This project and the long-term care projects in Queensland (RSL Care Dementia Pilot, South Brisbane and Gold Coast Innovative Dementia Pilot, and Ozcare Innovative Dementia Packages) and Western Australia (Dementia Care in Alternative Settings) focused on providing dementia-specific care packages that offer significantly higher hours of care per week than more widely available mainstream care packages. This greater flexibility enabled providers to address the needs of a care recipient and their carer (sometimes, entire families) more adequately through the provision of in-home ADL support, high level carer support including flexible respite care, and intensive case management and service coordination. The South Brisbane and Gold Coast Pilot catered exclusively to the needs of people from culturally and linguistically diverse backgrounds and their carers, for whom dementia and the use of community services often present special challenges that require a culturally sensitive approach and bilingual support. Other projects also offered culturally-specific care services to clients, for example, RSL Care, NEDID and FCS.

The Sundowner Club is distinguished from the rest of the projects as a respite care and socialisation program rather than being a care package program with case management. Sundowner Club clients and their carers benefit from a truly novel form of respite care that would complement other community care services for people with dementia and function as a useful early intervention.

Project coordinators experienced difficulties in some areas, most often related to recruiting and retaining suitably qualified staff, and occupancy management and exit strategies in the short-term care projects.

Carers expressed overwhelming support and gratitude for the services that they received through the Dementia Pilot. Approximately 83% of respondents to the Care Experience Survey indicated that they regarded the type of assistance received to be an appropriate form of care for their care recipient for the foreseeable future. Many carers reported reduced carer strain in parallel with receiving Pilot services and those who responded to the survey directly attributed their feelings of improved wellbeing to receipt of pilot services. Case study reports provide further solid evidence that Pilot services have made significant contributions to the quality of life of care recipients and their family carers.

More than half of the clients in short- and long-term care projects were still living at home when follow-up completed in mid-2005. Those people who had been admitted to residential aged care did so after a trial of care at home that helped to maximise function and delay admission for as long as possible. Carers of people admitted to residential aged care received support in the transition and were able to make a fully informed decision having had the opportunity to trial high level community care.

All nine projects appeared to be meeting their stated objectives with the overall aim of improving the quality of life of people with dementia and their carers and enabling people with dementia to live longer in the community.

Part B

Project reports

1 Dementia Behaviour Assessment and Management Service

1.1 Project description

The Greater Southern Area Health Service in New South Wales is the approved provider for a 16-place Dementia Pilot project, known as Dementia Behaviour Assessment and Management Service (DBAMS).[1] Greater Southern Area Health Service is an instrumentality of the New South Wales Government (NSW Health), which provides a range of primary and secondary specialist services and home- and community-based services, including Aged Care Assessment. DBAMS services a vast regional area of southern New South Wales, stretching from Hillston and surrounding district in the north to Albury in the south, and east to west from Tumut to beyond Hay, approximately 113,850 square kilometres in all. The project operates from the Area Health Service centre in Wagga Wagga.

DBAMS was initially funded to provide 16 flexible care places over a period of 2 years, commencing 1 June 2003. Clients are expected to remain in the program for an 8 to 12 week support period.

Objectives and target group

DBAMS has trialled a model of outreach and intermediate care for people with dementia or dementia-related behavioural symptoms with the aim of increasing carer and care worker confidence and competence in managing behavioural issues.

Specifically, DBAMS was designed to assess the effectiveness of:

1. a regional outreach education and support program to enhance the management skills of staff in residential care facilities dealing with dementia
2. an intermediate care model within an 8 to 10 week timeframe providing a comprehensive assessment and management program for people with dementia or dementia-related behavioural symptoms
3. early intervention and community-based assessment for people with dementia and dementia-related behavioural symptoms
4. an interactive model of care that involves the client, the carer and/or residential care provider and general practitioner through each stage of assessment and management.

The target group is people with dementia, living in the catchment area, who have been assessed by ACAT as eligible for high level residential aged care and who would benefit from the provision of a specialised assessment and behaviour management plan. An eligible participant will exhibit behavioural symptoms that mean he or she cannot be managed at home or in a residential care setting.

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[1] The original auspice for the project was the Greater Murray Area Health Service, which was merged with the Southern Area Health Service to form the Greater Southern Area Health Service as part of the 2004 restructuring of NSW Health services.

Care model

The DBAMS model comprises two main components:

- Intermediate care, including assessment, medication review and behaviour management, is provided in Yathong Lodge, a 16-bed aged care unit in Wagga Wagga with an adjoining Day Therapy Unit. Clients admitted to Yathong Lodge receive consultancy access to a psycho-geriatrician, specialist psycho-geriatric nurses, psychologist and allied health therapists. The assessment and management strategies are individually based with a focus on behavioural management supplemented by medical treatment where necessary.
- An outreach service provides dementia-specific services to the community including community-based assessments for people with acute dementia and related behavioural symptoms; a behaviour management program to support carers and staff in aged care facilities; referral pathways to relevant agencies; and education and support to health workers, carers and other agencies operating in the region. A telephone hotline is available to provide support 24 hours per day on 7 days a week for residential aged care services, smaller rural hospitals and carers and families in the community.

Case study 3 at the end of this section illustrates the delivery of complementary intermediate care and outreach support. Outreach is a critical component of the project because it provides almost immediate practical assistance and rapid access to specialist medical and psychogeriatric advice. Through the outreach arm, DBAMS enables aged care staff and carers at home to manage client behaviours, which in turn reduces demand on Yathong Lodge.

On receipt of a referral, an assessment of client needs is made in the home environment (aged care facility or private residence). At this point it is determined whether the client should be admitted immediately to Yathong Lodge for specialist assessment and management, or whether services can be delivered in place. Referrals that culminate in client admission to Yathong Lodge have come mostly from aged care facilities, with a smaller proportion from the community, the acute care hospital and smaller hospitals with nursing home-type beds. Medication review is a key component of assessment for clients in Yathong Lodge. The 'Sunshine Club', a program of small group activities for people with common interests and level of functioning, has been developed to encourage social interaction and participation for clients in Yathong. Under the supervision of a diversional therapist, clients are able to participate in music therapy, aromatherapy and similar activities. On discharge from Yathong Lodge, the DBAMS client returns to their usual place of residence or appropriate placement, as applicable. DBAMS assists with transitional arrangements and may provide on-site support for as long as required.

DBAMS facilitates access to psycho-geriatric assessment and behaviour management for people who remain at home, either in the community or in an aged care facility (the outreach arm). The DBAMS team conducts assessments in the home environment, coordinates any additional referrals, and develops a behaviour management plan that is implemented in situ, jointly with the carer and family together with aged care staff in the case of a client who resides in a facility. The 8 to 12 week intervention period allows time for observation of the client, medication review, establishment of a behaviour management plan and supported handover to workers in an aged care facility or family carers (or both in some instances).

Carers are supported by a social worker, psychologist, counsellor and dementia support worker. Carers generally receive assistance to coordinate other services and respite care.

Clients may be readmitted to the pilot if they are unable to be managed under a current behaviour management plan or if symptoms change necessitating additional assessment and support. This capability offers a 'safety net' for facilities and family carers.

Regular meetings of the DBAMS clinical team have proved critical to prioritising admissions and organising rapid, appropriate placement. Discharge case conferencing and behaviour management meetings also play a central role in the multidisciplinary coordination of access to intermediate care and outreach services.

DBAMS provides consultancy services for staff in residential facilities. Staff can access specialist geriatric and nursing expertise by telephone or organise outreach workers to visit the facility. Staff in facilities who have referred to DBAMS indicated to the evaluation team that the outreach service is highly valued and has helped them to manage challenging situations effectively, often avoiding the need to transfer a client to another facility such as hospital or Yathong Lodge.

DBAMS also delivers dementia-specific education programs to professionals, carers and interested members of the public throughout the service region. Between October 2003 and December 2004, 1,058 people attended DBAMS dementia-specific training sessions in 19 locations across the project's catchment area. The project supplied to the evaluation a DBAMS education program report (Part B, section 1.6)

Feedback from participants indicates that staff in residential aged care facilities find the training sessions interesting and useful, as they improve general understanding of dementia and associated behaviours plus practical ideas to assist staff to manage their clients. Participants also value the opportunity to access training in the workplace (or at least in their home towns), as this means more staff members can participate at a reduced cost. Generally travel time and costs make accessing training for people living and working in rural and remote locations difficult and expensive.

Staffing

The DBAMS care model is founded on a multidisciplinary team structure as follows:

- geriatrician
- two visiting psycho-geriatricians
- psycho-geriatric nursing team: psycho-geriatric clinical nurse consultant and two psycho-geriatric nurses
- social worker (2 days per week)
- occupational therapy, physiotherapy, psychology and podiatry services are subcontracted from Wagga Wagga base hospital or the Forrest Centre Aged Care Assessment Service on an as-needed basis
- diversional therapist.

Project coordination is the responsibility of the psycho-geriatric CNC, who also develops and delivers the professional education program. Social work is a key factor in the project's success. The social worker provides carer support, manages paperwork associated with guardianship and power of attorney, coordinates services and provides client and carer advocacy. In cases where a placement decision has been taken, the social worker assists carers and family members to locate suitable aged care accommodation and complete the admission procedures.

Brokered allied health professionals work with clients admitted to Yathong Lodge only. The project tried unsuccessfully to employ an occupational therapist and physiotherapist for Yathong Lodge. Brokerage has proved successful, but direct employment is viewed as offering more flexibility. Likewise, a diversional therapist works with clients in Yathong Lodge on 2 days per week (the project would employ a therapist for more hours if one was available). In-home allied health assessments and services are accessed via normal channels.

A cohesive, multidisciplinary team is thought to be a major factor in achieving outcomes for DBAMS. Highly selective recruitment was undertaken to fill positions in the outreach team.

Attracting qualified staff, especially psycho-geriatric nurses and allied health professionals is a significant and ongoing challenge in the region. Prior to DBAMS, one psycho-geriatric nurse covered both the northern and southern regions of the then Greater Murray Area Health Service. The cost of travel, both personal and financial, is exceptionally high.

Successes, challenges and lessons

DBAMS has functioned as a point of referral for rapid access to psycho-geriatric expertise for people in southern New South Wales who are caring for a person with behavioural and psychological symptoms of dementia. The outreach service ensures almost immediate access to specialist medical and nursing advice and practical assistance. Admissions to Yathong Lodge slowed as a result of increased awareness and use of the DBAMS community outreach service. This outcome illustrates the success of an outreach model in providing effective in-place support to clients with behaviour management needs. At the inception of the pilot, all 16 beds at Yathong Lodge were occupied and a waiting list had grown to 6–7 potential admissions; during 2005 occupancy averaged 12 inpatients with a maximum of one name on the waiting list at any one time. Very few calls are made to the telephone hotline, a further indication that the project has been able to reach people in need of specialist intervention and put in place appropriate management strategies.

An effective outreach service is observed to reduce the number of beds needed for intermediate care and it is thought that 12 beds plus an outreach component could meet demand in the area over the medium term. With dementia prevalence projected to double over the next 20 years, the need for beds to support this type of service will inevitably rise.

Outcomes for this project are difficult to quantify in a numeric sense because DBAMS is fundamentally about system capacity building and quality care for people with BPSD. Client behaviours may or may not alter, but the people who provide care in the home environment gain insight into behaviours and learn effective management and coping strategies. Outcomes closely relate to quality of life for clients, their families and carers, and work satisfaction and sense of competence for staff in facilities.

The project coordinator remarked that the alternative for many clients accepted into DBAMS would have been sedation in hospital or an aged care facility. Among clients coming in to Yathong Lodge, the DBAMS team has noted high use of chemical restraint for behaviour management. DBAMS intervention has not reduced the number of psychotropic medications in use by Pilot clients but benzodiazepines have in most cases been replaced by newer, safer medications administered in smaller doses.

Specialist medical assessment and behaviour management aims to identify the root causes of behavioural disturbance such as pharmacological or environmental factors, and seek a reduction in behavioural symptoms by addressing the underlying causes. Family carers and staff in facilities do not usually have the resources to tap into education programs to develop the necessary skills. DBAMS has imparted knowledge through the interaction of psycho-geriatric professionals with carers and care workers. Enhanced knowledge has been observed to greatly increase the confidence of people providing care at home.

Clinical involvement of Area Health Service specialists and visiting psycho-geriatricians has been critical to successful outcomes for clients. Their role is illustrated in case study reports included at the end of this section. Medical specialists have lent valuable expertise to the development and delivery of DBAMS education in the southern region.

Through the project, regional access to psycho-geriatric specialists has increased. DBAMS has attracted additional personnel with specialist skills to the area. Prior to the project, just one psycho-geriatric nurse was available to respond to calls from all general practitioners in the region. Multidisciplinary support for the psycho-geriatric nurses has increased considerably as a result of DBAMS.

Referral rates (to DBAMS) dropped following the first phase of the professional education program and it was suggested that this was in relation to increased behaviour management capacity in aged care facilities. The DBAMS team has observed a reduction in the use of chemical and physical restraints as means of coping with behavioural symptoms in facilities and hospitals.

It is expected that the DBAMS model would work well alongside EACH packages, the first allocation of which was made to the region in mid-2004. Project staff would like to see this type of intervention before carers reach crisis point and people with dementia are admitted to facilities.

Major challenges with providing effective care to members in the target group centre on workforce issues. There are limited numbers of registered nurses in aged care facilities and even fewer with psycho-geriatric training. This limits the capacity of facilities to provide effective management of clients with complex care needs. In this environment, staff need back-up from a specialist team. DBAMS has, itself, encountered recruitment difficulties. There is a widespread shortage of psycho-geriatric nurses. Finding appropriately qualified staff who fit in well with the team has been a challenge; turnover of staff once engaged is less of an issue. Staffing of Yathong Lodge has been less than straightforward, as the project carried over a staff from what was originally a NSW Health Confused and Demented Elderly unit. Changing the culture of an existing staff to be amenable to a philosophy of client-focused care has required some effort.

Travel is an additional complicating factor. DBAMS services a large geographic area and travel to cover the entire region is time consuming and demanding on staff. DBAMS staff has had access to an existing fleet of three cars that have not had to be funded from the project budget.

A lack of dementia-specific beds in the region has proved a major barrier to timely, appropriate placement of DBAMS clients.

Although not one of the most populous areas of New South Wales, it is estimated that the southern region along with the central west has relatively high concentrations of older people with very high care needs compared to other parts of the State (Brown et al. 2005). This pilot has successfully demonstrated an effective and efficient service model for people with dementia-related high care needs and their care providers. Demand for dementia-specific services is expected to grow while the nursing and aged care workforces are expected to contract over the next few decades. DBAMS has demonstrated that community outreach combined with intermediate care for older people with BPSD has the potential to increase efficiencies within aged care and health systems through improved client outcomes and increased skill and sense of competency in nursing staff, care assistants and family carers.

ACAT perspective

ACAT reported that DBAMS provides a new referral option and that ACAT has confidence in the knowledge that it is referring clients to a service that offers highly effective assessment and care. Prior to DBAMS, ACAT had a great deal of repeat contact with clients and their carers and facility staff. 'ACAT was the only place people know to go for help.' However, in many situations, ACAT had very limited options for providing assistance to members of the target group. This difficulty was far worse for outreach ACAT staff working with small communities, where ACAT is usually a one-person team.

ACAT indicated that DBAMS has facilitated resolution for a number of clients considered to be 'difficult placements', assisting the placement process by putting an effective care plan in place and providing an important source of ongoing support to clients and staff. ACAT also suspects that there has been a reduction in hospital admissions from aged care facilities as a result of the DBAMS pilot.

Aged care service perspective

The director of nursing at a 60-bed aged care facility provided further insight to the DBAMS service.

Access to support from specialists in the field of psycho-geriatrics has greatly enhanced the working experience of staff in the facility. Aged care nurses are able to visit Yathong Lodge to learn about a client's management plan before the client is discharged back to the facility. DBAMS educates facility staff on how to respond to client behaviour on their return home from Yathong. Guaranteed return to a facility after a period in Yathong Lodge allows facilities to make a referral without fear or worry that a client will lose a place. Transfers have been well handled to minimise distress.

A pre-DBAMS scenario was recounted for comparison with the DBAMS experience. Before the project was established, a facility requiring assistance for a client with behaviour management issues would refer to the one Area Health Service psycho-geriatric nurse and wait 10 to 14 days for a response. If consultation with a psycho-geriatrician was recommended, up to 2 months might elapse (a specialist from Sydney visits Wagga once a month). Following contact with the client's general practitioner to change the medication regime, there might be another lengthy delay for review by the visiting psycho-geriatrician. In total, 3 to 4 months might elapse simply for medication review and management. Under the DBAMS model, response and intervention is immediate.

Nursing staff in aged care facilities are drifting back to community nursing because of high levels of occupational stress. The DBAMS pilot has made inroads to reducing staff burnout by providing staff with strategies for the effective management of clients and by offering an immediate solution in situations where a client needs specialist diagnosis and management. In conclusion, DBAMS is seen as building capacity in the aged care system for effectively addressing the complex needs of a growing number of people with dementia.

Case studies

DBAMS provided three case study reports.

Case study 1

'One client admitted to DBAMS was aged in the late 30s at time of admission. This case study outlines client history and reason for admission to the project. The case highlights the lack of suitable facilities for younger people with dementia requiring care, the financial and emotional stress for carers in this situation and the need for advanced care directives.

Social background

The client was employed prior to initial diagnosis, separated from spouse but maintaining some contact with young children. The client's mother has a history of erratic behaviour but no diagnosis of psychiatric disorder. Client's father, stepmother and brother were the primary caregivers.

Medical history and events leading to admission and discharge from project

The participant was diagnosed in January 2004 with degenerative disorder of the white matter, described as sub-acute demyelinating syndrome of unknown origin. However, symptoms emerged in September 2002 and at that time the client displayed manic and psychotic behaviour. Client was admitted to a psychiatric unit for assessment and diagnosed with bipolar disorder. Client re-presented three weeks after discharge after several suicide attempts and was readmitted and treated for severe depression. In November 2003 the client had a focal seizure which led to a series of investigations in a hospital, 2 hours from home. Client was then transferred to a different hospital in the capital city (further from home) in January 2004 where the diagnosis of degenerative disorder was made. A brain biopsy in February 2004 'essentially showed multi-focal necrotising lesions in the white matter with some activation of endothelial cells and a mild chronic inflammatory reaction'. Electron microscopy did not confirm any particular diagnosis. Client was admitted to intensive care on three occasions in status epilepticus. After discharge from hospital in March 2004 the client was treated with chemotherapy at the original hospital which is over two hours from the home of carers. Client returned to the home town, where family took it in turns to provide care. They were concerned that the impulsive intrusive and slightly uninhibited behaviours were having a negative effect on a younger family member. Unable to access respite services, the family chose to hire a motel room in which to care for the client. This continued for several weeks.

When an ACAT assessor became aware of the client she tried to access services and eventually found respite with a dementia respite service in a group home situation that offered 4 days per month. The client absconded from this facility after 2 days. ACAT discussed the case with DBAMS but the client did not meet the DBAMS eligibility criteria and was not at that stage considered a candidate for the project. However DBAMS staff assessed the client and the case was discussed at the weekly intake meeting, mainly to get some input as to how DBAMS could assist ACAT.

After the respite had finished the client returned to the care of family for a few days. They were unable to cope with the client's increasingly demanding and erratic behaviour. The client was taken to the emergency department at the local hospital, and from there was transferred to the base hospital where a psychiatrist deemed the client's condition as due to an illness causing dementia. After consultation the client was admitted to Yathong Lodge in July 2004.

During the assessment period the client was reviewed by the visiting psycho-geriatrician, and returned to the hospital in the capital city for planned follow-up assessment by a neurologist, returning to the hospital 2 hours from home for further chemotherapy.

Outcome

After effective behavioural and pharmacological interventions were implemented, accommodation options were sought. The social worker with DBAMS tried many avenues all of which were unable to accept the client for permanent placement.

The client went into status epilepticus in January 2005 and was transferred to an intensive care unit, then returned to Yathong after a few days. The client's condition had markedly deteriorated; the client was no longer able to walk without the assistance of two people, could not communicate, and seizure activity was frequent. A family conference was held to determine the level of medical intervention. The client's condition was rapidly deteriorating necessitating transfer to the local hospital nearest to the client's family for palliative care. The client passed away shortly after.'

Case study 2

'Male client admitted to DBAMS in December 2003. This case study outlines the client's history and reason for admission to the project and the successful outcome in keeping a client at home with services when the local hospital and his GP were pushing for permanent placement in a residential aged care facility.

Social background

The client was an 85-year-old male who, until his admission to hospital, had been living with his wife of 60 years in a house he built on their farm. The farm had been sold some years ago, but the couple retained permanent tenancy of the home. They had only ever spent minimal time apart in their married life and this hospitalisation was the longest time they had been separated. The house is located close to a small town. They have two children, a son who lives in a major centre 1.5 hours drive away, and a daughter who lives in Canberra and a number of grandchildren but none living nearby.

Medical history and events leading to admission and discharge from project

The client had seen a neurologist in May 2003 and been diagnosed with dementia and commenced on Aricept which he did not continue to take because of side effects. He was admitted to hospital 3 months prior to admission to the project with pneumonia, from which he recovered. Then, following one day at home, the client had a mild cerebral vascular accident and was immediately readmitted to hospital. During the ensuing month he developed a urinary tract infection and for most of both admissions had a delirium which led to behaviours such as exit seeking, inappropriate urinating, intruding into other patients' rooms.

His MMSE on assessment was 15/30, he was disorientated in time but not place; short-term recall scored 0/3 but client was able to follow a three-stage command. He had problems with tasks requiring visual acuity as well. On the Cornell Scale for depression he scored 14/38, indicating probable major depression. Brief Cognitive Rating Scale 14/35 and Modified Barthels 51/115.

He was receiving treatment for depression which had developed after the sale of the farm. His wife also reported an increasing unfounded insecurity about finances, not allowing her to write cheques and becoming angry about phone bills.

He was admitted from the local hospital to Yathong when a bed became available a week after the initial assessment. In Yathong he settled well at first, then he began exit seeking, trying to climb the fence and refusing to accept that the car he saw in the car park was not his and wanting to ring the police to report his car stolen and becoming agitated and verbally aggressive towards staff.

Following an assessment by the psycho-geriatrician, who changed his anti-depressant medication, and a family meeting, it was decided to organise a home visit for a day to see whether his wife could manage him at home. During the home visit a number of possible problems were identified and these were addressed with education for his wife in behaviour management strategies and some environmental modifications. The family agreed the main risk would be if he drove the tractor but decided to accept the risk in the interest of his improved quality of life as he hated being in Yathong Lodge and even a year later referred to his stay there as being in prison.

Outcome

He was discharged home for 2 weeks trial 14 days after admission to Yathong—the trial was successful. Regular respite 4 hours a week was organised with the local dementia-specific respite service, Home Care came weekly to assist his wife with housework, and attendance at the local day care was organised for 2 days weekly. He was followed up in the community 1 month later and discharged from the project 4 months after that, the longer length of time in the project being caused by an inability to contact them at home as they had re-established their life in the local community and were often out of the house during the day.

On discharge from the project all assessment scores had improved: his MMSE was 16/30, his short-term memory had improved, Brief Cognitive Rating Scale 1/35 and Cornel Depression Scale 1/38 (no depression), Modified Barthels 100/115.

The client was again referred to the project in April 2005 when he had become physically aggressive towards his wife when she wouldn't let him drive the car. An offer was made to readmit him to Yathong Lodge which his wife rejected so a third day of respite in the local daycare was organised, and further education on strategies to enable her to prevent confrontations over the car and use of diversionary tactics were implemented.

As of July 2005 the client's name has been placed on the waiting lists for local dementia-specific hostels and the family is beginning to make arrangements for them to move to the larger centre where a son lives.'

Case study 3

'Female client aged 84 years, living in a high level aged care facility 350 km from the DBAMS office. She had moved into a low care facility in 2001 and moved to the current facility two months before referral to DBAMS. She was referred to DBAMS by the director of nursing due to agitation, aggression and delusional behaviours in December 2003.

Social history

Married for 63 years, her husband described the marriage as difficult. They have four children all living interstate, 11 grandchildren and 10 great-grandchildren. Client was the middle child in a family of seven siblings who are all still alive. She grew up on a farm and married a dairy farmer. They moved into town after 30 years on the farm. She was socially active with a good network of friends, played bowls, worked tirelessly for the Royal Blind Society and enjoyed singing in local church choir.

Medical history

In the past the client had breast cancer treated surgically. She is prone to chronic urinary tract infection. She received treatment for anxiety and depression in 1988; her earlier history is uncertain. In 2000 the mental health service diagnosed dementia with delusional ideation and hallucinations, then in August 2003 she developed increased confusion, agitation, hostile thoughts, and persecutory delusions as a result of an infected mouth. MMSE 11/30 at that time. Alprazolam and Serepax prn were ordered to treat the behaviours.

In October 2003 formal diagnosis of probable Lewy Body Dementia was made by a visiting psychiatrist.

Over the years she had been trialled on various medications: in 2003 Zyprexa and Aricept were ceased and Exelon commenced.

On admission to the project, assessment MMSE was unable to be tested due to non-responsiveness and level of confusion. Brief Non Cognitive Rating Scale 22/35; Cornell Depression Scale 22/38.

Current medications: Exelon 1.5 mg BD
Zyprexa 2.5 mg daily 3.00 pm
Panamax i-ii QID prn (not being given regularly)
Largactil 25 mg TDS 8.00 am 12.00 midday 5.00 pm
Avanza 30 mg ½ nocte
Durolax 5 mg 5:00pm

with PRN orders of Largactil 25 mg oral one daily, Largactil 25 mg IMI, and Durolax suppositories.

Observed behaviours: client was unresponsive when spoken to, talking to herself as if telling a story (delusional), became agitated when trying to engage her in conversation and began wandering around muttering. Client had been physically aggressive towards staff and there was increased agitation surrounding the husband's visits.

Medication changes instigated: increased Exelon and ceased Avanza for next 4 weeks—condition much improved but 1 month later client again became delusional, verbally agitated and uncooperative. Largactil increased by GP and restraints applied, assessed for infections and constipation—not detected. Largactil was ceased and a small dose of Serenace 0.5 mg prn was introduced in August 2004. Behaviours then settled. Client was still delusional at times but this was not causing her distress, staff had stopped informing her before her husband was to visit and she was much less agitated when he visited.

Training was also given to the staff in validating client emotions and distress and communication strategies. She seemed more depressed but not as aggressive or agitated and was going to be discharged from DBAMS but in October her behaviours escalated. Medications were reviewed and suggested Epilim increase to 200 mg BD and Serenace increase up to 2 mg TDS PRN, increase Exelon to 6 mg BD and introduce antidepressant. These changes were made one at a time to review the incremental effects. As a result of the review, the antidepressant was not introduced. When Exelon was increased to 6 mg there were 2 weeks of no behavioural problems and client did not require any PRN doses of Serenace. Antidepressant Zoloft 50 mg was commenced in November. By January 2005 her behaviours had escalated again. Exelon was ceased in January 2005 to see if it was having a paradoxical effect and Morphine 5 mg PRN was commenced in February. Client was much more settled in March and Serenace was ceased and Fentanyl patches 2.5 mg 3rd daily were commenced. Fentanyl patches were subsequently increased to 7.5 mg 3rd daily with Morpine 10 mg TDS PRN if required.

Outcome

In July 2005 the client was discharged from the project. Her agitation and verbal disruptions had ceased; when approached she responded appropriately, was friendly, smiling and she initiated appropriate conversation. She was still unable to complete most of the MMSE, scoring 2/30 and able to repeat 2 of the 3 words, the Cornell Depression Scale had improved to 10/38 and Brief Non Cognitive Rating Scale also improved 17/35.

Medications on discharge:	Fentanyl patches 7.5 mg 3rd daily
	Zoloft 50 mg daily
	Zyprexa 5 mg daily
	Morphine mixture 10 mg tds PRN
	Durolax 5 mg daily
	Microlax enema PRN

During the 18 months, DBAMS nurses visited the facility on 12 occasions and had phone contact a further six times. Consultation from the geriatrician took place in person once and with the DBAMS team, five times. Also, the majority of staff at the facility attended 12 hours of training from a DBAMS clinical nurse consultant on dementia, communication and behavioural management.

This case study reflects the advantages of having visiting specialist consultations, both nursing and medical expertise, to provide support, strategies and education to staff in isolated areas to assist them in obtaining a satisfactory outcome for their clients with difficult behaviours.'

1.2 Client profiles

DBAMS supplied evaluation data on 39 clients, including 21 males and 18 females.

DBAMS is unique among Innovative Pool Dementia Pilot projects in that it has targeted clients in aged care facilities and in the community. Twenty clients who participated in evaluation activities received services only in their usual place of residence—either an aged care facility or private residence—through the DBAMS outreach service. Nineteen clients spent time in the DBAMS inpatient unit, Yathong Lodge, 15 of whom also received DBAMS support services while at home (Table B1.1).

Table B1.1: Dementia Behaviour Assessment and Management Service, number of clients by service delivery setting.

Service delivery setting	Number of clients
Inpatient service only	4
Outreach services only	20
Combination of inpatient and outreach services	15
Total	**39**

Socio-demographic and ADL profiles presented below include clients across DBAMS service delivery settings. Profiles describe the client group during the 2004 evaluation period. Functional assessment results are presented separately according to usual accommodation setting: community (includes private residence and independent or supported living in a retirement village); low level residential aged care; and high level residential aged care.

Age and sex

The mean age of evaluation clients was 78.8 years (age ranges from 38 years to 98 years). Thirteen clients were aged 85 years or over (Table B1.2).

Table B1.2: Dementia Behaviour Assessment and Management Service, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
Less than 65	2	—	2
65–74	6	3	9
75–84	8	7	15
85+	5	8	13
Total	**21**	**18**	**39**
		(per cent)	
Less than 65	5.1	—	5.1
65–74	15.4	7.7	23.1
75–84	20.5	17.9	38.5
85+	12.8	20.5	33.3
Total	**53.8**	**46.2**	**100.0**

— Nil.

Language and communication

Seven clients had little or no effective means of communication. Two national languages were represented in this client group (Table B1.3). Nine clients could not communicate effectively in English.

Table B1.3: Dementia Behaviour Assessment and Management Service, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	30	7	1	38
Czech	—	—	1	1
Total	**30**	**7**	**2**	**39**

— Nil.

Accommodation and living arrangement

Private residences, retirement villages, and aged care facilities are represented in the mix of usual accommodation settings (Table B1.4). Three clients were in hospital at the time of referral to DBAMS.

Table B1.4: Dementia Behaviour Assessment and Management Service, number of clients by usual accommodation, living arrangement and accommodation setting at referral

	Usual living arrangement			
Accommodation setting	Alone	With family	With others	Total
Private residence	5	8	1	14
Retirement village—independent living	1	—	—	1
Retirement village—assisted living	1	—	—	1
Residential aged care—low care	—	—	11	11
Residential aged care—high care	—	—	12	12
Hospital	—	—	—	—
Total	**7**	**8**	**24**	**39**

— Nil.

Years at usual place of residence ranged from less than one to 50 years. Four clients had been living in the same home for 20 or more years. Eighteen of the 21 clients who had changed place of residence in the 2 years prior to entering DBAMS were residing in an aged care facility.

Carer availability

Twenty-nine clients had a family carer during the reporting period (Table B1.5). Seven carers elected not to participate in assessments for the evaluation. Ten carers were living with the care recipient.

Carers’ ages ranged from 40 to 89 years, averaging 64.7 years. Eight carers were aged 75 years or over (Table B1.6). Most carers were female.

Table B1.5: Dementia Behaviour Assessment and Management Service, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Total
Spouse or partner	6	6	12
Parent	1	—	1
Son or daughter	3	7	10
Son- or daughter-in-law	—	1	1
Other relative	—	3	3
Friend/neighbour	—	1	1
Not stated	—	1	1
Total clients with a carer	*10*	*19*	*29*
Clients without a carer	. .	. .	10
Total clients			**39**
Per cent of clients with a carer			74.4

— Nil.

. . Not applicable.

Table B1.6: Dementia Behaviour Assessment and Management Service, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	—	2	2
45–54	2	6	8
55–64	1	3	4
65–74	3	4	7
75–84	1	5	6
85+	—	2	2
Total	**7**	**22**	**29**

— Nil

Income and concession status

Government pensions were the primary source of cash income for 34 of the 39 clients (Table B1.7). Eighteen clients held a health care concession card. DBAMS does not charge fees for community-based clients. Clients admitted to Yathong Lodge for medical supervision and management contribute $37 per day towards accommodation costs.

Table B1.7: Dementia Behaviour Assessment and Management Service, number of clients by principal source of cash income, health care card status and project concession status

	Number of clients	Per cent
Principal source of cash income		
Age pension	27	69.2
Disability pension	2	5.1
DVA pension	5	12.8
Superannuation or annuities	4	10.3
Other cash income	1	2.3
Total	**39**	**100.0**
Health care concession card holder	18	46.1
Project concession status	1	1

Previous use of government community care programs

Twenty-three clients were admitted to DBAMS from a residential aged care facility.

Half of the 16 clients living in the community were not receiving assistance from government community care programs before DBAMS (Table B1.8). Six carers reported that, despite having had a need for respite care in the 12 months prior to DBAMS, they had not used a respite care service. Four carers reported using residential or in-home respite care prior to DBAMS; six carers said they had not needed respite care.

Table B1.8: Dementia Behaviour Assessment and Management Service, number of clients by use of government support programs prior to entering DBAMS, community-based clients only

Previous use of government support programs	Number of clients	Per cent
No previous government program support	8	50.0
Government support program		
Home and Community Care	2	12.5
National Respite for Carers Program	2	12.5
Veterans' Home Care	1	6.3
Multiple programs (HACC and NRCP)	3	18.8
Total	**16**	**100.0**
Use of respite care in the 12 months prior to DBAMS		
Respite care not needed	6	37.5
Respite care used	4	25.0
Respite care needed but not used	6	37.5
Total	**16**	**100**

Nine of the 16 community-based clients were on a waiting list for residential aged care.

Assessment and referral

DBAMS receives referrals from a variety of sources, with most originating from an ACAT or an aged care facility (Table B1.9). Client care is managed by a registered nurse (15 clients) or a multidisciplinary team (24 clients).

Twenty clients had completed an ACAT assessment at or before entry to DBAMS (Table B1.10).

Table B1.9: Dementia Behaviour Assessment and Management Service, number of clients by source of referral

Referral source	Number of clients
Aged Care Assessment Team	14
Another community service or agency	14
Hospital	4
Other person	4
Greater Southern Area Health Service	2
General practitioner	1
Total	**39**

Table B1.10: Dementia Behaviour Assessment and Management Service, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–20 days	20
After referral to project	
Between 2 and 42 days post-referral	8
Not stated	11
Total	**39**

Health conditions and health status on entry

The number of health conditions recorded for DBAMS clients at entry to the project ranges from zero to eight. Twenty-five clients had three or more health conditions at entry. Table B1.11 shows the primary health conditions recorded on the Aged Care Client Records for DBAMS clients.

Table B1.11: Dementia Behaviour Assessment and Management Service, number of clients by primary health condition

Primary health condition	Number of clients
Dementia (includes Alzheimer's disease and other dementias)	34
Delirium	2
Other neurotic, stress-related and somatoform disorders not elsewhere classified	1
Cerebrovascular disease	1
Amnesia	1
Total	**39**

Twenty-three clients were assessed as being at risk of falls due to impaired gait or balance (Table B1.12). More than one-third of clients had diagnosed depression, and around half showed signs of disorientation or confusion—a relatively high prevalence of these conditions compared to other Innovative Pool Dementia Pilot client groups.

Table B1.12: Dementia Behaviour Assessment and Management Service, number of clients with selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	23
Disorientation/confusion	18
Diagnosis of depression	14
Hearing impairment	9
Vision impairment	3

DBAMS clients were taking between zero and 11 different types of medication at the time of reporting. Seventeen clients were taking six or more different medications. Medication review is a key component of inpatient assessment and intervention at Yathong Lodge. The project reported that many clients' medication regimes have been changed as a result of specialist assessment and diagnosis. Medication use (or non-use) has been found to be a main contributing factor to the behavioural and psychological symptoms for many clients.

At the time of entry to DBAMS, each client or carer was asked to report on client health status and change in health status over the past 12 months using a five-point Likert scale. Six clients self-reported, eight family carers rated their care recipient's health status, supported accommodation staff rated 18 clients, and other care workers gave a report on five clients. The health status of two clients was not recorded.

Five clients were reported to be in very good health. Other ratings were good (12 clients), fair (12 clients), and poor (one client). Around one-third of respondents reported that the client was in better or much the same state of health as one year earlier. Around half said that client health was somewhat worse (12 clients) or much worse (four clients) than one year earlier, which suggests that care needs may have increased in the 12 months prior to entry. Reports were not given for 12 clients.

Level of core activity limitation

Most DBAMS clients experienced mild to moderate self-care limitation and mild or no limitation in mobility and communication (Table B1.13). Thus, DBAMS clients are in most cases ambulatory, but have highly impaired capacity for self-care.

Twelve clients had a severe or profound level of activity limitation in at least one area of core activity.

Table B1.13: Dementia Behaviour Assessment and Management Service, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	2	10	18	9	**39**
Mobility	17	15	3	4	**39**
Communication	10	19	5	5	**39**

Use of medical and hospital services prior to entry

Baseline profiles contain information about client use of medical and hospital services in the 6 months prior to entering the DBAMS—the 'pre-entry period'.

Four clients were reported as not having visited a general medical practitioner in the pre-entry period. The number of visits to a medical practitioner in this period varied from zero to 12 per client. Cumulatively, the 36 clients who had visited a medical practitioner recorded 124 visits to a medical practitioner outside of a hospital setting over an estimated 6,480 person days.

Sixteen clients contributed to a total of 19 hospital admissions in the pre-entry period. One client had a planned admission only, and one client had both a planned and an unplanned admission. The remaining 14 clients with one or more hospital admissions recorded solely unplanned or urgent admissions. The 15 clients with unplanned admissions collectively accumulated 200 patient days for unplanned/urgent admissions over approximately 2,700 person days. Individually, they recorded between one and 30 days in hospital for unplanned admissions.

Conditions recorded as occasioning admission to hospital for DBAMS clients in the pre-entry period include:

- delirium
- urinary tract infection
- diseases of the intestinal tract
- head injuries
- skin and subcutaneous tissue infections
- heart disease
- transient cerebral ischaemic attacks
- cerebrovascular disease
- psychoses and depression/mood affective disorders
- other mental and behavioural disorders.

Five of the recorded unplanned admissions in the pre-entry period were coded with a principal diagnosis of delirium.

Four clients suffered a fall with injury and three clients were rendered immobile and without assistance for more than 30 minutes during the 12 months before entering the project. Five clients had experienced another type of serious medical emergency.

1.3 Client assessment results

Cognitive function

Mini-Mental State Examination (MMSE) scores were recorded for all 39 clients when they entered DBAMS (Table B1.14). The 31 non-zero baseline MMSE scores range from 1 to 28 points out of a possible 30 points (mean 15.5).

Table B1.14: Dementia Behaviour Assessment and Management Service, number of clients by Mini-Mental State Examination score at entry

MMSE score	Number of clients
Zero	8
1–15	16
16–18	1
19–24	10
25–30	4
Total	**39**

Zero scores for community-based clients are excluded from calculations of MMSE summary statistics.

Clients in a private residence (n = 16) recorded scores ranging from 1 to 28 with a median score of 19 points (mean 17.6; standard deviation 8).

Clients in residential high care (n = 12) recorded scores ranging from zero to 23 with a median of 4.5 points (mean 8.1; standard deviation 9.3).

Clients in residential low care (n = 11) recorded scores ranging from zero to 26 with a median of 8 points (mean 9.3; standard deviation 8.7).

Cut-points to account for educational attainment were applied to the scores (Uhlmann & Larson 1991), indicating cognitive impairment in 10 of the 16 community-based clients, in 11 of the 12 residential high care clients, and in 10 of the 11 residential low care clients.

The MMSE administered at a later date for the remaining eight clients produced a positive screen for cognitive impairment.

Activities of daily living

Level of functioning in activities of daily living (ADL) was measured using the Modified Barthel Index (MBI). A classification scheme for the MBI (Shah et al. 1989) indicates that, at entry to DBAMS, 10 of the 16 community-based clients were moderately dependent in ADL (Table B1.15). Most clients in low level residential care were moderately or severely dependent in ADL, and most clients in high level care were severely or completely dependent in ADL when they entered the project.

Table B1.15: Dementia Behaviour Assessment and Management Service, number of clients by dependency in ADL by usual accommodation setting

	Usual accommodation setting			
Dependency in ADL	**Community**	**RAC—low**	**RAC— high**	**Total**
Independent	1	—	—	1
Slight dependency	—	1	—	1
Moderate dependency	10	4	1	15
Severe dependency	5	6	10	21
Complete dependency	—	—	1	1
Total	**16**	**11**	**12**	**39**

— Nil.

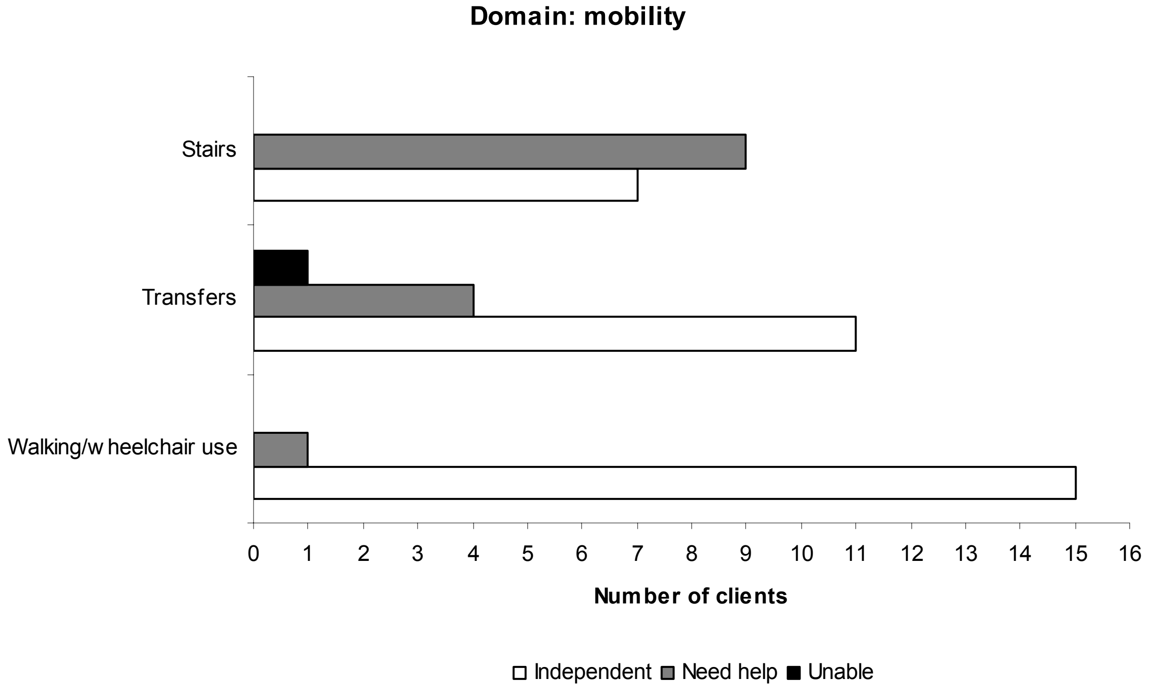
Community-based clients

Community-based clients needed assistance in most tasks involving self-care and mobility (Figure B1.1). Total MBI scores at entry ranged from 7 to 20 out of a total 20 points. The mean score was 13.5 points (Table B1.16). Thus, the middle of the distribution of MBI scores for community-based clients was in the range of moderate dependency in ADL.

Eight community-based clients required management for bladder and bowel incontinence. Fourteen clients were unable to bathe or shower without assistance. Fifteen clients were independently mobile.

Final ADL assessments for community-based clients were conducted on average 15.8 weeks after the baseline assessment.

Changes in MBI scores between baseline and final assessments ranged from –5 points (a 5-point decline in function) to 9 points (a 9-point improvement in function) (Table B1.16). The median change across all community-based clients was 1 point, that is, on average, level of functioning in ADL as measured by the MBI improved by 1 point between the baseline and final assessments. Of the clients with a non-zero change score, five clients moved to a lower dependency category and one client moved to a higher dependency category. Other clients did not record a marked change in ADL dependency during their time with DBAMS.



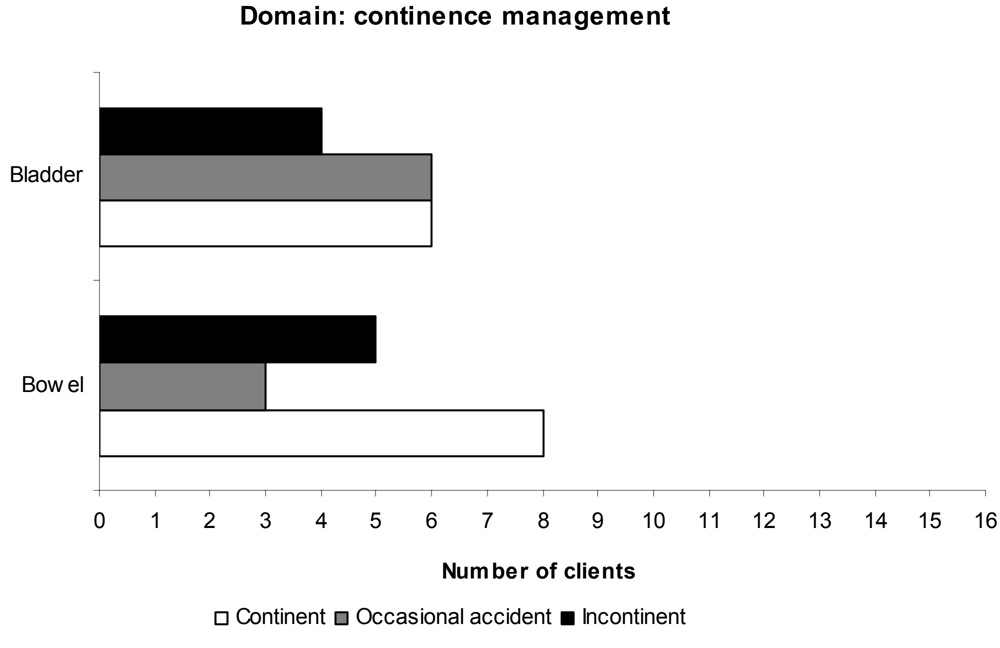


Figure B1.1: Dementia Behaviour Assessment and Management Service community-based clients, number of clients by level of ADL function

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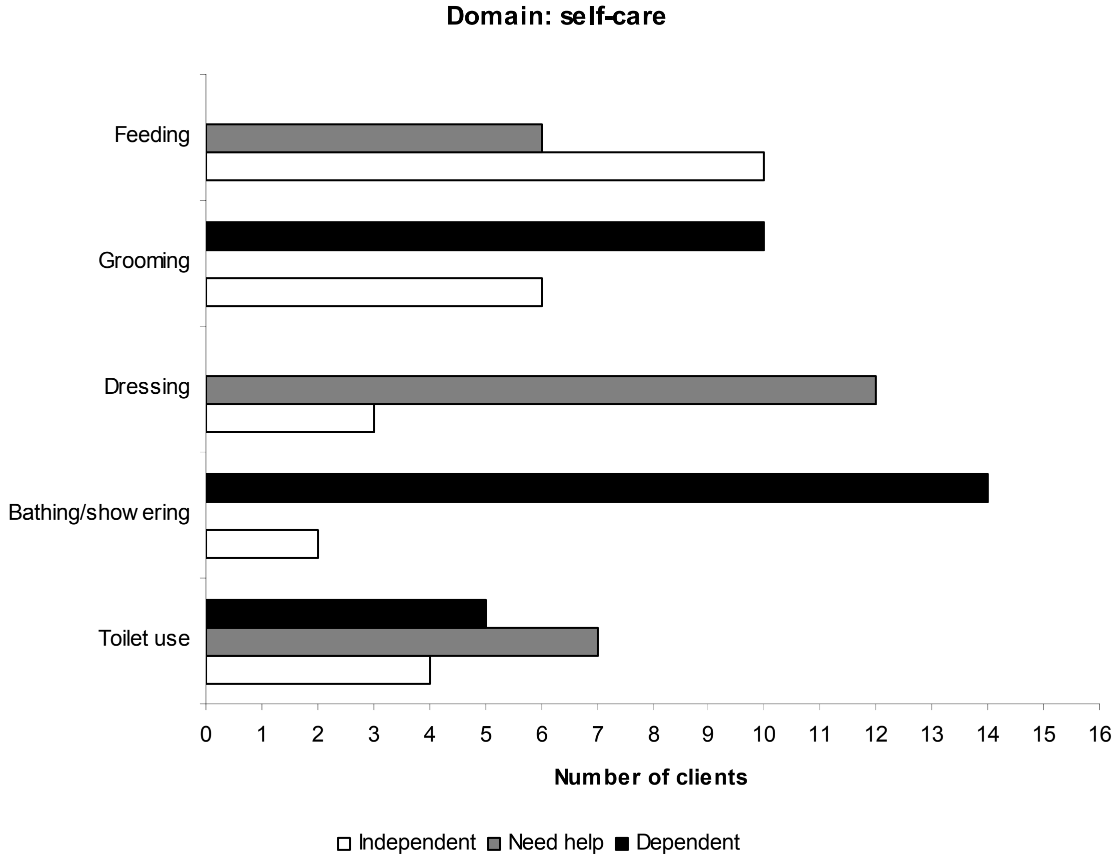
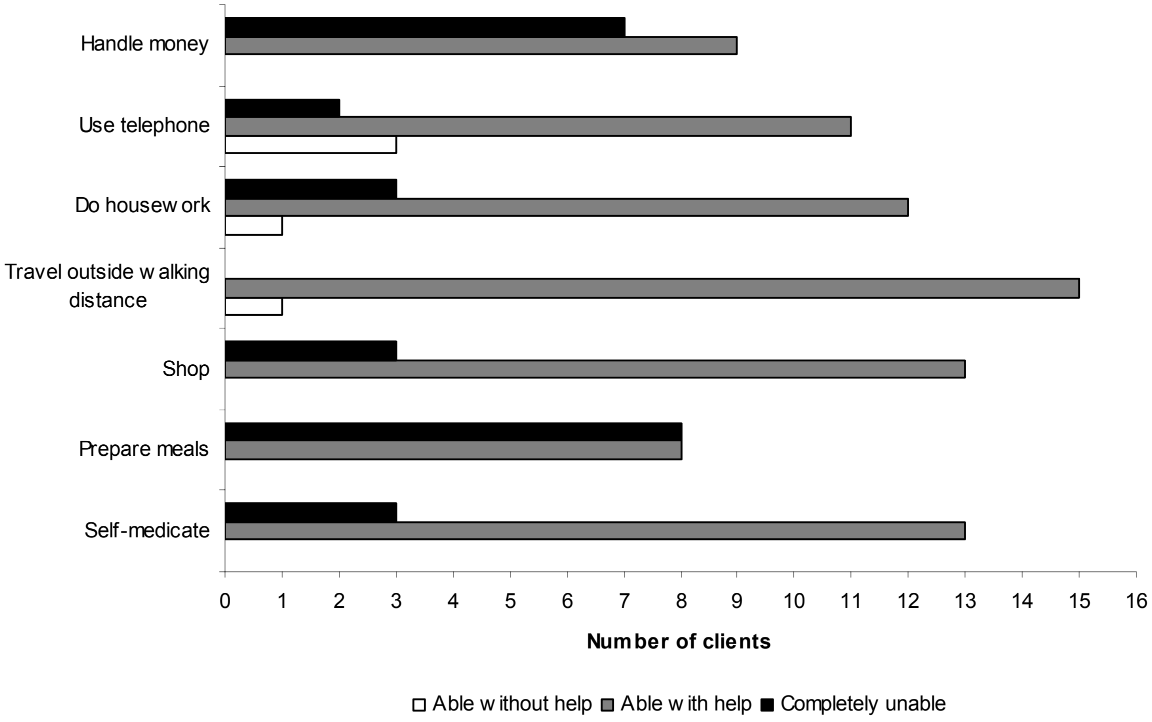


Source: Appendix Table B1.

Figure B1.1 continued: Dementia Behaviour Assessment and Management Service community-based clients, number of clients by level of ADL function

Most community-based clients either needed help to perform or were completely unable to perform IADL when they entered DBAMS (Figure B1.2). On average, these clients were completely dependent in one or two out of seven IADL at the time of entry to the DBAMS. All community-based clients were unable to prepare meals, shop, handle money or manage their own medication regimes without help. Although most clients registered as being able to walk independently, the mobility item on the IADL scale reveals that in all but one case, independent mobility was limited to the home environment.

The median baseline score on the IADL scale was 6 points (out of 14), with scores ranging from 2 to 9 points. Baseline results indicate that all community-based clients had lost some IADL function by the time they entered the project. The median change score on the IADL scale (between baseline and final assessments) was –1 point, with variation within the range of –3 to 2 points (Table B1.16). Sixty-three per cent of clients registered a decrease in IADL function between baseline and final assessments.



Source: Appendix Table B2.

Figure B1.2: Dementia Behaviour Assessment and Management Service community-based clients, number of clients by level of IADL function

Table B1.16: DBAMS community-based clients, baseline[(a)] and change[(b)] scores for ADL and IADL measures

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	16	7	13.5	20	13.5	3.4
Change in MBI	16	–5	1	9	0.9	3.7
ADL						
Baseline IADL	16	2	6	9	5.7	1.9
Change in IADL	16	–3	–1	2	–0.6	1.6

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Residential high care clients

According to MBI scores, all residential high care clients needed assistance in most tasks involving self-care and mobility (Figure B1.3). MBI scores at entry range from 1 to 16 out of a possible 20 points. The mean score recorded by this group was 9.3 points with a standard deviation of 3.5 (median 9), which indicates that the middle of the small sample of MBI scores for residential high care clients was in the range of severe dependency in ADL (Table B1.17). Nine of the 12 residential high care clients were doubly incontinent and all were unable to bathe or shower, dress or groom without assistance. Ten clients were independently mobile, one with the aid of a wheelchair.

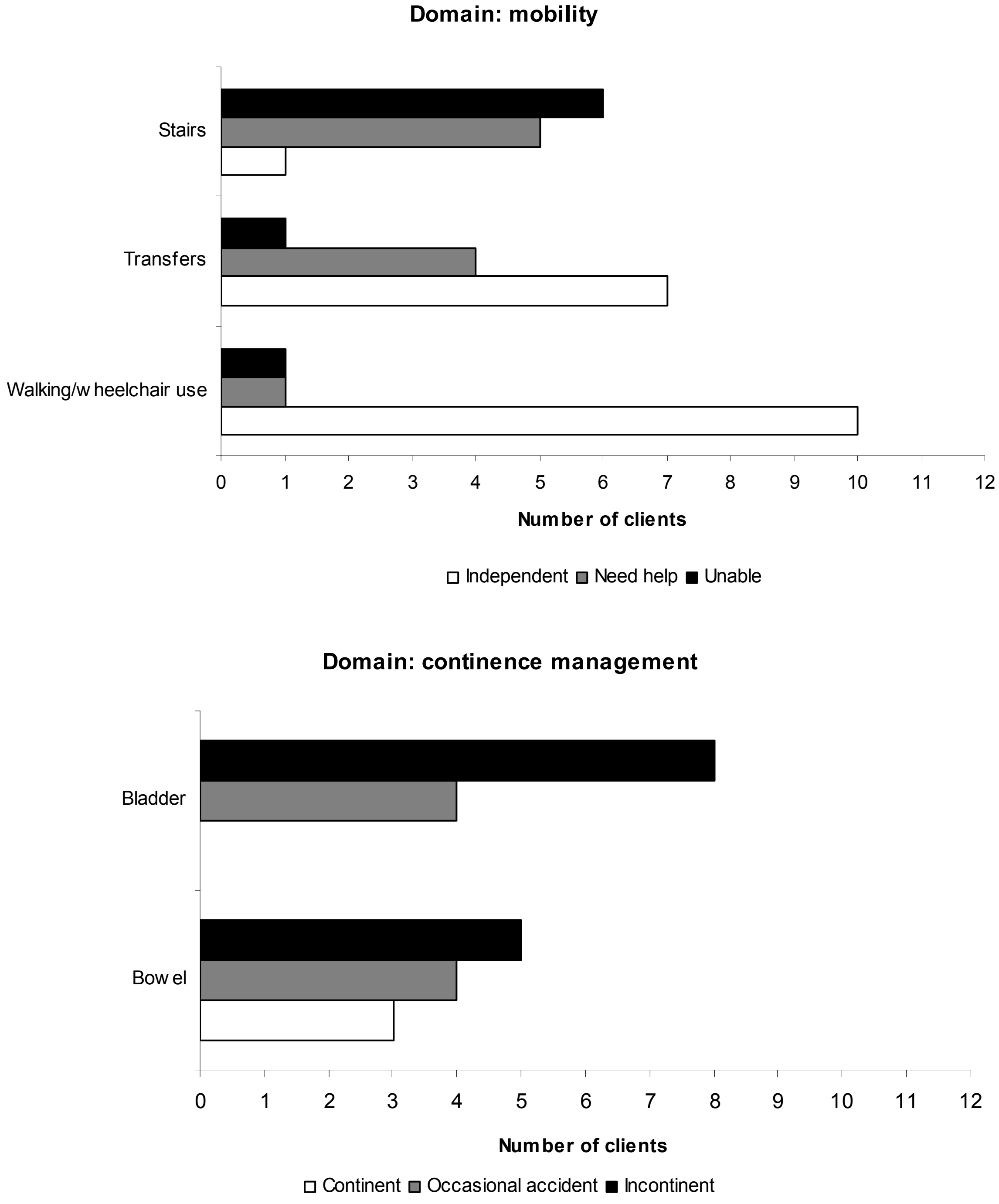


Figure B1.3: Dementia Behaviour Assessment and Management Service residential high care clients, number of clients by level of ADL function

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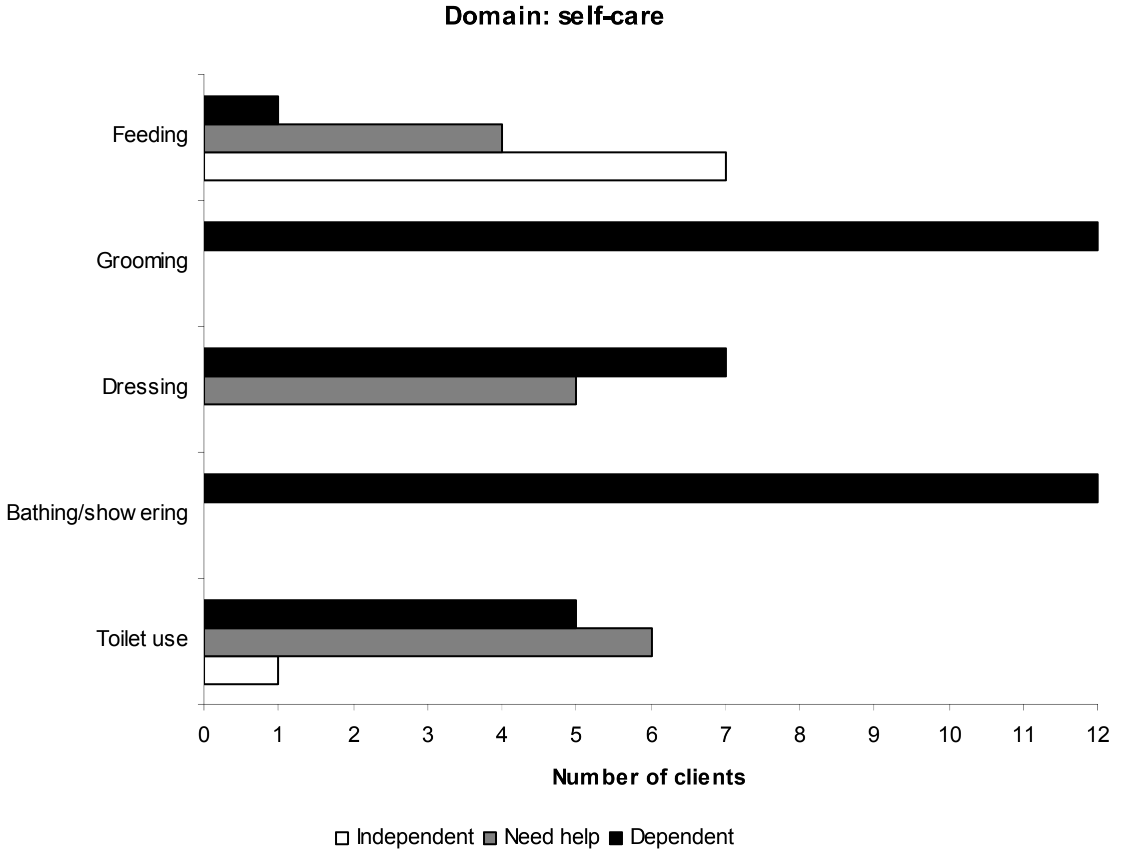


Source: Appendix Table B3.

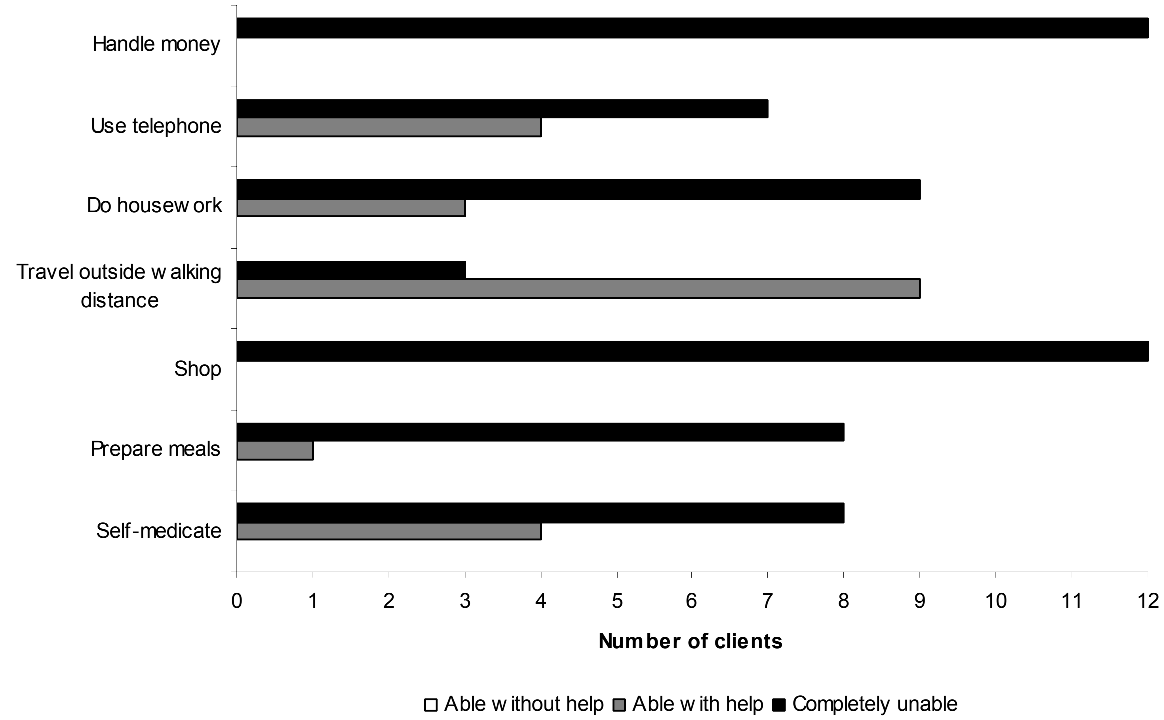
Figure B1.3 continued: Dementia Behaviour Assessment and Management Service residential high care clients, number of clients by level of ADL function

Final assessments for residential high care clients were conducted on average 14.4 weeks after entry.

Changes in the MBI between baseline and final assessments ranged from –6 points (a 6-point decline in function) to 4 points (a 4-point improvement in function) (Table B1.17). The median change was –0.5, i.e. on average, level of functioning in ADL as measured by the MBI decreased slightly between the baseline and final assessments. Of the clients with a non-zero change score, three moved to a higher level of ADL dependency, four moved to a lower level of ADL dependency, and four clients remained at broadly the same level of ADL dependency.

Most residential high care clients were highly dependent in IADL when they entered DBAMS (Figure B1.4). On average, a client in this group was completely dependent in five out of seven types of IADL.

The median baseline IADL score was 2 points, with scores ranging from zero to 5 out of a possible 14 points. Baseline results indicate that all DBAMS residential high care had experienced extensive loss of IADL capacity prior to entering the project.



Source: Appendix Table B4.

Figure B1.4: Dementia Behaviour Assessment and Management Service residential high care clients, number of clients by level of IADL function

The median change in IADL function was zero, with variation within the range of –1 to 1 point, reflecting minimal change in this functional domain over the period of observation (Table B1.17). Little change in levels of IADL functioning among this group of DBAMS clients largely reflects their very low levels of functioning at entry.

Table B1.17: DBAMS residential high care clients, baseline[(a)] and change[(b)] scores for ADL and IADL measures

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	10	7	9	16	10	2.7
Change in MBI	10	–6	–0.5	4	–1.0	2.9
IADL						
Baseline IADL	10	0	2	5	2.1	1.4
Change in IADL	10	–1	0	1	0	0.9

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Residential low care clients

Most residential low care clients needed assistance in some areas of self-care and mobility (Figure B1.5). MBI scores at entry range from 7 to 19 out of a total 20 points. The mean score was 12.9 points with a standard deviation of 4.1 points (Table B1.18). The mean baseline MBI score indicates that the middle of the small sample of MBI scores for residential low care clients was in the range of moderate dependency in ADL.

Four residential low care clients were doubly incontinent. All 11 clients were unable to bathe or shower without assistance. All clients were independently mobile when at home.

Final ADL assessments for residential low care clients were conducted on average 13.8 weeks after the baseline assessment.

Changes in the MBI between baseline and final assessments ranged from –3 points (a 3-point decline in ADL function) to 3 points (a 3-point improvement in ADL function). The median change was –2 points (Table B1.18), indicating that on average, level of functioning in ADL as measured by the MBI declined by 2 points between the baseline and final assessments. Of the clients with a non-zero change score, two clients moved to a higher level of ADL dependency and the remaining clients did not show a marked change in ADL dependency.

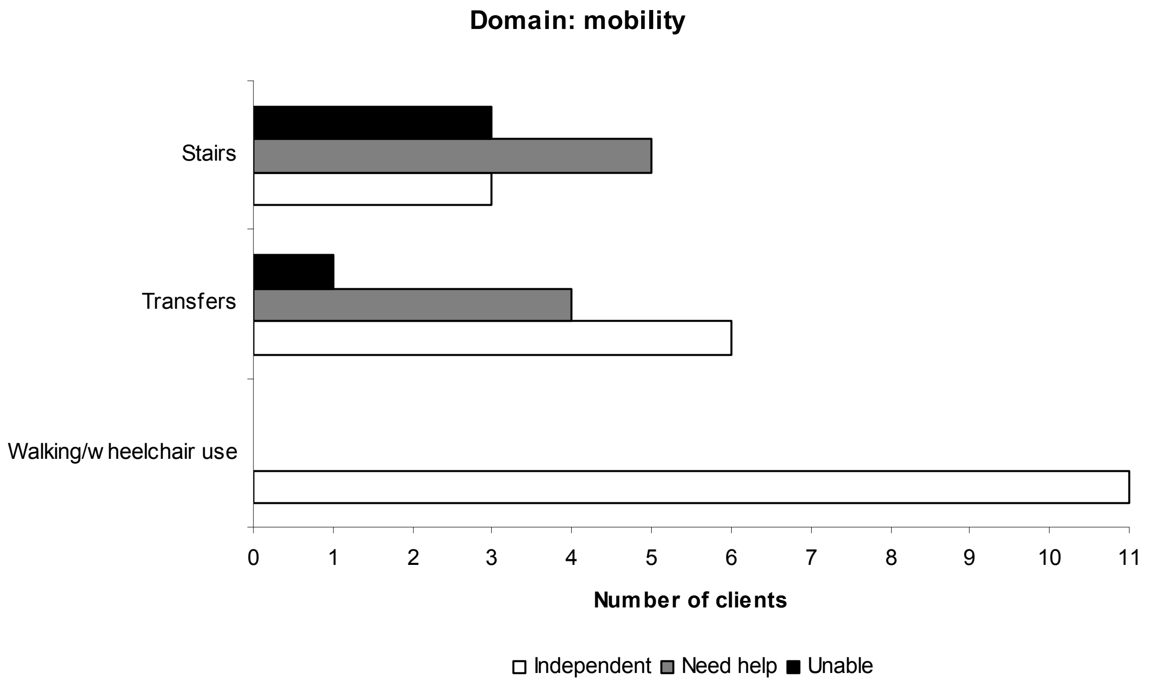


Figure B1.5: Dementia Behaviour Assessment and Management Service residential low care clients, number of clients by level of ADL function

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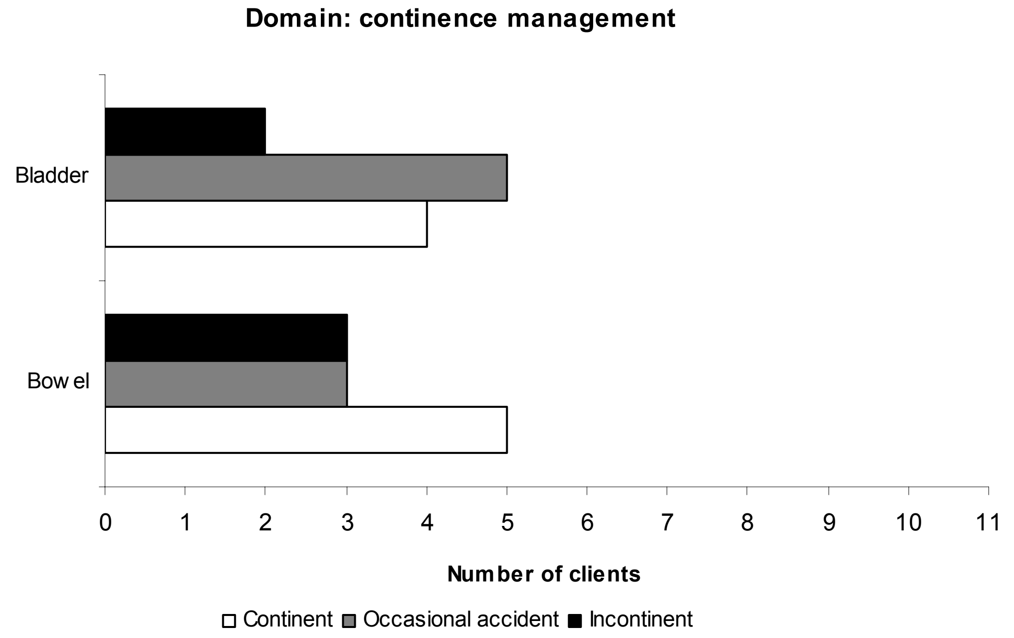
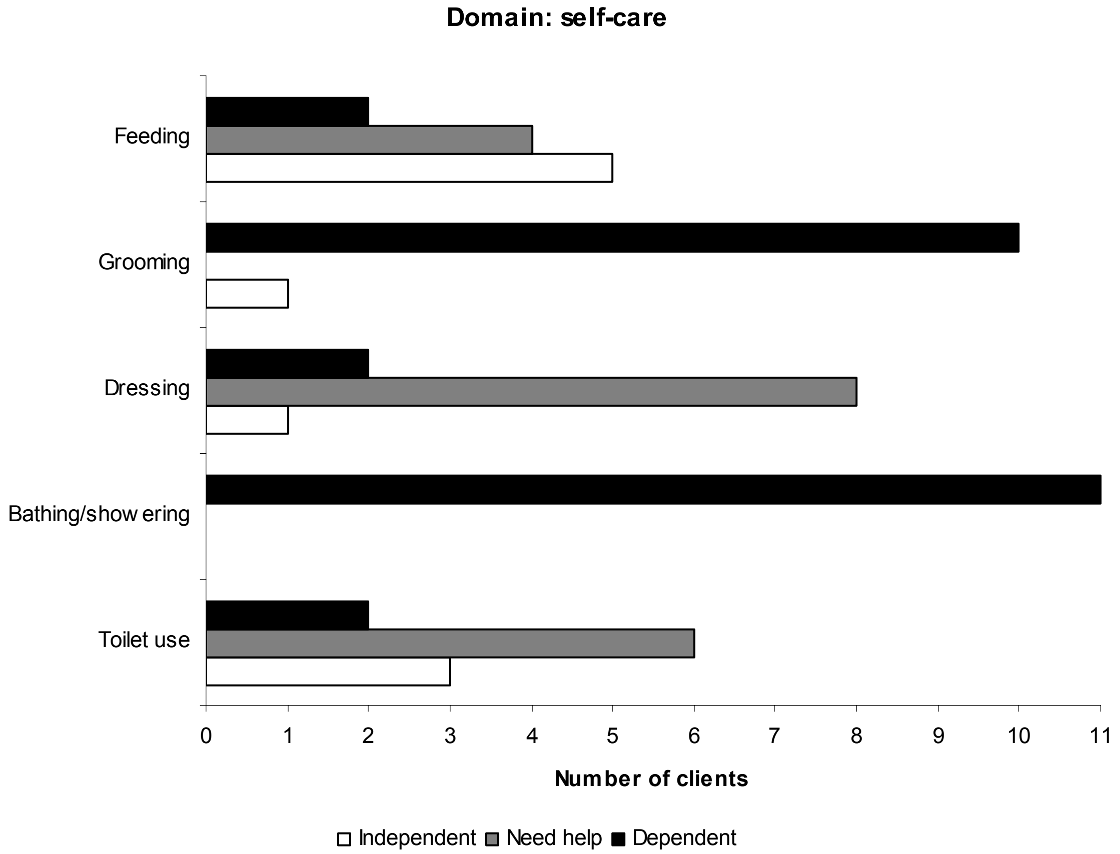


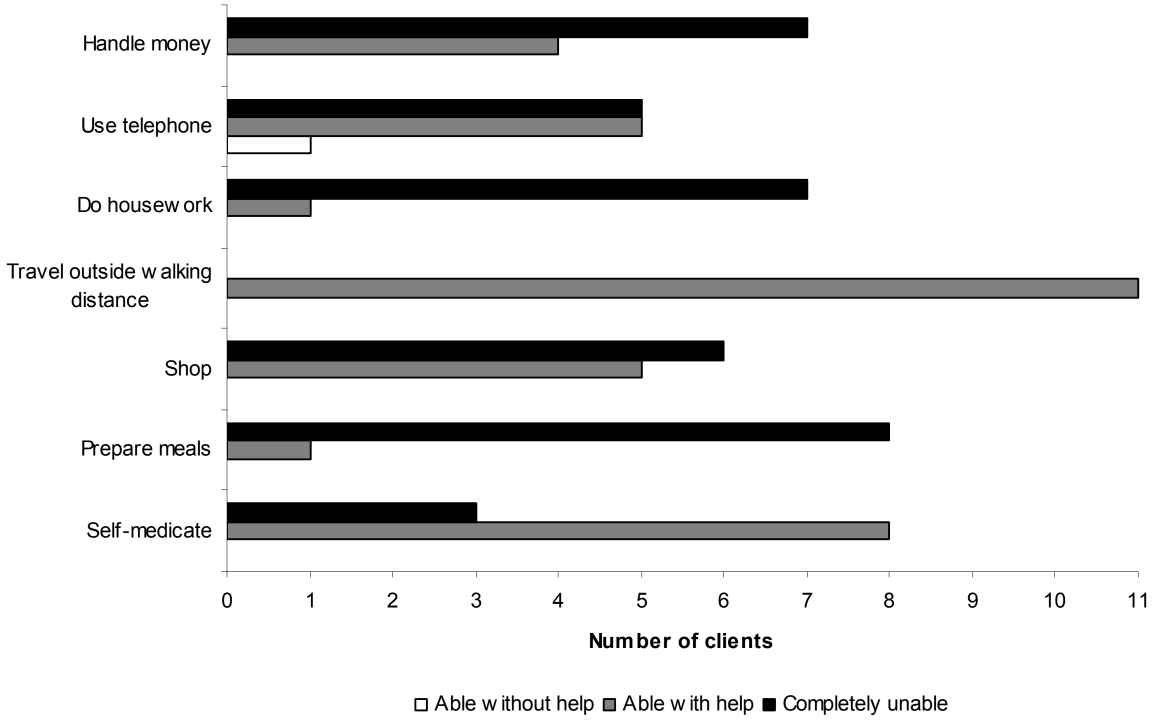


Source: Appendix Table B5.

Figure B1.5 continued: Dementia Behaviour Assessment and Management Service residential low care clients, number of clients by level of ADL function

Most residential low care clients had lost function in IADL by the time they entered DBAMS (Figure B1.6). On average, a client in this group was completely dependent in between three out of seven IADL by time of entry to the project.

The median baseline score on the IADL scale was 4 points, with scores ranging from 1 to 7 out of a possible 14 points (Table B1.18).



Source: Appendix Table B6.

Figure B1.6: Dementia Behaviour Assessment and Management Service residential low care clients, level of IADL function

The median change in IADL function between baseline and final assessments was –0.5, with variation within the range of –4 to 1 point (Table B1.18).

Table B1.18: DBAMS residential low care clients, baseline[(a)] and change[(b)] scores for ADL and IADL measures

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	7	7	13	19	12.9	4.1
Change in MBi	7	–3	–2	3	–0.6	2.8
IADL						
Baseline IADL	6	1	4	7	4.2	2.1
Change in IADL	6	–4	–0.5	1	–1.0	1.8

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Community-based clients

Twelve of the 16 community-based clients showed signs of memory loss on an intermittent or extensive basis at time of entry to the project (Figure B1.7). Fourteen clients presented a danger to self or others at least occasionally. One client was reported to be physically aggressive most of the time and another six clients were physically aggressive on an intermittent basis. Fourteen clients exhibited four or more psychological and behavioural symptoms on an intermittent or extensive basis, 11 of whom exhibited two or more symptoms on an extensive basis.[2]

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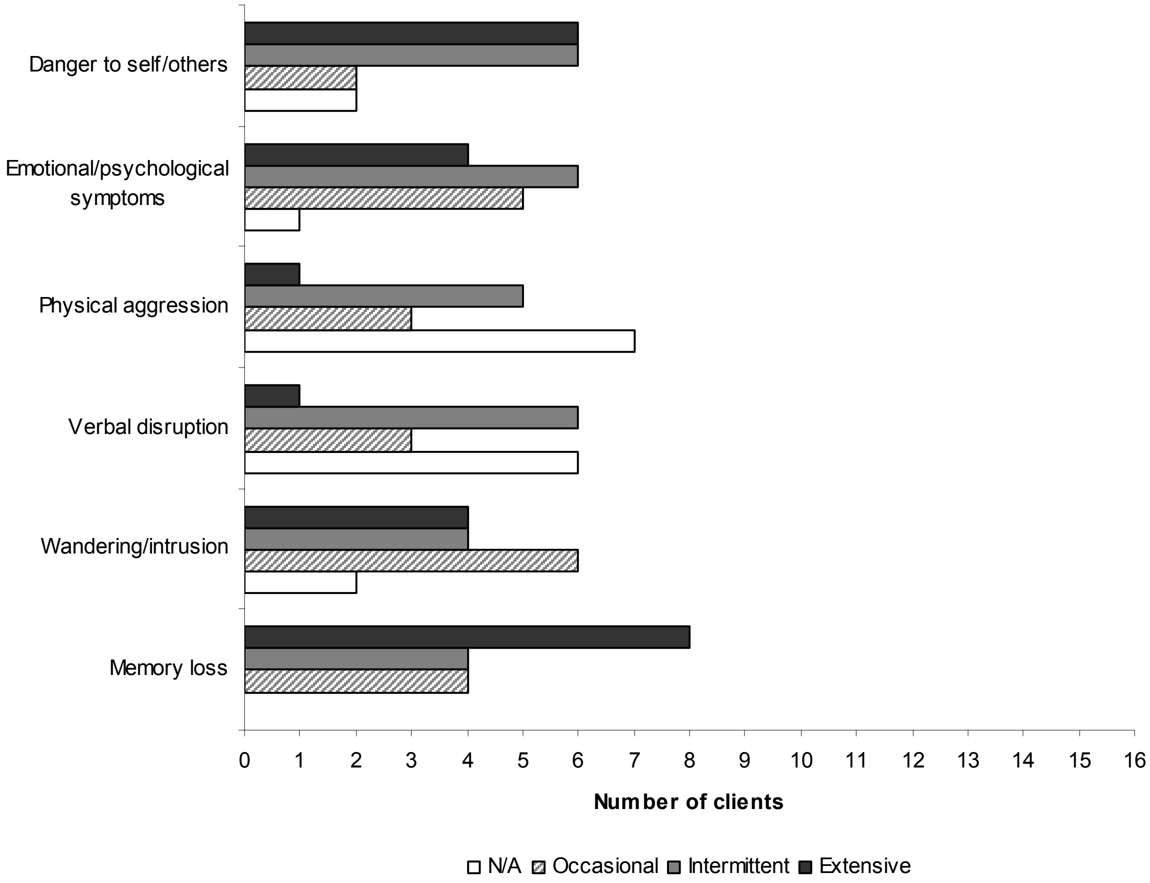
[2] Includes the six categories of behaviour shown in Figure B1.7 plus another category called 'other'.



Source: Appendix Table B7.

Figure B1.7: Dementia Behaviour Assessment and Management Service community-based clients, frequency of psychological and behavioural symptoms at entry to DBAMS

Residential high care clients (RAC—high)

At least half of the 12 RAC—high care clients showed signs of memory loss, wandering or intrusive behaviour, verbal disruption, emotional and psychological symptoms, and/or presented a danger to themselves or others on an extensive basis (Figure B1.8). Five RAC—high clients were physically aggressive on an extensive basis. All clients exhibited three or more behaviours on an intermittent or extensive basis, and 10 out of 12 clients exhibited two or more psychological and behavioural symptoms on an extensive basis.[3] As a group, DBAMS RAC—high clients display some of the highest prevalence and frequency of psychological and behavioural symptoms of dementia of any client group in the Innovative Pool Dementia Pilot.

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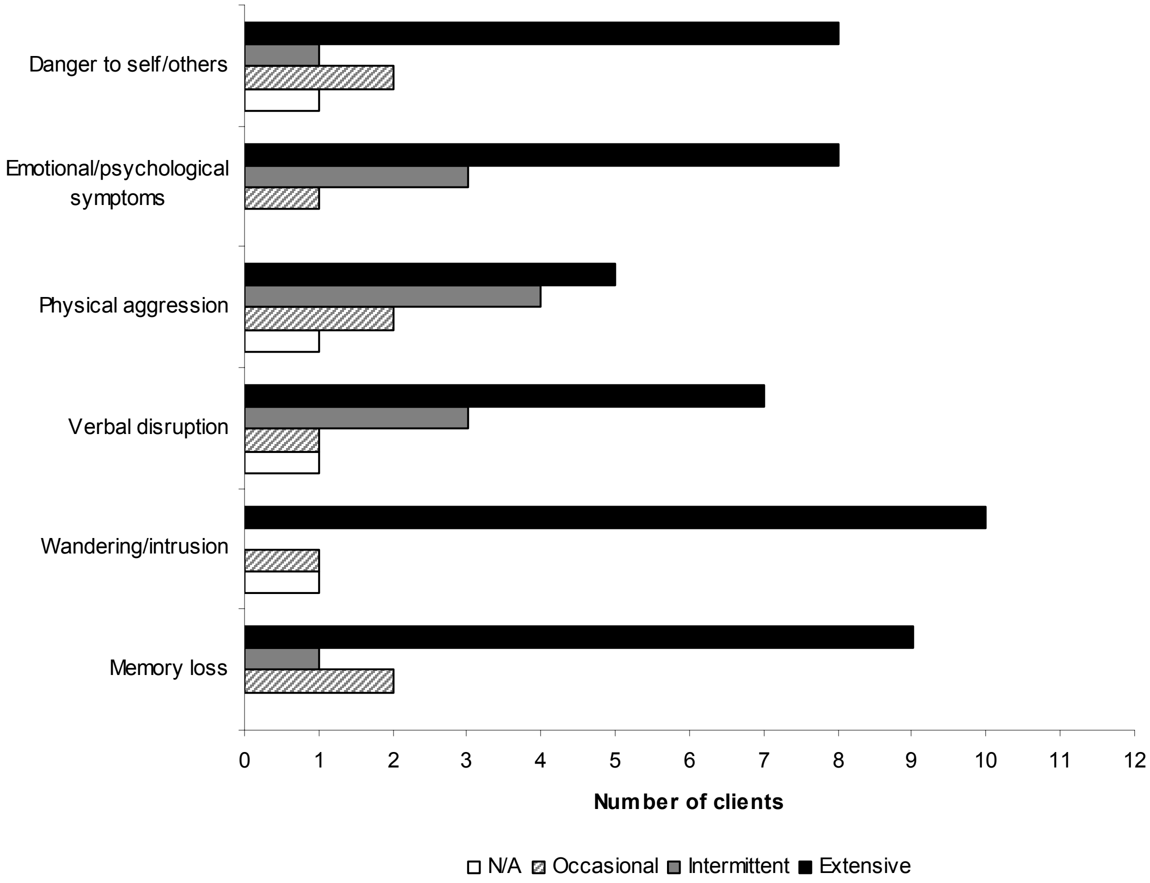
[3] Includes the six categories of behaviour in Figure B1.8 plus another category called ‘other’.



Source: Appendix Table B7.

Figure B1.8: Dementia Behaviour Assessment and Management Service residential high care clients, frequency of psychological and behavioural symptoms at entry to DBAMS

Residential low care clients

At least half of the 11 residential low care clients showed signs of memory loss, wandering or intrusive behaviour, emotional and psychological symptoms, and/or presented a danger to self or others on an extensive basis (Figure B1.9). Six clients were physically aggressive on an intermittent or extensive basis. All clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, and nine clients exhibited two or more psychological and behavioural symptoms on an extensive basis.[4]

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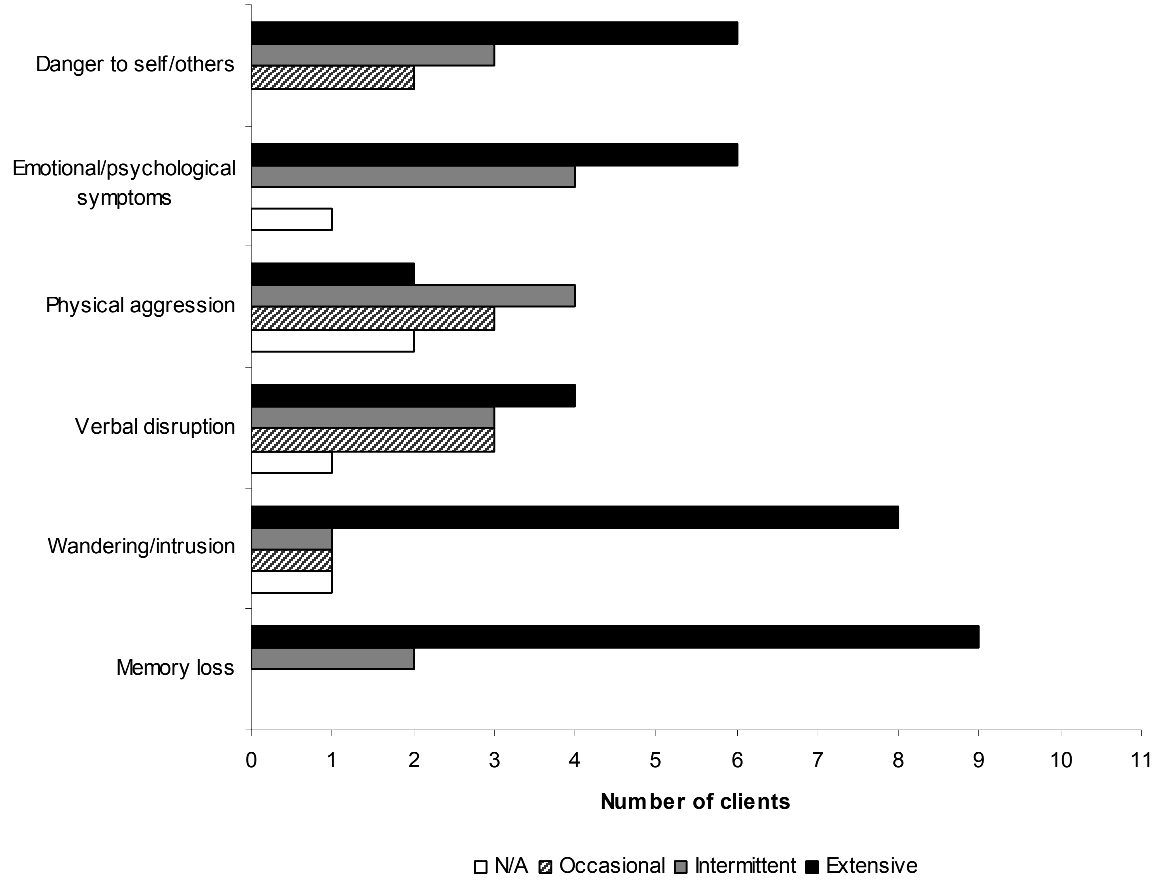
[4] Includes the six categories of behaviour in Figure B1.9 plus another category called 'other'.



Source: Appendix Table B7.

Figure B1.9: Dementia Behaviour Assessment and Management Service residential low care clients, frequency of psychological and behavioural symptoms at entry to DBAMS

The RCS scale for BPSD symptoms does not lend itself to data reduction for the purposes of assessing the severity of symptoms observed in an individual. A model of service provision proposed by Brodaty et al. (2003) and summarised in Part A, provides a useful way to summarise the BPSD ratings for evaluation clients. DBAMS is the type of specialist service referred to in the model definition of 'tier 5' service delivery. Tier 5 is described as comprising services for people with severe depression, aggression and marked agitation: 'people in tier 5 may not be able to be managed within mainstream aged care services and may require tailored intervention programs administered by a specialist multidisciplinary team'. Progression to tier 6 (very severe BPSD) or tier 7 (extreme BPSD) would occur if a client could not be managed by mainstream services following DBAMS assessment and intervention. The granularity of data gathered for the evaluation only enables clients to be classified as high as tier 5 but it is possible that clients classified into tier 5 could actually belong to tier 6 or tier 7.

Using the model definitions (see Box 2.1, p. 43), at entry to the project, 94% of DBAMS evaluation clients exhibited at least severe BPSD (3% moderate and 3% mild). At final assessment 26% of DBAMS clients recorded a lessening of symptoms to the extent that their assessment results place them at a lower level of BPSD severity; 74% were maintained at around the same level of severity but this proportion includes those clients who could have entered DBAMS at a higher level of severity than can be detected in the data, that is, there is a possible ceiling effect in the data. Assessment results for four DBAMS clients shows a lessening of symptoms equivalent to moving down two or three levels of severity, for example, from severe to mild BPSD or to dementia with no BPSD.

The DBAMS team reported that medication review and/or specialist intervention can be very successful in reducing the severity of BPSD in some clients, while in other cases the strategy is to increase understanding among primary care providers (family carers and aged care staff) of the causes and triggers for symptoms and to promote a sense of competency in providing care to a person with BPSD. The specific approach to be followed depends on the results of detailed investigation into the underlying causes of symptoms, which may be medical, historical (person's previous life experience), or related to/exacerbated by the current care environment.

1.4 Carer assessment results

Thirteen out of 22 carers who agreed to take part in carer assessments reported that they were in very good or good health at the time that their care recipient entered DBAMS. Two carers reported being in fair health. Self-reported health status was not recorded for seven carers.

Fifteen carers completed the Caregiver Strain Index (CSI) on entry to DBAMS to generate a mean score of 7.6 (median 7) with a standard deviation of 3.3 points. Scores ranged from 2 to 13 points. Ten carers recorded scores above the threshold of 7 points for high carer strain and two more carers scored just below the threshold.

Ten carers completed a repeat CSI assessment. The median change score was –1.5 points (mean –2.5; standard deviation 2.9) with a range of –7 (a 7-point decrease in carer strain) to 1 (a 1-point increase in carer strain), reflecting a decrease in the average level of carer strain. At the final assessment, three carers scored over the threshold for high carer strain, compared with seven carers at the baseline assessment.

At entry to DBAMS, 15 carers completed the General Health Questionnaire (GHQ-28). Six carers scored between 14 and 21 points on at least one subscale. Two carers recorded scores higher than 14 for somatic symptoms; six carers scored over 14 for anxiety and insomnia; and one carer scored over 14 for social dysfunction. No carer scored 14 or over for severe depression, although one carer scored 10 points and another scored 12 points on this sub-scale.

Ten carers completed the GHQ-28 at the final assessment, of whom one scored above 14 points on two sub-scales.

Change in GHQ-28 scores over time is examined in the overall profiles for the Innovative Pool Dementia Pilot projects due to small sample sizes in individual projects.

1.5 Service profile

The DBAMS service profile is more difficult to summarise than that of other projects where the focus is on ADL support and there are some notable areas of service provision missing in the evaluation data. For instance, DBAMS did not record services associated with the provision of accommodation in the intermediate care unit, Yathong Lodge. For the

19 evaluation clients who were admitted to Yathong Lodge there is no record of the level of personal assistance or meal services. Much of the service activity involves clinical review and case conferencing, the time and expense of which is not well reflected in time-based or event-based measures of service delivery. In addition, professional education has been a major aspect of DBAMS, and this cannot be summarised on a per client basis. A separate report of professional up-skilling and system capacity building through professional education is given below.

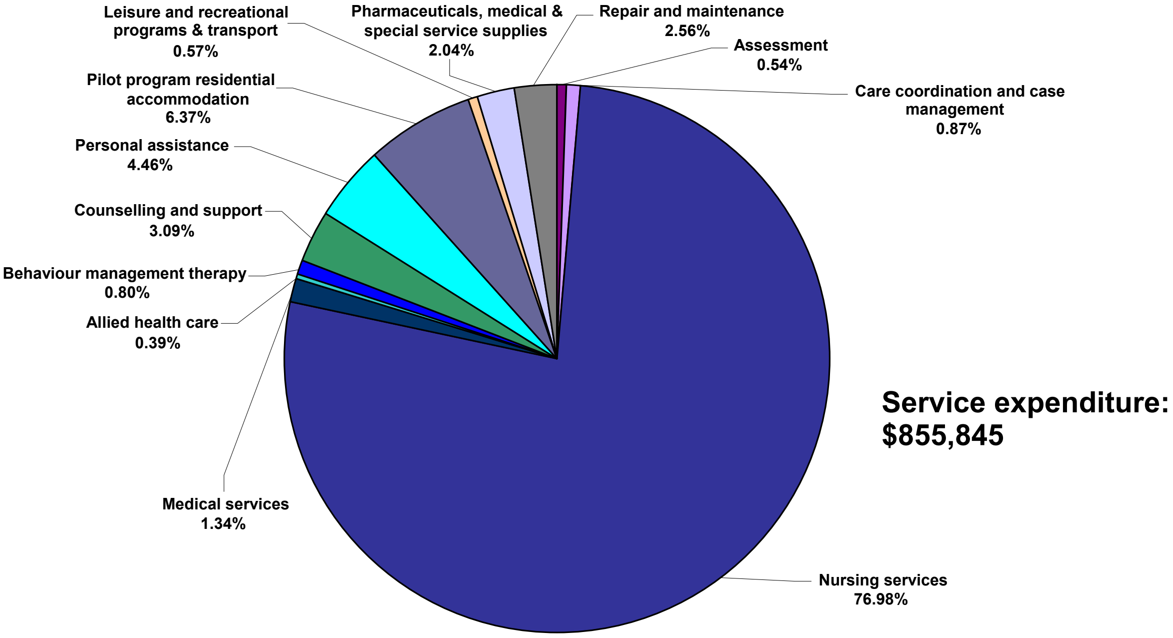
Table B1.19 provides an overview of the main areas of service delivered directly to clients from which can be seen the high clinical focus in medication review, specialist behaviour management, GP and geriatrician input and allied health care.

Table B1.19: DBAMS summary of services per client per week, June–November 2004

Service type	Service unit	Clients	Min.	Median	Max.	Mean	Standard deviation
Allied health combined	Hours	16	0.0	0.1	0.3	0.1	0.1
Social support	Hours	1	0.1	0.1	0.1	0.1	—
Medication review	No. events	37	0.1	0.3	2.5	0.6	0.6
Dementia care, memory and behaviour management	No. referrals	32	0.1	0.4	1.7	0.5	0.4
GP consultation	No. contacts	22	0.1	0.7	5.0	1.0	1.0
Geriatrician	No. contacts	22	0.0	0.3	1.3	0.5	0.4
Carer support other than respite	No. contacts	14	0.1	0.2	1.2	0.3	0.3
Nursing and medical care other	No. contacts	2	0.1	0.2	0.3	0.2	0.2
Dietetics	No. referrals	1	0.1	0.1	0.1	0.1	—
Information, advice and referral	No. events	1	0.1	0.1	0.1	0.1	—

— Nil.

A more informative picture comes from a breakdown of expenditure on client services, illustrated in Figure B1.10. Psycho-geriatric nursing care accounted for approximately 76% of service expenditure in the reporting period. This service category includes the work of specialist nurses in behaviour management and assessment for clients in Yathong Lodge and outreach clients at home. Note that reported service expenditure is expenditure from the project budget and does not include contributions from NSW Health in the form of existing infrastructure and medical expertise.



Source: Appendix Table B25.

Figure B1.10: DBAMS, expenditure on direct care services, 6 months ending 31 December 2004

1.6 DBAMS education program report

The following report summarises the DBAMS education program to December 2004.

Education program content

1. Introduction to dementia: types of dementia, different symptoms and behavioural presentations, medications, overview of person-centred dementia care—3-hour session
2. Communicating with people with dementia: effects of the negative and positive aspects of communication, importance of non-verbal/body language communication—3-hour session
3. Person-centred care in detail: validation, reminiscence, problem solving, identification of triggers for behaviour, managing behaviours of concern, case discussion, managing aggressive and sexual behaviours—6-hour session
4. Aggression management—2-hour session
5. Dealing with sexually inappropriate behaviours—2-hour session
6. Experiencing dementia workshop—3-hour session

7. Carer education—3-hour session
8. Quality dementia care— 2-hour session

Sessions 1, 2 and 3 are delivered over 2 days and form the basis of the initial education delivered to staff from hospitals, residential aged care facilities, community workers, carers and volunteers across the region. The other education sessions have been delivered at the request of aged care facilities and in response to situations that have arisen with particular clients.

Feedback has been very positive: DBAMS conducted an initial evaluation immediately after the education sessions (see below) and then 6–10 months later a follow-up evaluation was sent to all facilities with staff who had attended sessions to ascertain if staff felt their ability to care for people with dementia had improved following the program.

Comments from directors of nursing of participating facilities:

'Very beneficial, having the experience and latest research shared with staff in the facility helps us in striving for excellence in our care for people with dementia.'

'The staff have gained understanding and knowledge that has helped them to manage the behaviours of concern that our residents demonstrate at times effectively and with understanding.'

'Being able to have specific scenarios and issues that are concerning staff discussed and learning how to problem solve these issues has expanded the ability of the staff to understand the behaviours of people with dementia.'

From October 2003 to December 2004:

- Dementia-specific education was delivered in 19 locations across the region
- 1,058 people attended education sessions, with an average attendance of 5.5 hours per person.

Table B1.20: DBAMS education program, location, session type and attendance figures

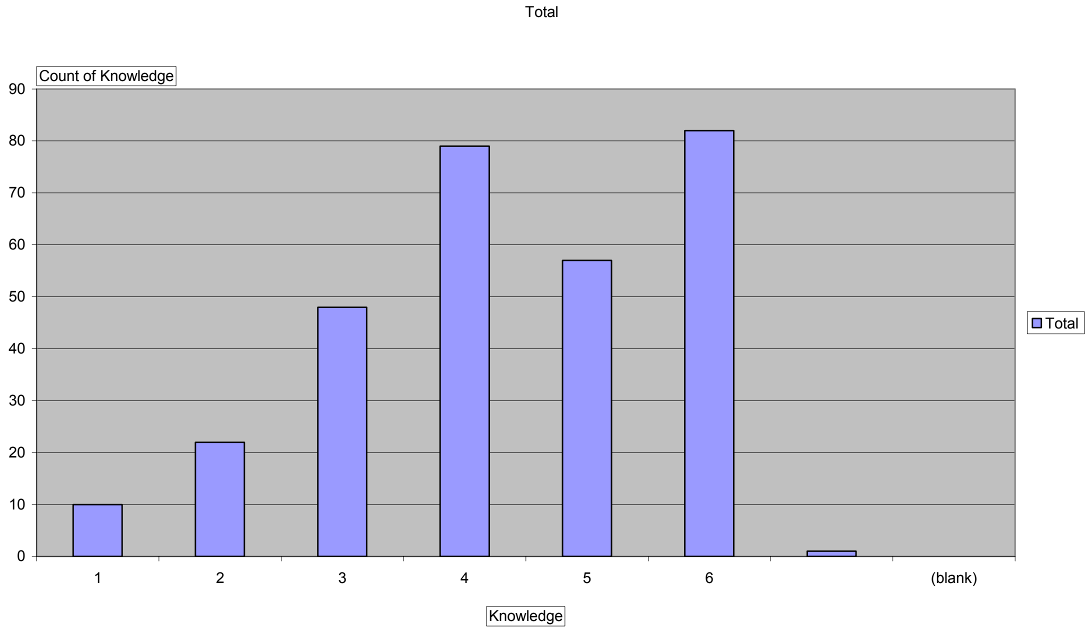
Place	Occasions	Session	Number in attendance
Albury	7	1, 2 & 3	258 (2 carers)
Albury UPA	4	8 (facility specific)	102
Albury	2	4	15
Albury	2	5	16
Berrigan	1	Client specific	8
Coolamon	2	1, 2 & 3	53
Cootamundra	4	1, 2 & 3	24
Corowa	4	1, 2 & 3	42
Culcairn	4	1, 2 & 3	34
Deniliquin	4	1, 2 & 3	156
Griffith	8	1, 2 & 3	63 (5 carers)
Gundagai	4	1, 2 & 3	42
Holbrook	4	1, 2 & 3	24
Holbrook	1	7	20 (10 carers)
Leeton	1	5 (client specific)	15
Leeton	2	2	6
Lockhart	4	1, 2 & 3	35
Moama	4	1, 2 & 3	52
Narrandera	4	1, 2 & 3	57
Temora	4	1, 2 & 3	58
Tocumwal	1	6	15
Tumbarumba	4	1, 2 & 3	28
Tumut	4	1, 2 & 3	53 (1 carer)
Tumut	1	8	12
Wagga Wagga	5	1, 2 & 3	154
Wagga Wagga	1	4	20
Wagga Wagga	1	8	15
Wagga Wagga	1	7	12 community
Wagga Wagga	1	1 & 2 (short version)	24 (4 volunteers)
Wagga Wagga	2	8	12 Yathong staff

Immediate post-education feedback (conducted on the day of training):

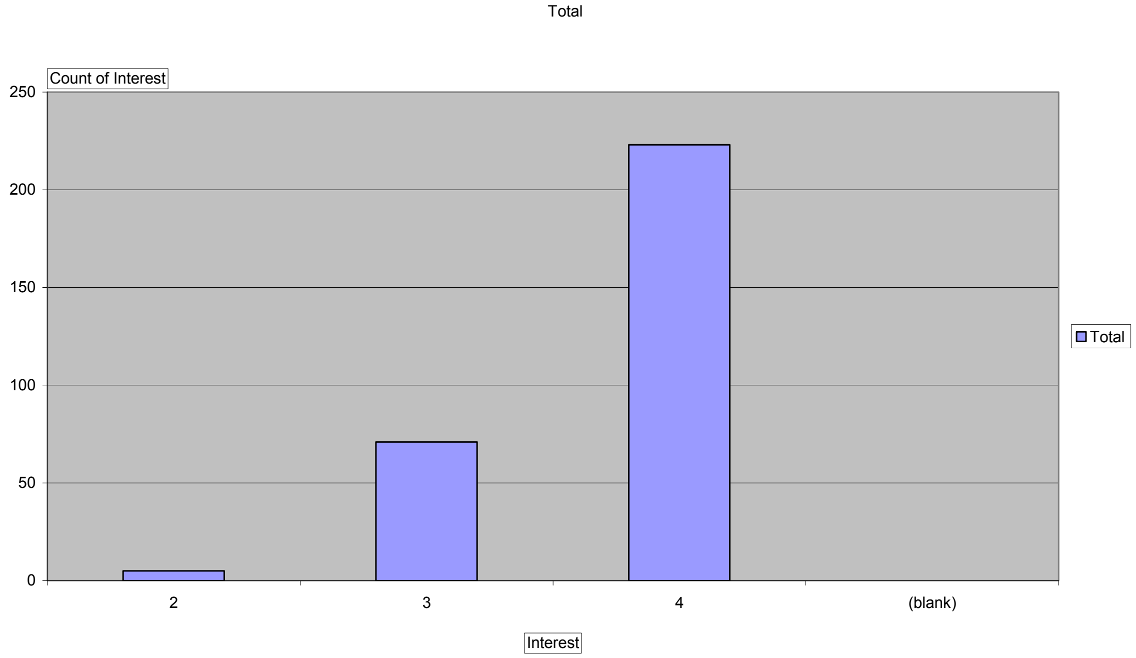
- 72% indicated a high level of interest in dementia prior to education
- 71% indicated a previous high level of knowledge of dementia prior to education.

Results of a survey completed after 2nd day of 2 days of dementia education

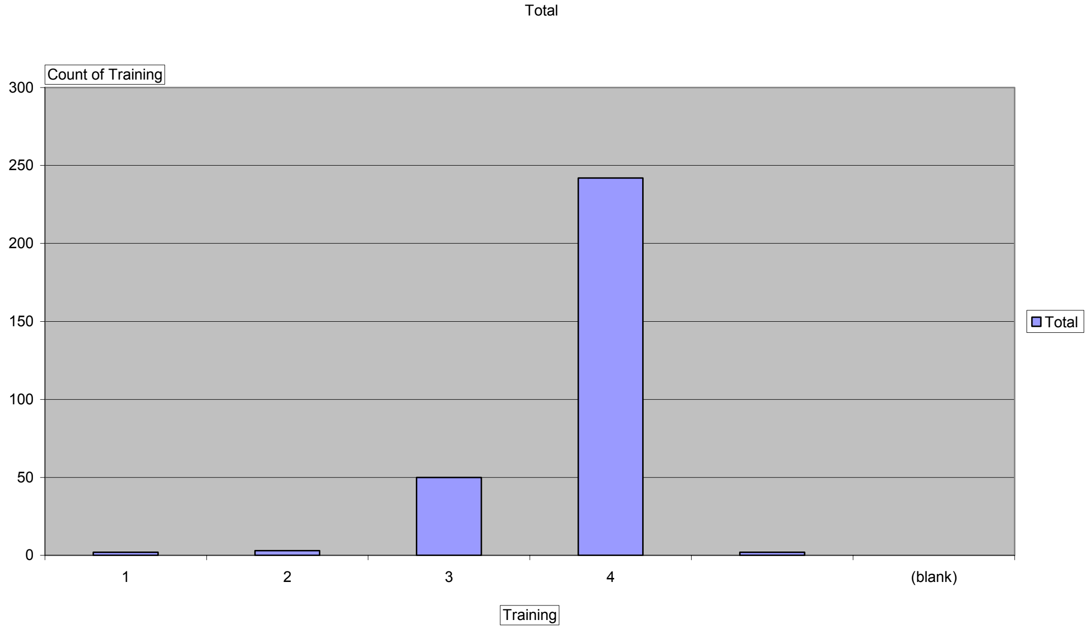
1. Rate your level of knowledge about care of a patient with dementia prior to education.
   Rating scale: (1) Little knowledge to (6) Well informed



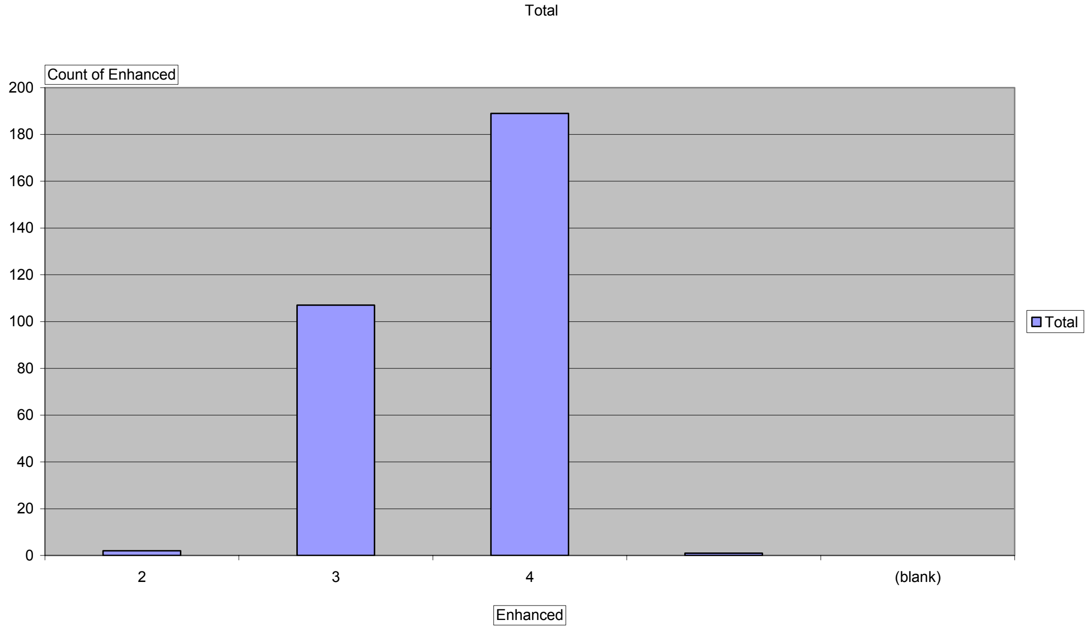
2. Rate your level of interest in training.
   Rating scale: (1) Low to (4) High



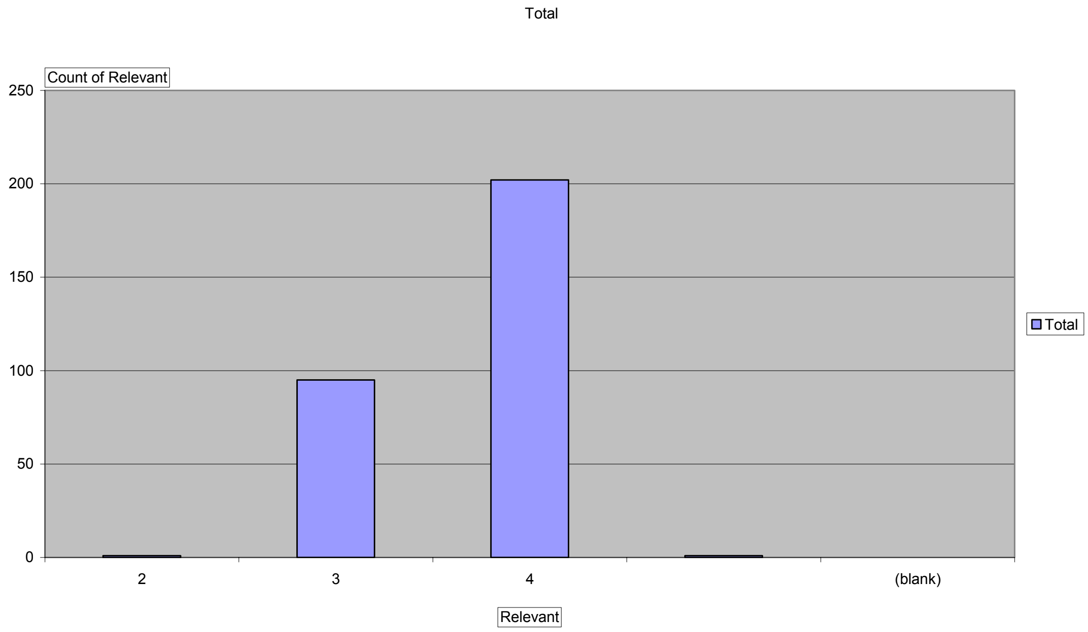
3) Rate the standard of the training.
Rating scale: (1) Low to (4) High



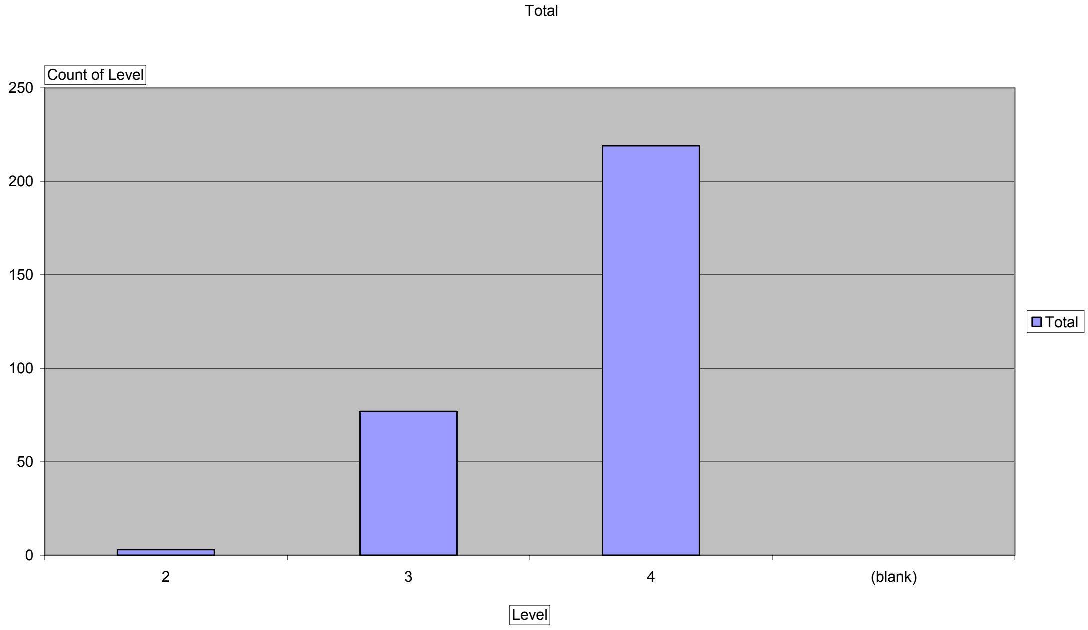
4) Has your level of knowledge of care of people with dementia been enhanced?
Rating scale: (1) Strongly disagree to (4) Strongly agree



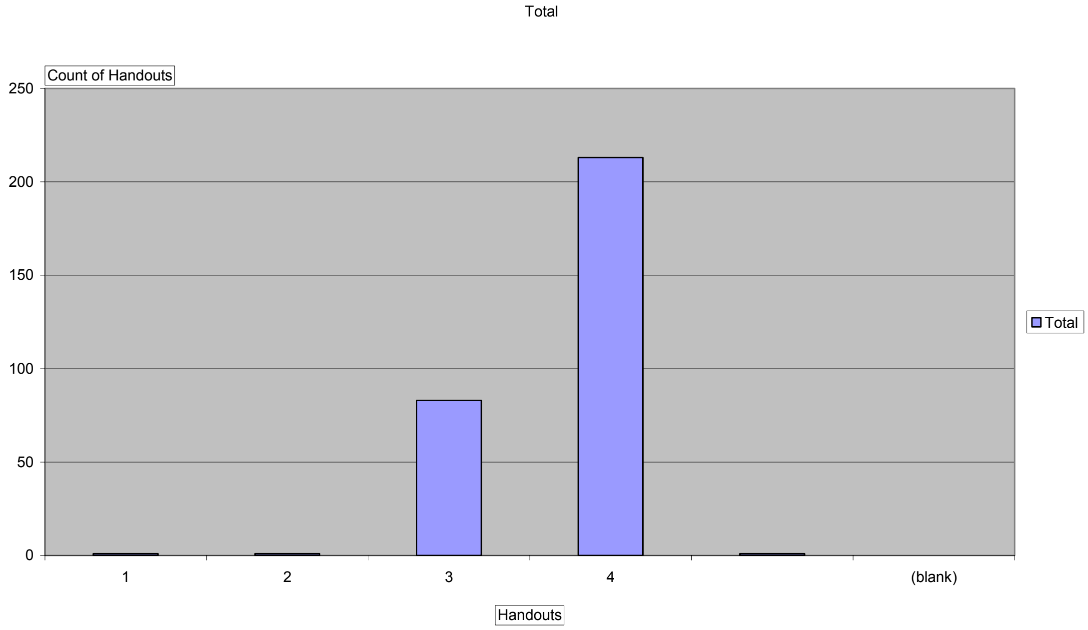
5) The education was relevant to your work.
Rating scale: (1) Strongly disagree to (4) Strongly agree



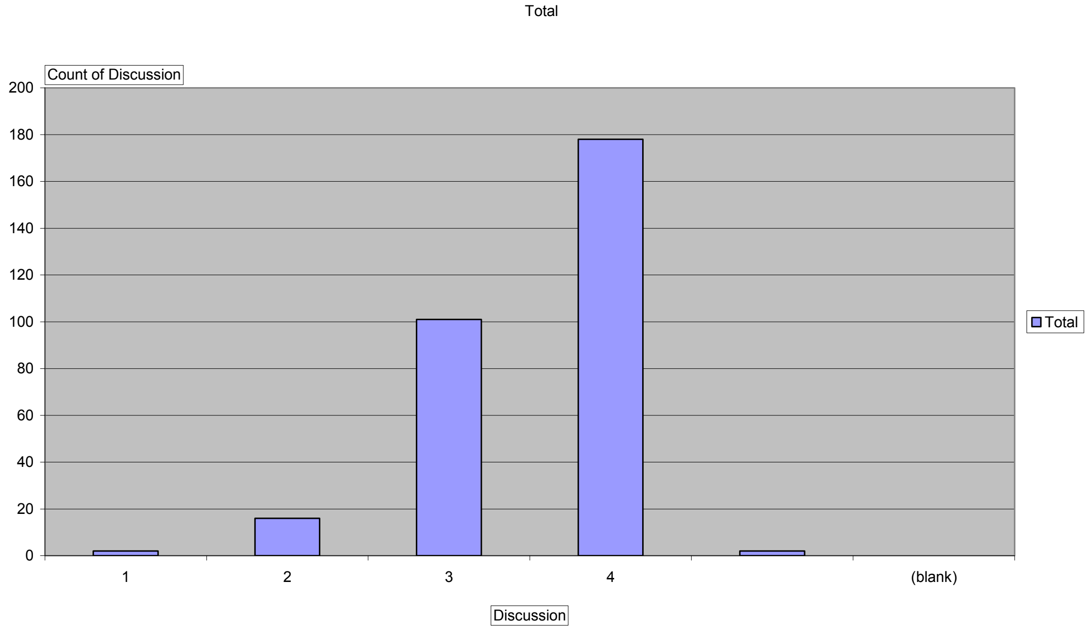
6) Content was at an appropriate level
Rating scale: (1) Strongly disagree to (4) Strongly agree



7) Handouts and visual supports useful/appropriate
Rating scale: (1) Strongly disagree to (4) Strongly agree



8) Adequate time given for discussion
Rating scale: (1) Strongly disagree to (4) Strongly agree



Comments of participants at the completion of education sessions 1 and 2:

‘I will use different strategies to handle behaviours. I learned a lot about dementia’

‘Helps me understand dementia and how to talk to and treat dementia patients’

‘Lots of information I didn’t know before, explained well’

‘Before this training I had a positive attitude towards dementia clients but was not sure if it was the right thing to do. Now I am so confident about it. The training was very informative and very useful’

‘Although I did know some things I still learned a lot’

‘I feel the knowledge gained will greatly influence my work practices’

‘It has given me a greater understanding of their actions’

These are just a few of over 200 positive responses to the question ‘will your work practices change?’.

Results from a survey conducted after the delivery of DBAMS education program *Understanding Dementia and Managing Behaviours of Concern*

Results are based on 46 responses from 25 facilities.

- Did you attend both days?

  Yes 43 No 3

- Where would you rate your level of understanding and knowledge of dementia before and after the education? (1 being very limited and 10 excellent up-to-date knowledge)

Scale	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Before	**0**	**1**	**4**	**5**	**13**	**8**	**5**	**7**	**2**	**0**
After	**0**	**0**	**0**	**0**	**0**	**1**	**11**	**17**	**11**	**6**

- Has your communication with clients with dementia improved since the education?

  Yes 45 No 1

- Has your ability to identify triggers to behaviours of concern increased since the education?

  Yes 45 No 1

- Have you improved the way you manage behaviours of concern experienced by people with dementia as a result of the education?

  Yes 44 No 2

- Are you better able to identify delirium and the causes of delirium in people with dementia since the education?

  Yes 39 No 4 Unsure 3

Some anecdotal reports are:

- *Aged care facilities:* Some facilities have reported decreased admission to specialist psycho-geriatric or psychiatric units but no data have been kept on actual hospital admissions. Some facilities reported that they could better manage clients with behavioural problems and those admitted to hospital would be due to medical need.

  Facilities are now requesting specific education regarding particular behaviours and the experiencing dementia workshop and for new staff to have access to the first two sessions early in their employment.

- *General practitioners:* A few GPs have begun to refer directly to the outreach service thus enabling the team to provide behavioural strategies and advice on the management of their clients. It is pleasing to know that the GPs have taken up the suggestions put forward by the team.

Learning outcomes for training sessions and education program evaluation survey results

Introduction to Dementia and Communication with People with Dementia

Expected outcomes

Participants will:

1. Be able to identify the functions of specific lobes of the brain and how the dementia affects the function of these areas and the disabilities the person with dementia will then exhibit.
2. Develop an understanding of how the health, personality, past history, current environment and social factors will influence the person with dementia's behaviour.
3. Know how to communicate effectively with people with dementia in using both verbal and non-verbal means and understand the impact of poor communication.

Understanding and Managing Difficult Behaviours in Dementia

Expected outcomes

Participants will:

1. Understand the differences between dementia, depression and delirium and be better able to identify causes of delirium developing in people with dementia.
2. Develop problem-solving skills and an ability to identify triggers that cause behaviour of concern.

3. Identify the causes of most aggressive behaviour and how to prevent or manage aggression from clients with dementia.
4. Understand both verbal and sexual disinhibition of people with dementia behaviour and how to respond appropriately.

Evaluation survey conducted on the day of training

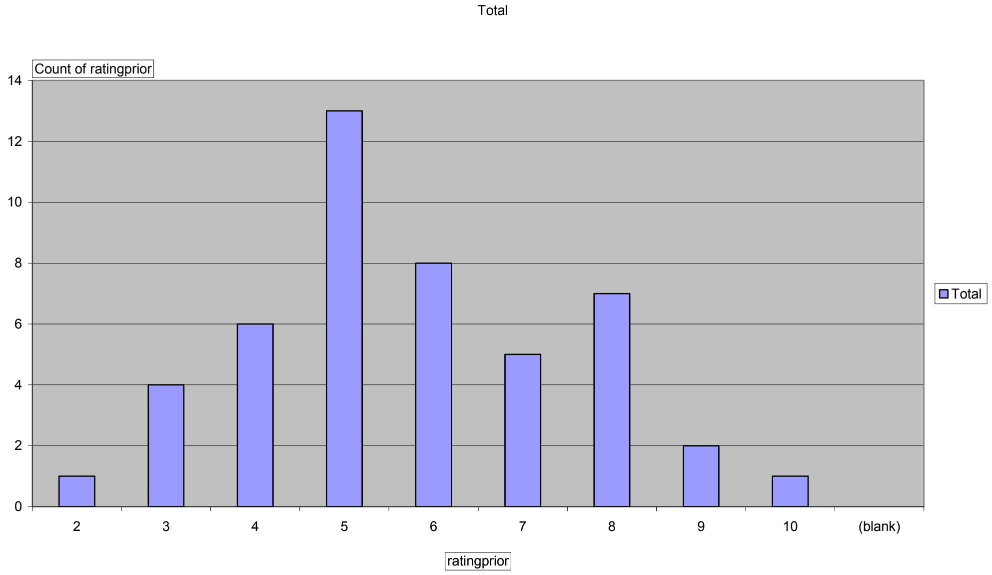
- Knowledge and skills enhanced: Yes 99%
- Relevance of training to work place: Yes 99%
- Content an appropriate level: Yes 96%
- Handout usefulness: Yes 98%
- Adequate time for discussion: Yes 92%
- Desire to improve work practices following education: Yes 99%

Comments indicated that the majority of participants believed they had gained an improved understanding of dementia, of communication with people with dementia and strategies to manage behaviours of concern, and ability to identify delirium, also ideas that they could incorporate into their work practices to improve the wellbeing of people with dementia.

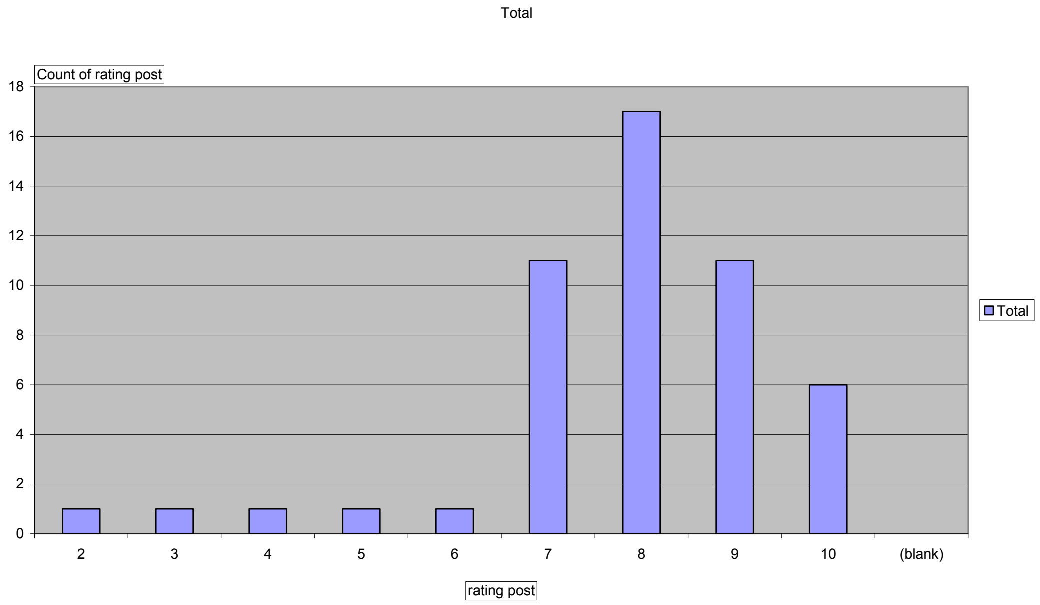
6–12 months post-education follow-up survey (49 responses from 300 participants)

39 attended both sessions, seven attended first day only and three attended second day only.

Self-rated knowledge of dementia prior to education (higher score indicates higher self-rated knowledge):



Self-rated knowledge of dementia post-education (higher score indicates higher self-rated knowledge):



Respondents indicated:

- communication ability improved in 99.5% of cases
- ability to identify triggers to behaviours of concern improved in 99% of cases
- improvement in ability to manage behaviours of concern in 89% of cases.

1.7 Accommodation outcomes

Projects were asked to record discharge outcomes during the evaluation period and at later follow-up for those clients who remained with the project at the end of the evaluation period. DBAMS follow-up was completed between 3 February and 21 April 2005.

Community-based clients

Community-based clients who were discharged from DBAMS during the evaluation period had spent between 56 and 150 days on the DBAMS program. Four clients were in the project for more than 100 days. The project reported difficulty in locating dementia-specific residential care beds in the region and this is likely to have increased length of stay for community-based clients who required a permanent residential placement following DBAMS.

By completion of follow-up, between 8 and 12 months from the start of the evaluation, 10 clients had completed DBAMS service and had entered permanent residential care (Table B1.21). Seven of these clients had been able to enter at low level care even though they had been assessed by ACAT as requiring high level care. Some of the clients who were in residential care at follow-up had been discharged from DBAMS to HACC services and had later entered a residential care facility when a bed became available.

Three clients were still in Yathong Lodge on a transitional basis.

Table B1.21: Dementia Behaviour Assessment and Management Service community-based clients, accommodation setting and government program support status at follow-up

Accommodation setting/government program support	Number of clients
At home	
CACP/National Respite for Carers Program	2
Total at home	*2*
DBAMS short-term accommodation—Yathong Lodge	3
Residential aged care	
Low care	7
High care	3
Total	*10*
Deceased	1
Total	**16**

Residential care clients

Two of the 12 residential high care clients were still with DBAMS at the end of the evaluation period and the remaining 10 high care clients had been discharged from DBAMS and were residing in their usual facility. Length of stay in DBAMS ranged from 48 to 169 days. Six clients had spent more than 100 days with DBAMS. At follow-up, nine of the original residential high care clients were still in a high care facility. One client had died, and two could not be located.

Three of 11 residential low care clients were still with DBAMS at the end of the evaluation. Four clients had been discharged back to low level residential care (length of stay in project 63–116 days), and three had entered high level residential care (length of stay in project 91–141 days). Four discharged clients had been in the project for more than 100 days. At follow-up, seven of the original residential low care clients remained in low level residential care, and three were living in high level residential aged care. One residential low care client could not be located.

The project has been successful in helping a number of clients to avoid moving to a new care facility by reducing the manifestation or impact of BPSD and/or enabling providers of care to manage clients in place. Most of the community-based clients entered residential low care instead of high care, and two clients were able to remain at home for a considerably longer period than expected.

Attachment: DBAMS education program evaluation instrument

The Aged Care Series 1/2

CARE OF THE PATIENT WITH DEMENTIA EVALUATION

WORKSHOP LOCATION: ________________________ DATE: __________________

1. Using the scale below, please circle the number that indicates how well you were informed on the subject of care of the patient with dementia before participating in this training session.

Little knowledge				**Very well informed**	
1	2	3	4	5	6

2. Please indicate your reaction to the training session by circling the number that best expresses your rating of each of the following statements:

	Low			**High**
My level of interest was	1	2	3	4
The standard of training was	1	2	3	4

3. Please indicate your reaction to the training session by circling the number that best expresses your rating of each of the following statements:

	Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
My level of knowledge & skills in the area of care of the patient with dementia has been enhanced	1	2	3	4
The sessions were relevant to my work	1	2	3	4
The content was delivered at an appropriate level	1	2	3	4
The handouts & visual supports were useful/appropriate	1	2	3	4
There was adequate time for discussion	1	2	3	4

4. Please indicate the three major points that you gained from the training sessions.

5. Do you feel the information gained from the training session will change your work practices? Please comment.

6. What professional development activities do you believe would be appropriate to follow up after this training session?

Additional comments:

Thank you for completing this evaluation form.
Your feedback is valued and confidentiality will be respected.

Wagga Wagga Aged Care Services

Dementia Behavioural Assessment Management Service(DBAMS): Client Evaluation of Services from RACF

Please help us to improve this service by answering some questions about help and assistance you have received at the Dementia Behavioural Assessment Management Service (DBAMS). We are interested in your honest opinion, whether positive or negative. We also welcome your comments and suggestions. Your opinions and comments will help us to improve this service.

(*Please circle the most appropriate answer on the scale bar)*

1. How would you rate the quality of dementia services received from DBAMS staff?

1	2	3	4	5	6	7	8	9	10
Poor									Excellent

2. To what extent has the DBAMS support met the staff's needs to assist in caring for your clients with dementia?

1	2	3	4	5	6	7	8	9	10
None of my needs have been met									Almost all of my needs have been met

3. If you had another client with dementia and challenging behaviours would you contact DBAMS staff?

1	2	3	4	5	6	7	8	9	10
No, definitely not									Yes, definitely

4. Have the dementia services you received from DBAMS helped you to deal more effectively with your client's problems?

1	2	3	4	5	6	7	8	9	10
No, seemed to make things worse									Yes, helped a great deal

5. Has the education provided by the DBAMS staff helped your staff to be successful in managing the difficult behaviours?

1	2	3	4	5	6	7	8	9	10
Unsuccessful									Very successful

6. In an overall general sense, how satisfied are you with the dementia services you have received from DBAMS staff?

1 2 3 4 5 6 7 8 9 10

Very dissatisfied Very satisfied

Comments

2 Dementia Rehabilitation At Home

2.1 Project description

NSW Health received an allocation of 15 flexible care places to operate a Pilot project for a period of 2 years. The project, Dementia Rehabilitation at Home (DRAH) offers service to eligible residents of the Northern Rivers region of New South Wales for a period of 8 to 12 weeks.

DRAH has a strong clinical focus with primary aims of achieving accurate medical diagnosis of physical and behavioural symptoms, and of linking clients and carers into the formal service network. This project is perhaps best described as extending the ACAT service model to intensive case management, including the capacity to facilitate specialist assessment and diagnosis for ACAT clients with dementia, suspected dementia or other causes of cognitive impairment.

Clients and carers are assisted to identify up to 16 rehabilitation goals, the achievement of which is intended to facilitate a successful 'transition' at a key milestone on the care continuum. In this context, 'transition' might be the passing from an unawareness or uncertainty of the presence of dementia through clinical diagnosis, education and counselling. Alternatively, it could involve a client's progression from an unstable care situation due to social isolation or behavioural symptoms of dementia to a more managed environment through the diagnosis and treatment of behavioural symptoms and establishment of in-home services.

Client care is developed and reviewed by a multidisciplinary team comprising a clinical nurse consultant, registered nurses (including psycho-geriatric nurse), geriatrician and psycho-geriatrician specialists, occupational therapist, social worker and gerio-psychologist.

Tele-health technology plays a central role in the DRAH clinical work-up model.

Partnerships

DRAH operates as a partnership between the North Coast Area Health Service[5] and Clarence Valley Council Community Services[6] in northern New South Wales. The Aged Care Assessment Team in Grafton auspices the project and the council is a partner for community care delivery.

Clarence Valley Council is a local government provider of services for Home and Community Care, Community Aged Care Packages, the Commonwealth–State/Territory Disability Agreement and various New South Wales Government programs.

DRAH is one of the first partnerships between health and community services to be piloted in the region.

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[5] The Northern Rivers Area Health Service, the original auspice, was subsumed into the North Coast Area Health Service as part of a restructuring of New South Wales health service administration.

[6] The Maclean Shire Council Community Services, the original partner, was subsumed into the Clarence Valley Council Community Services on council amalgamation.

Service environment

The project services four Local Government Areas that comprise the Clarence Valley, covering a region of 10,097 square kilometres (now amalgamated as one—Clarence Valley Council). Approximately 16.9% of the population is aged over 65 years, which is well above the state average. It is estimated that over 700 people in the Valley have dementia.

The service environment of Clarence Valley Council is characterised as having a relatively low level of service provision, poor access to medical specialists and mental health services, and a large service area.

Older people in the service region have limited access to geriatric and psycho-geriatric services. Tele-health enables DRAH to access a geriatrician (2 hours per fortnight) and psycho-geriatrician (up to 4 hours per fortnight). DRAH recipients are also assisted to travel to Coffs Harbour and Lismore to consult with specialists there, though the waiting period is generally around 4 months. The 8–12 week DRAH intervention is designed to achieve medical diagnosis or resolution of medical conditions, the establishment of appropriate in-home services, and support for carers and families who are adjusting to living with a person who has dementia.

Prior to the establishment of DRAH, six areas of unmet need are said to have existed in the Valley:

- lack of support for carers to decrease the burden of dementia care
- lack of post-hospitalisation support to reduce the length of hospital stay and services to help people avoid hospitalisation—hospital can be a very unfavourable environment for people with dementia
- a lack of attention to delirium in older hospitalised patients compounded by a drive within acute care settings for early discharge of patients to the community
- poor access to diagnostic services in the community that help to prevent inappropriate admission to aged care facilities and hospitals
- lack of flexible, client-centred service models for people with dementia who want to and can be cared for at home
- a lack of carer and family education programs that specifically address aspects of dementia care.

Polypharmacy is a major issue impacting on members of the target group and, in addition to diagnosis of dementia, is a principal reason for requiring increased access to medical specialists.

In the past, members of the target group are reported to have experienced difficulty accessing community care packages, Home Care, medical specialists (especially psycho-geriatricians) and carer support services.

Project objectives

Specific objectives of DRAH are to:

- assess the effectiveness of short-term post-hospitalisation support to increase or maintain functional independence at home for people with dementia or dementia-related challenging behaviours and their carers
- prevent inappropriate and premature admission to residential aged care or hospital

- decrease the burden of care for carers of people with dementia or dementia-related challenging behaviours.

According to the project proposal, DRAH was designed to test the effectiveness of:

1. short-term access to in-home, multidisciplinary, community-based, therapeutic interventions post-hospitalisation in improving the long-term functional capacity of individuals—dementia as a co-morbidity often rules a client out of rehabilitative type service provision
2. a mobile response team, in close partnership with general practitioners, with capacity to provide short-term, in-home support to maintain or improve levels of functioning for people with dementia or behavioural symptoms associated with dementia
3. a program of services to be tailored to individuals' service needs aimed at improving their long-term functioning
4. inter-agency cooperation and governance between NSW Health, Clarence Valley Council Community Services and the Australian Government.

Increased access to specialist medical diagnosis of dementia and dementia-related medical problems via tele-health evolved as a key feature of the DRAH service model, as is the integration of assessment and service coordination through a partnership of the Area Health Service and Clarence Valley Council.

Target group

The target group is people with cognitive impairment or dementia-related behavioural symptoms and their carers, living in their own homes, who would benefit from the provision of a time-limited period of intensive support and case management.

Eligible participants are those assessed by Clarence Valley ACAT as requiring high level flexible care. Clinicians further evaluate client needs and a care plan is developed and given to the service coordinator to commence an 8-week program targeted at improving or maintaining functional independence.

At the conclusion of a DRAH care plan, the client's progress is assessed and assistance is given to return the client to usual levels of integrated community service support, where appropriate.

Referrals have been accepted for care recipients with a somewhat different profile to that expected of the target group. Acute care and post-acute care needs have been less prominent than anticipated at the outset. The ACAT remarked that general practitioners and other service providers seemed to be referring clients earlier as awareness of the project increased. A higher than expected proportion of clients was referred from home (versus hospital) and it is thought that, in many cases, the project has helped people avoid hospital admission (in a survey of both hospitals in the area, the discharge planners and nurse unit managers reported a decrease in hospital admission of psycho-geriatric and dementia patients).

Service model

DRAH integrates intensive clinical assessment and work-up with community-based, in-home services. The ACAT provides overall case management and direction, covering clinical and community services.

A multi-disciplinary team comprising physiotherapist, gero-psychologist, specialist nurses, social worker and occupational therapist develops diagnostic plans, reviews client progress through weekly case conferences and contributes to the planning of community-based services. Geriatric and dementia specialist services in Sydney are accessed via tele-health when necessary. Two geriatricians in the Northern Rivers area also consult with DRAH clients. A person accepted into the project requiring confirmation of dementia or another investigation such as medication review or gero-psychiatric examination will typically undergo a period of intensive clinical work-up, possibly involving medical specialists, a clinical nurse consultant, and allied health professionals.

Weekly case conferences are held to review the progress of every care recipient. Calculated over the entire episode of care, this activity runs to an average of approximately 2 hours per client per week. This 'behind the scenes' clinical management activity is in addition to initial needs assessment and follow-up contact between the project coordinator and clients. Data recorded for the evaluation reflect the high 'assessment' component of DRAH services, which is in reality a mix of needs assessment and case management for the purposes of delivering community care and clinical work-up for medical diagnosis and management.

Care plans are designed to address up to 16 rehabilitation goals that are agreed between the care recipient, family and ACAT team.

Complementing clinical services, the community service arm of the project focuses on physical management (for example, personal and domestic assistance, food services), and social management (for example, social support, respite care, carer/family support and education). These services are delivered by Clarence Valley Council Community Services as specified in the client's care plan.

The DRAH carer support program aims to create an environment for carers and family members to better understand dementing illnesses. DRAH contracts with Community Programs Incorporated to deliver the 5-week program. Facilitated learning and discussion covers the causes, symptoms and stages of dementia, the impact on carers and families of living with a person who has dementia, management and coping strategies to use at home, and ways that carers can care for themselves. A major spin-off is the opportunity for participants to join carer networks that have arisen through the education program and which continue to provide support long after the period of DRAH service.

Care recipients in the first 6 months of DRAH operation averaged 8.2 weeks of service. A breakdown of the delivery of clinical services during this period is given in Table B2.1. The ACAT is heavily involved not just in the eligibility assessment, but also in weekly case reviews of all DRAH care recipients. The ACAT guides recipients through the program to ensure that clinical outcomes are reviewed regularly and achieved to the greatest possible degree. In addition to clinical services, care recipients and their carers receive a tailored package of 'ancillary services'—personal assistance, home help, respite care, aids and equipment, diversional therapies, transport service and carer education and home modifications and relocation. A total of 1,680 hours of ancillary services were delivered to 25 care recipients who completed their programs in the first 6 months of the project. Project coordination and administration consumed 1,344 person hours in this period (Dementia Rehabilitation At Home, 6-monthly report, 1 February – 31 July 2003).

Table B2.1: Dementia Rehabilitation At Home, clinical service delivery in the first 6 months

Clinical service	Hours per occasion of service	Number of clients in receipt of service (N = 39)	Total hours over 6 months
	Service hours client in attendance		
Specialist geriatric work-up	5	16	80.0
Psycho-geriatrician consultation	1.5	10	15.0
Gero-psychologist	1.5	11	16.5
Geriatrician	1.5	5	9.0
Occupational therapist	2–3	7	20.0
Dietician	2	5	10.0
Physiotherapist	2	1	2.0
Speech therapist	1.5	1	1.5
	Service hours client not in attendance		
Psycho-geriatric clinical nurse consultant	n.a.	n.a.	214.0
Social work	n.a.	n.a.	219.0
ACAT clinician registered nurse (1 fulltime equivalent)	n.a.	n.a.	227.0
Registered nurse part-time	n.a.	n.a.	99.0
Occupational Therapist part-time	n.a.	n.a.	157.0
Total			**1,070.0**

— n.a. not applicable.

Source: Dementia Rehabilitation At Home 6-monthly report:, 1 February–31 July 2003.

This pattern was repeated in the second 6 months, from 1 August 2003 to 31 January 2004. Approximately 960 hours of clinical services were delivered to 37 clients admitted in the period. The project delivered a total of 4,561 hours of ancillary services in the 6 months (it is assumed this figure covers newly admitted and established clients). Respite care made up approximately 48% of ancillary service hours; personal assistance, domestic assistance, transport and carer education each accounted for between 10% and 12% of total hours.

Staffing

In 2003, DRAH increased ACAT capacity by one fulltime equivalent clinician and administrative support three person days per week. In 2004 this was increased to one extra fulltime equivalent clinician and increased administrative support to full time.

Clarence Valley Council Community Service employed one fulltime coordinator to manage the service provision side of the project and 12 part-time support workers.

The usual case management load is one care manager per 15 care recipients.

Early progress

During the first 6 months of operations, 51 referrals were received from hospitals (15), family, friends or neighbours (14), community service providers (10), general practitioners (six), psychologists (three), community nurses (two) and one aged care facility, reflecting a widespread awareness of DRAH in the community. Twelve referrals were not accepted for various reasons including care needs that were too high to be adequately supported by the project (three), no rehabilitation goal (two), person refused or deferred services (three), a CACP was a more appropriate type of service (two), and person took up a place in an aged care facility (two).

Twenty-five care recipients were discharged during the first 6 months and 21 of these people were discharged to home with support services (Table B2.2).

Table B2.2: Dementia Rehabilitation at Home, discharge outcomes from project commencement to 31 July 2003

Discharge outcome	Number of clients
To home	
With CACP	9
With HACC	3
DVA Home Care	4
With Clarence Community Programs	2
With respite service (including DVA respite care)	3
Total at home	*21*
To care facility	
Hospital	1
Residential respite care	2
Residential low care	—
Residential high care	1
Total in care	*4*
Deceased	—
Total	**25**

— Nil

Source: Dementia Rehabilitation At Home, 6-monthly report, 1 February 2003–31 July 2003.

It is estimated that 97 hospital patient days were saved through early supported discharge as a result of DRAH in its first six months of operation. In addition, eight people received DRAH services as a complete alternative to hospital.

The project also reported a high rate of goal attainment during the first 6 months. The 25 care recipients who were discharged in the first 6 months collectively identified 88 rehabilitation goals, of which 64 goals were fully achieved, 15 partially achieved and eight goals were not achieved during the periods of care.

The 12-monthly report indicates that of the 58 clients who completed their program of care in the first year of the project, only seven had entered permanent care. Key achievements in the second 6 months included:

- an estimated saving of 204 acute care patient days through supported early discharge and hospital avoidance
- 16 carers trained in brain and behaviour, nutrition, self-care strategies, the importance of touch, and community service awareness

- a review of the carer program and launch of a new education program in February 2004
- 14 care workers from Clarence Valley Council trained in the management of dementia and dementia-related behavioural symptoms.

A major challenge faced during this period was the lack of community services for clients on discharge from DRAH. The Valley saw significant periods of time in which Home Care, CACP and dementia programs funded by non-government organisations were unable to accept new clients. DRAH allowed clients ready for discharge to continue on a maintenance program while they awaited community services. Several clients were discharged to multiple services in order to ensure continuity of care.

The general shortage of community care options is said to have affected not just DRAH clients, but all ACAT clients, since fee-for-service organisations were the only referral option for people needing personal and domestic assistance, in-home respite care and other standard care services.

Clarence Valley ACAT reported that the project has enhanced awareness and increased the clinical experience of its members. In particular, delirium is assessed more competently and it is believed that interventions for decreasing the intensity and duration of delirium are put into place more effectively. Fifteen DRAH recipients showed signs of delirium at referral. Thirteen clients are reported to have experienced a lessening of delirium symptoms while with DRAH.

Achievements, challenges and lessons

The DRAH model has demonstrated how tele-health technology can be used to increase access to specialist medical services for people with dementia and their families who live outside major metropolitan centres. Carers have attested to the relief that comes from firm diagnosis and information on how they can plan for the future.

Multidisciplinary team work has produced benefits for clinicians involved in the project, increasing knowledge and information exchange. The ACAT reports that the project has been a highly positive experience for its members through the partnership forged between local health and community services and geriatric specialists further afield and the way that the partnerships have facilitated client-centred coordinated care.

DRAH has experienced difficulty in discharging some clients and some compromises have been necessary in making discharge support arrangements due to a shortage of appropriate long-term community care options in the region. Nine clients discharged during the evaluation period are thought to have been placed into the best possible program. Table B2.3 compares actual discharge outcome with optimal discharge support as indicated by the DRAH team for the remaining 22 clients. Extended Aged Care at Home was thought to have been the best support program for 17 clients discharged to home with support from other programs or without formal support.

Four of the five clients discharged to CACP were assessed to have required an EACH service. Similarly, seven clients discharged to a HACC or Veterans' Home Care(VHC) service would have been more appropriately placed with an EACH service.

Table B2.3: A comparison of actual and optimal discharge outcomes for DRAH evaluation clients

	Optimal discharge support						
Discharge outcome	EACH dementia specific	EACH	CACP	NSW Homecare	DVA care package	Higher intensity respite	Total
Unable to discharge	—	1	—	—	—	—	**1**
Home without services or with services unspecified	2	2	1	—	—	—	**5**
HACC or VHC	4	1	—	—	1	—	**6**
HACC or VHC with Day Therapy Centre service	1	1	—	—	1	1	**4**
CACP	2	2	—	1	—	—	**5**
Residential care	1	—	—	—	—	—	**1**
Total	**10**	**7**	**1**	**1**	**2**	**1**	**22**

Note: New South Wales Homecare was recorded as a suitable alternative to EACH or CACP in six cases.

— Nil

Source: Dementia Rehabilitation at Home.

Case studies

The following case studies were supplied by the project.

Case study 1

'A referral was received from a neighbour for an 87 year old man (Mr F) caring for his 94-year-old wife who is hearing and sight impaired. They have no children and no contactable relatives. They have refused all services in past. The neighbour reported Mr F had gone for a drive and got lost 2 kilometres from home. A stranger had driven him home. The stranger reported this to the neighbour. Mr F's GP had not seen him for some time.

DRAH visited Mr F in his home, a two-storey house with a very narrow internal staircase. At the time he was giving his wife cold leftover potato chips for lunch. Mr F did not remember the incident with the driving and getting lost but he would accept help at home with meals.

Goals for the DRAH care plan included: acceptance of services; pursue diagnosis; maintenance of skills; environmental safety; and improve nutritional status.

Services commenced daily, although Mr F would often not let staff in. DRAH pursued diagnosis through his GP and geriatrician. Care workers helped transport Mr F to these appointments. In addition, DRAH facilitated the wife's visits to the GP which led to diagnosis of dehydration and malnutrition.

DRAH organised emergency respite care for Mrs F as Mr F had an episode where he did not recognise his wife and locked her out of the house. In addition, guardianship was organised with a family member as Mr F was no longer able to manage his finances (for example, he had tried to withdraw $25,000 from the bank to pay for a car battery).

Mr F also received 2 weeks respite care but was very agitated and returned home early. The hostel advised that Mr F would not be suitable in their Dementia Unit and would need nursing home dementia care. Mrs F is in hostel respite care awaiting nursing home placement. Mr F has refused placement.

Mr F is awaiting an EACH package as this would be a better alternative at the present time to a nursing home placement. He is orientated in his own home with support workers attending to meals and taking him to visit his wife.'

Case study 2

'An 84-year-old woman was referred by her family for ACAT assessment for respite to enable her elderly carer to have a break (client could not be left alone). Dementia and hypertension were listed as diagnoses on the referral.

The ACAT assessment referral stated that the client could not be left alone, had been seen by a geriatrician for agitation and anxiety 3 months prior to assessment, and was taking an antidepressant and a cholinesterase inhibitor. The client had six presentations to the emergency department and hospital in the 12 months prior to assessment.

DRAH assessment revealed that the client had features of delirium, a high risk of falls due to decline in mobility (frequent falls had been reported), was unsafe in the shower (and did not like having help) and was reluctant to go to day care. The carer was stressed due to constant demands and having to provide personal care assistance.

The client was admitted to DRAH with the goals of:

1. safety and compliance with medications;
2. acceptance of services/care;
3. reduced carer stress;
4. improved environmental safety.

DRAH services included a review by a geriatrician, which resulted in a change of medications (fewer), staff assistance with personal hygiene once daily and in-home respite care, a psychologist visit for the carer (for anxiety management strategies) and carer education sessions, and an occupational therapy assessment and home modifications. In addition, the client and carer were referred for a 'Care For U Holiday'[7] and to a dementia outreach service for ongoing support.

Outcome

On discharge from DRAH, the delirium had resolved, and the client's mobility had improved (transferring and mobilising independently). The client received a CACP which supported the carer and provided day respite three days a week. In addition the client had no falls or presentations to the emergency department or hospital since discharge from program.'

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[7] Care for U Holidays provide specifically designed short break holidays for people with dementia and related disorders and their carers. Holidays are four days & three nights (Monday-Thursday) at the Rainforest Resort, Byron Bay. Respite care staff provide 24-hour support and recreational activities for the person with dementia, and there are activity programs for carers. All transport is provided from the carer and client's home. Holidays are funded by the New South Wales Department of Health and Aged Care, with participants making a contribution of $40 per person.

Case study 3

'A 79-year-old woman (Mrs C) was referred by her daughter who had concerns about her mother's forgetfulness and increasing difficulty with ADL tasks at home. To compound matters, Mrs C's carer, her husband, was awaiting major surgery. Family were keen to have residential respite organised and plan for future support.

Mrs C had been physically well despite being diagnosed with diabetes and arthritis. Mr and Mrs C were both concerned about her short-term memory loss, evident for about 6 months. Mrs C queried 'am I going mad?'. They had only recently discussed it with their family, although close knit, because of concerns about what it would mean for the future. Their children had observed that Mr C was now cooking or prompting his wife with food preparation and housework, and monitoring insulin management. She tended to 'shadow' him and his role as carer was becoming increasingly onerous and impacting on his health. The closest family were about a three hours drive away.

Mrs C could walk around the block alone. The couple tend to shop locally in a familiar environment rather than travelling to the provincial city one hour away, as they had done previously.

Mr and Mrs C attended the ACAT assessment along with their son and daughter. It was found that Mrs C was aware of her short-term memory loss and her reliance on Mr C and was concerned about the impact on him. Along with memory loss she was found to have trouble with concentration and orientation, and accessing the bath. Mr C was quite distressed at the changes in Mrs C and sad to be 'losing' the person he had known for 60 years. He was worried about the seriousness of his impending surgery and how Mrs C would manage. Mr C was a well organised, caring, capable man. He was missing opportunities to pursue his previous interests.

DRAH commenced services with goals of: supporting the carer through illness, relieving carer stress, pursuing accurate diagnosis, ensuring safety and compliance with medications and having the clients accept services.

An accurate diagnosis was achieved by a tele-health appointment with a geriatrician, through which a diagnosis of Alzheimer's disease was made and the implications of the disease and medication options were discussed with Mr and Mrs C. Mrs C's GP was sent a copy of this report. In addition a referral was made to a diabetic educator, so Mrs C could attend a local diabetes clinic for regular monitoring and support. Day respite was organised, and DRAH implemented in-home respite and domestic assistance during Mr C's hospital stay and recovery period. Mr C also attended DRAH education sessions.

Outcome

An early intervention was possible and therefore residential respite and hospitalisation was avoided. Diagnosis and education were obtained enabling planning for future possibilities (the family renovated the bathroom for easy showering and are now aware of resources available). Mr C is now able to pursue his own interests knowing that his wife is safe at day club or having in-home respite care. Short- and long-term services are in place.'

Case study 4

‘A referral was received from hospital for an 82-year-old woman with a diagnosis of dementia and a carer who was unable to cope. The client had presented to the emergency department four times in 8 months. She had recently commenced on anti-cholinesterase medication for treatment of Alzheimer’s disease. Confirmation of diagnosis was made by a consultant physician or psychiatrist to prescribe medication, however, DRAH found inconsistencies in her MMSE score between physicians (one score indicated no cognitive impairment). Following commencement of medication the client became disorientated and confused. Her elderly husband was afraid to take her home from hospital.

DRAH implemented services with the following goals: reducing carer stress; pursuing diagnosis; ensuring adequate socialisation; maintenance of skills; acceptance of services; and ensuring environmental safety.

An urgent consultation via tele-health with a psycho-geriatrician was made to confirm the diagnosis of Alzheimer’s disease, with the client’s GP in attendance. The client was diagnosed with a major depressive episode, not dementia. The psycho-geriatrician recommended changes to medications including ceasing anti-cholinesterase medications. She was discharged from hospital straight after the consultation and service commenced immediately. Services were implemented daily to provide support to the client’s husband. All medications were put in a webster pack and extra medications taken to the chemist to avoid confusion. In addition, DRAH assisted with contact with social day care groups and referred the client to an occupational therapist and physiotherapist due to unsteady gait.

Outcome

The client was discharged to DVA Homecare and the GP was very happy with the outcome, stating that he wished referral had happened earlier.’

2.2 Client profiles

DRAH supplied evaluation data for 31 clients (12 men and 19 women).

Age and sex

The mean age of clients at the time of the evaluation was 79 years (ages ranged from 59 years to 94 years). Six clients were aged 85 years or over (Table B2.4).

Table B2.4: Dementia Rehabilitation at Home, number of clients by age group and sex

Age (years)	Males	Females	Persons
		Number	
Less than 65	1	—	1
65–74	3	1	4
75–84	7	13	20
85+	1	5	6
Total	**12**	**19**	**31**
		Per cent	
Less than 65	3.2	—	3.2
65–74	9.7	3.2	12.9
75–84	22.6	41.9	64.5
85+	3.2	16.1	19.4
Total	**38.7**	**61.3**	**100.0**

— Nil.

Language and communication

Two clients had little or no effective means of communication and the remaining clients could communicate effectively in spoken language. All participants in the evaluation were from an English-speaking background.

Accommodation and living arrangement

Most clients were living in private residences (Table B2.5). One client was in hospital at the time of referral to the project.

Table B2.5: Dementia Rehabilitation at Home, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement				
Accommodation setting	**Alone**	**With family**	**With others**	**Not stated**	**Total**
Private residence	7	22	1	—	30
Short-term crisis accommodation	—	1	—	—	1
Total	**7**	**23**	**1**	**—**	**31**

— Nil.

Years at usual accommodation ranged from less than one to 60 years. Eight clients had been living in the same home for 20 years or longer. Three clients had changed place of residence in the 2 years prior to entering DRAH.

Carer availability

Twenty-six clients had a carer, 18 of whom were living with the care recipient (Table B2.6). Carers' ages ranged from 47 to 85 years, averaging 64.4 years. Eight carers were aged 75 years or over (Table B2.7).

Table B2.6: Dementia Rehabilitation at Home, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Total
Spouse or partner	15	—	15
Son or daughter	3	8	11
Total clients with a carer	*18*	*8*	*26*
Total clients			**31**
Per cent of clients with a carer			83.9

— Nil.

Table B2.7: Dementia Rehabilitation at Home, number of carers by age group and sex

Age (years)	Males	Females	Persons
45–54	4	3	7
55–64	—	5	5
65–74	1	3	4
75–84	4	3	7
85+	1	—	1
Not stated	1	1	2
Total	**11**	**15**	**26**

— Nil.

Income and concession status

Evaluation clients were in receipt of Australian Government pensions as their primary source of income: age pension (29 clients), disability pension (one client), and the DVA pension (one client). All clients held a health care concession card.

DRAH does not charge client fees.

Previous use of government community care programs

Twenty-four clients were not receiving assistance from government community care programs when they entered DRAH. One client was receiving a CACP, four clients were receiving assistance through the HACC program, and one client received support through the National Respite for Carers Program (Table B2.8).

Of the seven carers who had accessed any form of respite in the 12 months prior to entering the project, three had accessed mainly in-home respite and four had accessed mainly residential respite. Nine carers reported that, despite having had a need for respite care in the 12 months prior to DRAH, they had not used a respite care service (Table B2.8).

Table B2.8: Dementia Rehabilitation at Home, number of clients by previous use of government support programs

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	1	3.2
Home and Community Care	4	12.9
National Respite For Carers	1	3.2
CACP and NRCP	1	3.2
Total clients with previous government program support	*7*	*23.1*
Clients without previous government program support	24	77.4
Total	**31**	**100.0**
Use of respite care in the 12 months prior to DRAH		
Respite care not needed	9	34.6
Respite care used	7	26.8
Respite care needed but not used	9	34.6
Not known	1	3.8
Total	**26**	**100.0**

Two clients were reported to be on a waiting list for residential aged care when they entered DRAH.

Assessment and referral

All DRAH clients were referred from different sources to ACAT for intervention and assessment; consequently ACAT were the identifiers of the need for DRAH in particular. ACAT recommended 23 clients for the project (Table B2.9).

Twelve clients had completed an ACAT assessment on the same day or prior to referral. For these clients, the time between completion of an assessment and referral to the project varied up to 13 days (Table B2.10). ACAT assessment was completed after referral to the project for 19 clients. Twelve clients are reported as having had two ACAT assessments in the 12 months prior to entering the project, and one client is reported as having three ACAT assessments in the same period.

ACAT assessment time is included in clients' initial needs assessment hours because of the central role of ACAT in the service model. 'Clinical work-up', which involves a weekly multidisciplinary case conference on each client, has been recorded separately and appears in the DRAH services summary.

Table B2.9: Dementia Rehabilitation at Home, number of clients by source of referral

Referral source	Number of clients
Multiple other sources of referral with final DRAH recommendation from ACAT	23
Hospital	3
Other community service agency	2
Other agency	1
Family	1
General practitioner	1
Total	**31**

Table B2.10: Dementia Rehabilitation at Home, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to DRAH	
0–20 days	12
Total	*12*
After referral to DRAH	
0–60 days post-referral	16
61–300 days post-referral	3
Total	*19*
Total	**31**

The care of DRAH clients is managed by a registered nurse (21 clients), an occupational therapist (three clients) or a social worker (seven clients). In addition, the progress of all clients is reviewed by a multidisciplinary team of clinicians.

Health conditions and health status on entry

The number of health conditions recorded for DRAH clients as at entry ranged from one to eight. Fourteen of the 31 clients had five or more health conditions. Table B2.11 shows the primary health conditions recorded on the Aged Care Client Records for clients.

Table B2.11: Dementia Rehabilitation at Home, number of clients by primary health condition at entry

Primary health condition	Number of clients
Dementia (Includes Alzheimer's and other types of dementia)	23
Delirium	1
Psychoses and depression/mood affective disorders	1
Mental and behavioural disorders due to alcohol and other psychoactive substance use	1
Transient cerebral ischaemic attacks	1
Heart disease	1
Cerebrovascular disease	1
Osteoporosis	1
Amnesia	1
Total	**31**

Eighteen clients were assessed as being at risk of falls due to impaired gait or balance (Table B2.12). Five clients were both vision and hearing impaired.

Table B2.12: Dementia Rehabilitation at Home, number of clients by selected sensory, mental health and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	18
Vision impairment	10
Diagnosis of depression	7
Hearing impairment	7
Disorientation/confusion	6
Vision and hearing impairment	5
Total or partial paralysis	3
Missing or non-functional limbs	1

Clients were taking between one and 11 different types of medication. Thirteen clients were taking seven or more different medications.

Clients and carers were asked to rate the client's health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Self-reported health status was reported by three clients, by carers on behalf of clients in 21 instances, and by a care worker for six clients. Respondent identity was not reported in one case. Clients rated their present state of health as good, fair or poor. Seventeen clients were rated (by another person) as being in fair health, seven as being in good health, one as being very good, and one as excellent. Two clients were rated as being in poor health. Ten raters believed that the client's health was about the same as it was a year earlier, and one rater reported that the client's health was somewhat better. Fifteen raters believed the client's health was somewhat worse and five raters stated that the client's health was much worse than 12 months earlier.

Level of core activity limitation

Most DRAH clients experienced mild or moderate activity limitation in the areas of self-care (22 clients), mobility (20 clients) and communication (22 clients) (Table B2.13). Eight clients recorded a severe or profound limitation in at least one core activity.

Table B2.13: Dementia Rehabilitation at Home, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	**No limitation**	**Mild**	**Moderate**	**Severe or profound**	**Total**
Self-care	4	13	9	5	**31**
Mobility	8	15	5	3	**31**
Communication	5	18	4	4	**31**

Use of medical and hospital services prior to entry

All of the 31 clients had visited a medical practitioner at least once in the 6 months before starting with DRAH. The reported number of visits to a medical practitioner in this period varied from one to 24 per client. Cumulatively, clients recorded 159 visits to a medical practitioner outside of a hospital setting over an estimated 5,580 person days.

Around two-thirds of clients recorded use of hospital services in the 6 months prior to entering DRAH. Sixteen clients contributed to a total of 31 hospital admissions in the pre-entry period. Forty-eight per cent of clients recorded unplanned or urgent hospital admissions and collectively accumulated 183 unplanned patient days over approximately 2,700 person days. Individually, they recorded between 3 and 29 days in hospital for unplanned admissions in the 6-month period.

Some of the admissions were directly associated with dementia or other cause of cognitive impairment such as delirium or dementia-related psychosis. Three clients recorded these types of admissions to hospital prior to entering DRAH (six admissions in total).

Altogether, conditions recorded as occasioning admission to hospital prior to entry to DRAH were either dementia-related or unrelated medical conditions:

- dementia
- delirium
- influenza and pneumonia
- acute upper respiratory tract infection
- osteoporosis
- fracture of the wrist
- dizziness
- nausea and vomiting

- pain
- diseases of the intestinal tract and other diseases of the digestive system
- heart disease
- hypertension
- other diseases of the circulatory system
- psychoses and depression/mood affective disorders.

That only three evaluation clients had been hospitalised for dementia or delirium suggests that DRAH has been helping people with dementia to avoid hospitalisation where possible, because given the lack of alternative means of accessing specialist services in the region it is likely that more of the high needs clients would have sought assistance from a hospital for dementia-related conditions.

Prior to entering DRAH, seven clients recorded a fall with injury, four clients were rendered immobile and without assistance for more than 30 minutes, and 11 clients suffered another serious medical emergency. Thus, DRAH services a client group in which a significant proportion of people are at increased risk of hospitalisation if assistance and monitoring at home is not available.

2.3 Client assessment results

Cognitive function

The MMSE scores recorded for clients when they entered DRAH range from a minimum of 6 to 28 points out of a possible 30 points (mean 19.9). Twelve clients scored around or below 16 points (Table B2.14).

Table B2.14: Dementia Rehabilitation At Home, number of clients by MMSE score at entry

MMSE score	Number of clients
1–15	5
16–18	7
19–24	12
25–30	6
Missing	1
Total	**31**

Cut-points to account for educational attainment were applied to the raw scores (Uhlmann & Larson 1991), indicating that 17 out of 30 clients showed probable cognitive impairment at date of entry to DRAH.

Of the 13 clients with a score that does not indicate cognitive impairment at baseline, three showed probable cognitive impairment at their final assessment. On the basis of recorded MMSE scores, it can be concluded that the DRAH is targeting a mixed group of clients, some of whom exhibited probable cognitive impairment on entry to the project, as might be expected for a project that targets people in need of assessment and diagnosis. All but five clients are reported as displaying behavioural symptoms at entry to the project (see Figure B2.3).

Activities of daily living

At least half of the clients needed assistance in tasks involving self-care and mobility (Figure B2.1). The MBI was used to record levels of ADL function on entry. Scores ranged from 6 to 20 out of a total 20 points. The mean score was 15.3 points, indicating that the middle of the MBI distribution for DRAH clients was in the range of moderate dependency in ADL (Table B2.15).

Using a classification system for the Barthel Index (Shah et al. 1989), the results indicate that seven clients were severely dependent and 14 clients were moderately dependent in ADL at time of entry. Five of the evaluation clients were slightly dependent and five were independent in ADL.

Five clients were sometimes or always doubly incontinent. Nineteen clients were unable to bathe or shower without assistance and 13 clients needed assistance to use the toilet. Twenty-six clients were able to walk independently and one was independently mobile with the use of a wheelchair. Around one-third of clients needed help in the areas of feeding and transfers, and around half of the clients needed assistance in grooming and dressing (Figure B2.1).

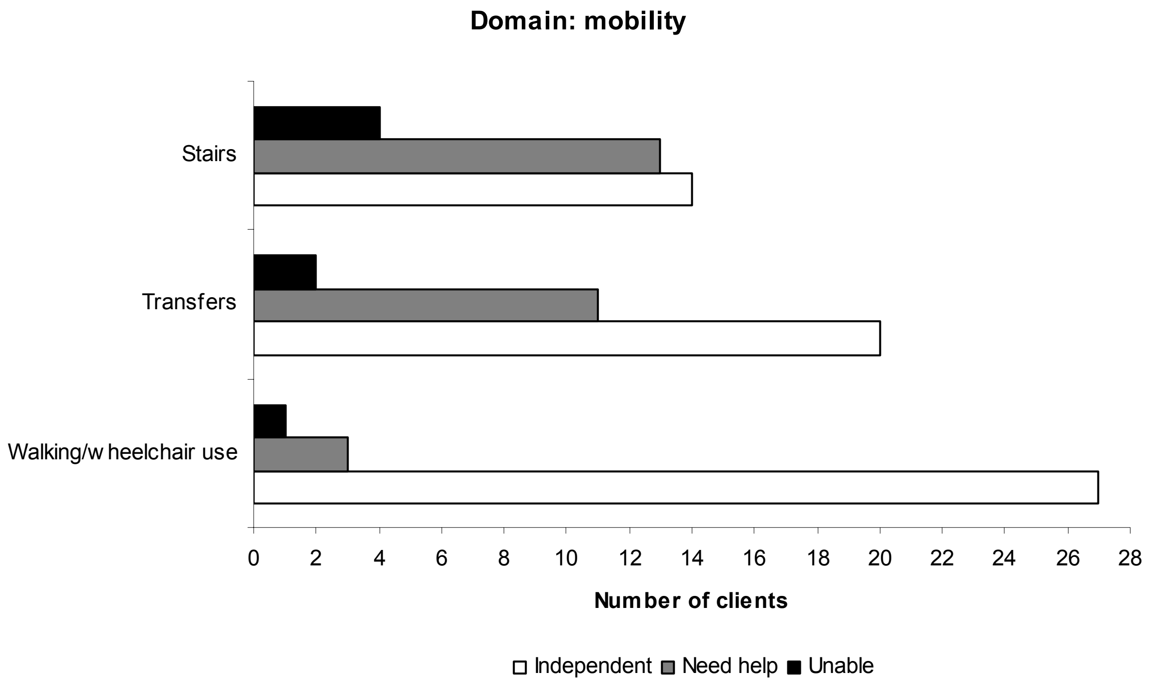
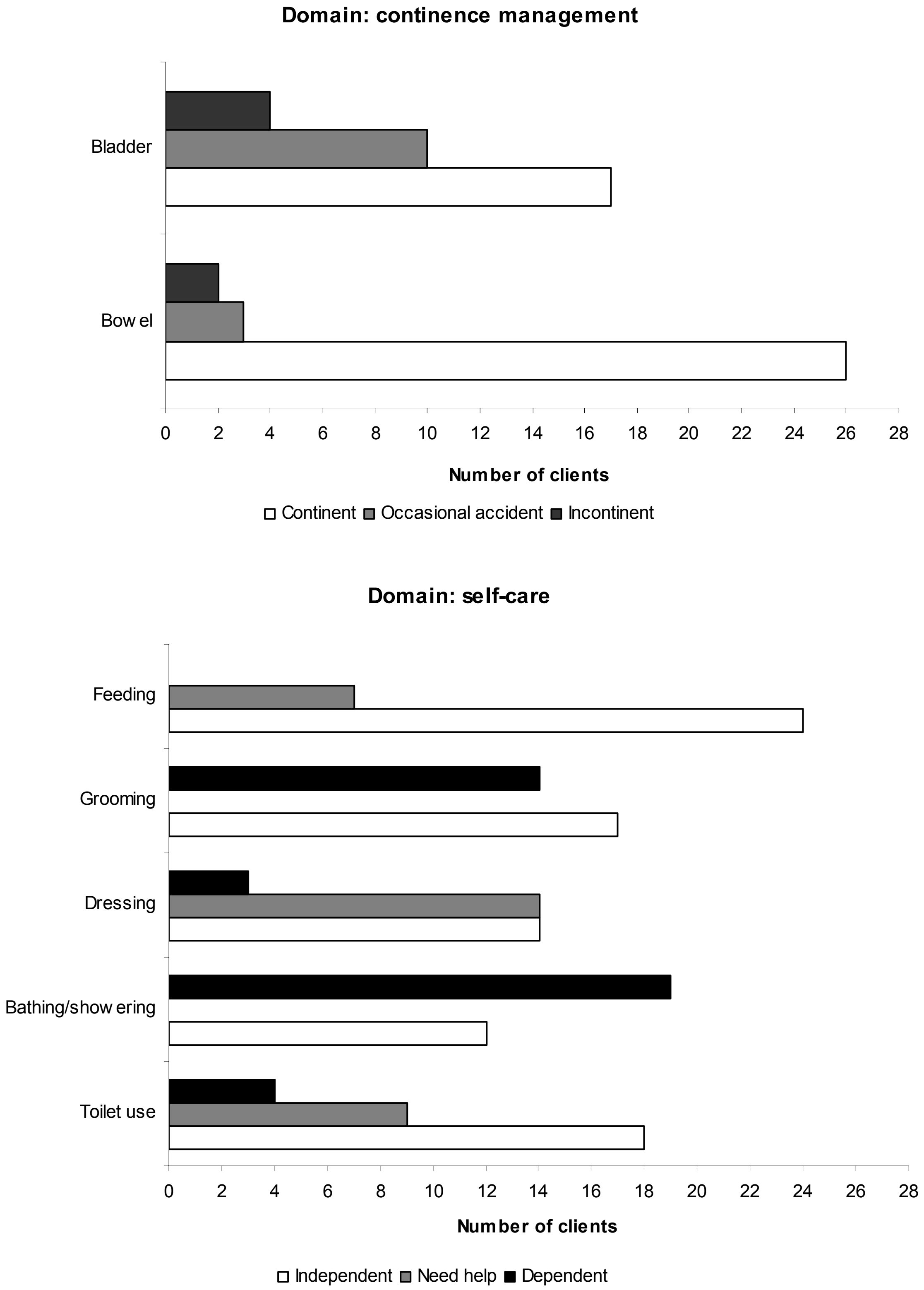


Figure B2.1: Dementia Rehabilitation at Home, number of clients by level of ADL function at entry to DRAH

(continued)

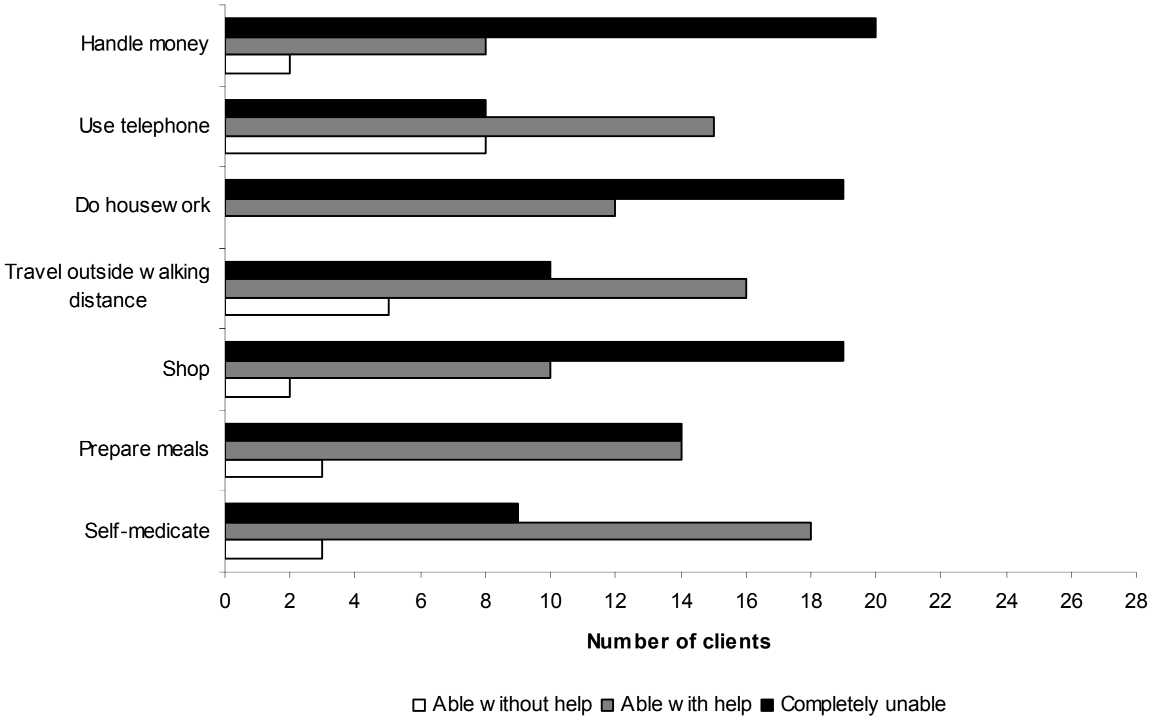


Source: Appendix Table B9.

Figure B2.1 continued: Dementia Rehabilitation at Home, number of clients by level of ADL function at entry to DRAH

The median baseline IADL score was 3 points, with scores ranging from zero to 12 out of a possible maximum of 14 points. Baseline results indicate that all DRAH clients had lost some IADL function by the time they joined the project.

DRAH clients were completely dependent in between zero and seven of the seven IADL at the time of entry (Figure B2.2). Three clients were unable to perform tasks in any of the seven IADL. Although 26 clients registered as being able to walk or use a wheelchair independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all but five cases, independent mobility was limited to the home environment.



Source: Appendix Table B10.

Figure B2.2: Dementia Rehabilitation at Home, number of clients by level of IADL function as at entry

Final assessments were conducted on average 77 days after entry.

Changes in the ADL scores between baseline and final assessments ranged from –7 (a 7-point decline in function) to 7 points (a 7-point improvement in function). The median change score was zero (Table B2.15), that is, on average the level of functioning in ADL was the same at baseline and final assessments. Of the 16 clients with a non-zero change score, nine changed to a different level of dependency, representing a mixture of cases of deterioration and improvement in ADL functioning.

The median IADL change score (between baseline and final assessments) was zero, with variation within the range of –7 to 3 points (Table B2.15). Thirty-three per cent of clients registered a decrease in IADL function between baseline and final assessments.

Table B2.15: Dementia Rehabilitation at Home, summary measures for ADL and IADL baseline[(a)] and change scores[(b)]

	Count	Minimum	Median	Maximum	Mean	Standard deviation
ADL						
Baseline MBI	27	6	15	20	14.7	4.0
Change in MBI	27	–7	0	7	0.4	3.2
IADL						
Baseline IADL	27	0	3	12	4.2	3.4
Change in IADL	27	–7	0	3	–0.5	2.0

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Of the 26 clients with baseline behaviour measures, 21 showed signs of memory loss on an intermittent or extensive basis (Figure B2.3). Seventeen clients showed intermittent or extensive signs of emotional or psychological symptoms of dementia. Seven clients were reported at time of entry to the DRAH to be sometimes physically aggressive. Four clients wandered or displayed intrusive behaviour and nine were verbally disruptive on an intermittent or extensive basis. Eleven clients were a danger to themselves or others either intermittently or extensively. Around half of the clients exhibited other unspecified types of behaviour, either intermittently or extensively, and four clients exhibited three or more psychological and behavioural symptoms on an extensive basis.

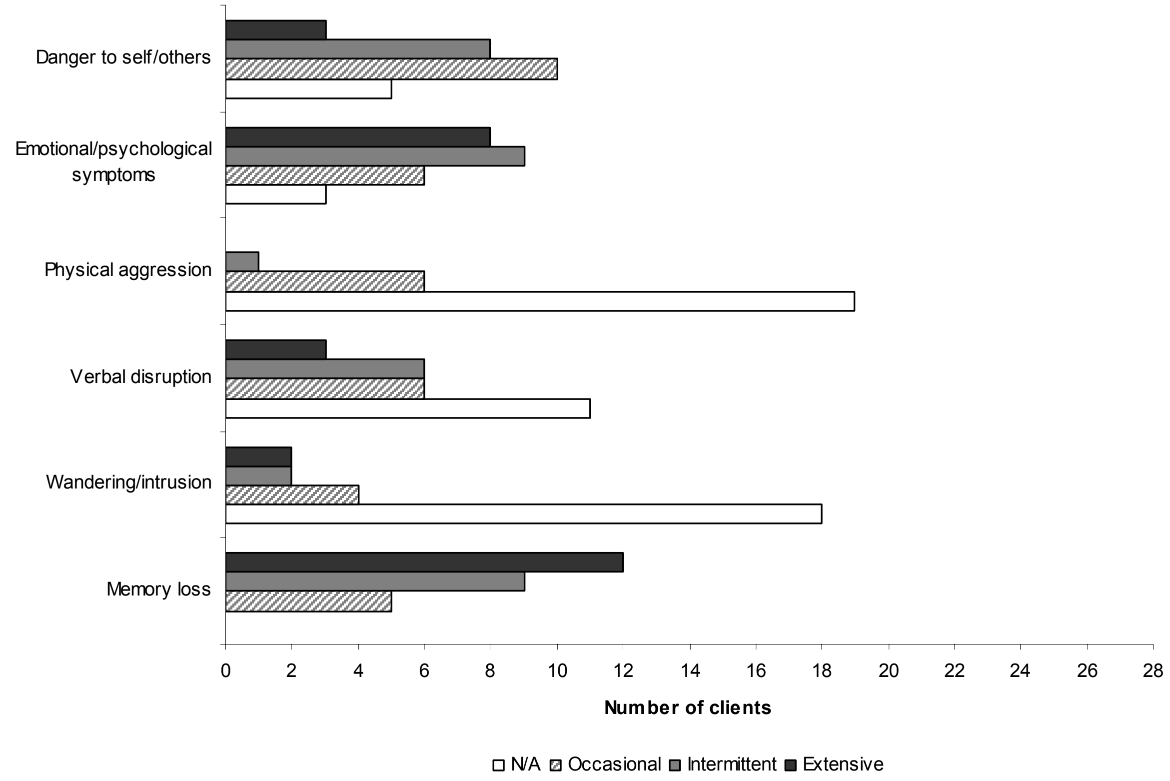


Figure B2.3: Dementia Rehabilitation at Home, number of clients by frequency of psychological and behavioural symptoms at entry

Other assessments

DRAH provided results of additional assessments for six to eight clients in addition to standard evaluation assessments. These data are summarised below.

Geriatric Depression Scale

The Geriatric Depression Scale is a 30-item questionnaire used to measure depression in older people, including those who are medically ill or mildly to moderately cognitively impaired. The scale has been used extensively in community, acute and long-term care settings (Kurlowicz 1999). Scores between zero and 9 points are considered normal, scores between 10 and 19 points indicate mild depression, and scores of 20 to 30 points indicate severe depression (Yesavage et al. 1983).

DRAH provided Geriatric Depression Scale scores for eight clients at entry. Seven of these clients scored within the normal range; three clients scored zero out of a possible 30 points and four clients scored between 1 and 6 points. One client scored 38 points (above the maximum allowable on the scale). This client was also recorded as having a diagnosis of depression on entry to the project. This client scored 14 out of 30 at the final assessment, which indicates mild depression at that time. The scores were not recorded for any other client at the final assessment.

Clock-face drawing test

The clock-face drawing test is a quick screening test for cognitive dysfunction secondary to dementia, delirium, or a range of neurological and psychiatric illnesses, to be used in conjunction with other tools and clinical assessment. There are numerous versions of the clock-face drawing test, all of which involve asking the patient to draw the face of a clock with the hands showing a particular time (Braunberger 2001).

A number of cognitive abilities, motor skills and perceptual functions are required simultaneously for a client to successfully draw a clock-face showing the appropriate time. These include orientation, conceptualisation of time, visual spatial organisation, memory and executive function, auditory comprehension, visual memory, motor programming, numerical knowledge, semantic instruction, inhibition of distracting stimuli, concentration and frustration tolerance. A well-drawn clock-face therefore suggests that a number of functions are intact and contributes to the weight of evidence that, for example, the patient's independent living skills may be intact. Abnormalities in the drawing may indicate potential problems warranting further investigation or resource allocation (Braunberger 2001).

There are a number of variations on scoring the clock-face drawing test. Most scoring systems are highly correlated with well-established measures including the MMSE, Dementia Rating Scale and the Global Deterioration Scale. DRAH scored the test using the Sunderland method, which allocates the client a single score from zero to 10 based on the completeness and accuracy of the drawing (Sunderland et al. 1983). This scoring method is not diagnostic (that is, the score cannot be used to establish whether or to what extent a client is cognitively impaired), but results can inform the overall clinical assessment of the client.

Sunderland scores were provided for six clients at baseline. One client scored zero out of 10 points, indicating that no attempt was made to complete the task. This client had a baseline MMSE score of 17 points. Five clients scored between 6 and 9 points, producing a clock-face with circle and numbers generally intact.

Sunderland scores were provided for eight clients at the final assessment (none of these clients had scores recorded at baseline). Four clients scored between 2 and 5 points, indicating that their drawings did not contain an intact circle and numbers. Three clients scored between 6 and 8 points, producing a clock-face with circle and numbers generally intact. One client did not make a recognisable attempt to complete the test and scored zero points.

There was general agreement between MMSE scores and scores derived from the clock-face test in all but two cases. One client recorded a baseline MMSE score of 27 but was unable to complete the clock-face test, scoring zero points. One client produced a clock-face with circle and numbers mostly intact at the final assessment but scored only 3 points on the MMSE.

Confusion Assessment Method

The Confusion Assessment Method is an assessment instrument that screens for overall cognitive impairment and distinguishes delirium or reversible confusion from other types of cognitive impairment (Waszynski 2001). DRAH conducted the test for seven clients at baseline and one client at final assessment. All clients scored zero points, meaning no signs of confusion or delirium were recorded during the assessments.

Nutritional Risk Screening and Monitoring Tool

The Nutritional Risk Screening and Monitoring Tool was developed by the Victorian Department of Human Services Home and Community Care Program as a method of screening older and vulnerable adults for nutritional risk and to identify the factors contributing to nutritional risk to inform care planning and intervention. Clients' height, weight and body mass index are recorded and a 10-item risk tool is used to generate a score of between zero and 10 points. If nutritional risk is identified (that is, the client scores 1 or above), a general needs assessment covering 23 factors which may contribute to nutritional risk is conducted. Results are used to inform care planning (VDHSHACC 2001).

DRAH provided nutritional risk scores for six clients at baseline. No nutritional risk was identified for four of these clients (scores of zero out of 10); two clients were identified to be at some nutritional risk (scores of 2 out of 10 and 3 out of 10). One client was assessed using the tool at the final assessment only, and scored 7 out of 10 suggesting nutritional risk which would be addressed in the client's care plan.

2.4 Carer assessment results

Eight out of the 26 carers reported that they were in very good or good health. Seven carers said they were in fair health and four reported poor health. Responses were not recorded for the remaining seven carers who took part in baseline assessments.

Twenty-three carers completed the CSI on entry to the DRAH, generating a mean score of 6.3 (median 6) with a standard deviation of 2.8 points. Scores ranged from 1 to 11 out of 13 points. Twelve carers recorded scores above the threshold for carer strain of 7 points.

Eighteen carers completed the CSI at the final assessment. Changes in the CSI between baseline and final assessments ranged from –8 (an 8-point reduction in carer strain), to 4 points (a 4-point increase in carer strain). The median change score was –1.0.

Of the 18 carers who completed both baseline and final assessments, eight scored over the threshold of high carer strain at baseline. Five of these clients recorded a lower CSI score at the final assessment that was sufficiently lower to no longer be considered as experiencing carer strain at that time; the other three carers continued to report high carer strain at the final assessment. One client who was below the threshold for high strain at baseline had exceeded the threshold by final assessment.

DRAH did not administer the GHQ-28 to carers on the basis that the instrument would cause undesirable response burden.

2.5 Service profile

DRAH combines multidisciplinary assessment and ongoing review (including medication review and allied health care) with in-home ADL support, respite care and other forms of carer support. The project service profile thus includes a long list of service types covering those of a clinical nature and others of a community service nature (Table B2.16). 'Multidisciplinary clinical work-up' includes ACAT assessment time and all specialist assessment and diagnostic activity that emanates from ACAT assessment. The case management capability of ACAT under the DRAH service model means that high ACAT involvement continues throughout the DRAH episode of care, as the ACAT is the central point of coordination of other health care providers involved in client care for example, geriatrician, psycho-geriatrician, general practitioner and allied health professionals.

On the community services side, Clarence Valley Council delivers in-home ADL support, transport and respite care. This project reported relatively high levels of transport and respite care hours per week.

Table B2.16: DRAH summary of services, average number of service units per client per week Results for period 14 June – 29 November 2004

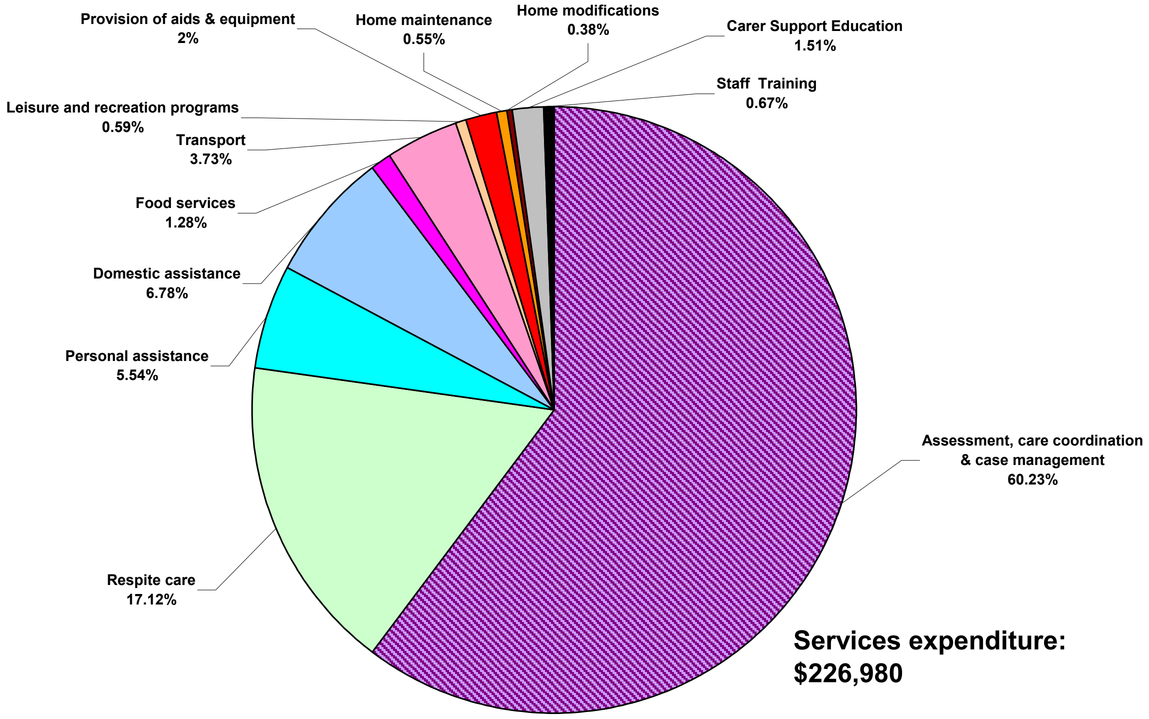
Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Multidisciplinary clinical work-up	Hours	31	0.1	1.8	4.2	1.9	0.9
Domestic assistance	Hours	24	0.0	0.8	9.0	2.2	2.9
Allied health[(a)]	Hours	24	0.1	0.3	1.3	0.3	0.3
Respite (in-home and day) [(b)]	Hours	24	0.5	7.4	19.7	7.6	4.5
Personal assistance	Hours	19	0.1	1.3	6.4	1.7	1.6
Social support	Hours	17	0.1	1.3	6.6	1.8	2.0
Food service other	Hours	14	0.1	0.4	2.9	0.7	0.8
Nursing care	Hours	9	0.0	0.4	0.8	0.3	0.2
Linen service	No. of deliveries	2	1.3	1.4	1.4	1.4	0.1
Home modifications and maintenance combined	Dollars	9	6.4	42.9	149.4	64.6	52.4
Aids and equipment	Dollars	7	10.0	35.0	47.3	26.8	15.5
Follow-up needs assessment	No. contacts	31	0.4	1.5	4.7	1.7	1.1
Dementia care, memory and behaviour management	No. contacts	24	0.2	1.1	6.4	1.9	1.7
Geriatrician	No. contacts	20	0.1	0.1	0.3	0.2	0.1
Nursing/medical other	No. contacts	5	0.1	0.2	0.5	0.2	0.2
GP consultation	No. contacts	2	0.4	0.6	0.7	0.6	0.2
Overnight respite	No. days/nights	2	0.3	2.5	4.6	2.5	3.0
Recreation/leisure programs	No. days/nights	1	1.2	1.2	1.2	1.2	—
Carer support other than respite	No. events	26	0.1	0.4	3.0	0.6	0.7
Medication review	No. events	25	0.1	0.2	0.6	0.2	0.2
Information advice and referral	No. events	19	0.1	0.3	2.8	0.5	0.6
Allied health other	No. events	7	0.1	0.2	1.6	0.4	0.5
Personal other	No. events	1	0.2	0.2	0.2	0.2	.
Delivered meals	No. meals	9	0.1	1.0	8.1	1.8	2.5
Community transport	No. one-way trips	23	0.5	1.8	10.2	2.2	2.2
Dietetics	No. referrals	3	0.1	0.1	0.2	0.1	0.1

(a) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(b) Assumes one-day respite equivalent to 5 hours.

— Nil.

Figure B2.4 gives a breakdown of direct care expenditure in DRAH between 1 July and 31 December 2004. The high clinical work-up component of DRAH means that ‘Assessment, care coordination and case management’ includes all of the clinical activity involved in referral to medical and nursing specialists, case conferencing and review, which is different to assessment and case management in most other projects. In the six months from 1 July to 31 December 2004, DRAH salaries expenditure included $87,926.98 for clinical case management (38% of salaries bill). The ‘wedge’ representing expenditure on assessment, care coordination and case management in Figure B2.4 is exploded in Figure B2.5 by clinical department. Nursing and allied health assessment and work-up and counselling services constitute a significant portion of expenditure on assessment, care coordination and case management. Clinical service delivery in DRAH was discussed in section 2.1 (Service model).



Source: Appendix Table B25.

Figure B2.4: Dementia Rehabilitation At Home, expenditure on services, 1 July–31 December 2004

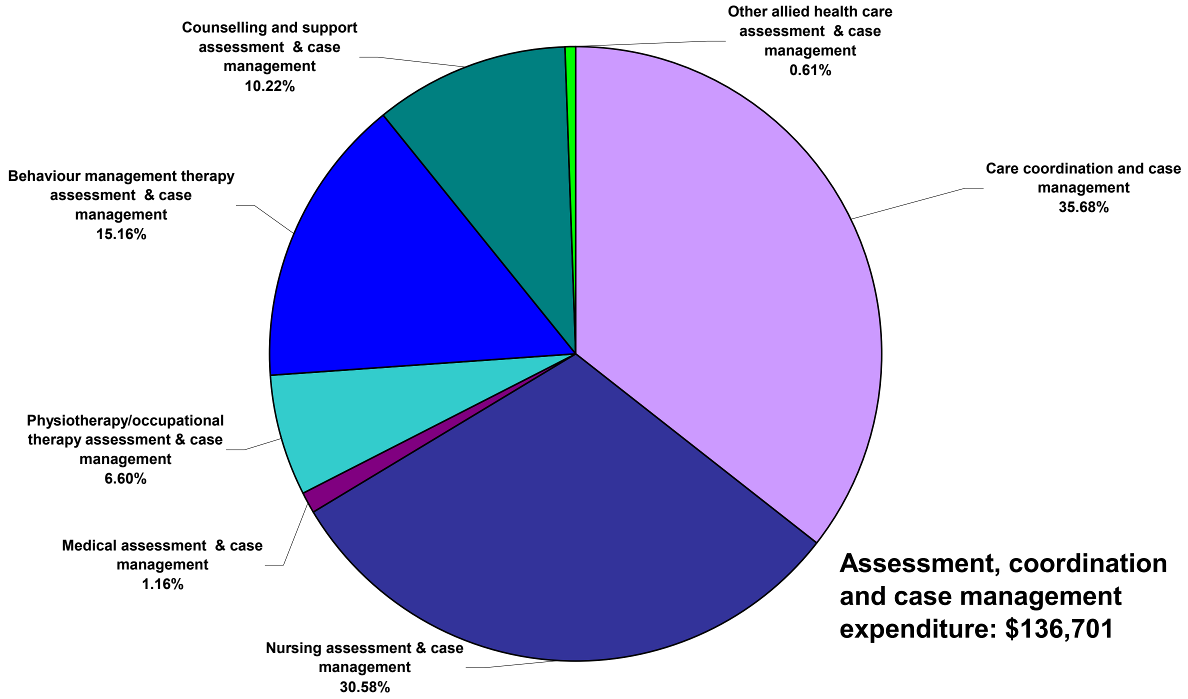


Figure B2.5: Dementia Rehabilitation At Home, expenditure on assessment, coordination and case management by activity type, 1 July–31 December 2004

2.6 Accommodation outcomes

Twenty-eight clients were discharged from DRAH during the evaluation. Two clients were discharged to high level residential aged care and one client was discharged to hospital (Table B2.17). The project indicated that an EACH package was the preferred discharge destination of one client who had entered an aged care facility (see Table B2.3). The remaining 25 clients who had completed their DRAH episode were at home following discharge from the project. Two clients continued with a DRAH maintenance plan because there was no appropriate program support available at the time of discharge.

The most common form of government program support for clients in the community on discharge from DRAH was CACP (seven clients), followed by HACC (five clients) and multiple program support, for example, HACC and Day Therapy Centre services or Veterans' Home Care plus HACC.

Five clients who were discharged during the evaluation had been in the project for over 100 days (112–142 days). During the AIHW site visit, project staff reported that difficulty in making suitable discharge support arrangements could result in clients remaining in the project for longer than the planned maximum length of stay of approximately 90 days.

Table B2.17: Dementia Rehabilitation at Home client discharge destination, number of clients by government program support on discharge and length of stay

Discharge destination/status	No. of clients	Length of stay (min – max days)
At home		
Without government program support	3	51–137
Community Aged Care Packages	7	39–142
Home and Community Care	5	55–112
Veterans' Home Care	1	44
National Respite for Carers Program	2	58–90
Multiple programs	5	64–91
Total discharged	*23*	*39–142*
DRAH maintenance—unable to discharge	2	88–90
Total at home	*25*	*39–142*
In care		
Hospital	1	87
Residential aged care—high	2	88–90
Total in care	*3*	*88–90*
Total	**28**	**39–142**

DRAH completed a follow-up of evaluation clients between 14 February and 27 April 2005. Table B2.18 shows the accommodation setting and government program support for all clients at follow-up, that is, approximately 11 months from the start of the evaluation period.

Between the end of the evaluation and the conclusion of follow-up, 15 community-dwelling clients had changed their formal support arrangements. Two clients who were discharged with no government program support and one client whose program support was unknown at discharge were receiving HACC services, and one client whose program support was unknown had begun HACC and NRCP services. One client who was discharged with no government program support and another whose program support was unknown at discharge were receiving a CACP. Two clients who were discharged onto CACPs were receiving HACC services in addition to the CACP. One HACC client transferred to a CACP, and one NRCP client began receiving HACC services in addition. Four clients receiving services from multiple sources at discharge were receiving HACC services only at the time of follow-up.

Table B2.18: Dementia Rehabilitation at Home, number of clients by accommodation setting and government program support at follow-up, April 2005

Location at follow-up	No. of clients
At home	
Without government program support	3
Home and Community Care[(a)]	10
Veterans' Home Care[(a)]	1
Community Aged Care Packages[(a)]	6
Multiple programs[(a)]	5
Not stated	1
Total at home	*26*
In care	
Residential aged care–high	3
Total in care	*3*
Deceased	1
Not located at follow-up	1
Total	**31**

(a) Clients on multiple program support included two clients on CACP plus HACC;
two clients on HACC plus NRCP;
one client on VHC plus Day Therapy Centre.

These results are indications of the instability of support arrangements following discharge which helps to confirm the advice of project staff that discharge outcomes were not always ideal. However, 84% of evaluation clients were still living in the community at the time of follow-up.

3 Flexible Care Service

3.1 Project description

annecto – the people network received an allocation of 20 flexible care places to operate a 2-year pilot project called Flexible Care Service (FCS). FCS provides home-based care of a finite term with an intended average length of stay of around 12 weeks. The project operates from offices in Canterbury, Melbourne, to service the eastern metropolitan region.

annecto is an established service provider for the CACP and HACC programs and the National Respite for Carers Program. Job Connections and the Supported Accommodation Assistance Program also fund *annecto* to deliver community services. Prior to its renaming to *annecto*, WiN Support Services had been providing community care for over 20 years and was operating in four metropolitan and two rural regions of Victoria. *annecto* (and formerly WiN Support Services) ordinarily provides case management and care coordination for people with complex care needs, including those with dementia and dementia-related behaviours.

The organisation delivers dementia-specific respite care services with funding from the Australian Government; the establishment of Flexible Care Service was a logical extension of these services using existing expertise and infrastructure.

Project objectives

Flexible Care Service aims to:

- provide a range of community service options for older people with dementia and/or dementia-related behaviours, to help improve functioning and stabilise behaviour
- increase the number of people with dementia and an Aged Care Assessment Service (ACAS)[8] approval for high level care who are able to remain in their own homes
- enable clients to remain at home wherever possible, or to enter residential aged care from the project with a higher level of functioning and independence than would otherwise have been possible
- test the effectiveness and efficiency of innovative service funding to provide short-term dementia care in the home.

This project, originally proposed as a long-term dementia care program, was implemented as a short-term intervention at the suggestion of the State Office of the Australian Department of Health and Ageing.

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[8] Aged Care Assessment Service is equivalent to Aged Care Assessment Team in other jurisdictions.

Target group

The target group is people living in the community with dementia-related high care needs. Acceptance into the project requires ACAS approval for residential high care. Prior to the launch of FCS, *annecto* targeted mainly people with low level care needs. FCS is therefore targeting a substantially different group from *annecto's* traditional clientele. It was originally envisaged to target people who present with high care needs but who have not previously used formal services in order to link them into the formal service network. Identifying people with no or minimal established services proved difficult and the project has found that the majority of people accepted into FCS have been using council HACC services at the least.

All FCS evaluation clients were referred from the community and remained in a private residence for the period of FCS service. FCS requires all care recipients to have a family carer.

The Department of Health and Ageing State Office directed *annecto* to develop clear selection criteria with a view to achieving good client outcomes. For example, the project needs to determine whether a potential client is seeking nursing home placement. If a placement is offered shortly after a client starts in the project, the client and family needs to make an immediate and significant decision on long-term care. Given the shortage of nursing home beds, people often feel that there is little alternative than to accept an offer of placement. For this reason, a person/family who is actively seeking placement would not normally be accepted into FCS.

Referrals have been sourced mainly from ACAS (the Peter James and Outer East ACAS accept referrals in the FCS service area). ACAS indicated that the types of clients referred to the project would otherwise be referred as a client in urgent need of a CACP, mainly because there are rarely vacant Linkages packages in the area. For this type of client, the ACAS often takes on a case management role that is outside the scope of its brief. Some community service providers have been observed to 'give up' on high care clients with very complex needs, leaving ACAS to pick up the pieces (although some day care centres offer quasi-case management, which provides valuable relief to the ACAS).

After receiving a referral from ACAS and checking that the client is approved for residential high care and high level respite care, the FCS coordinator initiates contact via a telephone screening assessment.

The needs of people in the target group are perhaps less likely to be temporary compared to client needs targeted by a post-acute/sub-acute service model. Approximately 75% of FCS care recipients have required personal care for continence management. Emotional and psychological symptoms of dementia and resistance to formal services are observed in many care recipients. People referred to FCS can be characterised as having experienced a crisis in care, as opposed to a recent medical event or recent diagnosis of dementia. FCS clients tend to have moderate to severe dementia and are at the point of no longer having access to care at home as a result of carer death, illness or burnout.

Implementation of a short-term intervention model for people with long-term high care needs has presented certain difficulties.

Entry criteria

Initial screening of referrals makes an assessment against the following criteria:

- ACAS approval for residential high care for a client with dementia

- there is a family or friend carer who makes daily contact with the client (there is no requirement for the carer to reside with the FCS client)
- the client is not on a waiting list for an EACH package (department State Office advice)
- the client is unlikely to require more than 2 weeks of respite care or acute care during the FCS service episode (department State Office advice)
- no palliative clients.

Service model

FCS is a full brokerage model. If a client has community services in place, such as a council HACC service, the aim is to leave these arrangements in place by taking over the funding and providing supplementary services to meet the assessed level of need.

Respite care is viewed as a core service for the target group, reflecting a primary aim of reducing levels of carer strain, stabilising care environments and introducing appropriate ongoing supports. Personal and domestic assistance services are other key features of the service model.

Care recipients have access to *annecto*'s Support Emergency After Hours Response Service (EARS). EARS is unique in Victoria and is available to clients of all *annecto* programs as well as being brokered by other agencies.[9] Clients/carers may not need to access EARS during their time in the project but knowing it is available increases confidence that support is available at any future time of need when no other help can be found.

Achievements, challenges and lessons

FCS has demonstrated considerable success in working with one of the higher needs groups in the Innovative Pool Dementia Pilot, despite a number of operational difficulties.

At time of follow-up, 50% of evaluation clients accepted into the project between June and October 2004 were found to be at home with support from government programs (25% deceased and 25% in high level residential care). A survey conducted by *annecto* in November–December 2004 of care recipients who had moved through the project between November 2003 and July 2004 revealed that approximately 47% had entered residential high care. The remaining people were at home (33%) or deceased (19%).

There is evidence that longer term outcomes in FCS have as much or more to do with services received after discharge as with the impact of FCS service. Evaluation clients discharged onto an EACH package were still at home with an EACH service at time of follow-up. Clients discharged to a HACC service were less likely to be at home with a HACC service at follow-up. A number of clients were discharged from FCS with support from multiple programs. This solution to a lack of high care community options appears to maintain people at home over the medium term but may not represent an efficient allocation of services that are perhaps better targeted at people with lower care needs. The number of people in each category is too small to report meaningful percentages; however, the trends are apparent and are consistent with the observations of FCS care managers.

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[9] For example, EARS is available to clients in the other Victorian Innovative Pool dementia project, North East Dementia Innovations Demonstration at the Austin and Repatriation Medical Centre, under a purchaser–provider agreement.

An important contribution of the project has been the level of support given to carers, many of whom experience high levels of strain associated with the caring role. The project has acted as a source of referral for people in crisis. Nineteen of the 22 carers who completed a carer strain assessment on entry to the project exceeded the recognised threshold for carer strain. Eight carers experienced a reduction in carer strain during the FCS service episode and five carers above the threshold for high carer strain when they entered the project registered below the threshold by completion of the FCS episode. The mean change in carer strain score between two assessments, averaged over all carers, is –1.4 points that is, on average, the level of carer strain has reduced during FCS service episodes. While an association between reduced carer strain and FCS intervention is speculative, it is clear that around half of evaluation clients previously faced an elevated risk of admission to residential care because of excessive levels of carer strain. Moreover, the results suggest that for a proportion of dementia carers, a short-term intervention may be insufficient to reduce symptoms of strain to within coping capacity.

During the first 6 months of operation *annecto* found it difficult to meet the occupancy target of 20 clients with only one case manager to manage existing clients and assess and establish clients from new referrals. The appointment of a second case manager greatly improved matters and reduced the load on staff to a more manageable level. It is thought that a ratio of no less than one coordinator per 10 clients is required to work effectively with this target group.

The early days proved to be a learning experience. *annecto* revised the client selection protocol and the Department of Health and Ageing was receptive to changes made. Occupancy-based funding arrangements have proved to be the biggest hurdle for the project to overcome. Managing occupancy in a program of 8 to 12 weeks service intervention involves intensive case management. The project team likens its role to ‘crisis management’ because there is so little time to establish a client with complex care needs and their carer in the project before it is time to commence discharge planning. Discharge planning is usually a complicated exercise for the type of client accepted into the project. It is rarely possible to reach a stage of stabilised care needs within 8 weeks, yet this is necessary in order to reliably assess maintenance of effort prior to discharge.

Discharge planning was further complicated by the limited availability of appropriate discharge options. FCS coordinators see Extended Aged Care at Home (EACH) and HACC Linkages packages as the best forms of ongoing support for the majority of clients discharged from FCS. The department’s State Office instructed *annecto* that referrals for people already on a waiting list for an EACH package should not be accepted on the rationale that this is consistent with the Innovative Pool Guidelines 2002–03 which state:

> Criteria should address the particular people within the broader target group who would be most likely to benefit from the proposed service and cannot access the care they require through other appropriate means.

Hence, the insertion of a clause in the Memorandum of Understanding between the department and *annecto* which states that the project is ‘not intended to replace Extended Aged Care in the Home Packages (EACH) for those who are eligible for EACH’. It is not clear that an FCS package could substitute for an EACH package because of the time-limited nature of FCS. Moreover, there is a definite advantage in being able to offer time-limited service to people in crisis who, because of waiting lists for EACH packages, face an immediate risk of admission to permanent residential care.

It is overly optimistic to equate eligibility to mainstream high level community-based aged care services with timely access in areas where demand for such services currently exceeds supply. Further, it seems illogical that a care recipient and their carer would enrol in an 8–12 week service if they were hopeful of being able to access an EACH package. Lengthy waiting lists for EACH packages proved to be a barrier to one potential effective discharge option and the said scarcity of Linkages packages ruled out the other most desirable option for many clients. The typical outcome following FCS was a long waiting period to achieve the best form of ongoing care during which time a significant proportion of clients accessed multiple program sources of funding, possibly with multiple service providers, to piece together something close to a high level care package.

Flexibility in the provision of respite care is a main objective of the project but FCS has encountered difficulty in accessing overnight respite services. If a client takes leave from the project to access residential respite care, *annecto* is unable to extend the client's stay beyond 12 weeks to make up the time. In some cases it has been possible to use a state government-funded Supported Residential Service to get around this problem but these services offer low level care and very limited access to registered nurses, which is not an ideal form of respite care for many people with severe dementia. Limited access to respite care is a major problem for the project because (a) respite care is a core component of the program that aims to reduce levels of carer stress and (b) many clients and carers have not used respite care before coming into the project and FCS offers an opportunity to introduce respite care services to help sustain the caring relationship over the longer term.

Reasons for rejecting referrals have mainly had to do with the entry criteria that exclude clients with ACAS approval for EACH; clients in hospital at time of referral; clients in permanent care; clients at risk at home; and case management not being required.

The project team is of the opinion that the FCS model does not lend itself to mainstreaming. It is thought that FCS services a specific target group that, at the time the project was established, was not adequately serviced by any other community service agency in the Eastern Metropolitan Region. Standard EACH packages are seen as unable to provide the required level of support to carers. Advanced dementia requires a unique program, which demands a level of expertise and flexibility that is not normally available through general package offerings. [The introduction of dementia-specific EACH packages was announced subsequent to these observations from the FCS team.]

annecto recommends that programs designed to meet the needs of older people with dementia should offer a flexible range of services tailored to meet the needs of the person with dementia and their carer. It is thought that dementia sufferers who are assessed at the high end of low level care should have access to this type of service to avoid the all too common scenario of a crisis marking the first contact that a client or carer has with a comprehensive case management service.

3.2 Client profiles

FCS supplied evaluation data for 24 clients, including eight men and 16 women. One client did not participate in functional assessments. Two care recipients who were active during the evaluation period opted not to take part in the evaluation.

Age and sex

The estimated mean age of FCS clients at the time of the evaluation was 80 years (ages of evaluation clients ranged from 69 years to 95 years). Four clients were aged 85 years or over (Table B3.1).

Table B3.1: Flexible Care Service, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
65–74	3	2	5
75–84	4	11	15
85+	1	3	4
Total	**8**	**16**	**24**
		(per cent)	
65–74	12.5	8.3	20.8
75–84	16.7	45.8	62.5
85+	4.2	12.5	16.7
Total	**33.3**	**66.7**	**100.0**

Language and communication

Five clients had little or no effective means of communication. Seven national languages are represented in this client group (Table B3.2).

Table B3.2: Flexible Care Service, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	12	3	—	15
Southern European[(a)]	1	3	2	6
Eastern European[(b)]	1	1	—	2
Japanese	—	—	1	1
Total	**14**	**7**	**3**	**24**

(a) Includes Italian, French and Spanish.

(b) Includes Hungarian and Serbian.

— Nil.

Accommodation and living arrangement

All clients were living in their usual place of residence (private residence) at time of referral. Years at usual residence ranged from less than one to 56 years. Seven clients had been living in the same home for over 40 years.

Carer availability

Carer availability is a requirement of the project; all evaluation clients had a co-resident carer (Table B3.3). Carers' ages ranged from 42 to 87 years, averaging 69.7 years. Thirteen carers were aged 75 years or over (Table B3.4).

Table B3.3: Flexible Care Service, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Total
Spouse or partner	16	16
Son or daughter	5	5
Other relative	2	2
Friend or neighbour	1	1
Total clients with a carer	*24*	*24*
Clients without a carer		—
Total clients		**24**
Per cent of clients with a carer		100.0

— Nil.

Table B3.4: Flexible Care Service, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	1	—	1
45–54	1	3	4
55–64	1	—	1
65–74	—	5	5
75–84	10	2	12
85+	1	—	1
Total	**14**	**10**	**24**

— Nil.

Income and concession status

Government pensions were the primary source of cash income for 19 clients (Table B3.5). Twenty clients held a health care concession card. FCS does not charge client fees in the belief that Australian Government flexible care subsidy covers costs and for a short-term intervention the overhead of administering client payments would be unsustainable. A co-payment would most likely be levied if FCS operated as a long-term program.

Table B3.5: Flexible Care Service, number of clients by principal source of cash income and health care concession card status

	No. of clients	Per cent
Principal source of cash income		
Age pension	19	79.1
Superannuation	2	8.3
Other income	1	4.2
Nil income	1	4.2
Not stated	1	4.2
Total	**24**	**100.0**
Health care concession card holder	20	83.3
Project concession status	N/A	N/A

Previous use of government community care programs

Twelve clients were not receiving assistance from government community care programs before FCS (Table B3.6). Six clients were receiving HACC-funded assistance prior to joining FCS.

Fourteen carers reported that, despite having had a need for respite care in the 12 months prior to FCS, they had not used a respite care service. Of the carers who had accessed any form of respite in the previous 12 months, four out of five had used mainly residential respite. Five carers stated that they did not need to access respite services in the 12 months prior to entering the project.

Table B3.6: Flexible Care Service, number of clients by use of government support programs prior to FCS

Previous use of government programs	No. of clients	Per cent
Government support program		
Home and Community Care	6	26.1
National Respite for Carers Program	2	8.7
Day Therapy Centre	1	4.4
Multiple (NRCP & DTC)	1	4.4
Other program	1	4.4
Not stated	1	4.4
Total clients with previous government support	*12*	*50.0*
Clients without previous government program support	12	50.0
Total	**24**	**100**

Twenty-two clients were not on a waiting list for residential aged care when they entered the FCS, and the waiting list status on entry of the remaining two clients is unknown.

Assessment and referral

Twenty-one clients had completed an ACAT assessment on the same day or prior to referral to the FCS. For these clients, the time between completion of an assessment and referral to the FCS varied up to 260 days (Table B3.7). ACAT assessment was completed after referral to the FCS for three clients. Four clients had had two ACAT assessments in the 12 months prior to entering the project.

Table B3.7: Flexible Care Service, number of clients by days between completion of ACAT assessment and date of referral to FCS

Completion date of ACAT assessment	No. of clients
Before referral to FCS	
0–20 days	11
21–30 days	3
31–60 days	2
61–90 days	2
91–120 days	1
181–365 days	2
Total	*21*
After referral to FCS	
1 and 5 days post-referral	3
Total	**24**

FCS receives most of its referrals from an ACAS (Table B3.8).

The care of FCS clients is managed by a social worker.

Table B3.8: Flexible Care Service, number of clients by source of referral

Referral source	No. of clients
Aged Care Assessment Service	15
Hospital	5
annecto (other programs)	1
Other health or community service	1
Other agency	1
Family	1
Total	**24**

FCS provided additional information regarding referrals for clients who could not be accepted into the project in the 6 months from June to December 2004, that is, referrals of clients who did not meet the eligibility criteria or who were otherwise deemed unsuitable for FCS (Table B3.9).

Table B3.9: Flexible Care Service, rejected referrals, June–December 2004

Reason for not accepting client	No. of clients
Client had valid EACH approval[(a)]	2
Client living in permanent care	2
Client in hospital at time of acceptance	1
Home environment unsafe/inappropriate for client	1
Client deceased before package available	1
Insufficient needs to warrant FCS package	1
Total	**8**

(a) FCS was instructed by the DoHA program manager that clients on the waiting list for an EACH package are not eligible for FCS services.

Source: Letter from FCS coordinator dated 18 January 2005.

Health conditions and health status on entry

The number of health conditions recorded for FCS clients ranges from one to eight. Eighteen of the 24 clients had three or more health conditions at entry. Dementia was the primary health condition for the majority of clients at the time of entry to FCS (Table B3.10).

Table B3.10: Flexible Care Service, number of clients by primary health condition

Primary health condition	No. of clients
Dementia (Includes Alzheimer's disease & other dementias)	21
Other disease[(a)]	3
Total	**24**

(a) Includes infections and parasitic diseases, heart disease and cerebrovascular disease.

Sixteen clients were assessed as being at risk of falls due to impaired gait or balance (Table B3.11).

Table B3.11: Flexible Care Service, number of clients by selected sensory, mental and physical conditions

Health condition	No. of clients
Impaired gait or balance—at risk of falls	16
Disorientation/confusion	3
Total or partial paralysis	1
Diagnosis of depression	1

The 24 clients with recorded medication use were taking between zero and 15 different types of medication. Twelve clients were taking four or more medications.

Carers were asked to report on client health status and change in health status over the 12 months prior to entry using a five-point Likert scale (Short-Form 36). Twenty-three carers reported on their care recipient's health status.

One client was reported to be in very good health; the remaining ratings were good (13 clients), fair (eight clients) and poor (one client). Thirteen carers said that the client's health was somewhat worse than a year earlier. Eight carers reported no change over the 12-month period and one carer reported that their care recipient's health was much worse than a year ago. One carer reported that their care recipient's health was much better than one year ago.

Level of core activity limitation

Most FCS clients experienced moderate to profound activity limitation in the area of self-care (20 clients) and mild to moderate activity limitation in the areas of mobility (18 clients) and communication (21 clients) (Table B3.12). FCS has recorded one of the higher rates of severe or profound limitation in self-care among the projects (38%).

Table B3.12: Flexible Care Service, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	**No limitation**	**Mild**	**Moderate**	**Severe or profound**	**Total**
Self-care	—	4	11	9	**24**
Mobility	2	10	8	4	**24**
Communication	—	11	10	3	**24**

— Nil.

Use of medical and hospital services prior to entry

Use of medical and hospital services in the 6 months before starting with FCS was recorded for 23 clients. All but one of these clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner varied up to 20 per client. Cumulatively, the 22 clients recorded 143 visits to a medical practitioner outside of a hospital setting over an estimated 3,960 person days.

Ten clients had been admitted to hospital in the 6 months prior to entering the FCS. Information on hospital admissions and number of unplanned days in hospital is available for nine clients, who contributed to a total of 15 hospital admissions in the pre-entry period. All 10 clients reported unplanned admissions to hospital. Nine clients had also visited a hospital emergency department. These 10 clients collectively accumulated 151 unplanned patient days over approximately 1,620 person days. Individually, they recorded between one and 30 days in hospital for unplanned admissions. Thus, although FCS has not operated as a post-acute/sub-acute model, a proportion of FCS clients are high users of hospital services and hospital leave will often need to be managed in the project.

Conditions recorded as occasioning admission to hospital for FCS clients in the pre-entry period include:

- diseases of the urinary tract
- heart disease

- disease of the respiratory system
- fractures
- injuries to arm/hands/shoulder
- unspecified urinary incontinence.

Two clients had experienced a serious medical emergency in the 6 months before joining FCS, one of whom had a fall with injury and was rendered immobile and without assistance for more than 30 minutes. Both clients had spent at least 2weeks in a rehabilitation facility. Five other clients had experienced a fall with injury, two of whom were rendered immobile and without assistance for more than 30 minutes and spent 14 and 30 days respectively in a rehabilitation facility.

A fairly high proportion of FCS clients are thus at high risk of fall-related injury or medical emergency, hospitalisation and, therefore, admission to permanent care following an acute episode. Recovery from illness or injury may be complicated by dementia and may present special difficulties for family carers.

3.3 Client assessment results

Cognitive function

Baseline MMSE scores were recorded for 16 clients. Three further clients were unable to be assessed and five clients had MMSE scores recorded by the Outer East ACAS which did not make MMSE scores available to the evaluation. The 16 recorded scores range from a minimum of 2 to 24 out of a possible 30 points (mean 11.8).

Table B3.13: Flexible Care Service, number of clients by Mini-Mental State Examination score at entry

MMSE score	No. of clients
1–15	11
16–18	2
19–24	3
25–30	—
Missing	8
Total	**24**

— Nil.

Cut-points proposed by Uhlmann & Larson (1991) to account for educational attainment were applied to the scores, indicating that 14 clients who completed the test had probable cognitive impairment at date of entry. Two clients scored on the threshold of probable cognitive impairment.

On the basis of reported MMSE scores, FCS was found to be appropriately targeting people with moderate to severe cognitive impairment.

Activities of daily living

As at entry to the project, FCS clients present as one of the lowest functioning groups in the Innovative Pool Dementia Pilot.

MBI scores for 22 clients reveal that most clients either needed assistance or were completely dependent in self-care tasks (Figure B3.1). Baseline scores ranged from 2 to 17 out of a total 20 points. The mean score was 10.5 points with a standard deviation of 3.4 (median 11), indicating that the middle of the MBI distribution for FCS clients at the time of the evaluation was in the range of severe dependency in ADL (Table B3.14).

Using a classification for the Barthel Index (Shah et al. 1989), the MBI results indicate that three clients were completely dependent on entry, 18 clients exhibited severe dependency and three clients exhibited moderate dependency in ADL.

Seventeen of the 23 clients for whom the MBI is recorded were doubly incontinent. Most clients were unable to bathe or shower, groom, dress, feed or use the toilet without assistance. Most clients were independently mobile.

Most FCS clients showed high IADL dependency when they entered FCS (Figure B3.2). IADL scores were recorded for 23 clients, although data on one client are incomplete. On average, FCS clients were completely dependent in four out of seven IADL. One client was totally dependent in all seven IADL. No clients were able to perform household duties or manage their finances, even with assistance.

Although 18 clients registered as being able to walk independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment. FCS clients were insufficiently mobile to get into or out of a car without assistance, and either incapable of using public transport or needed help to do so. The median baseline IADL score for the 20 clients with complete records was 3 points. Scores ranged from 1 to 4 out of a possible maximum of 14 points. Baseline results indicate that all FCS clients had lost a significant amount of IADL function before entering the project (Table B3.14).

Final assessments were conducted on average 73 days after entry.

Changes in the MBI between baseline and final assessments ranged from –6 (a 6-point decline in ADL function) to 2 points (a 2-point improvement). The median change was –1 point (Table B3.14), indicating that on average, level of functioning ADL dropped by 1 point between the baseline and final assessments. Of the clients with a non-zero change score, three clients changed level of ADL dependency: two clients moved from severe to total dependency and one client improved from severe to moderate dependency.

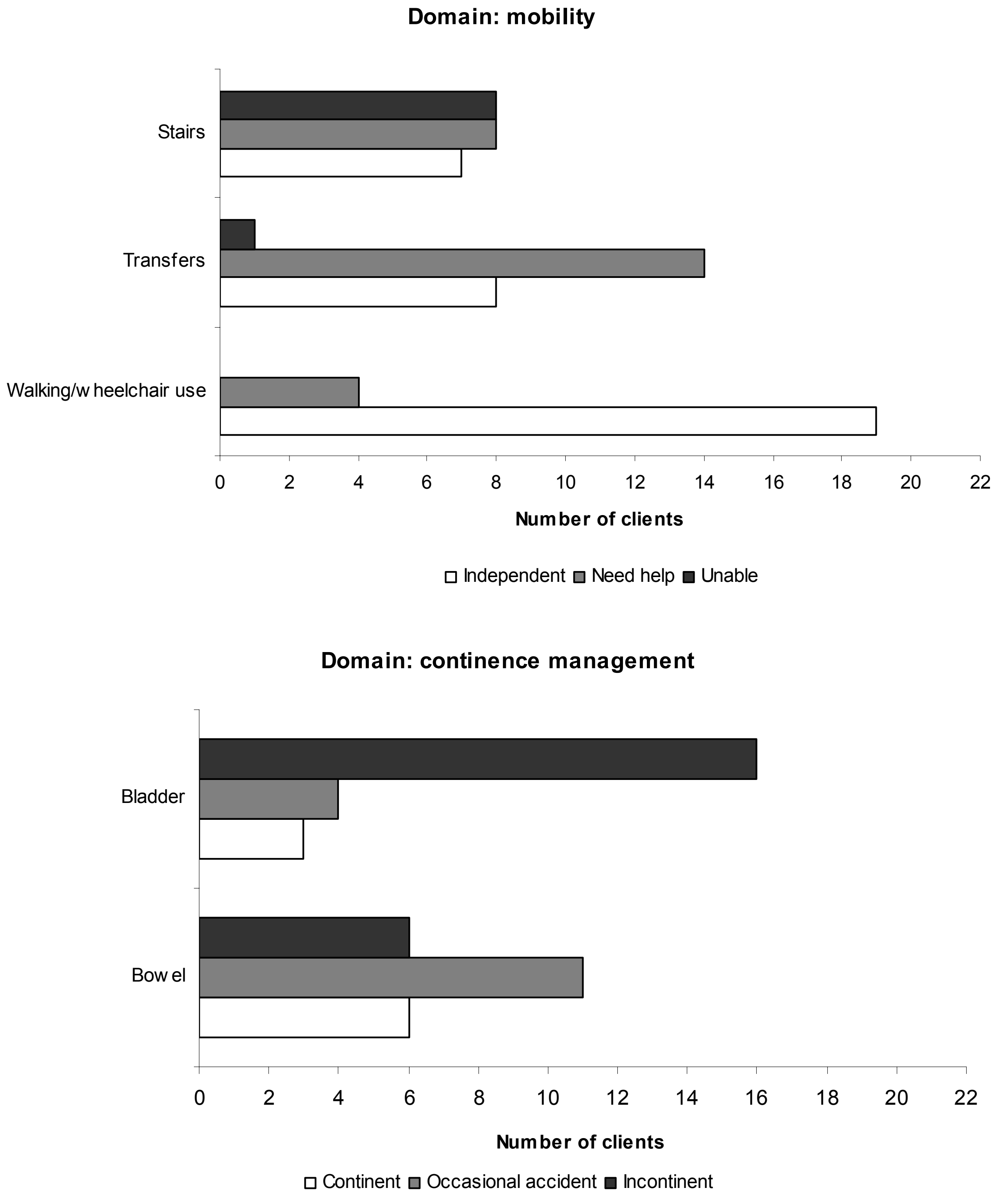
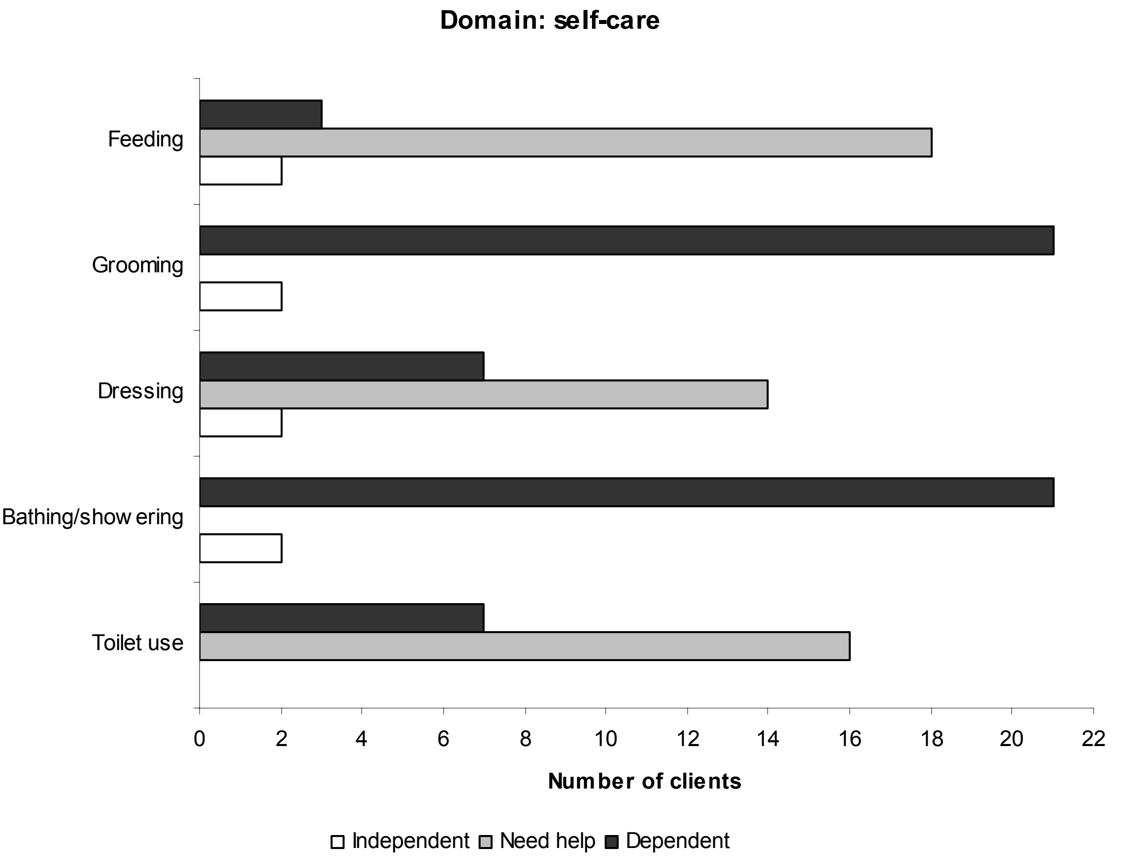


Figure B3.1: Flexible Care Service, number of clients by level of ADL function at entry

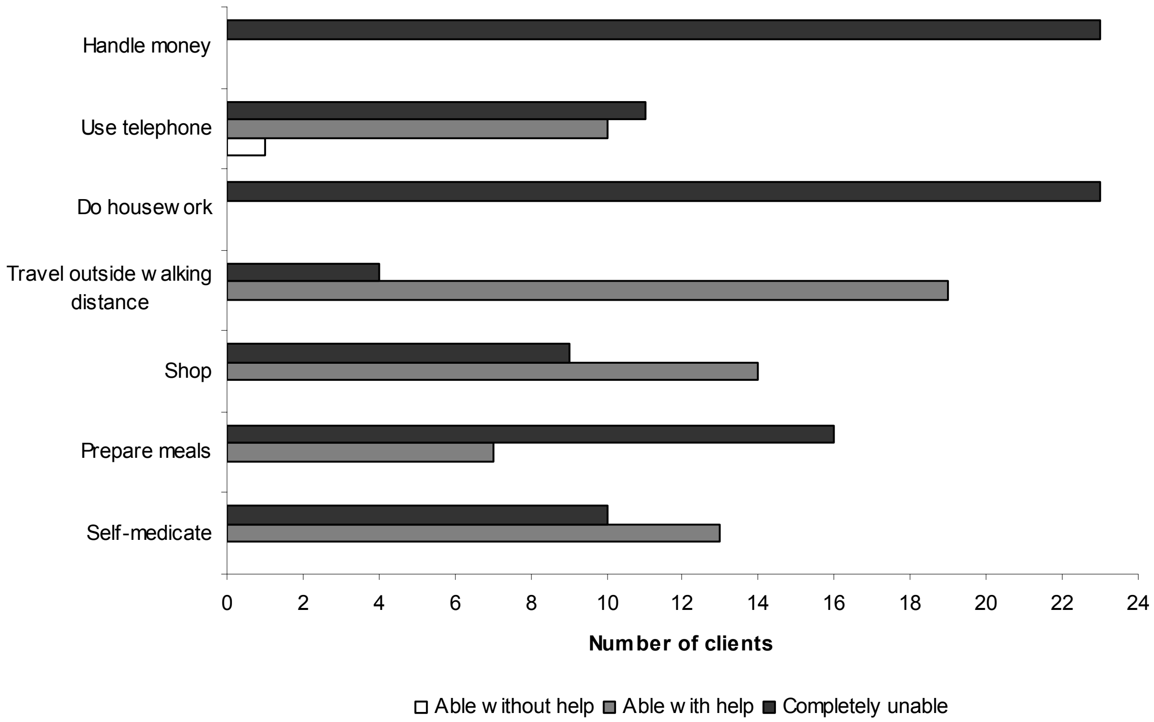
(continued)



Source: Appendix Table B11.

Figure B3.1 continued: Flexible Care Service, number of clients by level of ADL function at entry

The median IADL change score between baseline and final assessments was zero, with variation within the range of –3 to 1 point (Table B3.14). Thirty-five per cent of clients registered a decrease in IADL function between baseline and final assessments.



Source: Appendix Table B12.

Figure B3.2: Flexible Care Service, number of clients by level of IADL function at entry

Table B3.14: Flexible Care Service, summary measures for baseline[(a)] and change[(b)] in ADL and IADL

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	21	2	11	17	10.5	3.4
Change in MBI	21	–6	–1	2	–1.5	2.4
IADL						
Baseline IADL	20	1	3	4	3.1	0.9
Change in IADL	20	–3	0	1	–0.7	1.1

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Information on psychological and behavioural symptoms was recorded for 22 clients. Eighteen clients showed signs of memory loss and 13 clients showed signs of emotional or psychological symptoms of dementia on an intermittent or extensive basis (Figure B3.3). Wandering or intrusive behaviour was present in 10 cases. Fifteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, two of whom exhibited two or more symptoms extensively.

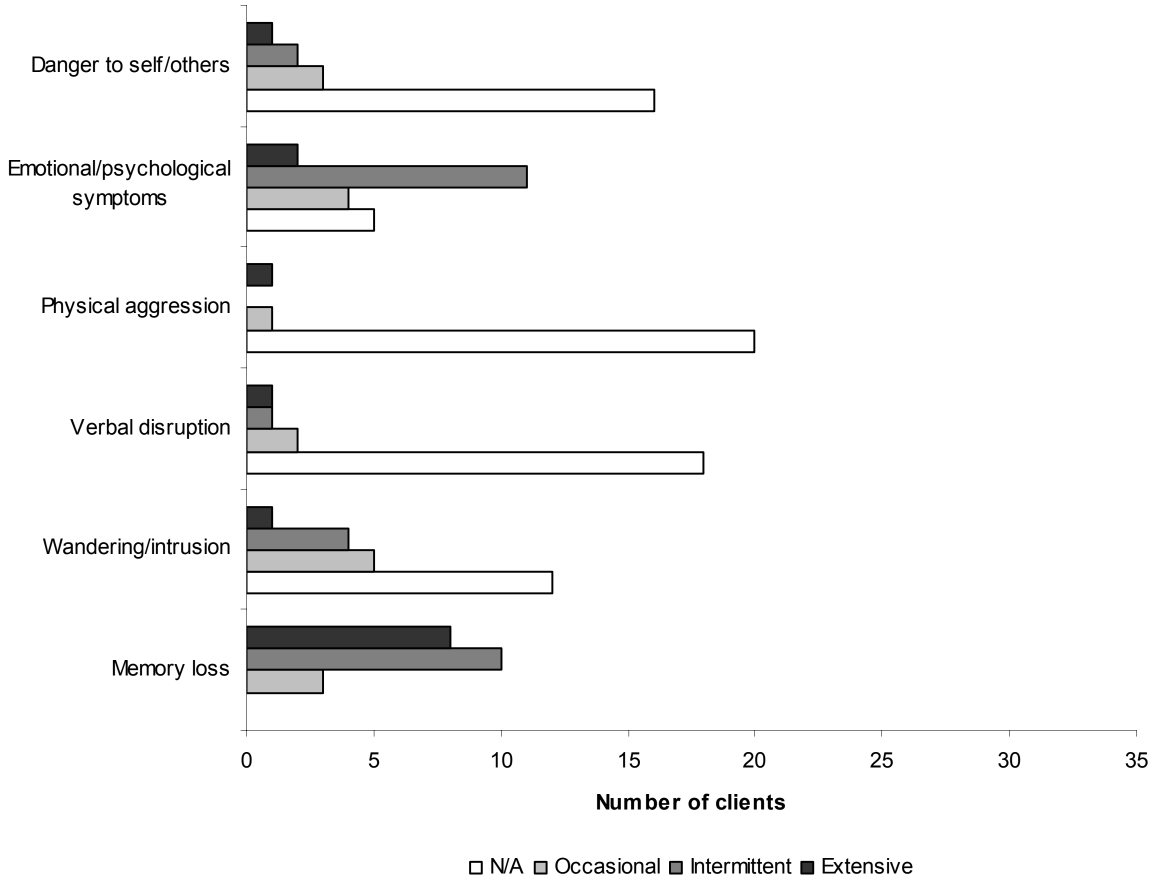


Figure B3.3: Flexible Care Service, number of clients by frequency of psychological and behavioural symptoms

3.4 Carer assessment results

Seventeen carers reported that they were in good health at the time that their care recipient entered FCS. Three carers reported they were in fair health and three reported that they were in very good health.

Twenty-two carers completed the CSI on entry to the FCS to generate a mean score of 8.6 (median 9) with a standard deviation of 3.5 points. Scores ranged from zero to 13. Eight carers recorded modal scores of 8 or 9 points. Nineteen carers recorded scores above the threshold for high carer strain.

Twenty-one carers completed the CSI at a final assessment. Changes in the CSI between baseline and final assessments ranged from –11 (an 11-point reduction in carer strain), to 3 points (a 3-point increase in carer strain). The median change score was zero (mean –1.4; standard deviation 3.4). Eight carers recorded a reduction in carer strain during the FCS service episode; 10 carers recorded no change; two carers recorded slight increases in carer strain. Five carers experienced a reduction in symptoms from above the threshold to below the threshold for carer strain. Twelve carers registered high carer strain at their final assessment.

Twenty-three carers completed the GHQ-28 at a baseline assessment. Five of these carers scored 14 to 21 points on at least one sub-scale. Two carers recorded scores of 14 or higher for somatic symptoms and four carers recorded scores of 14 or higher for anxiety and insomnia. One carer exceeded the 14 points on the social dysfunction subscale. No carer scored 14 or above on the severe depression sub-scale. Three carers scored highly on one out of four sub-scales, and two clients exceeded the case 14-point threshold on two out of the four sub-scales.

Twenty-one carers completed the GHQ-28 at the final assessment, of whom three scored above on at least one sub-scale. Analysis of change in GHQ-28 scores over time is included in the overall profiles for the Innovative Pool Dementia Pilot.

3.5 Service profile

Compared to other types of assistance, respite care, personal assistance, domestic assistance, aids and equipment and minor home modifications were recorded for higher numbers of FCS clients during the evaluation (Table B3.15). Information, advice and referral, carer support other than respite care, and dementia care/behaviour management also feature in the FCS service profile. This project has delivered high levels of in-home respite care and a number of carers received overnight respite. FCS reported that more carers could have benefited from overnight respite had it been easier to source.

The FCS service expenditure profile shows an extensive range of services were delivered during the evaluation. Almost 70% of expenditure on client services in the reporting period comprised combined expenditure on respite care (29.1%), care coordination and case management (21.9%), and personal assistance (15.1%) (Figure B3.4). Expenditure on care coordination and case management takes in staff time for discharge planning in addition to coordination of FCS services (including the management of brokerage arrangements for pre-existing services). The complexity and cost of discharge planning was underestimated at the outset. Expenditure on pilot program accommodation services was associated with the use of supported residential services for overnight respite care.

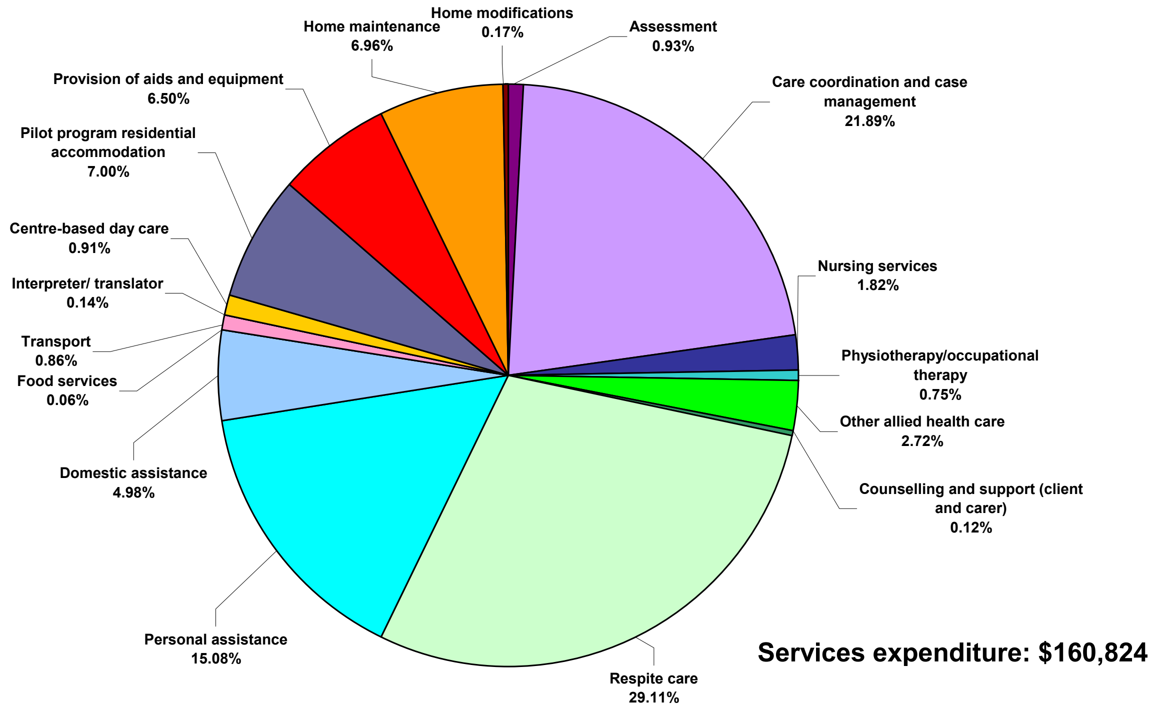
Table B3.15: Flexible Care Service summary of services delivered per client per week, results for the period 14 June–29 November 2004

Service type	Service unit	No. of Clients	Minimum	Median	Maximum	Mean	Standard deviation
Respite (in-home and day)[(a)]	Hours	23	2.0	5.6	14.6	6.7	4.0
Personal assistance	Hours	20	0.4	2.0	8.5	2.5	2.0
Domestic assistance	Hours	17	0.2	1.1	3.3	1.2	0.9
Nursing care	Hours	1	1.0	1.0	1.0	1.0	. .
Allied health[(b)]	Hours	8	0.1	0.2	0.5	0.2	0.1
Social support	Hours	2	0.1	0.1	0.1	0.1	0.0
Aids and equipment	Dollars	16	8.0	63.7	437.2	86.3	103.4
Home modifications and maintenance	Dollars	11	17.0	50.0	437.5	90.3	123.7
Residential services (e.g. SRS)	Dollars	1	73.3	73.3	73.3	73.3	. .
GP consultation	No. contacts	3	0.1	0.1	0.3	0.1	0.1
Geriatrician	No. contacts	2	0.1	0.1	0.1	0.1	0.0
Nursing/medical other	No. contacts	1	7.1	7.1	7.1	7.1	. .
Overnight respite	No. days/nights	6	0.3	1.2	2.1	1.3	0.6
Recreation/leisure programs	No. days/nights	3	0.8	1.1	1.1	1.0	0.2
Rehabilitation service	No. days/nights	1	1.0	1.0	1.0	1.0	. .
Information advice and referral	No. events	13	0.1	0.3	0.5	0.3	0.1
Carer support other than respite	No. events	9	0.1	1.1	1.5	0.9	0.6
Dementia care, memory and behaviour management	No. events	7	0.1	0.1	1.0	0.2	0.3
Community transport	No. one-way trips	5	1.6	2.5	4.9	2.9	1.2

(a) Assumes one day respite date is 5 hours.

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

. . Not applicable



Source: Appendix Table B25.

Figure B3.4: Flexible Care Service, expenditure on services, 1 July–31 December 2004

3.6 Accommodation outcomes

Twenty clients were discharged from FCS during the evaluation (Table B3.16). Clients discharged to the community were most often placed onto multiple support programs, for example, HACC plus Day Therapy Centre plus National Respite for Carers Program services. Three clients received an EACH package upon discharge, two clients were discharged onto CACP and three clients received HACC services.

FCS reported great difficulty in discharging a number of clients because of a lack of appropriate high care packages through Linkages (otherwise known as HACC Community Options) and the imposed eligibility criterion that clients should not have been approved for an EACH package prior to entry to FCS. However, only one client who was discharged during the evaluation had been in the project for over 100 days. Thus, despite reported difficulty finding suitable discharge destinations and support programs for clients, FCS appears to be maintaining the planned length of stay of approximately 90 days.

Table B3.15: Flexible Care Service evaluation clients, number of clients by discharge destination and government program support for clients discharged during the evaluation

Discharge status	No. of clients	Length of stay (days) (min– max)
At home		
Community Aged Care Packages	2	50–97
Extended Aged Care at Home	3	50–97
Home and Community Care	3	86–103
Multiple	5	76–95
Total discharged to community	*13*	*50–103*
In care		
Hospital	3	48–51
Residential aged care—high	2	0–83
Total deceased, hospital, RAC	*5*	*0–83*
Deceased	2	22–26
Total	**20**	**0–103**

FCS completed a follow-up of evaluation clients by 3 June 2005. Table B3.16 shows accommodation setting and government program support for all clients at this time (that is, 6 to 12 months from initial needs assessment). Six more clients had entered high level residential care in the intervening period. Three of these clients were initially discharged from the project onto HACC services, two were receiving services from multiple programs on discharge, and one was receiving a CACP after leaving FCS.

The three clients who were discharged from FCS onto EACH packages continued to be maintained on this program at follow-up. In total, half of the clients were still living at home when followed up.

Table B3.16: Flexible Care Service evaluation clients, accommodation and government program support status at follow-up

Location and support program at follow-up	No. of clients
At home	
Community Aged Care Packages	1
Extended Aged Care at Home	4
Home and Community Care	1
Multiple programs	5
Unknown	1
Total at home	*12*
In care	
Residential aged care—high care	8
Total in care	*8*
Deceased	4
Total	**24**

annecto conducted its own follow-up survey in November and December 2004 of care recipients who were in FCS between September 2003 and July 2004. Results are summarised in Table B3.17, showing one-third of clients still living at home.

Table B3.17: Flexible Care Service, accommodation setting at exit and at follow-up survey for care recipients in FCS between September 2003 and July 2004

Accommodation setting	No. of care recipients on exit from FCS	No. of care recipients at time of survey
At home	***20***	***12***
In care		
Residential aged care	10	17
Hospital	5	—
Total in care	*15*	*17*
Deceased	2	7
Total	**37**[(a)]	**36**

(a) Survey counts (unable to identify).

— Nil

Source: annecto.

annecto also asked about government program support in the community for care recipients at home following discharge and at the time of the survey. The results show the number of care recipients receiving different types of services, which sum to more than the number of care recipients at home because some recipients were receiving services from multiple programs. Table B3.18 summarises known services for clients in the community. Care recipients in an unknown program could be accessing one or more of NRCP, residential respite, day centre program and/or other services. Care recipients in a known program may be also accessing one or more of these services. Clients who left FCS and commenced with an EACH package service were still at home and receiving EACH services. Of the 15 clients discharged from FCS onto a HACC service, only four were still at home at follow-up.

Table B3.18: Flexible Care Service, government program support at exit and at follow-up survey for care recipients in FCS between September 2003 and July 2004 discharged to the community

Government program support in the community	No. of care recipients on exit from FCS	No. of care recipients at time of survey
Community Aged Care Packages	1	—
Extended Aged Care at Home	2	3
Home and Community Care	15	4
Linkages	1	1
Unknown	1	4
Total	**20**	**12**

Source: annecto.

— Nil.

The numbers of clients in either the evaluation or *annecto* surveys, broken down by program support at time of follow-up, are too small to draw general conclusions about the success or otherwise of different programs for maintaining high care clients with dementia at home and providing an adequate level of support to family carers. Evaluation data suggest that high care clients who would be best supported by an EACH or EACH-type package are being supported by HACC plus additional services and it is not known to what extent this might place an unreasonably high case management and service coordination on already strained family carers. There are indications that HACC and multiple support programs do not maintain high care clients for the longer periods observed for clients discharged directly to an EACH service.

The evaluation has concluded that the time-limited nature of FCS is not suited to the care model of FCS and that FCS would have been better established as a long-term care pilot for the types of service it delivers. Based on ADL measures and behaviour measures, there is no evidence of marked reduction in the support needs of FCS clients during the FCS service episode (and no reason to expect that this would occur given the characteristics of the target group). The transitioning of clients and their carers from a flexible package service onto lower levels of support or multiple program support perhaps without overall care management and service coordination seems to carry a risk of service disappointment. As a short-term care intervention, a service such as FCS could provide a solution to long waiting lists for EACH packages but that possibility was specifically excluded from this trial.

4 North East Dementia Innovations Demonstration

4.1 Project description

Austin Health was allocated 10 flexible care places for the North East Dementia Innovations Demonstration (NEDID) project. NEDID was designed to deliver an average of 10 weeks of care to eligible residents of the north-eastern metropolitan region of Melbourne.

Austin Health is an approved provider of residential aged care and delivers an extensive range of inpatient, ambulatory, community and residential care services. Specialist services for older people include Geriatric Evaluation and Management, rehabilitation, transition care, Older Veterans' Mental Health Program and Allied Health Veterans Liaison, an Aged Care Assessment Service, and care coordination teams. Continence management clinic, memory clinic, wound management and community rehabilitation are included in Austin Health ambulatory services.

Austin Health had for a number of years experienced a steady increase in demand for hospital-based care for older people who no longer required acute medical care but who were unable to return home without case management and community supports. A number remained in hospital awaiting access to residential care. The Trial at Home pilot was one of a number of Austin Health initiatives in response to this demand. Trial at Home demonstrated that 85% of participants continued to live at home successfully 10 months after its introduction. Client feedback was positive and participants were observed to benefit from improved health and functional capacity during their time on the pilot. More than half of the 17 participants suffered from dementia. Funding for Trial at Home was not assured beyond June 2003.

Austin Health applied for Innovative Pool funding on the strength of the success of Trial at Home and in recognition of the special needs of patients with dementia for well-managed transition care. NEDID is able to draw on referral channels and service contacts established for Trial at Home.

Project objectives

The objectives of the North East Dementia Innovations Demonstration (NEDID) are:

1. to facilitate the detailed and individual assessment and care planning for eligible older persons suffering from mild to moderate dementia where assessment by the ACAS has resulted in a recommendation for high care
2. to adopt assessment processes that focus on people's abilities, lifestyle and interests, assessment of behaviour and the development and implementation of appropriate behaviour management strategies as key elements of care plans
3. to provide these older people with a period of intensive community support within their own home or their carer's home with a structured individual care plan developed and

supported by a specialist dementia team; further, to enable the long-term care needs of the participants to be reassessed during this period

4. to assist older persons with dementia through the provision of short-term support by a specialist dementia care team, the development of individual care plans, lifestyle assessments and behavioural management strategies
5. to improve the links between community services, hospitals and residential care providers and include local general practitioners, specialist dementia services and other specialist service networks.

Through a period of specialist assessment and review and transition care, NEDID aims to enable Austin Health clients to remain at home wherever possible, or to enter residential aged care from the project with a higher level of functioning and independence than would otherwise have been possible.

Target group

NEDID initially serviced the north-eastern suburbs of Melbourne that comprise the Local Government Areas of Banyule, Nillumbik, Darebin, Whittlesea, Moreland and Manningham. The program later expanded to include Yarra and Murrundindi.

Eligibility for NEDID is determined on the basis of a person having a current ACAS approval for residential high care (from November 2004 NEDID was able to carry one low care client at any one time), suffering from mild to moderate dementia, and able to be cared for in the home environment. In most cases, NEDID will require that a care recipient has support available from family carers.

NEDID has accepted a small number of clients without a clear dementia diagnosis, but who were assessed as suffering cognitive decline. Careful screening at selection has been maintained.

The project reported difficulty at times in sourcing referrals from the target group. This has been attributed to the plethora of aged care programs operating in the northern region, which creates confusion about what each can offer and has the undesirable effect of limiting patterns of referral in the community care sector. Despite long waiting lists for other programs, NEDID did not receive the anticipated number of referrals in the beginning. However, in time this changed and indications are that sometimes it takes a while for a new program to become established and the benefits seen. That the project has not achieved a waiting list due to a lack of steady referrals does not imply a lack of demand for this type of service but is thought to instead reflect the inefficiency that can result from a complex service delivery system.

Service environment

The aged proportion of the population in the pilot catchment area is marginally higher than the state and national averages, however there are pockets of significantly older resident populations. For example, Preston, Heidelberg, Coburg and Moreland each recorded 17% or more people aged 65 years or over in the 2001 ABS Census of Population and Housing.

Culturally and linguistically diverse backgrounds are represented in significant numbers, especially European ethnic groups. People with dementia who originate from diverse cultural backgrounds are thought to be at a particular disadvantage in care environments where their preferred language is not spoken.

The Austin Health proposal for NEDID highlighted an undersupply of dementia-specific residential and community services in Melbourne's north-east at the time. Long waiting lists existed for dementia-specific beds, there were no community care options targeted to people with high care needs associated with dementia, and only minimal day care services that offered dementia-focused programs.

NEDID was designed to address five specific areas of unmet need in the provision of community services for people with dementia living in the catchment area:

1. Need for immediate brokered service provision to support dementia clients with high care needs who wish to stay at home. Prior to NEDID only one program with this level of brokerage existed.
2. Very limited immediate access to case management programs in the area, with long waiting lists. Northern Community Options had a waiting list of 84 names in mid-2004. There were no Extended Aged Care at Home (EACH) packages in the region at that time.
3. Limited training among service providers for working with the target group. For example, service provision for clients who require hoist transfer or PEG feeding can be difficult to source.
4. Few culturally specific agencies to cater for high level of cultural diversity.
5. Availability of residential respite care—NEDID is able to make residential respite care more readily available for dementia clients with high care needs by supplementing the care in facilities, for example, personal care, overnight carer. These clients would previously not have been able to use residential respite because of their behaviours/high care needs.

NEDID service model

NEDID operates from Austin Health in Heidelberg. NEDID is a multidisciplinary team comprising a nurse case manager, social worker and neuropsychologist. A geriatrician is available for assessment, behaviour management requiring medical intervention and consultancy to the general practitioner and the NEDID staff.

NEDID offers a flexible model for an innovative dementia care service in the community setting. NEDID provides a strong focus on case management, individual needs assessment, counselling and education, and a tailored package of community services.

Services offered in an individual's care package may include:

- nursing care
- allied health
- personal and domestic assistance
- home respite
- equipment hire
- planned activity group programs
- carer support and education
- personal alarms and out-of-hours support through Emergency After Hours Response Service (brokered from *annecto—the people network*)
- access to the skills of a specialist Dementia Care Team.

The NEDID coordinator/care manager contributes to a comprehensive initial assessment of client and carer needs in collaboration with the ACAS and relevant hospital, community care staff and general practitioner. Patients referred for NEDID services and their carers are actively involved in this assessment and development of a care plan that identifies short- and long-term care goals and a weekly service schedule. The care manager undertakes regular review visits to all clients and maintains close contact with family and carers.

NEDID identified the innovative features of the service to include:

- intensive case management in the setting of a team approach, with a strong focus on input from hospital social work and neuropsychology departments
- flexibility around exit times, as determined by the individual care plan
- dementia education tailored to client need by a neuropsychologist or care manager, depending on the type of dementia and behaviours exhibited
- definitive selection process
- weekly case conference for community care clients.

Achievements, challenges and lessons

NEDID has achieved considerable success in working at the interface of hospital and community services. This has required a persistent and concerted effort to educate hospital staff on the objectives of the project and appropriate referral practice. Much of the success of the model is due to the high skill levels of the team and the level of case management that facilitates a holistic approach to addressing client and carer needs. NEDID has accepted clients on the verge of admission to an aged care facility, but has been able to stabilise care needs and modify behaviours, enabling the client to remain at home for a period of time while helping to significantly reduce carer strain. NEDID reports that in situations where a client has entered an aged care facility, the NEDID experience has helped to make the placement decision an informed one. In some cases, a new Aged Care Client Record has been required to reflect the improvements that have occurred.

Over 90% of NEDID care recipients receive personal care, which is reflected in high weekly hours of assistance for personal care and in-home respite compared to other Innovative Pool Dementia Pilot projects. Carer commitment to providing care at home and a sustainable care plan with options for easily accessible appropriate continuing care at the conclusion of NEDID services are said to be the most important selection criteria for this type of program.

Some challenges have arisen for staff on hospital wards when the discharge recommendation has been that residential placement is the only option for people in the target group. Ongoing education of a constantly changing hospital staff to understand the profile of NEDID as a valid discharge option has been required.

The case management load was perhaps underestimated at the outset and project coordination time had to be increased from 0.8 to 1.0 full-time equivalent. While clients accepted into NEDID have been of the type originally anticipated, the complexity of some clients' needs has exceeded expectation. Some of the unanticipated workload has arisen from the need to address issues that are more appropriately the domain of hospital ward staff. For example, the NEDID care manager purchased occupational therapy services when needed to ensure a client's aids and equipment needs were met.

Some clients were unable to be discharged from NEDID at the end of their NEDID service episode due to lengthy waiting lists for programs which provide ongoing case management.

This has led to the development of the Step-Down program to offer reactive case management and limited respite care for clients who are awaiting a long term community case management program (Step-Down is outlined at the end of this chapter). The aim is to maintain throughput in NEDID by offering a reduced level of transitional support to exiting clients, similar to that which is available through mainstream services.

Carer issues including the co-payment policy and the level of support available through the project have arisen. NEDID has observed standard policy for the collection of co-payments. It is always emphasised that inability to pay does not preclude participation; four evaluation clients received a waiver, one received a discount, and the others paid the standard rate of $5.67 per day. Yet co-payment has proved a contentious issue with some carers and has had to be sensitively approached. In addition, some carers had unrealistic expectations of the project's ability to provide 24-hour care. Generally, carers committed to caring for their family member at home have welcomed any help offered.

From the NEDID experience, occupancy monitoring for a program of time-limited care intervention, particularly in the context of a small number of packages, would prove a critical issue for mainstreaming this type of program. The level of program occupancy monitoring applied to NEDID is considered unsustainable over the longer term. It was suggested that funding based on 90% occupancy might be a more viable proposition for a short-term intervention targeting this client group.

4.2 Client profiles

NEDID provided data for 14 evaluation clients, including seven males and seven females. Evaluation tools were supplied in languages other than English; however, language barriers have meant that the evaluation group does not fully reflect the cultural diversity of care recipients who have moved through NEDID.

Evaluation data summarised below describe the NEDID client group during the evaluation.

Age and sex

Clients' ages ranged from 64 to 93 years (mean 79.9 years). Four clients were aged 85 years or over (Table B4.1).

Table B4.1: North East Dementia Innovations Demonstration, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
Less than 65	1	—	1
65–74	2	1	3
75–84	2	4	6
85+	2	2	4
Total	**7**	**7**	**14**
		(per cent)	
Less than 65	7.1	—	7.1
65–74	14.3	7.1	21.4
75–84	14.3	28.6	42.9
85+	14.3	14.3	28.6
Total	**50.0**	**50.0**	**100.0**

— Nil.

Language and communication

One NEDID client had little or no effective means of communication. The remaining 13 clients in the evaluation had effective spoken communication. Five national languages are represented in this client group (Table B4.2) and 10 national languages have been represented in the wider NEDID client intake.

Table B4.2: North East Dementia Innovations Demonstration, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	9	—	—	9
Greek	—	1	1	2
Danish	1	—	—	1
Italian	—	1	—	1
Arabic	—	1	—	1
Total	**10**	**3**	**1**	**14**

— Nil.

Accommodation and living arrangement

Clients were living in private residences or retirement villages (Table B4.3). Four clients were in hospital when they were referred to the project.

Table B4.3: North East Dementia Innovations Demonstration, number of clients by usual accommodation setting and living arrangement and accommodation at time of referral to project

	Usual living arrangement		
Accommodation setting	**Alone**	**With family**	**Total**
Private residence	1	12	13
Retirement village—independent living	1	—	1
Total	**2**	**12**	**14**

— Nil.

Years at usual accommodation ranged from less than one to 55 years. Five clients had been living in the same home for over 30 years. Three of the four clients who had changed place of residence in the two years prior to entering NEDID were being cared for by a son or daughter.

Carer availability

All 14 NEDID clients had a carer, 12 of whom were living with the care recipient (Table B4.4). Carers' ages ranged from 46 to 81 years, averaging 66.4 years. Four carers were aged 75 years or over (Table B4.5).

Table B4.4: North East Dementia Innovations Demonstration, number of clients by carer availability, carer sex, relationship to client and co-residency status

Carer relationship to client	Carer lives with client	Carer does not live with client	Total
Spouse or partner	6	—	6
Son or daughter	3	2	5
Son- or daughter-in-law	3	—	3
Total clients with a carer	*12*	*2*	*14*
Total clients			**14**
Per cent of clients with a carer			**100**

— Nil.

Table B4.5: North East Dementia Innovations Demonstration, number of carers by age group and sex

Age (years)	Males	Females	Persons
45–54	2	—	2
55–64	—	3	3
65–74	1	4	5
75–84	2	2	4
Total	**5**	**9**	**14**

— Nil.

Income and concession status

Government pensions were the primary source of cash income for 11 clients (Table B4.6). Twelve clients held a health care concession card and one client received a discounted weekly contribution rate for the project due to financial hardship.

Table B4.6: North East Dementia Innovations Demonstration, number of clients by principal source of cash income, health care concession card status and project concession status

	Number	Per cent
Principal source of cash income		
Age pension	9	64.3
Veteran's Affairs pension	2	14.3
Superannuation or annuities	1	7.1
Cash income— primary	1	7.1
Cash income— property	1	7.1
Total	**14**	**100.0**
Health care concession card holder	12	85.7
Project concession status	1	7.1

Previous use of government community care programs

Half the clients had not been receiving assistance from government community care programs prior to NEDID (Table B4.7). HACC had been providing assistance to four clients. Twelve carers reported that, despite having had a need for respite care in the 12 months prior to NEDID, they had not used a respite care service. The remaining two carers said they had not needed respite care.

Table B4.7: North East Dementia Innovations Demonstration, number of clients by use of government support programs prior to the project

Previous use of government support programs	Number of clients	Per cent
Government support program		
Home and Community Care	4	28.6
Veterans' Home Care	1	7.1
Day Therapy Centre	1	7.1
Other	1	7.1
Total	**7**	**100.0**
No previous government support program	7	50.0
Use of respite care in the 12 months prior to NEDID		
Respite care not needed	2	14.3
Respite care used	—	—
Respite care needed but not used	12	85.7
Total	**14**	**100.0**

— Nil.

Three clients were on a waiting list for residential aged care when they joined NEDID.

Assessment and referral

Most evaluation clients were referred to NEDID by Austin Health services, including the Heidelberg ACAS and acute care facilities (Table B4.8). Referrals recorded over a longer period for a larger group of 35 NEDID clients included 40% of referrals from hospitals, 48% from ACAS (Heidelberg and Bundoora) and 11% from the community.

Table B4.8: North East Dementia Innovations Demonstration, number of clients by source of referral

Referral source	Number of clients
Heidelberg Aged Care Assessment Service	7
Hospital	5
Another community service	1
Other person	1
Total	**14**

Eleven clients had completed an Aged Care Client Record prior to referral to NEDID. For these clients, the time between completion of the documentation and referral to the project varied from day of referral to 305 days (Table B4.9). Client record documentation was completed after referral to the project for three clients. The longer time between completion of the record and referral to NEDID may indicate a change in client care needs.

Table B4.9: North East Dementia Innovations Demonstration, number of clients by days between completion of ACAT assessment and date of referral to pilot

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–20 days	4
21–30 days	3
31–60 days	1
61–90 days	1
121–180 days	1
181–365 days	1
Total	*11*
After referral to project	
5, 7 and 54 days post-referral	3
Total	**14**

A registered nurse manages the care of all NEDID clients.

Health conditions and health status on entry

The number of health conditions recorded for NEDID clients at entry ranged from two to nine. Eleven clients had three or more health conditions at entry. Table B4.10 shows the primary health conditions recorded on the Aged Care Client Records for NEDID clients.

Table B4.10: North East Dementia Innovations Demonstration, number of clients by primary health condition at entry

Primary health condition	Number of clients
Dementia in Alzheimer’s disease	8
Parkinson’s disease	2
Vascular dementia	1
Non-Hodgkin’s lymphoma	1
CVA (stroke)	1
Other health condition, not elsewhere classified	1
Total	**14**

Eight clients were both hearing and vision impaired at time of entry to NEDID, and 11 clients were assessed as being at risk of falls due to impaired gait or balance (Table B4.11). Just under 50% of NEDID clients had diagnosed depression.

Table B4.11: North East Dementia Innovations Demonstration, number of clients by presence of selected physical, sensory and mental health conditions at entry

Health condition	Number of clients
Impaired gait or balance—at risk of falls	11
Vision impairment	10
Hearing impairment	8
Both hearing and vision impairment	8
Diagnosis of depression	6
Disorientation/confusion	3
Total or partial paralysis	1

NEDID clients were taking between two and 11 different types of medication at the time of reporting. Eleven clients were taking four or more different medications.

Carers were asked to report on their care recipient's health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). One client was reported to be in very good health; other ratings were good (six clients) and fair (five clients). Most carers said that the client's health was somewhat worse (seven clients) or much worse (five clients) than one year earlier. Health status and change in health status were not reported for two clients.

Level of core activity limitation

Most NEDID clients experienced moderate to profound activity limitation in self-care (12) and mobility (nine) (Table B4.12). Six clients are recorded as having a severe or profound core activity limitation.

Table B4.12: North East Dementia Innovations Demonstration, number of clients by level of core activity limitation at entry

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	2	8	4	**14**
Mobility	1	4	5	4	**14**
Communication	1	8	4	1	**14**

— Nil.

Use of medical and hospital services prior to entry

All clients had visited a medical practitioner at least twice in the 6 months before joining NEDID. The reported number of visits to a medical practitioner in this period varies from two to 20 per client. Two clients recorded 20 medical consultations outside of hospital. Both of these clients had suffered a fall with injury. Cumulatively, the 14 clients recorded 128 visits to a medical practitioner outside of a hospital setting over an estimated 2,520 person days.

Seven clients contributed to a total of 14 hospital admissions in the pre-entry period. Two clients had planned admissions only. The remaining five clients with one or more hospital admissions recorded either solely unplanned/urgent admissions, or both unplanned/urgent and planned admissions. These five clients collectively accumulated 201 hospital bed days over approximately 900 person days. Individually, they recorded between 4 and 114 days in hospital for unplanned admissions. The client with the highest number of unplanned hospital days recorded two unplanned admissions, two visits to a hospital emergency department and six consultations with a medical practitioner in the pre-entry period.

Conditions recorded as occasioning admissions to hospital before NEDID include:

- influenza and pneumonia
- injury, poisoning or other effect of an external cause
- transient cerebral ischaemic attack
- haemophilia
- heart disease
- non-Hodgkin's lymphoma
- cerebrovascular disease
- skin cancer.

Four clients had experienced a serious medical emergency during the pre-entry period, three of whom had spent days in hospital for unplanned admissions. Another client suffered a fall with injury, becoming immobile and without assistance for more than 30 minutes.

4.3 Client assessment results

Cognitive function

MMSE scores were recorded for 10 clients when they entered NEDID. Four missing values were recorded for clients with no or little ability to communicate in English. The 10 valid baseline scores range from 4 to 24 points out of a possible 30 points (mean 13.2).

Table B4.13: Flexible Care Service, number of clients by Mini-Mental State Examination score at entry

MMSE score	Number of clients
1–15	6
16–18	2
19–24	2
25–30	—
Missing (ESL) (a)	4
Total	**14**

(a) Clients with English as a second language.

— Nil.

Cut-points proposed by Uhlmann & Larson (1991) to account for educational attainment were applied to the NEDID MMSE scores. The results indicate that nine of the 10 clients who completed the test had probable cognitive impairment on entry to NEDID. The remaining client scored on the threshold of probable impairment.

On the basis of reported MMSE scores, it is concluded that NEDID has targeted people with cognitive impairment.

Activities of daily living

At least half of NEDID clients needed assistance in tasks involving self-care and mobility when they entered the project (Figure B4.1). The MBI was completed for all clients. Baseline scores ranged from 3 to 20 out of a total 20 points. The mean score of 10.1 points (median 10) indicates that the middle of the MBI distribution for NEDID clients was in the range of severe dependency in ADL (Table B4.14).

Using a classification system for the Barthel Index (Shah et al. 1989), the MBI results indicate that two clients were completely dependent in self-care and mobility; eight clients exhibited severe dependency; and three clients exhibited moderate dependency. One client was independent in self-care and mobility but showed high dependency in IADL (see below).

Ten clients were either sometimes or always bowel incontinent and 12 clients were sometimes or always bladder incontinent at the time of entry. Five clients were doubly incontinent. Ten clients were unable to bathe or shower without assistance. Six clients needed assistance to walk–from verbal guidance and prompting through to full physical support–and nine needed help to get in or out of a bed or chair.

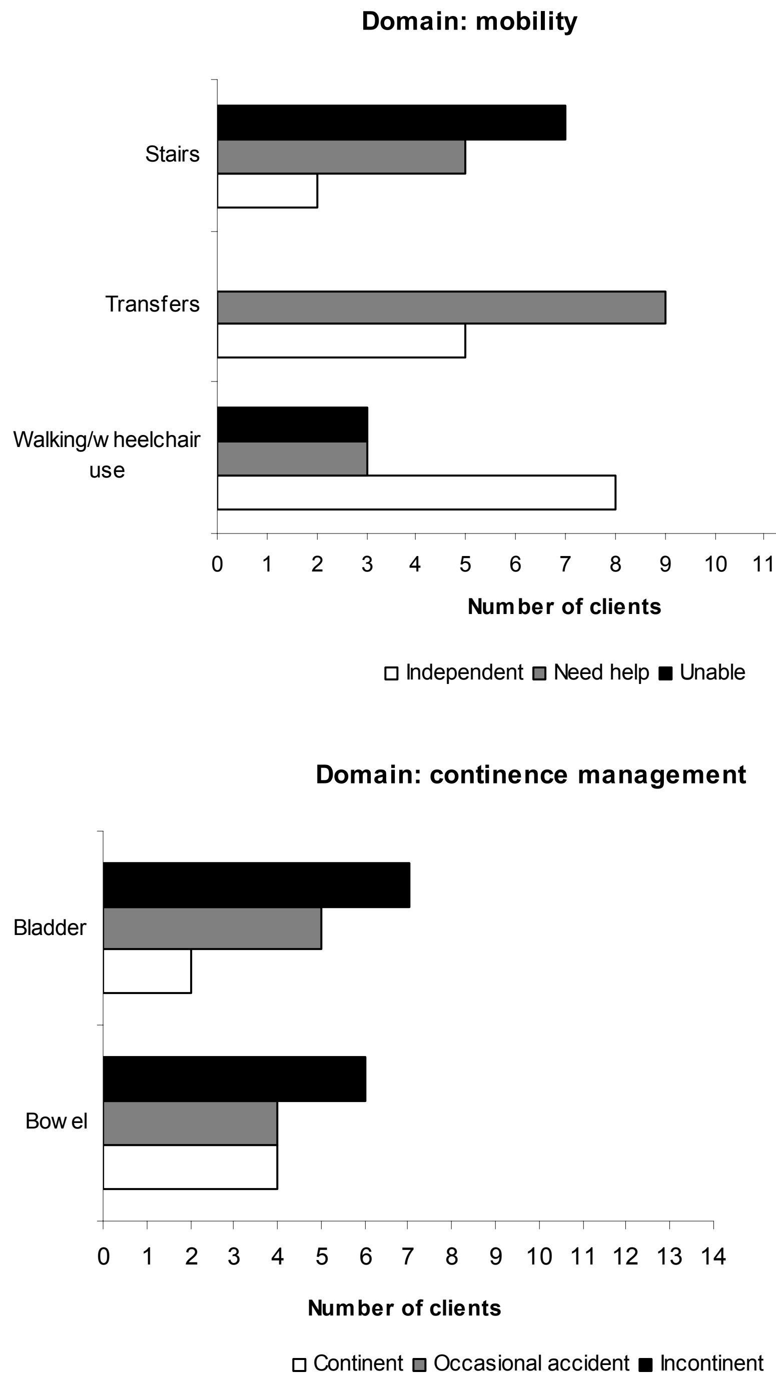
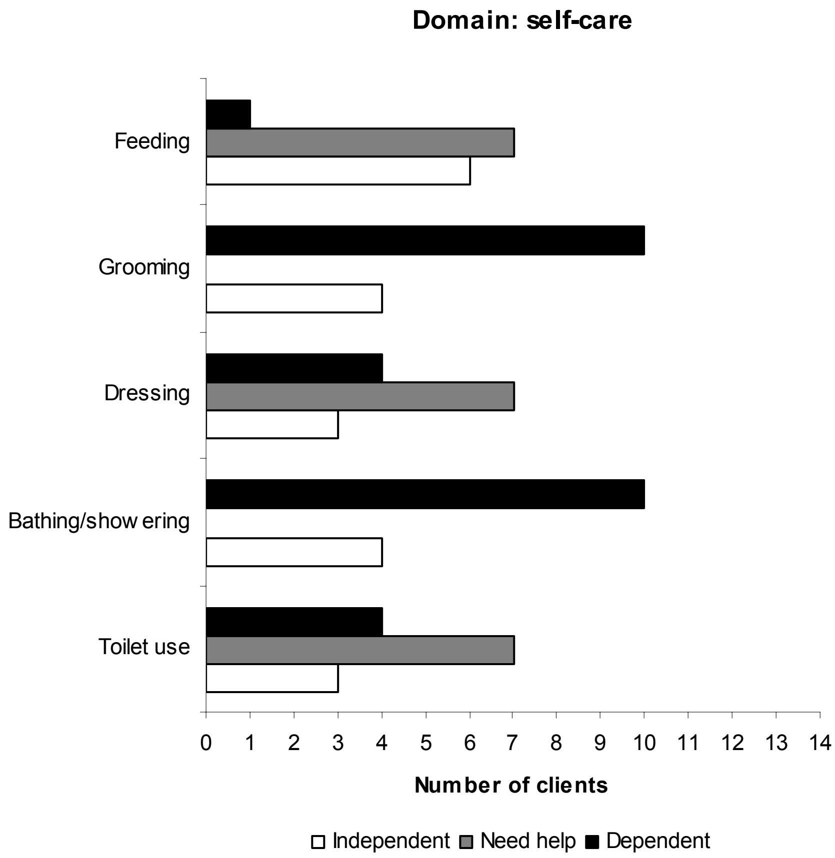


Figure B4.1: North East Dementia Innovations Demonstration, number of clients by level of ADL function at entry

(continued)



Source: Appendix Table B13.

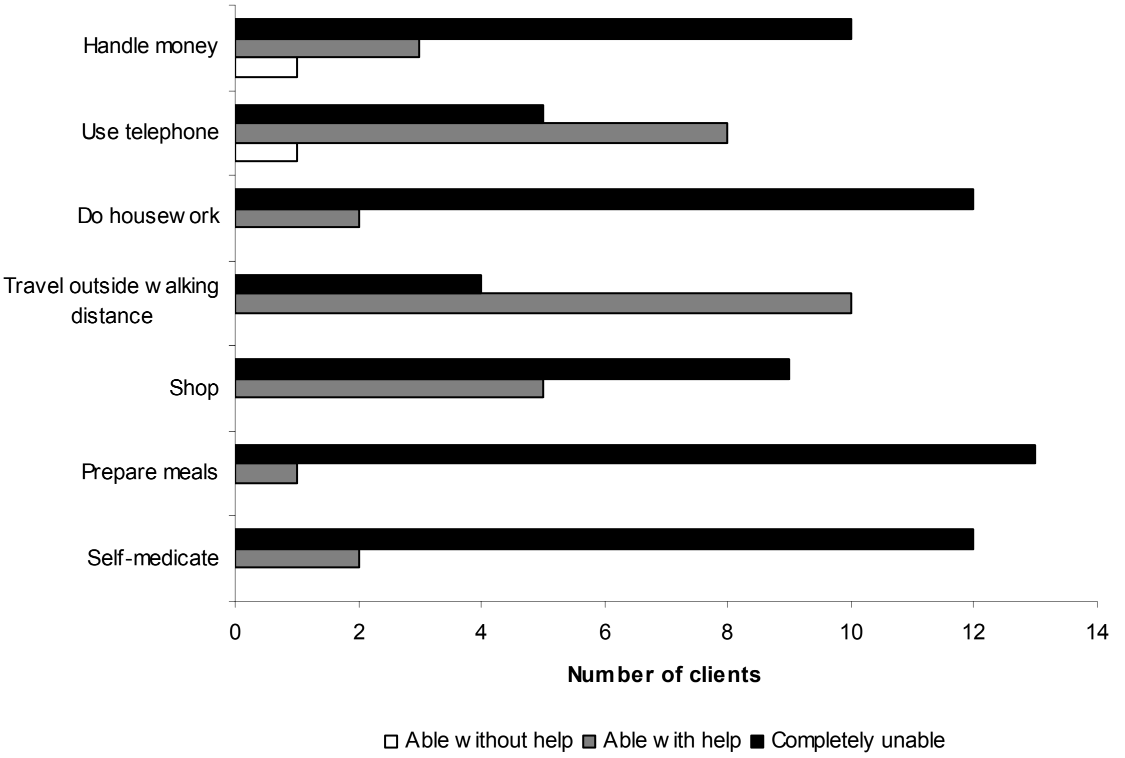
Figure B4.1 continued: North East Dementia Innovations Demonstration, number of clients by level of ADL function at entry

Most NEDID clients were highly dependent in IADL when they entered the project (Figure B4.2). On average, NEDID clients were completely dependent in five out of seven IADL and three clients were completely dependent in all seven IADL. No client was independent in more than one IADL.

All clients either needed assistance or were completely unable to go anywhere outside of walking distance. Although eight clients registered as being independently mobile on the MBI, the mobility item on the IADL scale reveals that in all cases, independent mobility was limited to the home environment. All clients were insufficiently mobile to get into or out of a car unassisted, and were physically incapable of using public transport.

Twelve clients were not able to self-medicate safely.

The median baseline score on the IADL scale was 2 points, with scores ranging from zero to 4 out of a possible 14 points (Table B4.14). Baseline results indicate that all NEDID clients had lost a great deal of IADL function by the time they commenced with NEDID.



Source: Appendix Table B14.

Figure B4.2: North East Dementia Innovations Demonstration, number of clients by level of IADL function at entry

Final assessments were conducted on average 109 days after entry.

Changes in the MBI between baseline and final assessments ranged from –6 (a 6-point decline in function) to 5 points (a 5-point improvement). The median change score was –1 (Table B4.14), that is, on average, level of functioning in ADL declined by 1 point between the baseline and final assessments. No client scored the same at first and final assessments; however, only four clients experienced a marked change in dependency to the extent of moving from one level of dependency to another. Two of these clients moved to a higher level of dependency and two moved to a lower level of dependency.

The median IADL change score (between baseline and final assessments) was zero, with variation within the range of –2 to 5 points (Table B4.14). Four clients registered an increase in IADL function between baseline and final assessments; two of these clients had entered NEDID from hospital.

Table B4.14: NEDID, summary measures for baseline[(a)] and change[(b)] scores for ADL and IADL

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	11	3	9	18	9.1	4.9
Change in MBI	11	–6	–1	5	–0.6	3.5
IADL						
Baseline IADL	11	0	2	4	21	1.4
Change in IADL	11	–-2	0	5	0.9	2.1

(a) Clients with complete (baseline and final assessment) records.

(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Thirteen clients showed signs of memory loss or emotional/psychological symptoms of dementia on an intermittent or extensive basis (Figure B4.3). Eleven clients presented a danger to themselves or others at least occasionally. One client was reported to be physically aggressive most of the time. All clients exhibited two or more psychological or behavioural symptoms on an intermittent or extensive basis and 12 clients exhibited two or more symptoms extensively.

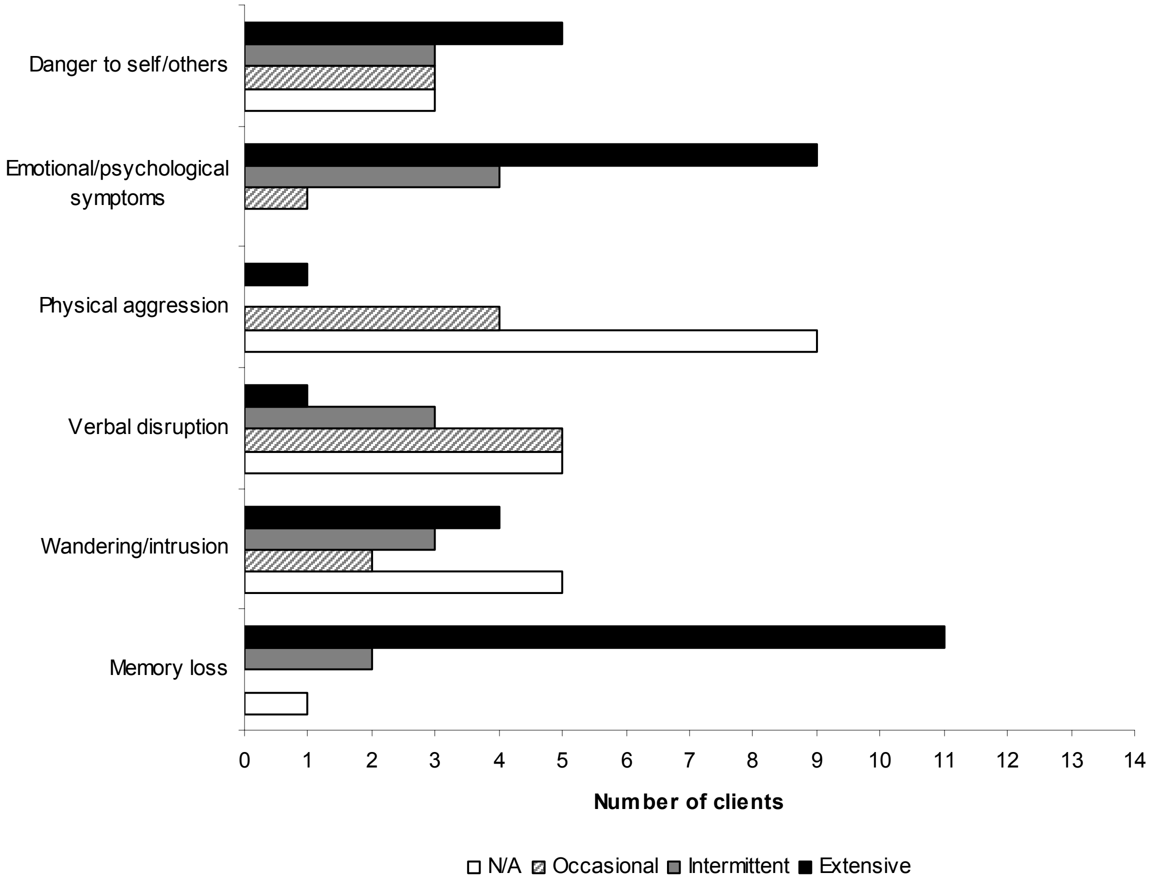


Figure B4.3: North East Dementia Innovations Demonstration, number of clients by frequency of psychological and behavioural symptoms at entry to project

4.4 Carer assessment results

Eleven carers reported that they were in very good or good health at the time that their care recipient entered NEDID. One carer reported being in poor health. Two carers did not give a self-report of health status.

All 14 carers completed the CSI at a baseline assessment, generating a mean score of 9.5 points (median 10) with a standard deviation of 2.5 points. Scores ranged from 5 to 13. Eleven of the 14 carers recorded scores above the threshold for high carer strain and two scored the maximum possible score of 13 points.

Ten carers completed the CSI at a final assessment. Changes in the CSI between baseline and final assessments ranged from –13 (a complete reduction in carer strain), to 1 point (a 1-point increase in carer strain). The median change score was –0.5 (mean –2.4; standard deviation 4.5), that is, on average carer strain decreased during NEDID service episodes. Of the 10 carers with both baseline and final assessment results, seven were over the threshold at baseline. Two of these seven carers had improved dramatically by the final assessment and the other five were still considered to be experiencing considerable strain associated with the caring role at the time of their final assessment.

All 14 carers also completed the GHQ-28 at the baseline assessment. Four scores were 14 points or higher on at least one sub-scale. Three carers recorded scores of 14 points or higher for somatic symptoms; one carer scored close to the maximum for anxiety and insomnia; and one carer scored over 14 points for social dysfunction. No carer scored 14 or over for severe depression, although two carers scored 10 points or more on this sub-scale. Overall, three carers scored 14 points or above on one sub-scale and one carer scored 14 points or higher on two sub-scales.

At the final assessment, 10 carers completed the GHQ-28, of whom two scored over 14 points on at least one sub-scale. One carer was over the threshold on one subscale and another was over the threshold on two sub-scales.

Change in CSI and GHQ-28 scores is analysed across projects in Part A of the evaluation report.

4.5 Service profile

The NEDID service profile indicates that the project has focused on the provision of high levels of personal assistance, respite care and other forms of carer support, allied health care, behaviour management therapy and aids and equipment in addition to multidisciplinary assessment and management (Table B4.15). The service profile reflects an extensive range of service types has been delivered to clients. NEDID recorded the highest median weekly hours of service, excluding ancillary services, among the short-term care projects and some of the highest weekly hours per client by service type recorded during the evaluation.

Assessment/care coordination and case management, respite care (including day centre respite), personal assistance and counselling together made up 87% of direct care expenditure in the reporting period (Figure B4.4).

Table B4.15: NEDID summary of services delivered per client per week: Evaluation clients, 14 June–29 November 2004

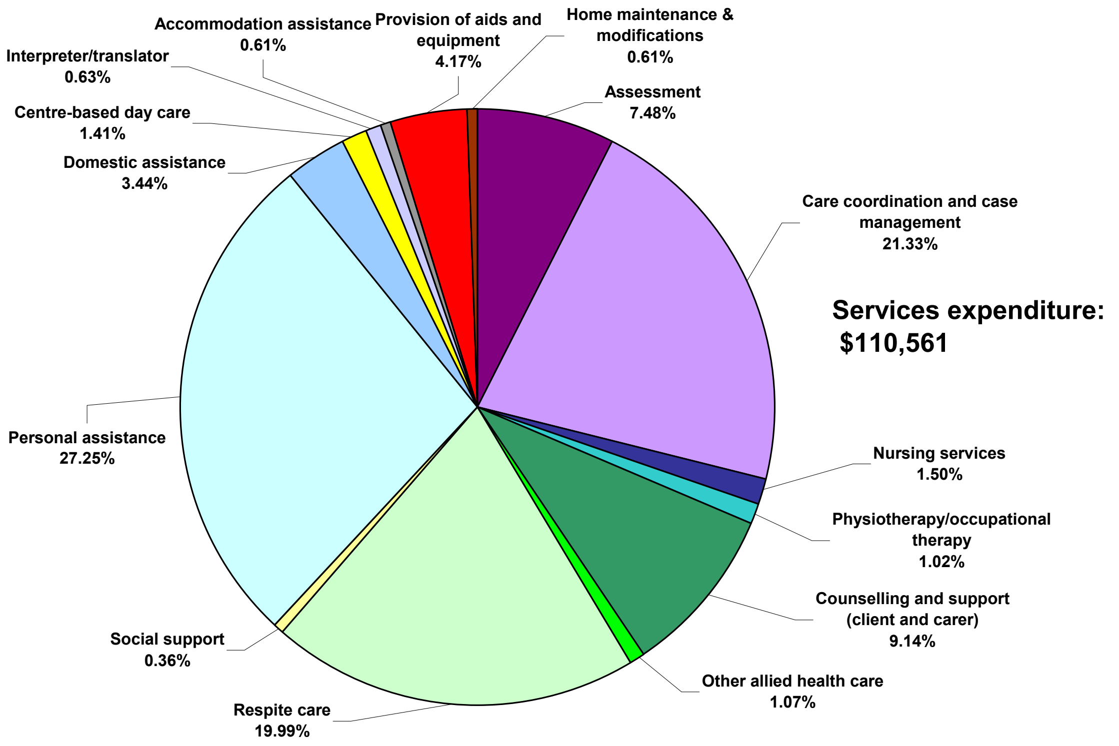
Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Personal assistance	Hours	13	1.9	8.6	29.2	10.8	8.1
Allied Health[(a)]	Hours	13	0.1	0.4	12.8	1.5	3.4
Respite (in-home and day)[(b)]	Hours	13	0.5	5.8	23.7	9.5	7.9
Domestic assistance	Hours	4	0.1	0.9	2.1	1.0	0.9
Nursing care	Hours	1	2.5	2.5	2.5	2.5	—
Social support	Hours	1	3.8	3.8	3.8	3.8	—
Dementia/behaviour care combined	No. referrals	12	0.1	0.5	1.4	0.6	0.4
Community transport	No. one-way trips	1	0.1	0.1	0.1	0.1	—
Delivered meals	No. meals	1	12.4	12.4	12.4	12.4	—
Personal other	No. events	1	1.5	1.5	1.5	1.5	—
Carer support other than respite	No. events	12	0.1	0.8	3.9	1.0	1.0
Information advice and referral combined	No. events	6	0.2	0.3	1.5	0.5	0.5
Allied health other	No. events	2	0.1	0.4	0.6	0.4	0.4
Medication review	No. events	4	0.1	0.1	0.2	0.1	0.0
Overnight respite	No. days/nights	3	1.0	2.2	3.7	2.3	1.3
GP consultation	No. contacts	11	0.1	0.3	0.3	0.2	0.1
Neurologist	No. contacts	3	0.1	0.1	0.4	0.2	0.2
Geriatrician	No. contacts	1	0.1	0.1	0.1	0.1	—
Pilot program residential accommodation	Dollars	1	168.0	168.0	168.0	168.0	—
Home modifications and maintenance	Dollars	1	52.4	52.4	52.4	52.4	—
Aids and equipment	Dollars	12	0.0	23.3	165.7	39.1	49.0
Interpreter/translator	Dollars	2	8.6	12.6	16.7	12.6	5.7

(a) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(b) Assumes one-day respite date is 5 hours.

— Nil

Source: NEDID evaluation database.



Source: Appendix Table B25.

Figure B4.4: NEDID, expenditure on services, all care recipients, 1 July–31 December 2004

4.6 Accommodation outcomes

Ten clients (out of 14) were discharged from the project during the evaluation (Table B4.16). Five of these clients were admitted to hospital or entered residential aged care and five remained at home with EACH or HACC services.

Table B4.16: NEDID, client discharge destination, government program support and length of stay: clients discharged from project during evaluation period, current 30 November, 2004

Discharge destination	Clients	Length of stay (min – max)
In care		
Residential aged care—high	2	15–98
Residential aged care—low	2	65–80
Hospital	1	18
Total in care	*5*	*15–98*
At home		
With Extended Aged Care at Home	3	63–95
With Home and Community Care	2[(a)]	73–109
Total discharged to community	*5*	
Total	**10**	**15–109**

(a) One client was discharged in early December.

NEDID completed follow-up of evaluation clients between 28 April and 2 June 2005. Table B4.17 shows accommodation setting and government program support for all clients at follow-up (that is, approximately 11 months from the start of the evaluation period). By this time one client who was discharged from the project onto an EACH package had entered high level residential care.

Of the remaining clients who had been discharged to the community during the evaluation, those who had been receiving EACH were still on an EACH package, with or without additional formal support. Clients who had been receiving assistance from HACC had either transferred to a CACP with additional support or were receiving other services in addition to HACC.

Table B4.17: NEDID, client accommodation setting and government program support status at follow-up, current June 2005

Accommodation setting and support status	Number of clients
In care	
Residential aged care—high	3
Residential aged care—low	2
Hospital	1
Total in care	*6*
At home	
Multiple program support	3[(a)]
EACH	2
Other program support	2
On NEDID	1
Total at home	*8*
Total	**14**

(a) Includes one client on EACH plus other services, one client on HACC plus other services and one client on VHC plus other services.

One client was still on NEDID at the end of May 2005 as the case manager was unable to place the client in an appropriate program. This client had been in NEDID for approximately 10 months. One of the clients discharged to another program received services from Austin's Step-Down program. This client had also been difficult to place and had spent 7 months on NEDID. Two other clients who were discharged to EACH and multiple programs had been in the project for between 6 and 7 months.

NEDID demonstrated a high degree of success in helping people with very high support needs to remain at home or return home after hospital. Eight of the original group of 14 evaluation participants were still at home when follow-up was completed in mid-2005. The project's base within Austin Health facilitates liaison with hospital staff to ensure that required occupational therapy and physiotherapy assessments are completed before a patient is discharged from hospital. NEDID has assisted with the acquisition of aids and equipment and the smooth transition from hospital to home. Those clients who entered residential care did so after a trial period at home. Two clients with ACAT approval for high care entered residential care at low care level.

Attachment: NEDID Step-Down Case Management Program

Austin Health

North East Dementia Innovations Demonstration Pilot (NEDID)

Proposal for Enhancement to the Pilot for 2004–05

Background

On completion of the 2003–04 acquittal the North East Dementia Innovations Demonstration Pilot has a surplus of approximately $40,000 (full details as included in the NEDID acquittal).

Following discussions with the Australian Government Department of Health and Ageing, an invitation has been given to write a proposal for an enhancement to the NEDID Pilot to utilise these surplus funds during 2004–05.

Two components are proposed to utilise the surplus funds as detailed below:

Component 1—one additional place

That the NEDID Pilot be allowed to operate at 11 places at any one time. The additional place will be based on demand and may be allocated to a client who has been assessed either at high or low level care.

Component 2— Step-Down case management

Due to long waiting lists for Linkages and EACH places, it is becoming increasingly difficult to discharge some clients from NEDID who require the ongoing support of a case management program. This is being compounded in recent weeks by long or closed waiting lists for respite programs in the region. Every effort is made to decrease services received at the end of the NEDID Pilot to those that can be provided by HACC/other mainstream services, however the outstanding need that often remains is the need for case management and respite.

As a result the NEDID Pilot would like to offer the clients and their carers who require this additional support a 'Step-Down Case Management Program'.

This Step-Down Case Management Program would provide:

- maintenance level case management–where possible through a reactive approach rather than a proactive team approach as used in the NEDID model;
- limited funds for respite;
- after-hours support through our after-hours provider;
- clients would access the usual services available in the community–such as HACC, Community Health and Respite Services.

No fees would be charged to clients for the Step-Down enhancement as clients and carers would often be paying fees to usual HACC providers and/or for continence/other aids.

The aim where possible would be to reduce levels of support further to that available through mainstream services to enable throughput in our NEDID Pilot and the Step-Down program.

This Step-Down case management model would be available to two–five clients at any one time and would be based on the assessed needs of the client and carers.

5 RSL Care Innovative Dementia Care Pilot

5.1 Project description

RSL Care in Queensland received an allocation of 45 flexible care places to operate the RSL Care Innovative Dementia Care Pilot for a period of three years. This project services Brisbane North, Brisbane South and Ipswich/West Moreton.

RSL (Qld) War Veterans' Homes Limited, commonly referred to as RSL Care, is the approved provider for the purposes of the pilot. The organisation was founded in the 1930s to provide residential care services for ex-service men and women. Today, RSL Care is a large not-for-profit provider of aged care services in Queensland and the Northern Rivers area of New South Wales. A strategic expansion of home care service provision has taken place since 1999 so that in addition to the operation of low and high level aged care facilities, dementia-specific units, and retirement living, RSL Care offers a range of home care services including home nursing, care packages, therapy centre and transitional care services. Major sources of government funding include the CACP, HACC, Veterans' Home Care and Day Therapy Centre programs. RSL Care services are available to veterans and other members of the community.

Project objectives and innovative features

The stated objectives of the project are to:

- provide a comprehensive approach to dementia services for people with behaviours that normally would be difficult to manage in the community or residential setting
- provide a service that focuses on sustaining the relationship of client and carer and maintaining their social capacity
- increase support to carers of people with dementia and associated challenging behaviours living in the community through delivery of flexible service options such as live-in respite, weekend and evening respite and emergency in-home respite
- reduce premature admission of clients to residential care.

The service has been designed to deliver genuinely individualised packages of care with a level of allied health, registered nursing and carer support that is not normally available through mainstream packaged care. Respite services are tailored to individual needs and preferences. Diversional therapy, behaviour management, alternative therapies, carer mentoring and education were cited as specific focuses of a multidisciplinary approach to service delivery and client care.

Target group

The project targets people with dementia who are living in the community and whose needs are not being met through mainstream services, particularly people who cannot be adequately supported by existing levels of service provision and in group settings due to a need for individually tailored one-on-one care. The project also aims to cater to the needs of people from culturally and linguistically diverse backgrounds and reported increasing referrals from this special needs group. RSL Care brokers bilingual and culturally specific staff as necessary and has sourced services from culturally and linguistically diverse service providers and allied health services, providing a multidisciplinary approach to the support provided to people with dementia and their carers in this project.

People accepted into the project are required to live in the catchment areas for the pilot, have a primary diagnosis of dementia, and have ACAT approval for high level residential care.

Identified areas of unmet need

RSL Care identified four main areas in response to the question of unmet needs in the target group:

1. respite care—flexibility in setting and timing of receipt of respite care; emergency and dementia-specific day respite care services
2. information and support in the caring role, for example, manual handling training for family carers; education and information on the disease process to enable forward planning
3. navigating the aged care system: locating and accessing services and information
4. seamless service delivery and continuity of care.

The Innovative Dementia Care Pilot aims to address these issues as they pertain to individuals accepted into the project.

Flexible respite care was identified as a critical factor for maintaining high care clients with dementia at home and is a primary focus for the project. It was suggested that many relatives and carers of older people with dementia do not receive adequate respite from the caring role due to the inflexibility of most mainstream services. Carers need respite care that fits into their lifestyles and the routines of care recipients, yet many respite services are designed more with the availability of care workers in mind, leaving little flexibility for consumer choice to be exercised. The experience of the Pilot has shown that in-home respite is usually more suitable than day centre respite for people in the target group, particularly for very high needs clients and those with severe behavioural symptoms. Unfamiliar environments can be particularly unsupportive for a person with dementia, their family and carer. Residential respite care is often not appropriate for a person with dementia-related high care needs—home-like environments are preferable for periods of out-of-home respite care.

A very high level of unmet need for emergency respite care was said to exist in the catchment area. People often experience difficulty locating emergency respite services in times of crisis and do not always meet with a quick response. RSL Care reported that responsiveness of respite care services in times of family crisis is a major issue.

Dementia-specific day centre services need to expand to allow people with dementia to receive appropriate activities without impacting adversely on cognitively intact clients of day programs. Quality dementia-specific day centre services may assist family carers to continue in paid employment.

RSL Care cautions that there is no one-size-fits-all solution to respite care service provision. The provision of respite care needs to be based on an assessment of individual needs and carers should be able to choose from a range of flexible in-home or 'home-like' respite care settings and dementia-specific day programs.

Staff at RSL Care noted that many family members find themselves in a caring role without the necessary training for safe manual handling and general occupational health and safety awareness that is mandatory for paid care workers. This is a safety issue for both carer and care recipient. Carer education is a major focus for the Innovative Dementia Care Pilot.

The other two identified areas of unmet need—locating and accessing services and seamless service delivery—are closely related. RSL Care reports that awareness of Commonwealth Carelink among older people is low. Younger carers tend to be more resourceful and adept at negotiating the system than their older counterparts. Older people find it very difficult to acquire information on the range of community services and are often seen to withdraw from the service network in the face of multiple assessment procedures, multiple service points and complex co-payment arrangements with multiple service providers. Older carers and care recipients tend to have fewer resources available to them. They may not have access to the internet, for example, and poor eyesight can limit their access to print media. This group requires more intensive case management than older care recipients with regular assistance from younger carers.

Program boundaries can result in access barriers to specific groups within the target population. This is observed to be a particular problem for Veterans' Home Care clients who try to access a higher level of service through HACC when the minimal level of service available through Veterans' Home Care is unable to meet their increasing needs.

Hours of direct care to CACP recipients are said to be decreasing because CACP funding has not kept pace with increasing costs, primarily related to increasing case management loads. The gap between HACC and CACP is observed to be narrowing. Although CACP is designed to provide flexibility and client-centred care, current funding levels are too low to support most members of the Innovative Dementia Care Pilot target group. An RSL Care CACP delivers an average of 6 hours per week. The RSL Care Innovative Dementia Care Pilot provides care recipients with up to 12 hours of direct care per week in addition to case management and facilitated access to allied health and community nursing.

Care model

RSL Care Innovative Dementia Care Pilot is a community-based, dementia-specific, comprehensive care package service. The project targets clients with intensive care management needs and is designed to provide high level support for people living with dementia and their families and carers, with a strong emphasis on the provision of flexible and creative/innovative respite care.

Flexible funding provides for the delivery of higher service hours than is possible through a CACP. The application for funding proposed three levels of care with increasing estimates of total weekly service hours per client, starting at around the upper limit of a CACP:

- Level S4 provides for up to 10 hours per week (7 hours personal care; 2 hours allied health and nursing; 1 hour care coordination and administration).
- Level S3 provides for up to 15 hours per week (10 hours personal care; 3 hours allied health and nursing; 2 hours care coordination and administration).
- Level S2 provides for up to 18 hours per week (12 hours personal care; 4 hours allied health and nursing care; 2 hours care coordination and administration).

A dementia-specific focus allows for high level carer support and close monitoring and therapy for care recipient behavioural and psychological symptoms. Referrals to the project have been made mainly on the basis of behaviour management need rather than ADL limitations. Higher hours of care are related to the dementia specificity of the project and not merely the fact that the project is servicing a high needs group. Dementia care can place heavy demands on family carers and this requires a higher level of coordination and flexibility to reduce carer strain. The care workers require support, education and coaching and skills to communicate effectively with the person with dementia to provide support with activities of daily living.

Packages deliver high-level coordination and management, and a multidisciplinary approach to assessment which is not generally available in mainstream low care packages. The complexities of the community care system alluded to above present significant problems for the family carer of a person with dementia. Innovative Pool funding allows RSL Care to enter into flexible brokerage arrangements to supplement standard RSL Care services with dementia-specific services tailored to the needs of an individual care recipient and carer. A holistic, multidisciplinary approach to assessment and case management for care recipient and carer is seen as the main innovative feature of the project.

Rostering of care workers is designed in such a way as to maximise flexibility of arrangements for the care recipient and carer. With flexible funding it has been possible to avoid the situation where clients are inconvenienced by waiting for services that are not delivered at the designated time. In addition, it is more possible to satisfy requests for changes in arrangements at short notice. The project aims to maximise the wellbeing of client and carer and to limit the number of care workers to a maximum of three attending a client to maintain familiarity and ensure continuity of care.

Respite care is arranged soon after the initial needs assessment to help reduce carer strain and enable them to be part of the care team for care planning. Early carer support has been found to be a critical early intervention for people coming onto the Pilot.

Personal care and home services are delivered by care workers and volunteers who are employed across the full range of RSL Care community programs (see 'Staffing arrangements', below).

Staffing arrangements

Three project coordinators (one each for Brisbane North, Brisbane South and Ipswich/West Morton) are responsible for coordinating assessment and care services for Innovative Dementia Care Pilot care recipients. The project coordinators liaise with RSL Care community program managers (HACC, CACP and so on) for access to staff in the RSL Care care worker pool.

In mid-2004, the staffing structure comprised 15 full-time equivalent care workers (20 individuals), seven case managers and six administration staff working across all programs, including the Innovative Dementia Care Pilot. In most cases it has been possible to limit to two the number of care workers assigned to each client.

Physiotherapy, occupational therapy, speech therapy and music therapy services are brokered on a case-by-case basis.

Home care workers complete specialist dementia training workshops, workplace health and safety training and dementia conferences convened by area dementia specialists with RSL Care. Newly recruited care workers undergo orientation training. Care workers and family carers receive mentoring in the implementation of risk management and client behaviour management strategies from area dementia specialists. Supervised problem-solving and on-the-job training takes place in the client's home environment and aims to impart the same knowledge to care workers and family carers. RSL Care brokers to physiotherapists and occupational therapists to train workers and family carers in manual handling for individual clients and specific items of equipment.

Project coordinators have experienced some difficulties in releasing staff for dementia training and managing the turnover of staff that tends to occur after completion of training workshops.

Pairing appropriately qualified staff with a client to the satisfaction of the client and maintaining continuity of personnel and daily visitation patterns are additional challenges in staffing a service for the target group. Sourcing bilingual care workers and staffing a roster to cover a large geographical area have also presented problems for the project coordinators.

Successes, challenges and lessons

Prior to establishment of the Innovative Dementia Care Pilot, RSL Care clients with dementia were being supported through CACP with supplementation from dementia-specific respite care services, often funded by the National Respite for Carers Program. RSL Care reports that the Pilot has enabled more efficient and longer term support of high care clients than a set of services designed for low care clients cobbled together under different funding arrangements. The ability to address the needs of care recipient and carer under the one funding arrangement is seen as a major benefit of the Pilot. It was suggested that innovative funding arrangements should be geared to more proactive care management for the target group in a mainstream service context. A widespread gap in service knowledge among older people and the confusion caused by different eligibility and funding requirements complicate the process of determining the most appropriate service for a client. RSL Care recommends flexible service delivery at an earlier stage of the care continuum for people with dementia so that supports are in place to avoid crisis situations from developing.

Initial estimates of the resources needed for assessment and care coordination for Pilot clients were too low. Coordinators reported on the lengthy time that is required to establish rapport, build confidence and understand family dynamics impacting on the situation of carers and clients. In many cases, clients and carers either have not received services before, or have become disenchanted. Considerable ground may need to be recovered before a coordinator can establish a comprehensive care plan for the client. This may take several weekly visits over a number of weeks. Early respite care assists greatly to ease the client and carer into acceptance of formal assistance. The early phase must be managed carefully to avoid further 'service disappointment'.

In terms of weekly hours once a care plan is established, Pilot experience suggests that a minimum of 10 hours per week is required to support a client and carer. Case management load varies depending on the geographical distribution of care recipients. As an indication, Brisbane North has two case managers for 10 packages; Brisbane South has two case managers for 20 packages; and Ipswich/ West Morton has one case manager for 15 packages. All case managers are employed full-time. Each client has continuous interaction from one case manager.

The first wave of referrals comprised clients with dependency levels more like EACH clients than the anticipated target group. Initially, referring ACATs were insufficiently familiar with the level of service that could be offered but over time, a more appropriate referral pattern developed.

ACAT representatives indicated that assessment of clients for the project aligns with ACAT 'core business'. Referrals to ACAT have come mainly from family, general practitioners and hospitals. An increase in the number of practice nurses in recent years has helped to raise awareness of community services in general practice, providing a valuable link between primary and community care for older people. However, ACAT believes that more needs to happen to deliver appropriate services to older people with dementia before they reach a crisis in care. Education, particularly a raising of awareness of assessment and services among general practitioners, practice nurses, acute care staff and the community in general would result in more timely referrals to community services.

The client groups in the Brisbane North and Brisbane South arms of the project are different in a number of respects. Brisbane North has tended to source a younger client group. Many referrals to this arm of the project have come from other service providers which can no longer cater to the clients' needs. The Brisbane North coordinator noted that younger people with dementia are usually highly committed to staying at home and are less likely to fit into group care environments. Brisbane South has attracted a much older clientele. High level case management is often needed for the older client with an older carer, due to a generally more limited capacity of older carers to advocate and coordinate services. High level case management for younger clients and carers is most often associated with the impact of client behavioural symptoms on family carers.

Overall, the project's client base is younger and more ambulant than anticipated. The very high needs clients tend to be younger, ambulant, and with behaviour management needs, whereas it was expected at the outset that high care needs would be associated with age-related frailty and dementia. Behaviour management needs have resulted a higher than expected demand for training and support for care workers and family members. Levels of case management needed to support a client and carer have been much higher than anticipated, mainly because referrals have generally been for people who have reached crisis point.

There has been a greater than expected need to enter into partnerships to ensure continuity of care for clients and to meet the needs of clients with culturally and linguistically diverse backgrounds.

Factors identified by project coordinators which may delay or prevent a client from taking up this type of service include:

- agency 'ownership' of community care clients—some services prefer to hold onto clients rather than refer them on for a more appropriate level of service. This practice leads to system-wide inefficiencies and poor quality care.
- the reluctance of some HACC clients receiving services for free to transfer to a CACP or the Innovative Pool project because of client co-payments, even if their needs would be better met with one of these other services. RSL Care observes that this seems to be a peculiarly 'Queensland mindset' and notes that co-payments are being introduced for HACC clients in Queensland some years after their introduction in other jurisdictions.
- a high level of carer strain and/or lack of family support for the client to remain at home.

Diagnosis of dementia, carer strain, high level behaviour management needs coupled with physical assessment are thought to be the primary selection criteria for this type of service. In addition, the client (and carer) should show a strong determination to stay at home.

Risks to maintaining a client at home with project services include:

- absence of a family carer—it has proven more difficult to maintain a client if they do not have a relative or friend actively involved in the care plan, particularly if the client has behaviours which require 24-hour supervision, for example, problem wandering. Brisbane South has a small number of clients who live alone, but each has a high level of family or community support. All people who have received services from the project would be unable to function at home by themselves. However, each case needs to be assessed on its own merit, considering the entire support network which may include neighbours, friends, community and charitable organisations
- carer characteristics—age-related frailty or ill health, lack of access to a wider support network, limited capacity for manual handling where required
- client characteristics—severe mobility limitation, particularly the requirement for assisted bed transfers
- care environment factors—occupational health and safety concerns for care workers, for example, physically aggressive clients or unsafe home physical environments.

5.2 Client profiles

The RSL Care Innovative Dementia Care Pilot supplied evaluation data for 32 care recipients—10 men and 22 women. This section presents profiles of the evaluation client group during the evaluation period (or at entry to the project, as indicated).

Age and sex

Ages of clients ranged from 59 years to 96 years during the evaluation (mean 81.3 years). Thirteen clients were aged 85 years or over (Table B5.1).

Table B5.1: RSL Care Innovative Dementia Care Pilot, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
Less than 65	—	2	2
65–74	—	3	3
75–84	7	7	14
85+	3	10	13
Total	**10**	**22**	**32**
		(per cent)	
Less than 65	—	6.3	6.3
65–74	—	9.4	9.4
75–84	21.9	21.9	43.8
85+	9.4	31.3	40.6
Total	**31.3**	**68.8**	**100.0**

— Nil.

Language and communication

Ten clients had little or no effective means of communication (spoken or non-spoken). Three national languages were represented (Table B5.2).

Table B5.2: RSL Care Innovative Dementia Care Pilot, number of clients by language spoken at home and English language proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	25	3	2	30
Dutch	—	1	—	1
Mandarin	—	1	—	1
Total	**25**	**5**	**2**	**32**

— Nil.

Accommodation and living arrangement

Clients were living in private residences or retirement villages (Table B5.3). Two clients were referred to the project from hospital.

Table B5.3: RSL Care Innovative Dementia Care Pilot, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement				
Accommodation setting	Alone	With family	With others	Not stated	Total
Private residence	4	24	1	1	30
Retirement village—self-care	1	1	—	—	2
Total	**5**	**25**	**1**	**1**	**32**

— Nil.

Years at usual place of residence ranged from less than one to 62 years. Five clients had been living in the same home for over 40 years.

Carer availability

All 32 clients had a carer and 26 of the carers were living with the care recipient (Table B5.4). Carer's ages ranged from 26 to 91 years, averaging 65.3 years. Eight carers were aged 75 years or over (Table B5.5).

Table B5.4: RSL Care Innovative Dementia Care Pilot, number of clients by carer availability, carer relationship to client and carer co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Total
Spouse or partner	14	—	14
Son or daughter	8	5	13
Son- or daughter-in-law	2	1	3
Other relative	1	—	1
Not stated	1	—	1
Total clients with a carer	*26*	*6*	*32*
Total clients			**32**
Per cent of clients with a carer			100

— Nil.

Table B5.5: RSL Care Innovative Dementia Care Pilot, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	—	2	2
45–54	—	2	2
55–64	3	5	8
65–74	5	2	7
75–84	2	4	6
85+	2	—	2
Not stated	1	4	5
Total	**13**	**19**	**32**

— Nil.

Income and concession status

Government pensions were the primary source of cash income for 27 clients (Table B5.6). Seventeen clients held a health care concession card and four clients received a discounted co-payment rate due to financial hardship.

Client co-payment amounts ranged from nil to $6 per day (median of $5.59 per day).

Table B5.6: RSL Care Innovative Dementia Care Pilot, number of clients by principal source of cash income, health care concession card status and project concession status

	Number of clients	Per cent
Principal source of cash income		
Age pension	18	56.3
DVA pension	8	25.0
Other income	2	6.3
Disability pension	1	3.1
Spouse or partner	1	3.1
Property cash income	1	3.1
Other government payment	1	3.1
Total	**32**	**100.0**
Health care concession card holder	17	54.9
Project concession status	4	12.5

Previous use of government community care programs

Twelve clients were not receiving assistance from government community care programs before the project (Table B5.7). Ten clients were previously receiving assistance through the CACP or HACC programs.

Table B5.7: RSL Care Innovative Dementia Care Pilot, number of clients by previous use of government support programs

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	6	18.8
National Respite for Carers Program	4	12.5
Home and Community Care	4	12.5
Multiple programs[(a)]	4	12.6
Veterans' Home Care	2	6.3
Total clients with previous government program support	*20*	*62.5*
Clients without previous government program support	12	37.5
Total	**32**	**100.0**
Use of respite care in the 12 months prior to RSL Care Innovative Dementia Care Pilot		
Respite care used	19	59.4
Respite care needed but not used	6	18.8
Respite care not needed	1	3.1
Not stated	6	18.8
Total	**32**	**100.0**

(a) Two clients were receiving a mixture of HACC and National Respite for Carers Program and two clients were receiving a CACP plus Day Therapy Centre services.

Of the carers who had accessed respite care in the 12 months prior to entering the project, 12 had used mainly in-home respite and seven had mainly used residential respite care. Six carers reported that, despite having had a need for respite care in the 12 months prior to the RSL Care project, they had not used a respite care service (Table B5.7).

Thirteen clients are reported to have been on a waiting list for residential aged care when they joined the project.

Assessment and referral

Twenty-one RSL Care clients were referred to the project by an ACAT (Table B5.8). Six clients were referred by either RSL Care or another community service agency.

Table B5.8: RSL Care Innovative Dementia Care Pilot, number of clients by source of referral

Referral source	Number of clients
Aged Care Assessment Team	21
RSL Care	3
Other community service agency	3
Other agency	2
Hospital	1
Family	1
Friend	1
Total	**32**

Twenty-five clients had completed an ACAT assessment on the same day or prior to referral to the project. For these clients, the time between completion of an assessment and referral to the project varies from day of referral to 413 days (Table B5.9). ACAT assessment was completed after referral to the project for seven clients.

Needs assessment for care planning purposes has involved the RSL care community care coordinator, area dementia specialist, community nurse and allied health professionals. Some clients have required an interpreter/translator.

Table B5.9: RSL Care Innovative Dementia Care Pilot, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–20 days	18
21–60	—
61–90 days	1
91–120	—
121–180 days	1
181–365	4
Over 1 Year	1
Total	*25*
After referral to project	
2, 8, 28, 48, 79, 152 and 303 days post-referral	7
Total	**32**

Assessment and care coordination for this client group has proven more expensive than anticipated during proposal development. RSL Care budgeted on the basis of approximately 2 hours of case management time per client per fortnight, or around 1.5 full-time equivalent staff. Experience has shown that two full-time case managers and two full-time administrative assistants is the minimum requirement for 45 packages distributed over the Pilot's service area. Initial needs assessment for care planning purposes involves multiple home visits and liaison with other service providers for handover or to ensure continuity. Little concrete care planning may be possible on the first visit because the care manager will typically be received by a highly strained carer. This visit is often about becoming familiar with family dynamics and reaching a point at which constructive discussion and planning can take place. The assessment will often need to proceed while the family carer goes about his or her normal household routines, which can slow the assessment and care planning process considerably.

Project coordinators remarked on the length of time that it can take to establish rapport and build confidence in carers and care recipients, possibly necessitating visits over a number of weeks. Once confidence is established, most carers become heavily involved in care planning and management.

Referral to allied health services and subsequent assessment of capacity to meet workplace health and safety guidelines before commencing home services has in some cases incurred lengthy delays.

The cost of initial needs assessment, following ACAT approval, can be anywhere between $100 and $400 per client, depending on case complexity. Needs assessment times have varied from 3 to 12 hours, including travel time to rural and remote locations.

A range of professional backgrounds is represented among client care managers (Table B5.10).

Table B5.10: RSL Care Innovative Dementia Care Pilot, number of clients by care manager profession

Referral source	Number of clients
Nurse manager	1
Registered nurse	3
Welfare & community worker	8
Other profession	15
Multidisciplinary team	5
Total	**32**

Health conditions and health status on entry

The number of health conditions recorded for RSL Care clients at entry to the project ranges from one to nine. Twenty-six clients had three or more health conditions at entry. Table B5.11 shows the primary health conditions recorded on Aged Care Client Records.

Table B5.11: RSL Care Innovative Dementia Care Pilot, number of clients by primary health condition

Primary health condition	Number of clients
Dementia (includes Alzheimer's disease and other dementias)	30
Slowness & poor responsiveness	1
Heart disease	1
Total	**32**

Nineteen clients were assessed as being at risk of falls due to impaired gait or balance and eight clients had diagnosed depression (Table B5.12).

Table B5.12: RSL Care Innovative Dementia Care Pilot, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	19
Diagnosis of depression	8
Vision impairment	5
Hearing impairment	4
Disorientation/confusion	4
Missing or non-functional limbs	2
Total or partial paralysis	2

Data on medication use were recorded for 30 clients. Clients were taking between zero and 12 different medications at the time of reporting. Eighteen clients were taking four or more different medications.

Clients and carers were asked to rate client health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Five clients were reported to be in good health; the remaining ratings were fair (eight clients), and poor (8 clients).

Most respondents said that the client's health was somewhat worse (10 clients) or much worse (six clients) than one year earlier, which suggests that the care needs of most RSL Care clients had increased in the 12 months prior to entry.

Level of core activity limitation

Most RSL Care clients experience severe to profound core activity limitation in self-care and moderate to profound mobility limitation (Table B5.13). This project has recorded a relatively high proportion of clients with severe or profound communication limitation (11 clients). Twenty-two clients experienced a severe or profound activity limitation in at least one area of core activity during the evaluation.

Table B5.13: RSL Care Innovative Dementia Care Pilot, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	**No limitation**	**Mild**	**Moderate**	**Severe or profound**	**Total**
Self-care	1	6	5	20	**32**
Mobility	5	9	9	9	**32**
Communication	10	6	5	11	**32**

Use of medical and hospital services prior to entry

Use of medical and hospital services in the 6 months before joining the project was recorded for 29 clients. Twenty-six of these clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner varies from zero to 45 per client. Cumulatively, 26 clients recorded 161 visits to a medical practitioner outside of a hospital setting over an estimated 4,680 person days.

Eleven clients reported a total of 19 hospital admissions in the pre-entry period.

Conditions recorded as occasioning admission to hospital for RSL Care clients in the pre-entry period include:

- diseases of the intestinal tract
- other injury, poisoning or consequences of external causes
- injuries to arm/hands/shoulder
- other diseases of genitourinary system
- oedema
- fractures
- falls
- urinary tract infection
- heart disease

- skin cancer
- transient cerebral ischaemic attacks.

Eight clients experienced a serious medical emergency during the pre-entry period, two of whom had also suffered a fall with injury which rendered them immobile and without assistance for more than 30 minutes. Three other clients also suffered a fall with injury.

5.3 Client assessment results

Cognitive function

Entry MMSE scores were recorded for 18 clients (14 missing values; Table B5.14). Five zero scores were excluded from summary statistics.

The 13 valid non-zero scores range from 3 to 18 out of a possible total 30 points (mean 12.6 and standard deviation 4.4). RSL Care clients with recorded MMSE scores thus reflect a group with moderate to severe cognitive impairment.

Table B5.14: RSL Care Innovative Dementia Care Pilot, number of clients by MMSE score at entry

MMSE score	Number of clients
Zero	5
1–15	9
16–18	4
19–24	—
25–30	—
Missing	14
Total	**32**

— Nil.

Activities of daily living

Modified Barthel Index (MBI) scores for 31 clients reveal that at least half of the group needed assistance in tasks involving self-care and mobility when they entered the project (Figure B5.1). Client MBI scores at entry range from zero to 20 out of a total 20 points (mean 9.6).

A classification scheme for MBI scores (Shah et al. 1989) indicates that five clients were completely dependent in self-care and mobility, 19 clients exhibited severe dependency, six clients exhibited moderate dependency and one client displayed slight dependency at entry to the project. One client was independent in self-care and mobility but showed high dependency in IADL (see below).

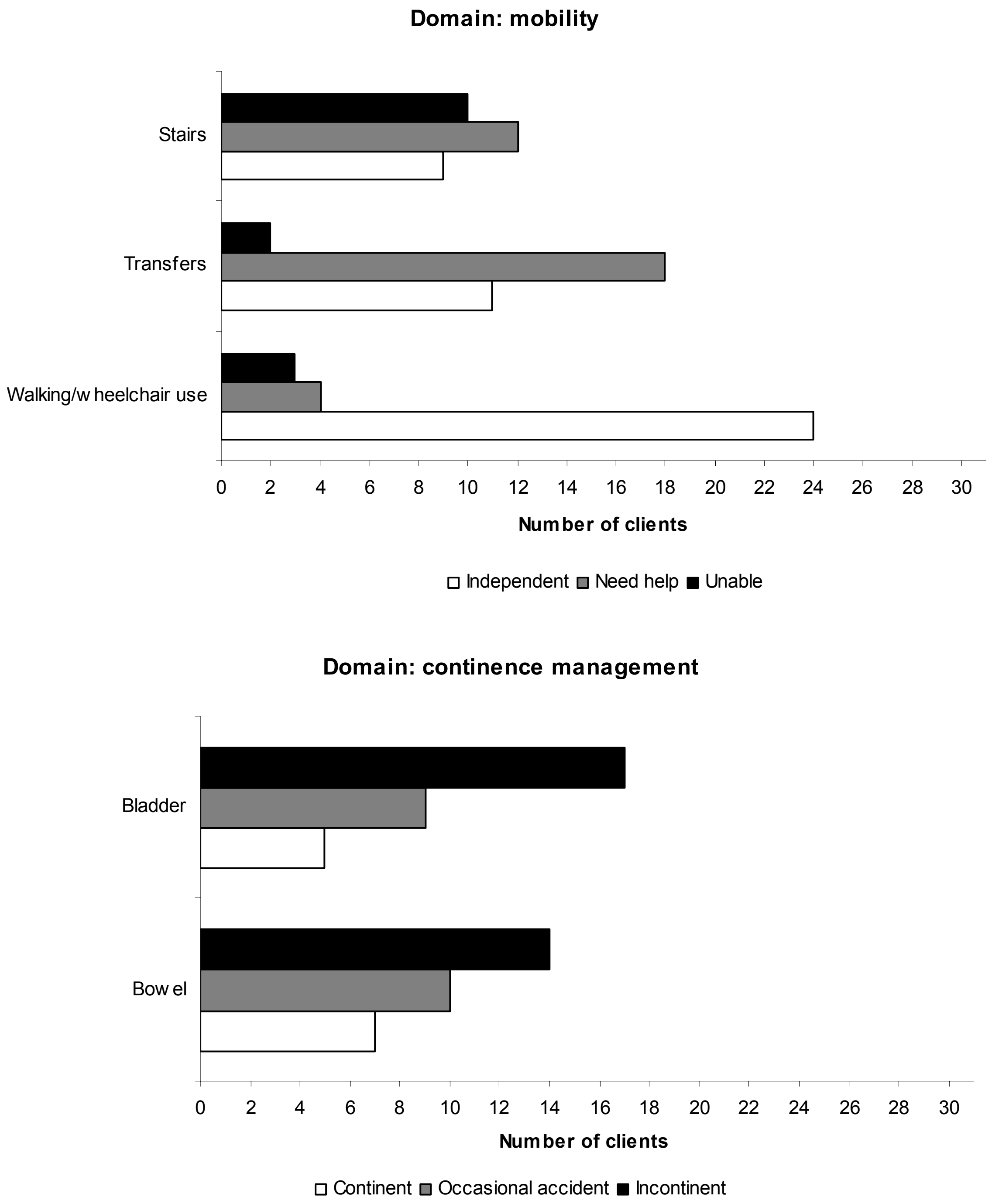
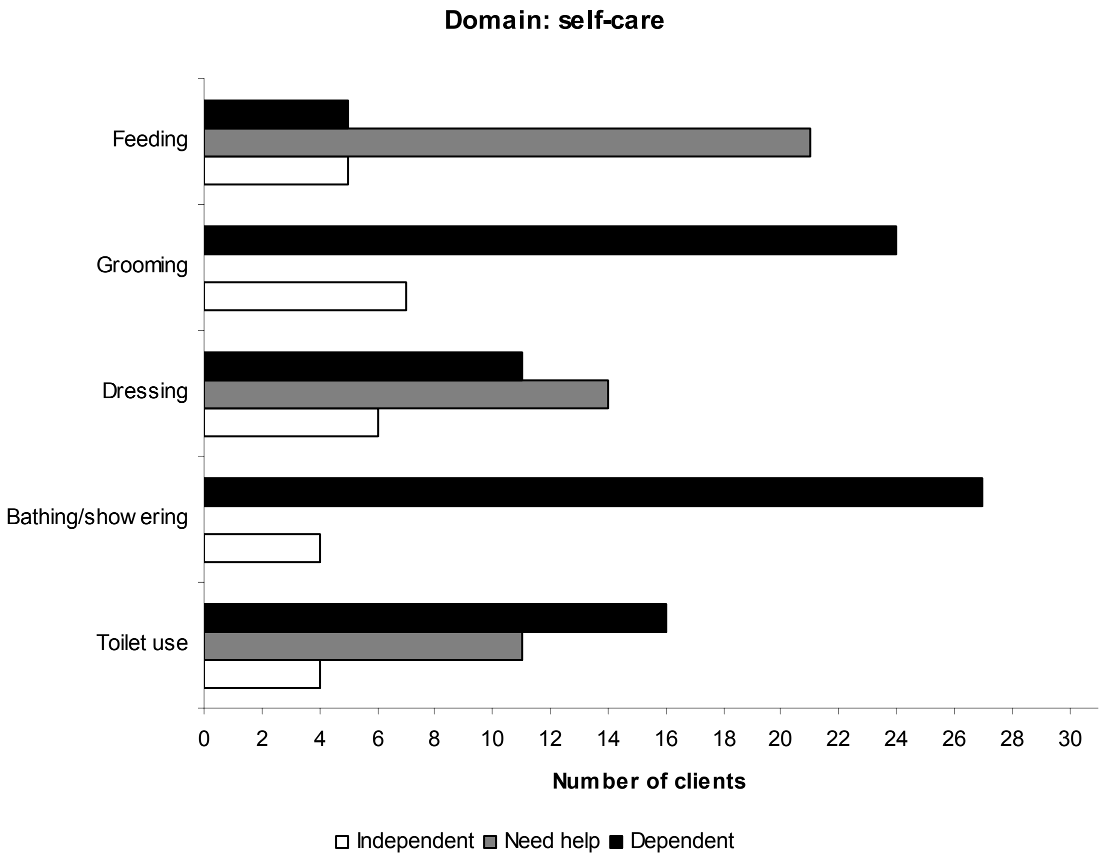


Figure B5.1: RSL Care Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

(continued)

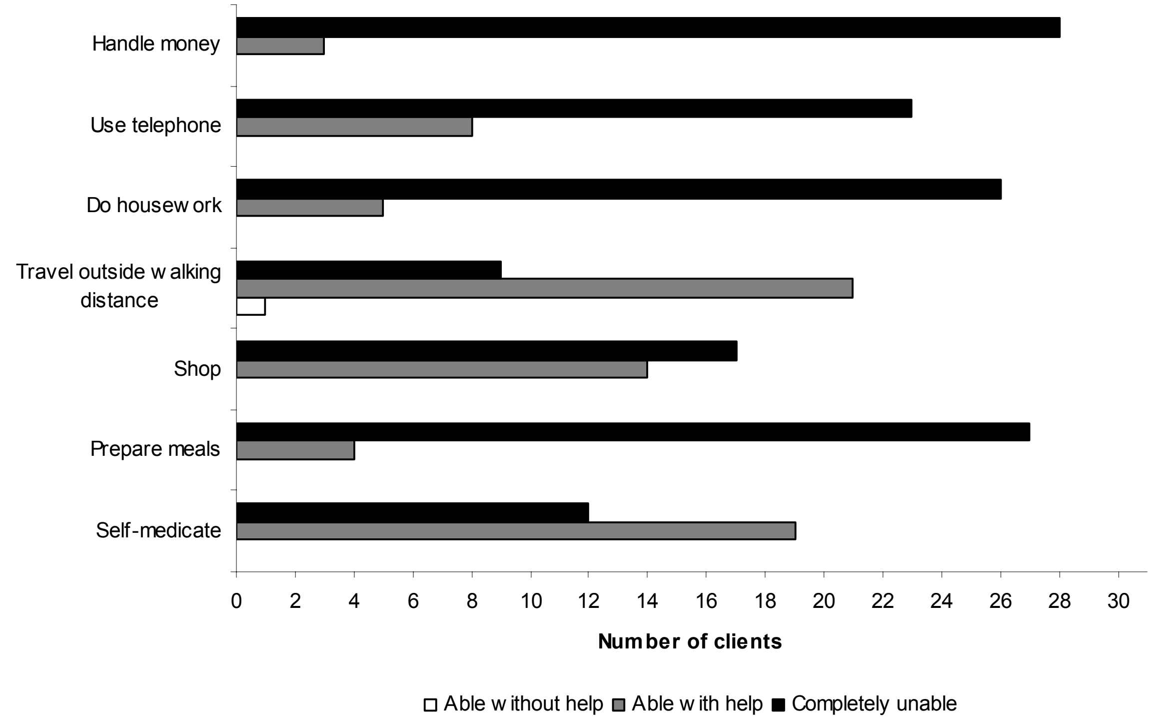


Source: Appendix Table B15.

Figure B5.1 continued: RSL Care Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

Most RSL Care clients were highly dependent in IADL when they entered the project (Figure B5.2). On average, clients were completely dependent in four to five out of seven IADL at the time of entry. Five clients were completely dependent in all seven IADL.

Although 22 clients registered as independently mobile, the IADL mobility item (travel outside of walking distance) reveals that in all but one case, independent mobility was limited to the home environment.



Source: Appendix Table B16.

Figure B5.2: RSL Care Innovative Dementia Care Pilot, number of clients by level of IADL function at entry

RSL Care was asked to take two more assessments after baseline to generate an interim and a final assessment. In some cases only one further assessment was possible. Figure B5.3 shows the MBI scores for clients at baseline, interim and final assessment by accommodation setting at follow-up. Clients in care at follow-up were either in residential high or low care, or in hospital. Clients in the community were either still with the Innovative Dementia Pilot, in other community care or were at home and not accessing government-funded care.

Very low MBI scores and decreasing ADL function over time were recorded for clients who entered aged care facilities and for clients who remained in the community. There is no discernible pattern of ADL functioning in relation to residential outcome.

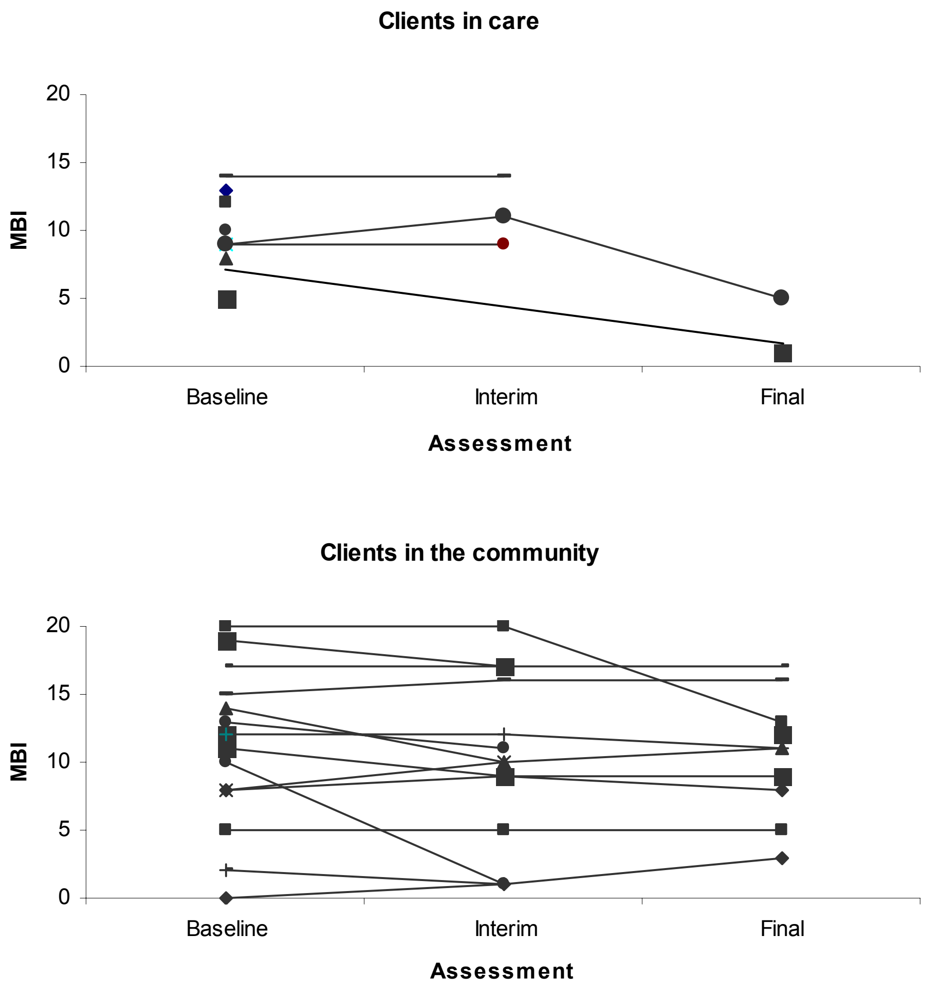


Figure B5.3: RSL Care Innovative Dementia Care Pilot, MBI at baseline, interim and final assessment by follow-up accommodation setting (one symbol per client)

Psychological and behavioural symptoms

Of the 21 clients for whom behavioural data were recorded (extent of memory loss is recorded for 20 clients), 17 clients showed signs of memory loss on an intermittent or extensive basis at the time of entry to the project (Figure B5.4). Twelve clients exhibited emotional or psychological symptoms of dementia at least occasionally. One client was reported to be physically aggressive most of the time. Ten clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, and five of these clients exhibited two or more symptoms on an extensive basis.

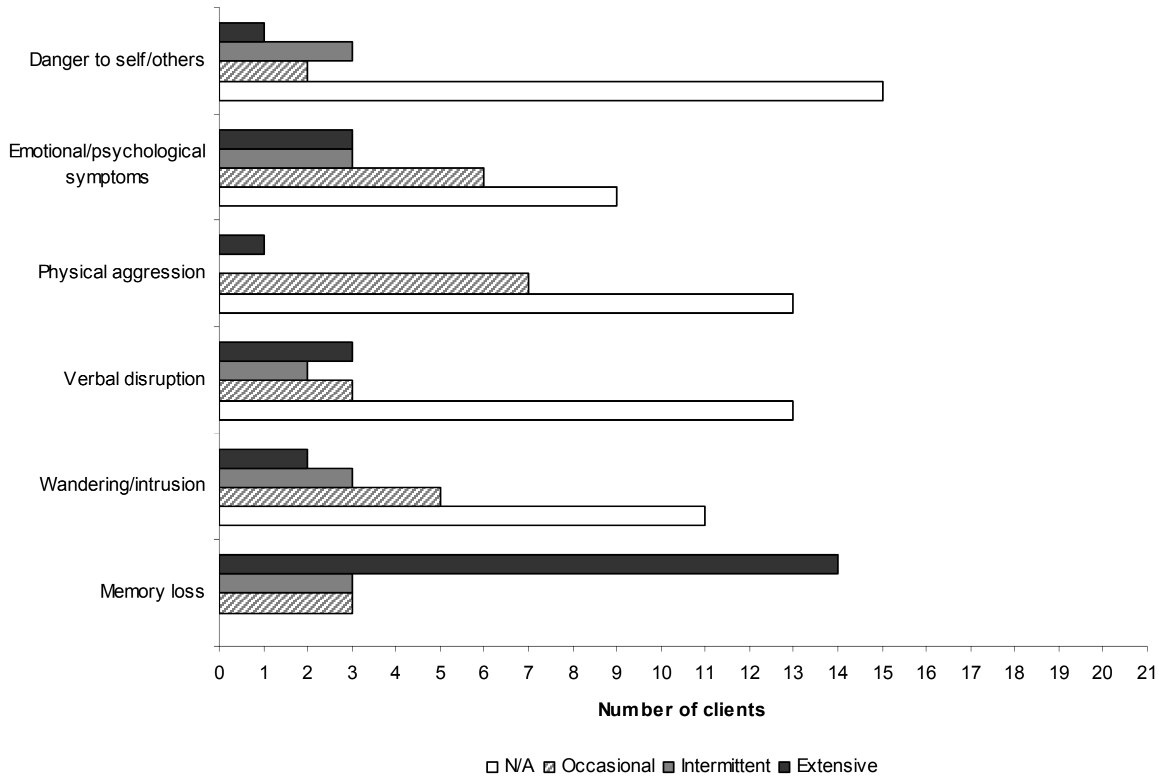


Figure B5.4: RSL Care Innovative Dementia Care Pilot, frequency of psychological and behavioural symptoms at entry

5.4 Carer assessment results

Fourteen out of 29 carers reported that they were in very good or good health. Five carers reported fair health and 10 reported poor health.

Twenty-eight carers completed the CSI to generate a mean baseline score of 9 points. Scores range from 4 to 13. Twenty-four carers recorded scores above the threshold for high carer strain and two scored slightly below the threshold.

Only 10 carers completed the CSI on three occasions. In most cases, a CSI score was recorded close to the start of the evaluation, or at entry to the project but was not recorded again. Considering just the completed sets of CSI assessments, seven of the 10 carers recorded a score at or above the threshold for high carer strain at the first assessment. Final assessments were completed a median of 20.7 weeks after the baseline assessment. Just three carers remained at or above the threshold for high carer strain at the time of the final assessment. Changes in CSI score (final minus baseline score) range from –7 points (a 7-point reduction in carer strain) to 1 point (a 1-point increase in carer strain).

Twenty-six carers completed the GHQ-28 at the baseline assessment. Half of the group scored above 14 points on at least one sub-scale. Six carers recorded scores of 14 points or higher for somatic symptoms, including one carer who scored the maximum 21 points; 10 carers recorded scores of 14 points or higher for anxiety and insomnia, six of whom scored the maximum 21 points; eight carers scored 14 points or higher for social dysfunction; and four carers scored 14 points or higher on the severe depression scale. Three carers scored 14 or higher on one sub-scale, five carers scored 14 or higher on two sub-scales, and five carers scored 14 or higher on three sub-scales.

Twelve carers recorded GHQ-28 scores at the final assessment. None of these carers scored 14 points or higher on any of the four sub-scales.

In summary, high levels of carer strain and recent emergence of psychological symptoms are evident in the assessment results for a significant proportion of carers participating in the evaluation. Analysis of change in CSI and GHQ-28 scores has been conducted across the long-term care projects due to the small sample size for individual projects.

5.5 Service profile

During the evaluation, higher numbers of clients in the project received respite care, personal assistance, nursing care, domestic assistance and social support than other forms of assistance (Table B5.15). Carer support services comprised mainly respite care and information and referral services. Ongoing needs assessment is a feature of this project: on average, a care manager made contact with each client once per fortnight for needs assessment and care plan review.

Almost 90% of direct care expenditure was used for respite care, personal assistance and domestic assistance combined, with respite care accounting for the highest proportion of expenditure on direct care services (Figure B5.5).

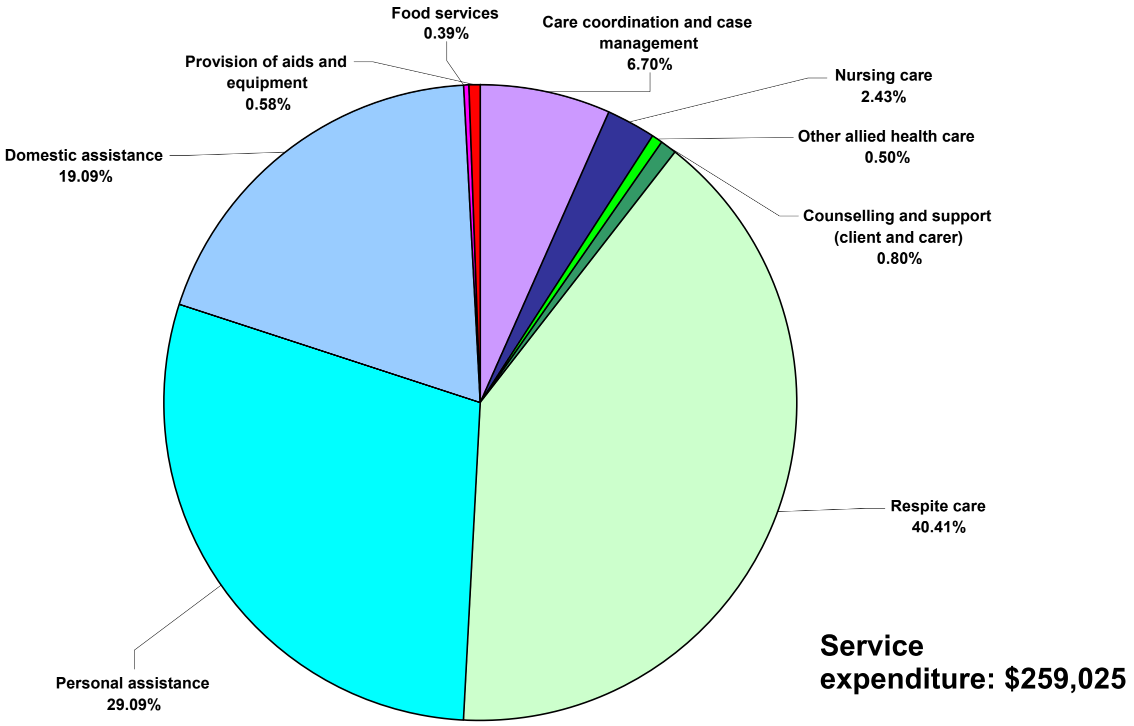
Table B5.15 : RSL Care Innovative Dementia Care Pilot, summary of services delivered per client per week, 14 June–29 November 2004

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Respite (In-home and day)[(a)]	Hours	22	0.4	2.8	9.1	3.5	2.7
Personal assistance	Hours	21	0.1	1.4	11.8	2.7	3.2
Nursing care	Hours	17	0.0	0.1	3.2	0.3	0.8
Domestic assistance	Hours	16	0.2	1.5	6.1	2.0	1.5
Social support	Hours	11	0.1	0.5	3.2	0.7	0.9
Food service other	Hours	2	1.5	1.8	2.1	1.8	0.5
Allied health[(b)]	Hours	2	0.0	0.3	0.6	0.3	0.4
Aids and equipment	Dollars	9	1.6	8.5	50.2	15.9	16.4
Follow-up needs assessment	No. contacts	27	0.0	0.4	6.4	0.8	1.3
Carer support other than respite	No. contacts	1	0.0	0.5	2.5	0.7	0.7
GP consultation	No. contacts	7	0.0	0.1	1.9	0.4	0.7
Overnight respite	No. days/nights	1	0.0	0.0	0.0	0.0	—
Information advice and referral	No. events	12	0.0	0.3	3.2	0.5	0.9
Needs assessment other	No. events	12	0.1	0.4	1.3	0.4	0.3
Medication review	No. events	3	0.1	0.1	0.2	0.1	0.1
Delivered meals	No. meals	1	7.1	7.1	7.1	7.1	—
Community transport	No. one-way trips	3	0.0	0.3	0.4	0.2	0.2

(a) Assumes one-day respite care equivalent to 6 hours.

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

— Nil.



Source: Appendix Table B26.

Figure B5.5: RSL Care Innovative Dementia Care Pilot, expenditure on services, 6 months ending 31 December, 2004

5.6 Accommodation outcomes

Follow-up of RSL Care Innovative Dementia Care Pilot evaluation clients was completed by 7 June 2005. At that time, 50% of clients were still living at home (Table B5.14).

Table B5.14: RSL Care Innovative Dementia Care Pilot, client accommodation setting and government program support status at follow-up, June 2005

Follow-up status	Number of clients
At home	
RSL Care Innovative Dementia Care Pilot	15
Without government program support	1
Total living in community	*16*
In care	
Residential aged care—high care	9
Total in care	*9*
Deceased	5
Not located	2
Total	**32**

6 South Brisbane and Gold Coast Innovative Dementia Care Pilot

6.1 Project description

The Islamic Women's Association of Queensland received an allocation of 20 flexible care places to operate the South Brisbane and Gold Coast Innovative Dementia Care Pilot for a period of three years. The Association works in partnership with the Multicultural Communities Council of the Gold Coast and the Queensland Transcultural Mental Health Centre to deliver the project. The project was established in November 2003 to service eligible residents of Brisbane South and the Gold Coast.

Both the Islamic Women's Association and the Multicultural Communities Council of the Gold Coast are experienced providers of community aged care services. The Islamic Women's Association has been delivering HACC and CACP services since 1995, and operates a day respite unit servicing around 90 clients every week. Services are delivered to eligible recipients on a non-denominational basis. The Multicultural Communities Council began providing HACC and CACP services in 1996, and also operates a day respite centre which services approximately 70 clients per week in three different cultural clusters. Many Council clients are post-World War II immigrants of German, Austrian, Finnish or Polish origin.

For the purposes of the Innovative Pool project, the service catchment area is split between the partner organisations, with Islamic Women's Association servicing Brisbane South and the Multicultural Communities Council servicing clients on the Gold Coast. Project coordination is divided accordingly. The Queensland Transcultural Mental Health Centre provides clinical, education and training support to the Association and Council.

A project steering committee comprises:

- the Management Committees of the Islamic Women's Association of Queensland and the Multicultural Communities Council, Gold Coast
- two ACAT representatives
- a representative of the Australian Government Department of Health and Ageing
- a representative of the Aged Care Mental Health Team based at the Princess Alexandra Hospital, Brisbane
- a representative of the Alzheimer's Association of Queensland
- a representative of the Queensland Health Mental Health Unit with responsibility for Aged Care.

Project objectives and target group

The South Brisbane and Gold Coast Innovative Dementia Care Pilot is designed to meet the dementia care needs of people from culturally and linguistically diverse backgrounds through the provision of culturally appropriate care, including personal care, short-term intensive interventions, carer support and respite care. People selected to join the Pilot must have an ACAT assessment for high level residential care, live in the catchment areas, and have a primary health condition of dementia.

The stated objectives of the project are to:

- meet the dementia care needs of people from culturally and linguistically diverse backgrounds through the provision of culturally appropriate and flexible care including short-term intensive interventions, carer support and respite care
- provide appropriate care and support to carers through psychologically focused individual support strategies, for example, psycho-education, development of coping strategies and group support
- increase access to culturally appropriate dementia health care for people from culturally and linguistically diverse backgrounds
- increase awareness in mainstream dementia care and other relevant mainstream services about the dementia care needs of people from culturally and linguistically diverse backgrounds.

Needs of the target group

An important characteristic of the targeted communities is a strong desire to maintain family members with age-related frailty or disability at home. The Islamic Women's Association and Multicultural Communities Council of the Gold Coast operate Community Aged Care Packages services that deliver 6 to 8 hours of care per week, although both organisations have, through goodwill, delivered up to 12 hours per week to very high needs CACP clients. Funding for mainstream community care packages has been found to be insufficient to support a high needs dementia client and the family carer for an extended period of time.

Needs in the target group reflect both cultural and linguistic diversity and a range of psychosocial factors associated with separation, resettlement and, in some cases, the aftermath of war and persecution. After people immigrate to Australia, many strive to maintain their cultural practices. Continuity in language, food and meal patterns, religious observation, family roles, and living at home is central to cultural identity. For many such older people a move away from the family home to a setting that is not sympathetic to language and cultural observance or acceptance usually entails loss of home and identity. Language barriers in institutional settings impact on socialisation and more fundamental functioning such as food and fluid intake and psychological wellbeing. Providing access to a bilingual care worker means that the client is more likely to eat well and medicate safely. It may be equally difficult for many members of the target group to accept help from outsiders, particularly in the presence of language barriers and lack of cultural and experiential awareness.

Project coordinators remarked on a widespread scarcity of culturally specific care services for older people. A small number of culturally specific residential facilities are in operation but they generally service a limited geographic area. Culturally specific community care is very hard to access. The Gold Coast is said to have no multicultural aged care services apart from the South Brisbane and Gold Coast Pilot.

It is thought that, typically, the family carer pays the price for this lack of formal support. Given the cultural reluctance to use residential care even when needs are at an extremely high level, carers struggle on to their detriment. Carers feel the pressure from other family members and the multicultural community at large to continue in the caring role without seeking outside support. Any sign of not coping is perceived as failing the care recipient and failing the community. Carers in culturally and linguistically diverse communities who have not had access to culturally sensitive services have become used to not seeking help. In most cases, the caring role falls to wives and daughters. It can be a long process to bring a carer to the point of willingness to accept help. Carer support is thus an important aspect of providing a culturally sensitive service to high needs clients.

Care model

The Pilot offers comprehensive packages of care to people with dementia from culturally and linguistically diverse backgrounds who require bilingual support and a culturally sensitive approach to care. Following referral of a client to the project coordinators, if confirmation of dementia is required the Queensland Transcultural Mental Health Centre is able to provide a bilingual mental health consultant from the same cultural background as the client.

The project has devoted time to developing processes and procedures which allow the coordination and integration of care services, a task complicated by the need to source and deploy suitably qualified and experienced staff across a wide range of cultural and language groups and a distributed geographical catchment area.

Whenever possible, clients are matched with care workers from their own culture and language group. This means care workers are able to communicate with clients in their first language, and understand and support clients' social, cultural, religious and culinary needs and preferences. This is particularly important in light of evidence that dementia can cause asymmetrical language loss in bilingual people and has the greatest effect on a person's more recently acquired language (Mendez et al 1999).

Flexible respite care is offered to assist family carers to maintain social participation. This extends to weekends, for example, to allow carers to attend religious services or impromptu outings with friends at shorter notice than is normally possible through mainstream respite services where bookings need to be made in advance and for pre-defined periods of time. Respite care often involves two bilingual workers—one to stay with the person with dementia and one worker to accompany the carer to assist with shopping and appointments, as many carers have limited command of English.

The project provides a 24-hour emergency call service.

Successes and challenges

There are many challenges that arise in delivering care to older people from culturally diverse backgrounds, particularly in relation to dementia care. Some cultures have entrenched views on who should provide care to older family members and this can lead to excessive levels of carer strain. Dementia carries social stigma in some communities which can result in denial and resistance to accepting help from people outside the family. The South Brisbane and Gold Coast Innovative Dementia Care Pilot employs and trains care workers who are familiar with these issues through their own cultural exposure.

Assessment and care planning are complicated by the need to provide bilingual workers and/or translation services for all face-to-face sessions and paperwork (including specialist and allied health assessments), which increases the resources that need to be dedicated to each client's care.

Considerable progress has been made in assisting family carers to look after themselves and reduce the strain and isolation that is often associated with the caring role. Bilingual support for care recipients makes it easier for formal assistance to be introduced or for higher levels of assistance to be accepted. In turn, this eases pressure on family carers.

The project has worked to educate ACAT assessors on approaches to the assessment of people from culturally and linguistically diverse backgrounds, for example, to promote an understanding that it is in some cases inappropriate for a male ACAT member to assess a female client, or that the shame associated with letting a visitor see an untidy house or with 'failing' in the culturally assigned role of caring for a relative can lead carers and families to go to extreme lengths to maintain the impression that they are coping despite high strain.

The AIHW was made aware that the project encountered delays in obtaining referrals from ACATs in its early days, stemming largely from the fact that ACATs were not familiar with the type of service on offer. It was apparent that, at that stage, care recipients were commencing services prior to completion of ACAT assessment. Some clients were said to be transferring from a CACP, having received ACAT approval some time ago. It is not clear that these approvals would have been for high care in all cases, or that each ACAT approval for CACP clients was current at the time of transfer. However, the evaluation data reflect mostly sound referral and assessment patterns, with only one client recording an invalid ACAT approval.

Evaluation issues

Data collection for the evaluation has proved to be a significant challenge for the South Brisbane and Gold Coast Innovative Dementia Care Pilot. Interim services data, due in October 2004, were not supplied. Services data were made available for the first time in April 2005, some four months after the specified deadline. Repeated requests were necessary to extract these data.

As at 4 April 2005, the AIHW was still awaiting a completed evaluation database, the due date for which was 20 December 2004. Socio-demographic and client assessment data are patchy and of inconsistent quality. Identified errors and inconsistencies have been corrected where possible in consultation with the project coordinators.

The project supplied an occupancy report for an incorrect reporting period; hence these data cannot be used. Requested financial reports were not submitted.

Project coordinators expressed dissatisfaction with the lack of information provided by the Department of Health and Ageing on evaluation requirements at the time the project was established and the short period of time to prepare for evaluation prior to its commencement in 2004. English as a second language has made it more difficult for coordinators in this project to manage comprehensive evaluation.

6.2 Client profiles

The South Brisbane and Gold Coast Innovative Dementia Care Pilot provided data for 26 clients, with equal numbers of men and women.[10]

Age and sex

The ages of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients ranged from 63 years to 94 years during the evaluation (mean 79.6 years). Six of the 26 clients were aged 85 years or over (Table B6.1).

Table B6.1: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
Less than 65	1	—	1
65–74	4	1	5
75–84	6	8	14
85+	2	4	6
Total	**13**	**13**	**26**
		(per cent)	
Less than 65	3.8	—	3.8
65–74	15.4	3.8	19.2
75–84	23.1	30.8	53.8
85+	7.7	15.4	23.1
Total	**50.0**	**50.0**	**100.0**

— Nil

Language and communication

Eleven clients had little or no effective means of communication. Another 11 clients had effective spoken communication and two had effective non-spoken means of communication. Means of communication was not stated for two clients.

All clients spoke a language other than English—15 national languages are represented in the evaluation group (Table B6.2). This linguistic (and cultural) diversity makes the South Brisbane and Gold Coast Innovative Dementia Care Pilot unique among the Innovative Pool Dementia Pilot projects.

Linguistic diversity has had an impact on some of the client assessments required for evaluation. In particular, the project reported difficulty in administering the MMSE.

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[10] Two clients recorded leave days in excess of their length of stay in the project. One client was admitted to hospital and entered high level residential aged care after 63 days. It is not possible to tell whether the other client accumulated the 30 leave days during the evaluation period. These two clients are not included in the evaluation because it is not clear that they were actively receiving services from the project during the evaluation period.

Table B6.2: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by language spoken at home and English language proficiency

	How well does client communicate in English?				
Language spoken at home	Very well or well	Not well	Not at all	Not stated	Total
Bosnian	—	1	5	—	6
Arabic	1	—	2	—	3
German	—	1	1	—	2
Spanish	—	—	2	—	2
Hungarian	—	1	1	—	2
Polish	2	—	—	—	2
Greek	—	—	1	—	1
Italian	—	—	1	—	1
Czech	—	1	—	—	1
Finnish	1	—	—	—	1
Latvian	1	—	—	—	1
Romanian	—	—	1	—	1
Serbian	—	1	—	—	1
Ukranian	—	—	—	1	1
Urdu	—	—	1	—	1
Total	**5**	**5**	**15**	**1**	**26**

— Nil.

Accommodation and living arrangement

Clients were living in private residences or retirement villages (Table B6.3). Two clients were in hospital at the time of referral to the project.

Table B6.3: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement			
Accommodation setting	Alone	With family	With others	Total usual accommodation
Private residence	4	18	1	23
Retirement village—self-care	1	—	—	1
Not stated	2	—	—	2
Total	**7**	**18**	**1**	**26**

— Nil.

Years at usual place of residence ranged from one to 32 years. Six clients had been living in the same home for 10 or more years. Two clients changed residence in the two years prior to entering the project.

Carer availability

Twenty-one clients had a carer, 16 of whom were living with the care recipient at the time of the evaluation (Table B6.4).

Carers' ages ranged from 25 to 82 years, averaging 60.2 years. Seven carers were aged 75 years or over (Table B6.5).

Table B6.4: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by carer availability, carer relationship to client and carer co-residency status

Relationship of carer to client	**Carer lives with client**	**Carer does not live with client**	**Not stated**	**Total**
Spouse or partner	10	—	—	10
Son or daughter	6	3	—	9
Other relative	—	1	—	1
Not stated	—	—	1	1
Total clients with a carer	*16*	*4*	*1*	*21*
Total clients				**26**
Per cent of clients with a carer				80.7

— Nil.

Table B6.5: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of carers by age group and sex.

Age (years)	**Males**	**Females**	**Persons**
25–44	3	2	5
45–54	1	2	3
55–64	1	2	3
65–74	—	2	2
75–84	1	6	7
Not stated	—	1	1
Total	**6**	**15**	**21**

— Nil.

Income and concession status

The age pension was the primary source of cash income for all 26 clients (Table B6.6). All but one client held a health care concession card. Eighteen clients received a discounted weekly contribution rate for the South Brisbane and Gold Coast Innovative Dementia Care Pilot due to financial hardship.

Table B6.6: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by principal source of cash income, health care card status and project concession status

	Number	Per cent
Principal source of cash income		
Age pension	26	100.0
Total	**26**	**100.0**
Health care concession card holder	25	96.1
Project concession status	18	69.0

Client co-payments ranged from nil to $7 per day, with a median of $4.50 per day.

Previous use of government community care programs

Four clients were not receiving assistance from government community care programs when they entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot (Table B6.7). Sixteen clients had been receiving assistance through CACP prior to joining the project, and three clients were receiving HACC-funded services. One client was receiving assistance through the EACH program, and one carer had accessed the National Respite for Carers Program. Project coordinators reported that clients were transferred from mainstream programs to receive higher hours of care and/or dementia-specific care with bilingual support.

Table B6.7: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by previous use of government support programs

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	16	61.5
Extended Aged Care At Home	1	3.9
Home and Community Care	3	11.5
National Respite For Carers Program	1	3.9
Other program	1	3.9
Total clients with previous government program support	*22*	*84.6*
Clients without previous government program support	4	15.4
Total	**26**	**100.0**
Use of respite care in the 12 months prior to project		
Respite care needed but not used	11	52.4
Respite care used	4	19.0
Respite care not needed	3	14.3
Not stated	3	14.3
Total	**21**	**100.0**

All of the carers who had accessed any form of respite in the 12months prior to entering the project had used mainly residential respite (four carers). Eleven carers indicated that they had not needed respite but had not accessed respite services. Three carers said that they had not need respite services in the 12 months prior to entering the pilot. Previous respite care use is not recorded for three carers.

Four clients were reported to be on a waiting list for residential aged care when they started with the project.

Assessment and referral

The majority of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients were existing clients of the Islamic Women's Association or Mutlicultural Communities Council, were known to these organisations or were referred by an ACAT (Table B6.8). Six clients were referred by another agency.

Table B6.8: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by source of referral

Referral source	Number of clients
Islamic Women's Association/Multicultural Communities Council	9
Aged Care Assessment Team	8
Other agency	6
Hospital	1
Family	1
Not stated	1
Total	**26**

Nine clients completed an ACAT assessment on the same day or prior to referral to the project ACAT assessment was completed after referral to the project for 17 clients. In most of these cases, the pattern of referral and assessment involved, firstly, a referral to the project, followed soon after by initial needs assessment (screening) by a project coordinator. ACAT assessment would be completed within a short timeframe and services commenced shortly thereafter, subject to ACAT approval. In some cases there was a lengthy delay between approval and commencement of services. Thus, referral date in many cases did not coincide with service commencement.

Table B6.9: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–20 days	5
21–120 days	—
121–180 days	3
Over 180 days	1
Total	*9*
After referral to project	
Between 6 and 337 days post-referral	17
Total	**26**

— Nil.

The care of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients is managed by a social worker (14 clients), a nurse manager (six clients) or a welfare and community worker (six clients).

Health conditions and health status on entry

The number of health conditions recorded for clients at entry to the project ranged from two to nine. Fifteen of the 26 clients had five or more health conditions. Table B6.10 shows that dementia is the most frequently recorded primary health condition.

Table B6.10: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by primary health condition

Primary health condition	Number of clients
Dementia (includes Alzheimer's and other types of dementia)	22
Neurotic, stress related and somatoform disorders	1
Mental and behavioural disorders	1
Diseases of the circulatory system	1
Diseases of the kidney and urinary system	1
Total	**26**

Twenty-five of the 26 clients were assessed as being at risk of falls due to impaired gait or balance and 25 displayed signs of disorientation. Eighteen clients had a diagnosis of depression (Table B6.11).

Table B6.11: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	25
Disorientation/confusion	25
Diagnosis of depression	18
Vision impairment	9
Hearing impairment	6
Missing or non-functional limbs	2
Total or partial paralysis	3

Clients were taking between zero and 21 different medications. Ten of the 26 clients were taking 10 or more different medications.

Clients and carers were asked to rate client health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Proxy reports were given by 13 carers and by a care worker in seven cases. One client self-reported. Self-reported health status is missing for all other clients. Seventeen clients were reported to be in poor health.

Two respondents indicated that the client was in a better state of health than a year earlier and four clients were said to be in about the same state of health. Ten respondents said that the client was in a worse state of health than 12 months earlier (four much worse).

These results suggest that the care needs of at least half of the clients may have increased in the 12 months prior to entering the project.

Level of core activity limitation

Most South Brisbane and Gold Coast Innovative Dementia Care Pilot clients experienced severe to profound activity limitation in all three core activity areas: self-care, mobility and communication (Table B6.12).

Twenty-one clients are reported to have experienced severe or profound activity limitation in at least one core area at the time of the evaluation.

Table B6.12: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	1	4	21	**26**
Mobility	1	3	5	17	**26**
Communication	—	6	5	15	**26**

— Nil.

Use of medical and hospital services prior to entry

Use of medical and hospital services in the 6 months before joining the project was recorded for 25 clients. Among these clients, 22 had visited a medical practitioner at least once. The reported number of visits to a medical practitioner in the 6-month period varied from zero to 25 per client. Cumulatively, the 22 clients recorded 187 visits to a medical practitioner outside of a hospital setting over an estimated 3,960 person days.

Less than 25% of clients were recorded as having used hospital services in the 6 months prior to entering the project. Five clients contributed to a total of 11 hospital admissions in the pre-entry period. The four clients who recorded unplanned hospital admissions collectively accumulated 69 unplanned hospital bed days over approximately 720 person days. Individually, they recorded between 5 and 35 days in hospital for unplanned admissions.

Conditions recorded as occasioning admission to hospital for South Brisbane and Gold Coast Innovative Dementia Care Pilot clients in the pre-entry period include:

- falls
- heart disease
- other diseases of the digestive system.

One client recorded a fall with injury, one client was rendered immobile and without assistance for more than 30 minutes, and one client suffered another serious medical emergency during the pre-entry period. Another client suffered a serious medical emergency and was rendered immobile without assistance in the same period.

6.3 Client assessment results

Cognitive function

MMSE scores were recorded for 21 clients when they entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot. A score of zero was recorded for eight clients. Non-zero scores range between 3 and 22 out of a possible 30 points (mean of non-zero scores 10.1; standard deviation 6.1; median 8.5). The Gold Coast arm of the project recorded missing values (five) or scores of zero (four) or 6 points (three) only. The AIHW has concerns that this pattern of scores may not reflect real entry levels of cognitive function, particularly in view of known limitations of the MMSE for use in culturally and linguistically diverse groups. MMSE scores from the Gold Coast arm and zero scores from the Brisbane arm of the South Brisbane and Gold Coast Innovative Dementia Care Pilot were excluded from analysis of the data, leaving 10 valid MMSE scores from this project.

Cut-points to account for educational attainment were applied to valid entry MMSE scores (Uhlmann & Larson 1991). This indicated that all 10 clients for whom a valid score was recorded were likely to have had cognitive impairment when they entered the project. It is noted that application of the MMSE has not been validated in culturally and linguistically diverse populations and therefore these results should be interpreted with caution.

Activities of daily living (ADL)

At entry to the project at least half of South Brisbane and Gold Coast Innovative Dementia Care Pilot clients needed assistance in tasks involving self-care and mobility (Figure B6.1). MBI scores at entry range from 5 to 18 out of a total 20 points. The mean score was 11.3 points with a standard deviation of 4.3 (median 11).

Using a classification scheme for the Barthel Index (Shah et al. 1989), the entry scores indicate that five clients were totally dependent in self-care and mobility when they commenced with the project, 15 clients exhibited severe dependency, and four clients exhibited moderate dependency. Twenty of the 23 clients for whom MBI entry scores are recorded were either sometimes or always bowel incontinent and 18 clients were sometimes or always bladder incontinent at the time of entry. Twenty-two clients were unable to bathe or shower without assistance. Most clients needed help in the areas of dressing, grooming, feeding and transfers.

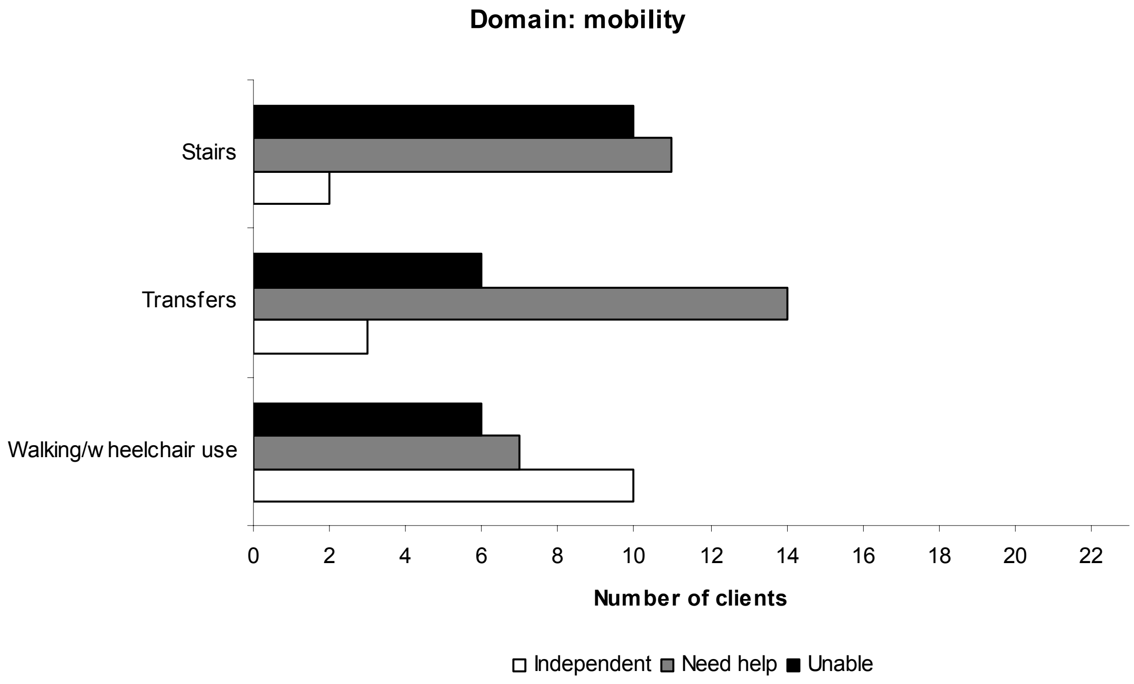
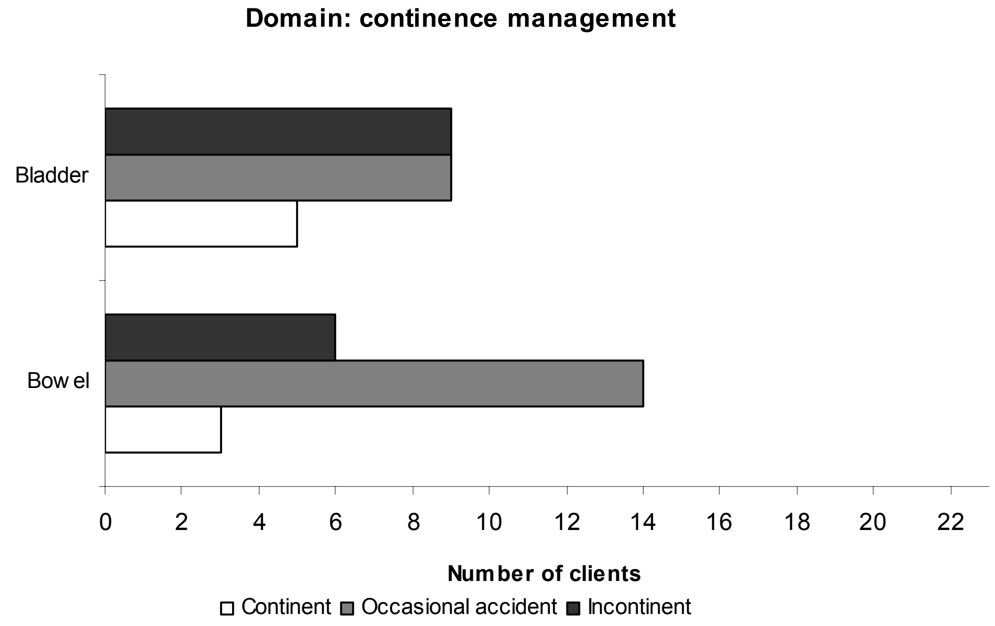
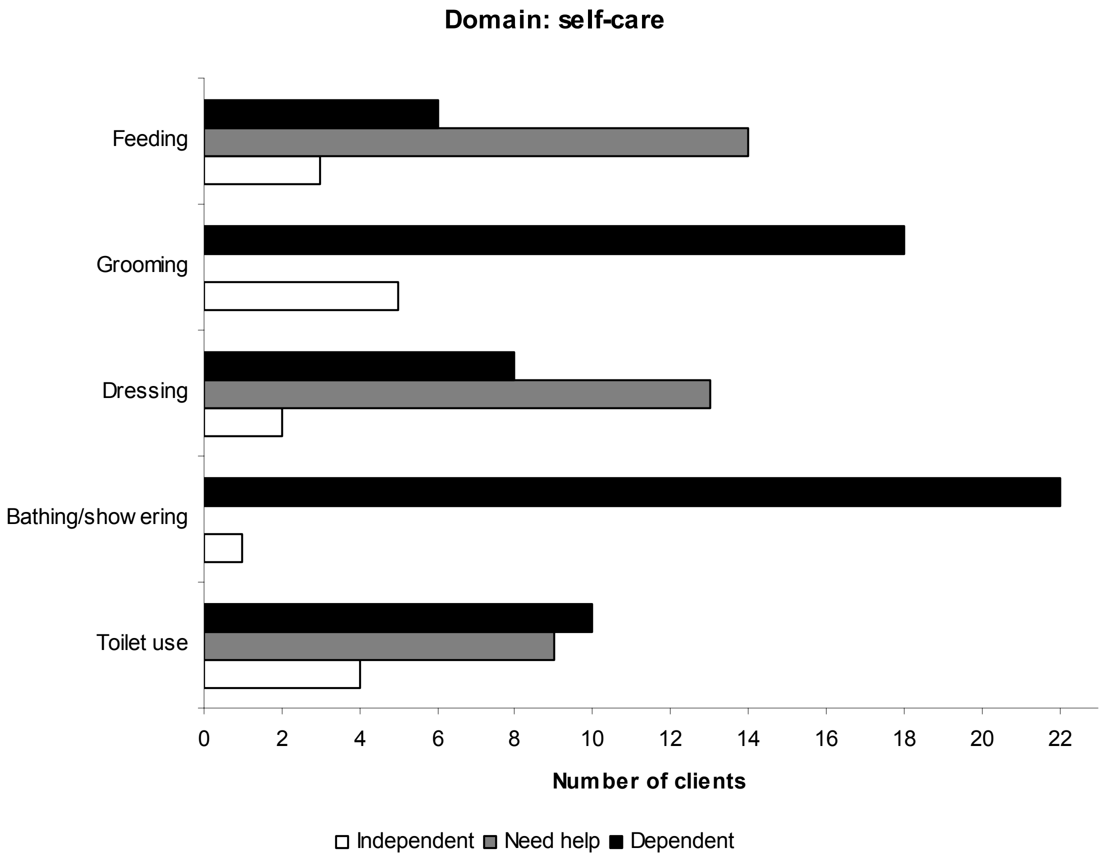


Figure B6.1 continued: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

(continued)

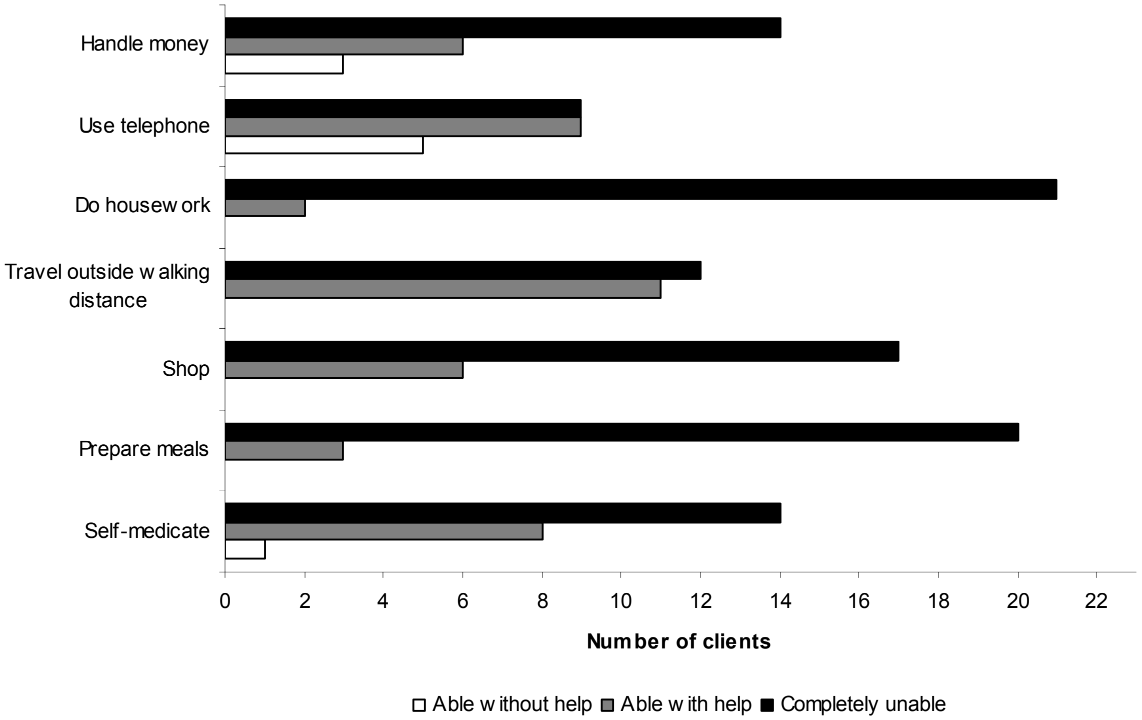




Source: Appendix Table B17.

Figure B6.1 continued: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

Most clients were highly dependent in IADL when they entered the project (Figure B6.2). On average, clients were totally dependent in between four and five out of seven IADL. Although 10 clients could mobilise independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment.



Source: Appendix Table B18.

Figure B6.2: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of IADL function at entry

The project was asked to take two more assessments after entry. In some cases only one further assessment result was recorded. Figure B6.3 shows the MBI scores for clients at baseline, interim and final assessments for clients in the community at follow-up. Clients in the community were either still with the project, in other community care or were not accessing formal care. Only three clients exited to an aged care facility, one of whom had an MBI score of 10 points at entry and 8 points at final assessment. The other two clients recorded MBI scores of zero at all assessments.

A wide range of functioning in ADL at entry is evident, as is marked variation in change in functioning over time. A considerable number of clients continued to be supported at home despite low baseline levels of ADL function and/or significant deterioration between the interim and final assessment points.

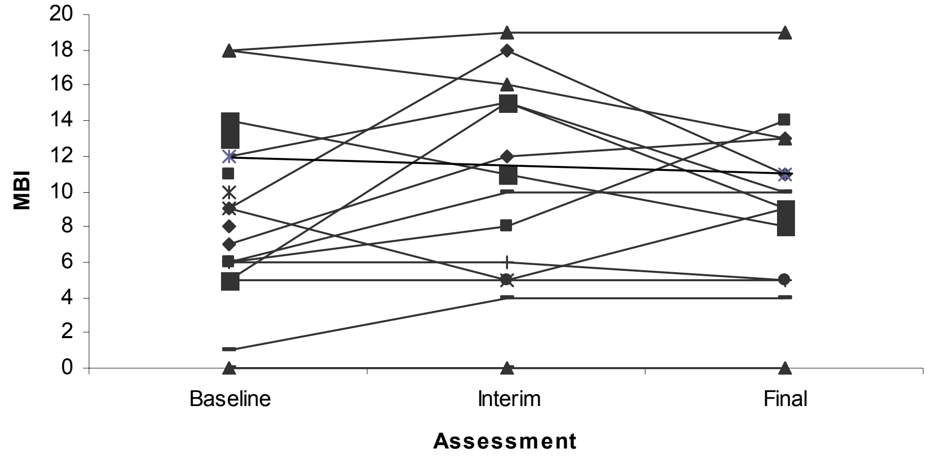


Figure B6.3: South Brisbane and Gold Coast Innovative Dementia Care Pilot clients, MBI at baseline, interim and final for clients living in the community at follow-up (one symbol per client)

Psychological and behavioural symptoms

Baseline behavioural data were recorded for 23 clients. Sixteen clients showed signs of memory loss on an intermittent or extensive basis when they entered the project (Figure B6.4). Thirteen clients showed intermittent or extensive signs of emotional or psychological symptoms of dementia. One client was reported to be physically aggressive most of the time, and eight others displayed intermittent or occasional physical aggression. Seven clients wandered or displayed intrusive behaviour on an intermittent or extensive basis. Six clients presented a danger to self or others intermittently or extensively. Around half of the clients are recorded to have exhibited other, unspecified, dementia-related behaviour, either intermittently or extensively. Eight clients exhibited two or more psychological and behavioural symptoms on an extensive basis.

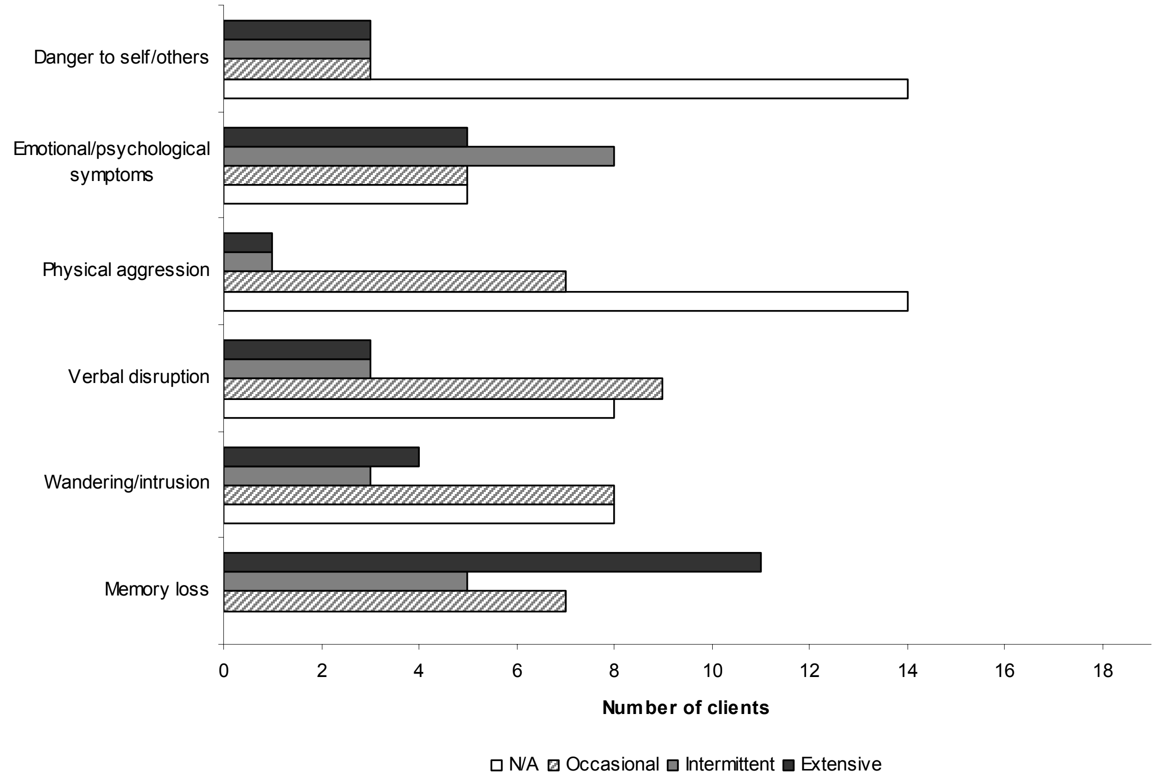


Figure B6.4: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by frequency of behavioural and psychological symptoms at entry

6.4 Carer assessment results

Three of the 21 carers reported that they were in good health at the time that their care recipient entered the South Brisbane and Gold Coast Innovative Dementia Care Pilot, eight reported fair health, and five reported poor health. Self-reported health status was not recorded for five carers.

Fourteen carers completed the CSI to generate a mean score of 9.9 points. Scores ranged from 3 points to 13 points. All but one carer recorded a score above the threshold for high carer strain. Ten of these carers completed a second assessment. The median change score (final score minus baseline score) was zero (mean –0.1 point). Individual change scores range from –2 to 3 points.

The 14 carers also completed the GHQ-28. Four carers scored above 14 points on at least one sub-scale. Three carers recorded scores of 14 points or higher for somatic symptoms; four carers recorded scores of 14 points or higher for anxiety and insomnia, one of whom scored the maximum 21 points; and two carers scored over 14 points for social dysfunction. No carers scored 14 points or higher for severe depression.

Eleven carers completed the GHQ-28 at a final assessment. Three of these carers scored 14 points or higher on at least one sub-scale.

Analysis of change in CSI and GHQ-28 scores was performed across the projects due to small sample sizes in individual projects.

6.5 Service profile

South Brisbane and Gold Coast Innovative Dementia Care Pilot recorded a wide range of service types during the evaluation. Higher numbers of clients received personal assistance, domestic assistance, respite care, social support, nursing care and allied health care and transport (Table B6.13). The project also reported a considerable level of activity in transporting clients to medical appointments, arranging referrals to health care providers and providing advocacy and bilingual support to clients and carers on these occasions.

Respite care provision in this project is likely to be relatively expensive because of the bilingual support requirements and provision of two workers for many respite care sessions; however, the project declined to provide financial data and a breakdown of costs of care by service type is not available.

Table B6.13: South Brisbane and Gold Coast Innovative Dementia Care Pilot, summary of services per client per week

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Personal assistance	Hours	21	0.2	3.2	8.4	3.6	2.5
Domestic assistance	Hours	21	0.4	2.4	10.2	3.2	2.4
Respite (in-home and day)[(a)]	Hours	18	0.0	2.6	16.4	5.3	5.6
Social support	Hours	18	0.0	1.0	6.5	1.7	1.8
Food service other	Hours	17	0.3	1.6	4.9	1.8	1.3
Allied health[(b)]	Hours	17	0.0	0.1	0.2	0.1	0.1
Nursing care	Hours	14	0.0	0.3	9.6	1.2	2.5
Aids and equipment	Dollars	12	6.2	17.5	73.6	21.9	16.9
Interpreter/translator	Dollars	8	3.3	10.4	21.0	11.8	6.6
Home modifications and maintenance	Dollars	1	1.7	1.7	1.7	1.7	—
Assist.—GP consultation	No. contacts	14	0.1	0.4	1.3	0.5	0.4
Community mental health service	No. contacts	3	0.0	0.1	0.1	0.1	0.0
Assist.—GP–EPC consultation[(c)]	No. contacts	2	0.6	0.6	0.6	0.6	0.0
Geriatrician	No. contacts	2	0.0	0.1	0.1	0.1	0.0
Assist.—psychiatrist consultation	No. contacts		0.1	0.1	0.1	0.1	—
Assist.—neurologist consultation	No. contacts	1	0.0	0.0	0.0	0.0	—
Recreation/leisure programs	No. days/nights	3	0.1	0.1	1.0	0.4	0.5
Rehabilitation service	No. days/nights	1	0.2	0.2	0.2	0.2	—
Living skills development	No. days/nights	1	0.0	0.0	0.0	0.0	—
Medication review	No. events	21	0.1	0.6	1.9	0.8	0.5
Information advice and referral	No. events	12	0.0	0.2	3.2	0.5	0.9
Carer support other than respite combined	No. events	12	0.1	0.3	1.2	0.5	0.9
Allied health other	No. events	1	0.1	0.1	0.1	0.1	—
Delivered meals	No. meals	1	0.6	0.6	0.6	0.6	—
Community transport	No. one-way trips	18	0.2	1.8	11.2	2.7	2.6
Dementia care, memory and behaviour management	No. referrals	11	0.1	0.3	3.8	0.8	1.1
Dietetics	No. referrals	6	0.1	0.1	0.4	0.2	0.1

(a) Assumes one-day respite equivalent to 5 hours. .

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(c) EPC—Enhanced Primary Care

— Nil.

6.6 Accommodation outcomes

South Brisbane and Gold Coast Innovative Dementia Care Pilot follow-up was completed by 8 June 2005. Table B6.14 shows accommodation setting and government support program for all clients at follow-up (that is, between approximately 9 and 12 months from the start of the evaluation period).

Fourteen clients were still living in the community and being supported by the South Brisbane and Gold Coast Innovative Dementia Care Pilot project.

Formal follow-up was not completed for the three clients who were discharged to hospital during the evaluation. The project coordinator was able to report that one client who was discharged to hospital after approximately 2 weeks in the project eventually returned home with HACC services. One other client who was discharged to hospital subsequently entered residential aged care after approximately 2 months. These two clients are included in the 'Not located at follow-up' category in Table B6.14, as no formal follow-up was conducted and consequently the accommodation setting and government support status at the time of follow-up is unknown.

Table B6.14: South Brisbane and Gold Coast Innovative Dementia Care Pilot, client accommodation setting and government program support at follow-up, June 2005

Location and program support at follow-up	Number of clients
At home	
Receiving services from the Pilot service	14
Community Aged Care Packages	1
Home and Community Care	1
Total living at home	*16*
Residential aged care—high care	1
Deceased	5
Not located at follow-up	4
Total	**26**

Notes

1. One client left the project to be admitted to hospital and returned home with HACC services after 2 months in hospital.
2. One client moved out of the area and could not be contacted.
3. Two clients transferred to another agency (type of agency not stated) and were not contacted for follow-up.
4. The client listed as being in high level residential care had been discharged from the project to hospital and entered an aged care facility via hospital.

7 Ozcare Innovative Dementia Care Packages

7.1 Project description

Ozcare in Queensland received an allocation of 30 flexible care places to operate the Ozcare Innovative Dementia Care Packages project for three years. The project services the cities of Bundaberg, Rockhampton and Gladstone and their surrounding regions, a catchment area that extends approximately 350 km from Ridgelands, north-west of Rockhampton, south to Bundaberg, and 100 km inland from Bundaberg to Mt Perry.[11] Service is coordinated from centres in Bundaberg and Rockhampton.

Ozcare is a large and long established not-for-profit provider of community and residential aged care services in Queensland (Ozcare formerly operated as St Vincent's Community Services). The organisation delivers HACC, CACP, EACH, Veterans' Home Care, and National Respite for Carers Program services from over 20 locations state-wide. Community nursing is delivered with funding from HACC and the Department of Veterans' Affairs. A range of other services cater to the needs of special needs groups such as services for homeless people, women's shelters, and drug and alcohol rehabilitation programs.

Approval to commence services was received on 13 October 2003 and the first care recipients were accepted into the project over the following week.

Project objectives and target group

The stated objectives of the project are to:

- provide a comprehensive approach to dementia services for people with behaviours that normally would be difficult to manage in a community setting
- provide a service that focuses on the maintenance of clients' and carers' social capacity and functioning through behaviour management programs for clients
- increase support to carers of people with dementia and associated challenging behaviours living in the community through delivery of flexible service options such as live-in respite, weekend and evening respite and emergency in-home respite
- reduce premature admission of clients to residential care.

The project targets people with a primary diagnosis of dementia who wish to remain living in the community and who have a current ACAT approval for residential high care. A mix of frail aged and middle-aged ambulatory clients with advanced dementia was anticipated. It was also expected that the project would support clients with or without a family carer. Most people accepted into the Pilot had been receiving assistance from family or friends.

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[11] The catchment area for the Bundaberg arm includes Isis, Kolan and Mt Perry Shires; Rockhampton/Gladstone arm includes Mt Morgan, Gracemere, Capricorn Coast, Alton Downs, Ridgelands, Gladstone, Boyne Island and Tannum Sands.

In addition to high hours of care, delivered flexibly, key innovative features of the service include:

- access to alternative therapies
- flexible hours
- block respite care for overnight and weekends
- multiple service encounters per day.

Identified areas of unmet need

Ozcare reported on past experience in servicing high care community clients. A typical pattern was described as a person with ACAT approval for high level residential care who is waitlisted for placement at one or more aged care facilities. Many family carers would prefer their partner or parent to remain living with them in the community, however, limited hours of care and limited access to respite care can leave the carer with little alternative but to actively pursue permanent placement, particularly when faced with increasing behaviour management difficulties. Thus, the primary area of unmet need in the target group is access to high hours of community care with flexible delivery. In this respect, the project does not represent a significant departure from Ozcare's existing service model for the client group, but it allows Ozcare to deliver an adequate level of service to an existing client base more effectively and efficiently through flexible funding.

The spread of resources over a large geographic region, which involves high travel costs to rural and remote areas, has a considerable impact on service delivery in the region.

On the question of specific issues that impact on older people with dementia-related needs and their carers, Ozcare made a number of observations:

1. People can experience great difficulty in obtaining a medical diagnosis of dementia and this limits their timely access to appropriate community services. For example, at the time of reporting, people in the region had no access to a geriatrician; a neurologist visited Rockhampton once a month; Bundaberg had no visiting neurologist. By the time services receive a referral, more than likely the care recipient is exhibiting advanced behavioural symptoms.
2. Many people with dementia and their families and carers would benefit from earlier introduction to formal services through the National Respite for Carers Program together with CACP or HACC services. Diagnosis and medical management are critical to implementing appropriate care pathways.
3. There is a lack of access to memory clinics.
4. Family members and carers are generally reluctant to use advisory services that are located in the south, for example, the Dementia Advisory Service call centre that operates from South Australia.
5. Carers can be reluctant to use residential respite services because of the time constraints that are often involved. Many residential respite services offer care for a minimum of 7 days and many care recipients do not respond well to a prolonged period away from home and familiar faces. Day respite centres are an alternative respite option but are not available in all areas and travel time to regional centres can be prohibitive.

Care model

The project provides ongoing comprehensive dementia-specific care in order to cater for clients with high care dementia needs under a single package of care rather than multiple funding categories or multiple service providers, and to improve continuity of care and case management. A multidisciplinary approach to care planning places an emphasis on carer involvement, carer support and respite services. In particular the project aims to fill identified gaps for dementia-specific respite care services (residential and in-home) and transport services.

All client assessments are conducted by a project coordinator (care manager) or assistant coordinator. Specialised assessments are brokered to the appropriate professionals, for example, occupational therapist or social worker. Initial needs assessment typically takes 1.5 to 2 hours in the home. Record keeping, obtaining informed consent, care planning and scheduling following an initial assessment can take up to an additional 2 hours. This activity often extends to organising enduring power of attorney and referrals to outside providers for additional services (medication management, meals on wheels, home nursing). Care plans are reviewed 1 month after commencement and then every 2 to 3 months. Carers are consulted in the first fortnight to check on progress.

The range of services available to approved recipients includes but is not limited to the following, in addition to case management and coordination:

- personal care
- nursing and allied health care
- respite care, including block respite and overnight care
- domestic assistance
- meal preparation and nutrition management
- assistance with minor home modifications and access to aids and equipment
- transport
- emergency medical alarm
- carer education.

Salaried employees deliver personal and domestic assistance service and Ozcare brokers to other organisations for nursing care, alternative therapy and allied health, home maintenance and delivered meals.

The project aims to increase social participation for people with dementia and provide dementia-specific care plus short-term residential respite options.

At the outset it was anticipated that care recipients would need an average of 15–20 hours of care per week. An upper limit of 20 hours per care recipient per week was set, with scope for adjustment depending on the prevailing needs of the client group.

Care workers trained in manual handling and behaviour management are available to assist carers with special needs. Carer support also involves referral to and provision of information on other assistance programs, for example, the Dementia Hotline and education offered through Queensland Council of Carers and Alzheimer's Association.

Staffing

Four care managers (two full-time equivalent staff) are responsible for assessment, care planning and service coordination for project clients in addition to clients in other programs. The 30 places are divided evenly between the Rockhampton and Bundaberg regions so that each care manager would normally be responsible for seven or eight clients. One full-time equivalent staff member provides administrative support.

Care workers for the project work across the range of Ozcare community care programs. In mid-2004, approximately 30 individuals (12 full-time equivalent staff) were delivering client care. Care managers aim to limit to three the number of care workers who attend an individual client. Covering staff leave is usually manageable with this system. Registered nursing and allied health services are brokered as needed.

The Pilot has highlighted workforce issues in working with the target group. There is a need for higher levels of training, in particular. A Certificate III is a very basic qualification and may not adequately equip staff to work with clients who have high dementia-related needs. Numbers of staff had to be increased to ensure that several workers became sufficiently familiar with every client and the staff roster needs to be flexible enough to provide after-hours services, including overnight care.

Successes, challenges and lessons

The Ozcare Innovative Dementia Care Packages has demonstrated that it is possible to maintain high care clients with dementia at home with a comprehensive care package and a dementia-specific focus to care provision. Notable successes include two clients who returned home from aged care facilities to take up a package and another client who received a package at a time of crisis in care (while waiting for residential placement) and decided to continue with the package rather than take a residential place when one became available. Based on past experience, it has been observed that comprehensive care packages and high level care management enable Ozcare to support clients at home for longer. Families of clients who have died or entered residential care have stated that, were it not for the care package, the care recipient would likely have died in hospital or entered into care via hospital. Many package clients have accessed residential respite care in the past but families have expressed much higher satisfaction with package care at home. Such examples demonstrate a strong preference for high care at home provided appropriate formal supports are in place.

Overall, the service model has developed in line with Ozcare expectations, although social support and community access aspects of the service have expanded in response to needs within the target group. The client base for the Pilot is what was expected from the Ozcare experience of operating dementia-specific services for the National Respite for Carers Program and CACP. Limited access to aids and equipment and high hours for care coordination have presented two practical constraints to flexible service delivery.

It was suggested that the type of service offered through the Pilot could be mainstreamed into the EACH program.[12] Key factors said to distinguish this service from most currently available service models for the target group are attention to dementia-specific needs through knowledge and understanding of the needs of people with dementia, their carers and families; skills in assessment and care planning; maintaining the group as a service

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[12] Dementia-specific EACH packages were announced subsequent to these discussions.

target to prevent care recipients from being relegated to the 'too hard' category; and access to staff training for specialised areas of care. It was suggested that this target group should be classified as a special needs group.

Ozcare identified lack of early referral and timely intervention as a main challenge to maintaining clients in community care. Many people have reached crisis point by the time of their first ACAT assessment, so that it can be difficult or impossible for the client and family to consider community-based care. Alternatively, a package may be accepted as a perceived solution to the waiting for placement period. Many people in this situation expect that residential care is the only real longer term option. The project identified two factors which contribute to delays in referral to community-based services:

1. Difficulty gaining a definitive diagnosis of dementia means that referral to appropriate services is not timely for many members of the target group. People are often reluctant to discuss symptoms with their doctor and access to specialist geriatric practitioners is limited in rural areas. Diagnosis is typically triggered by a crisis event.
2. Some clients refuse services because of co-payment policy, even though the level of fee is negotiable. This can delay clients receiving appropriate care, which can increase the risk of an acute episode or sustained functional decline. Ozcare suggested that people do not always refuse services with a co-payment attached because of affordability, rather, as a matter of principle. Reference was made to a general resistance in Queensland to the 'user pays' philosophy.

Distance is another challenge in rural/remote regions such as those serviced by this project. Lack of access to allied health and specialist medical services, vehicle availability, and limited public transport all contribute to the tyranny of distance. Staff travel in the course of service delivery is expensive and time consuming: Ozcare estimates that one hour of staff travelling time is required for every 7.2 hours of care services delivered in the region.

Approximately half of the people accepted into the project have had a nursing assessment for continence management. The 'retraining' approach to continence management (regular toileting without the use of continence aids) creates a number of issues for services and family carers. Multiple home visits per day are usually required, with carer assistance on each occasion. Skilled continence nurses should attend for training purposes. Ozcare remarked that some family carers reject this care-intensive approach to continence management.

A number of risks to maintaining a person in the target group at home with high level support have been observed:

- pressure from family members for the person to enter residential aged care
- occupational health and safety issues, including unsafe home environments and client aggressive behaviour
- limited availability of aids and equipment—some clients require equipment such as a hoist and specially trained staff. The project supplies smaller pieces of equipment but not large items or major home modifications
- unsafe client behaviours, for example, wandering, in a client who lives alone. The project manages risks to the extent possible, for example for one client, the gas stove was disconnected and a microwave was installed. Risk needs to be assessed on a case-by-case basis and carer availability can be a major consideration in the assessment.

In conclusion, Ozcare believes that flexible, high care packages have enormous potential and views this type of service as offering potential for continual improvement and a means of attracting new services to the region. The Pilot has allowed staff to further develop the skills to deliver some of the new initiatives in dementia care. Earlier intervention is thought to be one critical factor in achieving the desired outcomes for this target group and holds the promise of long-term benefits for clients and families, service providers and the health and aged care systems.

7.2 Client profiles

Ozcare Innovative Dementia Care Packages supplied evaluation data for 35 clients, including nine men and 26 women. These data, summarised below, describe the group during the evaluation (June to November 2004) or, where indicated, at date of entry to the project.

Age and sex

Ages of Ozcare clients ranged from 55 years to 93 years (mean 80.2 years). Twelve clients were aged 85 years or over (Table B7.1).

Table B7.1: Ozcare Innovative Dementia Care Packages, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
Less than 65	—	2	2
65–74	2	4	6
75–84	5	10	15
85+	2	10	12
Total	**9**	**26**	**35**
		(per cent)	
Less than 65	—	5.7	5.7
65–74	5.7	11.4	17.1
75–84	14.3	28.6	42.9
85+	5.7	28.6	34.3
Total	**25.7**	**74.3**	**100.0**

— Nil.

Language and communication

Eight clients had little or no effective means of communication. Two national languages were represented (Table B7.2).

Table B7.2: Ozcare Innovative Dementia Care Packages, number of clients by language spoken at home and proficiency in English

	How well does client communicate in English?				
Language spoken at home	**Very well or well**	**Not well**	**Not at all**	**Not stated**	**Total**
English	27	5	1	1	34
Italian	—	1	—	—	1
Total	**27**	**6**	**1**	**1**	**35**

— Nil.

Accommodation and living arrangement

Clients were living in private residences and retirement villages (Table B7.3). Five clients were living alone.

Table B7.3: Ozcare Innovative Dementia Care Packages, number of clients by usual accommodation setting, living arrangement and accommodation setting

	Usual living arrangement		
Accommodation setting	**Alone**	**With family**	**Total**
Private residence	4	26	30
Retirement village—independent living	1	2	3
Other, not stated	—	2	2
Total	**5**	**30**	**35**

— Nil.

Years at usual place of residence ranged from less than one to 58 years. Four clients had been living in the same home for over 40 years.

Carer availability

Thirty-two clients had a carer, 28 of whom were living with the care recipient (Table B7.4). Recorded ages of carers range from 45 to 91 years with an average of 67.6 years. Seven carers were aged 75 years or over (Table B7.5).

Table B7.4: Ozcare Innovative Dementia Care Packages, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Total
Spouse or partner	20	—	20
Son or daughter	8	3	11
Other relative	—	1	1
Total clients with a carer	*28*	*4*	*32*
Clients without a carer			3
Total clients			**35**
Per cent of clients with a carer			91.4

— Nil.

Table B7.5: Ozcare Innovative Dementia Care Packages, number of carers by age group and sex

Age (years)	Males	Females	Persons
45–54	1	5	6
55–64	1	3	4
65–74	8	4	12
75–84	4	2	6
85+	1	—	1
Not stated	2	1	3
Total	**17**	**15**	**32**

— Nil.

Income and concession status

Government pensions were the primary source of cash income for 31 clients (Table B7.6). Thirty clients held a health care concession card and six clients received a discounted weekly contribution rate for the project due to financial hardship.

Table B7.6: Ozcare Innovative Dementia Care Packages, number of clients by principal source of cash income, health care card status and project concession status

Principal source of cash income	Number of clients	Per cent
Age pension	27	77.1
DVA pension	4	11.4
Superannuation	3	8.6
Spouse or partner	1	2.9
Total	**35**	**100.0**
Health care concession card holder	30	85.7
Project concession status	6	17.1

Client co-payment amounts ranged between $1 and $6 per day (median $5 per day).

Previous use of government community care programs

Twelve clients were not receiving assistance from government community care programs before they entered the project (Table B7.7). Six clients had been using a HACC service.

Two carers reported that, despite having had a need for respite care in the 12 months prior to the Ozcare project, they had not used a respite care service. Of the carers who had accessed respite care in the 12 months before entering the project, 15 had used mainly in-home respite and eight had used mainly residential respite. Six carers said they had not needed respite.

Table B7.7: Ozcare Innovative Dementia Care Packages, number of clients by previous use of government support programs

Previous use of government support programs	Has a carer	No carer	Total	Per cent
Government support program				
National Respite for Carers Program	15	2	17	48.6
Home and Community Care	5	1	6	17.1
Total clients with previous government program support	*20*	*3*	*23*	*65.7*
Clients without previous government program support	12	—	12	34.3
Total	**32**	**3**	**35**	**100.0**

— Nil.

Nineteen clients were on a waiting list for residential aged care.

Assessment and referral

The project receives most referrals from ACAT (Table B7.8).

Table B7.8: Ozcare Innovative Dementia Care Packages, number of clients by source of referral

Referral source	Number of clients
Aged Care Assessment Team	21
Ozcare	11
Other health or community service	2
Family	1
Total	**35**

Thirty clients had completed an ACAT assessment on the same day or prior to referral to the project. For these clients, the time between completion of an assessment and referral to the project varied from day of referral to 675 days (Table B7.9).

ACAT assessment was completed after referral to the project for five clients.

The project encountered some early difficulties that were associated with a lack of knowledge of the service and approval requirements among ACAT staff. Ozcare remarked that people seeking ACAT approval for placement might not have been given the option of a high care package and it is felt that slow early referrals were due to poor briefing and a lack of guidelines for referring ACATs.

Table B7.9: Ozcare Innovative Dementia Care Packages, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–20 days	20
21–30 days	2
31–60 days	1
61–90 days	2
91–120 days	—
121–180 days	1
181–365 days	2
Over 1 year	2
Total	*30*
After referral to project	
1, 4, 12, 41 and 373 days post-referral	5
Total	**35**

— Nil.

Health conditions and health status on entry

The number of health conditions recorded for Ozcare clients ranges from one to nine. Twenty-six of the 35 clients had three or more health conditions at entry. Dementia was recorded as the primary health condition for 34 clients.

Twenty-nine clients out of 35 were assessed as being at risk of falls due to impaired gait or balance and 11 clients showed signs of disorientation (Table B7.10). Eight clients had been diagnosed with depression and the majority of clients were vision impaired.

Table B7.10: Ozcare Innovative Dementia Care Packages, number of clients by selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	29
Vision impaired	21
Hearing impaired	13
Disorientation/confusion	11
Diagnosis of depression	8
Missing or non-functional limbs	1
Total or partial paralysis	1

Clients were taking between zero and 14 different medications. Twenty-one clients were taking four or more different medications.

Clients and carers were asked to report on client health status and change in health status over the 12 months prior to entry using a five-point Likert scale (Short-Form 36). In most cases, a carer reported; two clients gave a self-report. In 18 cases, the response is missing or a care worker gave a proxy report—these are considered invalid for the purposes of self-assessment. Of the 17 valid responses, three indicate the client was in very good or excellent health; the remaining ratings are good (four clients), fair (six clients) or poor (four clients).

About half the raters said that the client's health was somewhat worse (six clients) or much worse (three clients) than one year earlier, which suggests that the care needs of these clients had increased in the 12 months prior to entry. Nine raters reported no change over the previous 12-month period and two raters reported improvement in health status. Reports are not available for 15 clients.

Level of core activity limitation

Most Ozcare clients experienced moderate self-care limitation and mild to moderate mobility limitation at the time of the evaluation (Table B7.11). Around one-third of clients had a severe or profound communication limitation.

Sixteen clients had a severe or profound level of activity limitation in at least one area of core activity.

Table B7.11: Ozcare Innovative Dementia Care Packages, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	9	17	9	**35**
Mobility	5	11	12	7	**35**
Communication	12	8	4	11	**35**

— Nil.

Use of medical and hospital services prior to entry

Twenty-nine clients had visited a medical practitioner at least once in the 6 months before joining the project. The reported number of visits to a medical practitioner in this period varied from zero to 50 per client. One client reported 50 medical consultations outside of a hospital setting, two emergency department visits and 20 unplanned hospital days in the 6months prior to entering the project. Cumulatively, the 28 clients recorded 244 visits to a medical practitioner outside of a hospital setting over an estimated 5,220 person days.

Thirteen clients were admitted to hospital in the 6months prior to entering the project. Detailed information on admissions is recorded for 11 clients, who collectively contributed to 20 hospital admissions in the pre-entry period. Information on the number of days for unplanned hospital admissions is available for 12 clients (including three clients who did not provide further details). These 12 clients collectively accumulated 153 unplanned hospital bed days over approximately 2,160 person days. Individually, they recorded between five and 29 days in hospital for unplanned admissions in a 6-month period.

Conditions recorded as occasioning admission to hospital include:

- diseases of the intestinal tract
- diabetes mellitus
- breast cancer
- heart disease
- transient cerebral ischaemic attacks
- other health conditions.

Thirteen clients experienced a serious medical emergency during the pre-entry period. Four clients experienced a fall with injury; three were rendered immobile and without assistance for more than 30 minute;s and nine clients suffered another type of medical emergency.

7.3 Client assessment results

The Ozcare project commenced in late 2003 and most clients in the evaluation were with the project before the evaluation commenced. Ozcare did not reconstruct baseline assessments for clients in the evaluation; therefore, baseline assessment information reported below pertains to the first assessment for each client during the evaluation.

Cognitive function

MMSE scores were recorded for 26 clients at their first assessment (Table B7.12). Three zero scores were excluded when calculating summary statistics. Non-zero scores ranged from 1 to 26 points out of a possible 30 points (mean 16.2).

Table B7.12: Ozcare Innovative Dementia Care Packages, number of clients by Mini-Mental State Examination score at first assessment

MMSE score	Number of clients
Zero	3
1–15	11
16–18	1
19–24	8
25–30	3
Missing	9
Total	**35**

Cut-points to account for educational attainment were applied to the non-zero MMSE scores (Uhlmann & Larson 1991). Sixteen (16) of the 23 scores indicate probable cognitive impairment. Although the MMSE does not classify a proportion of clients as cognitively impaired, all but one of the 35 clients had some type of dementia recorded as their primary health condition.

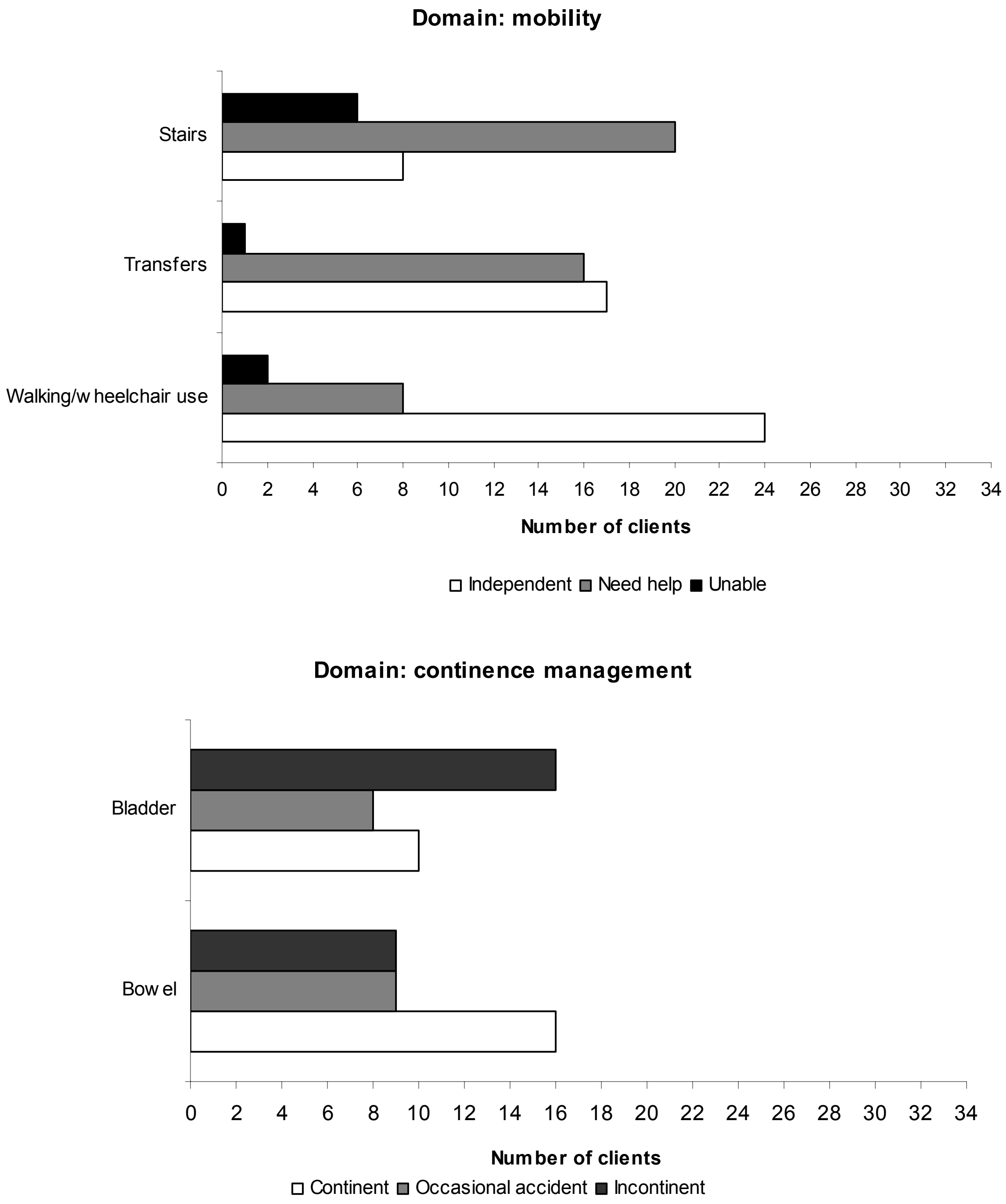
Activities of daily living

Most clients needed assistance in self-care activities at the time of their first assessment (Figure B7.1). MBI scores ranged from 1 to 19 points out of a possible 20 points. The mean score was 11.2 points.

A classification for Barthel Index scores (Shah et al. 1989) indicates that, at the first assessment, two clients were completely dependent in self-care and mobility, 16 clients exhibited severe dependency, 15 clients exhibited moderate dependency and one client showed slight dependency in ADL.

Twenty-four of the 34 clients for whom data are recorded had continence management needs. Seventeen clients were doubly incontinent. Most clients were unable to bathe or shower, groom, dress or use the toilet without assistance. Yet, most clients were independently mobile.

High levels of dependency in IADL were recorded (Figure B7.2). On average, clients were completely dependent in between three and four out of seven types IADL. Three clients were completely dependent in all seven IADL and most other clients either needed assistance or were unable to do things such as manage personal finances, self-medicate, shop, or do housework. Although 22 clients were able to mobilise independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment.

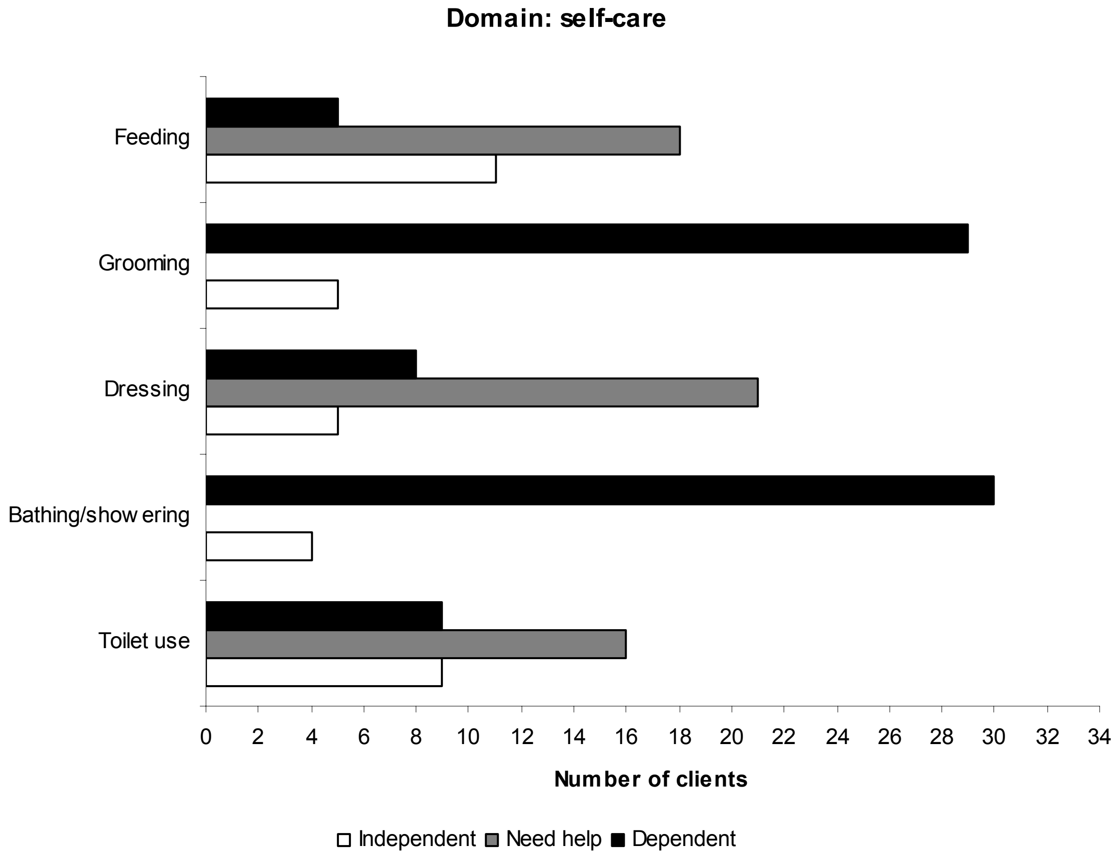


Domain: mobility

Domain: continence management

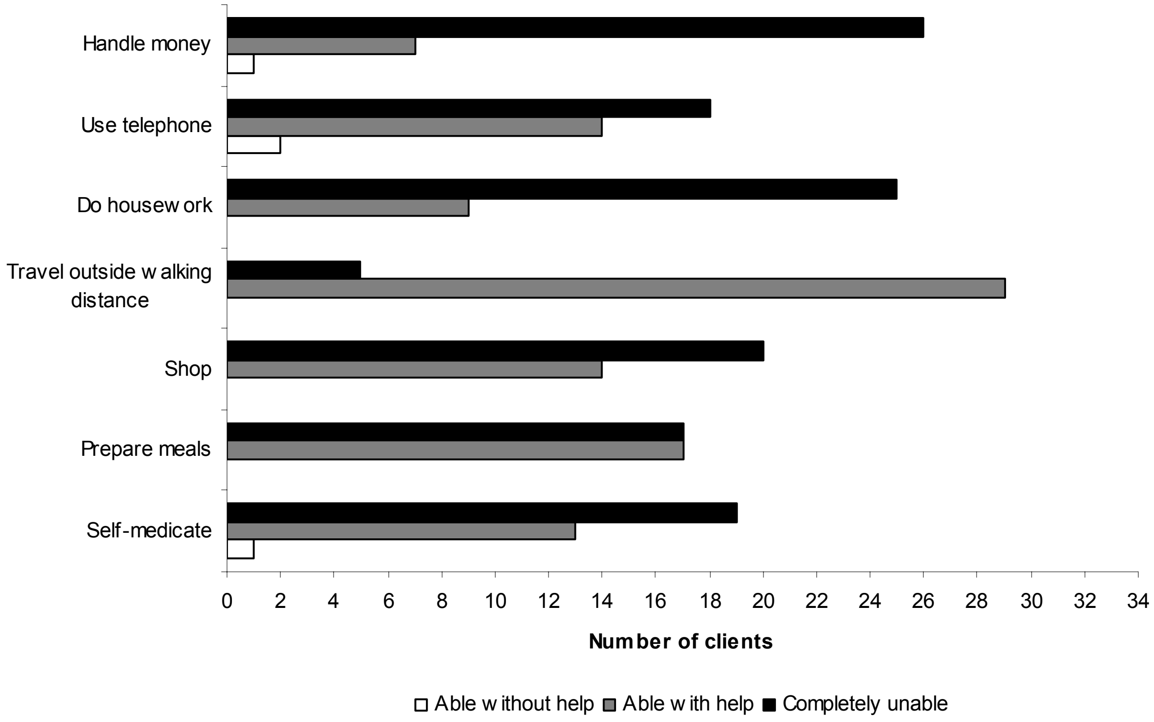
Figure B7.1: Ozcare Innovative Dementia Care Packages, number of clients by level of ADL function at first assessment

(continued)



Source: Appendix Table B19.

Figure B7.1 continued: Ozcare Innovative Dementia Care Packages, number of clients by level of ADL function at first assessment



Source: Appendix Table B20.

Figure B7.2: Ozcare Innovative Dementia Care Packages, number of clients by level of IADL function at first assessment

Ozcare was asked to record the results of three functional assessments in total. In some cases only one further assessment was possible. Figure B7.3 shows the MBI scores for clients at baseline, interim and final assessment by accommodation setting at follow-up. Clients in care at follow-up were either in residential high or low care, or in hospital. Clients in the community were either still with the Ozcare project, in other community care or were not accessing government-funded care.

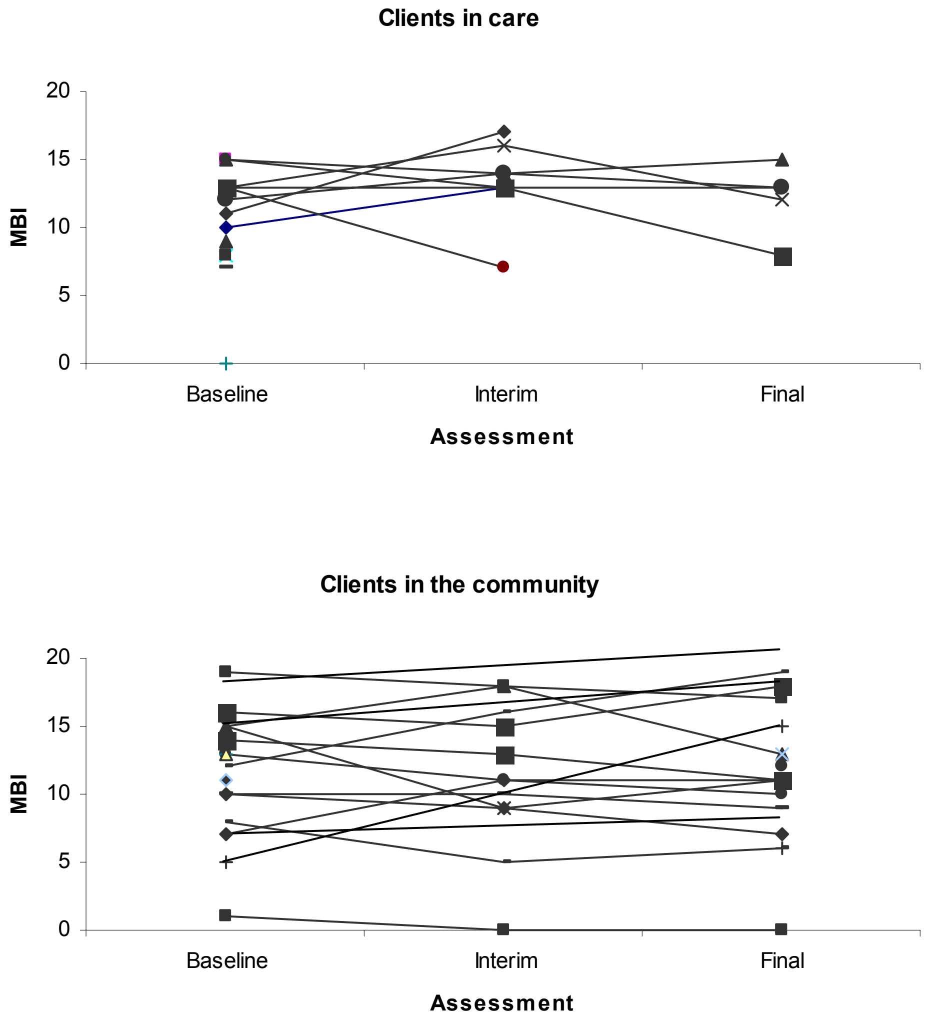


Figure B7.3: Ozcare Innovative Dementia Care Packages, baseline, interim and final MBI scores by follow-up accommodation setting (one symbol per client)

Psychological and behavioural symptoms

Twenty-five clients showed signs of memory loss on an intermittent or extensive basis (Figure B7.4). Wandering or intrusive behaviour were present in half of the cases (17 clients) and seven clients wandered extensively. Seventeen clients showed signs of emotional or psychological symptoms at least occasionally. Fourteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, six of whom exhibited two or more symptoms on an extensive basis.

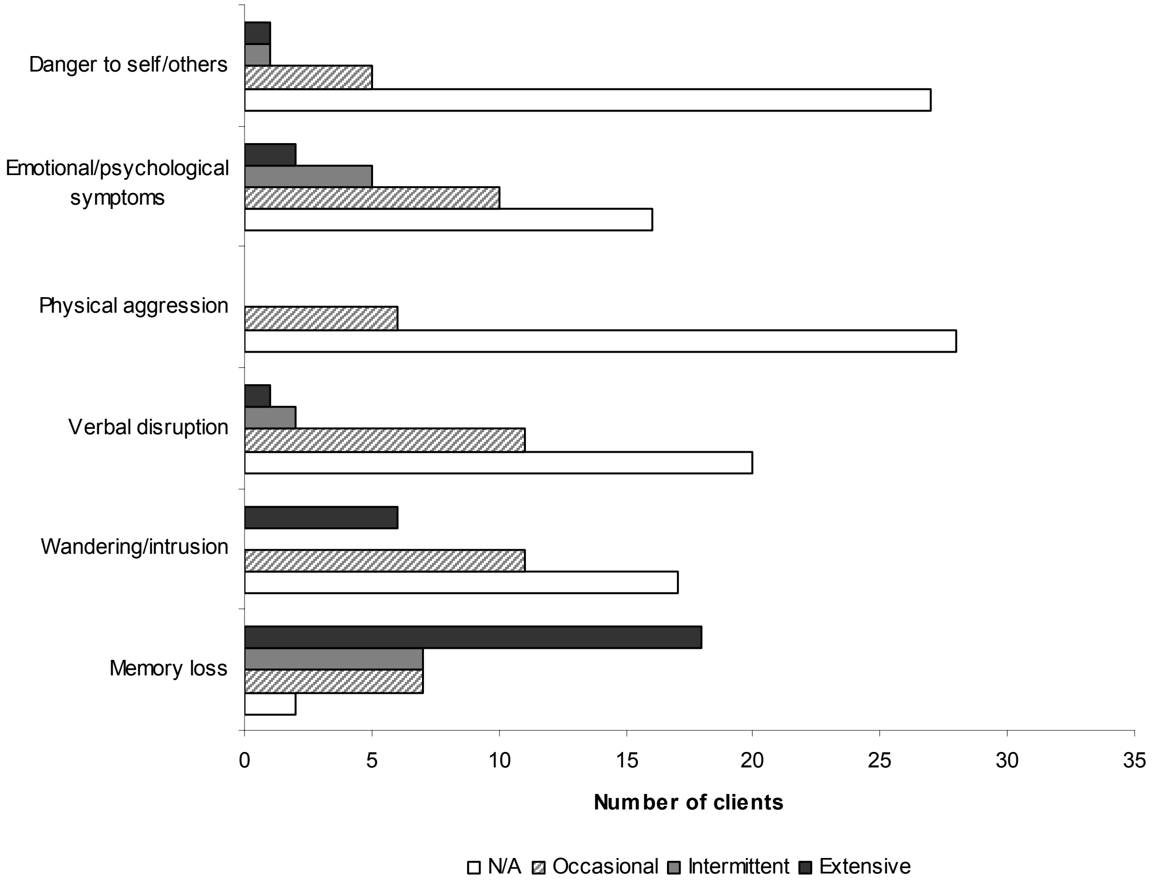


Figure B7.4: Ozcare Innovative Dementia Care Packages, number of clients by frequency of behavioural and psychological symptoms, first assessment

7.4 Carer assessment results

Thirteen carers reported that they were in excellent, very good or good health at the time of the first assessment. Ten carers reported fair health and four reported poor health. Two carers did not self-report.

Thirty carers completed the CSI at the first assessment to generate a mean score of 7.4 points. Scores ranged from 1 to 12 points. Nineteen carers recorded scores above the threshold for high carer strain and six more carers scored 1 point below the threshold. Twenty-one carers completed the CSI at a third assessment, on average 22 weeks after the first assessment. The median recorded change in CSI was –1 point. Individual carers recorded changes of between –5 (a 5-point reduction in carer strain) and 7 points (7-point increase) between the first and final assessments. At the final assessment, 11 of the 21 carers recorded a CSI score above the threshold for high carer strain. Thus, although the average level of carer strain was observed to decrease over the assessment period, there is evidence that a high proportion of carers continued to experience negative consequences from their caring roles.

Twenty-nine carers completed the GHQ-28 and another two carers completed all but the depression sub-scale of the GHQ at the baseline assessment. Four carers scored above 14 points on at least one sub-scale. Two carers recorded scores of 14 points or higher for somatic symptoms; three carers recorded scores of 14 points or higher for anxiety and insomnia and one carer scored over 14 points for social dysfunction. The results indicate that these carers were experiencing health and psychological symptoms associated with a recent change in circumstances. No carer scored over 14 points for severe depression.

Twenty-one carers completed the GHQ-28 at the final assessment. One carer scored above 14 points on one sub-scale at the final assessment. There is an overall reduction in high sub-scale scores, which may reflect a ‘settling’ of circumstances in which carers find themselves.

More detailed examination of CSI and GHQ-28 scores is included in the overall analysis of the Innovative Pool project data, due to small sample sizes in individual projects.

7.5 Service profile

During the evaluation, the types of services delivered to higher numbers of clients included respite care, personal assistance, domestic assistance, social support, food services and transport (Table B7.13). Some clients used transport assistance extensively, in one case an average of seven trips per week was recorded. This is seen to reflect the regional/rural location of the project in which clients and their carers may have to travel long distances for medical services and other appointments and services.

Follow-up needs assessment involved a median of approximately one visit or contact every month, but some clients required quite high levels of case management, for example, up to two contacts from a case manager per week.

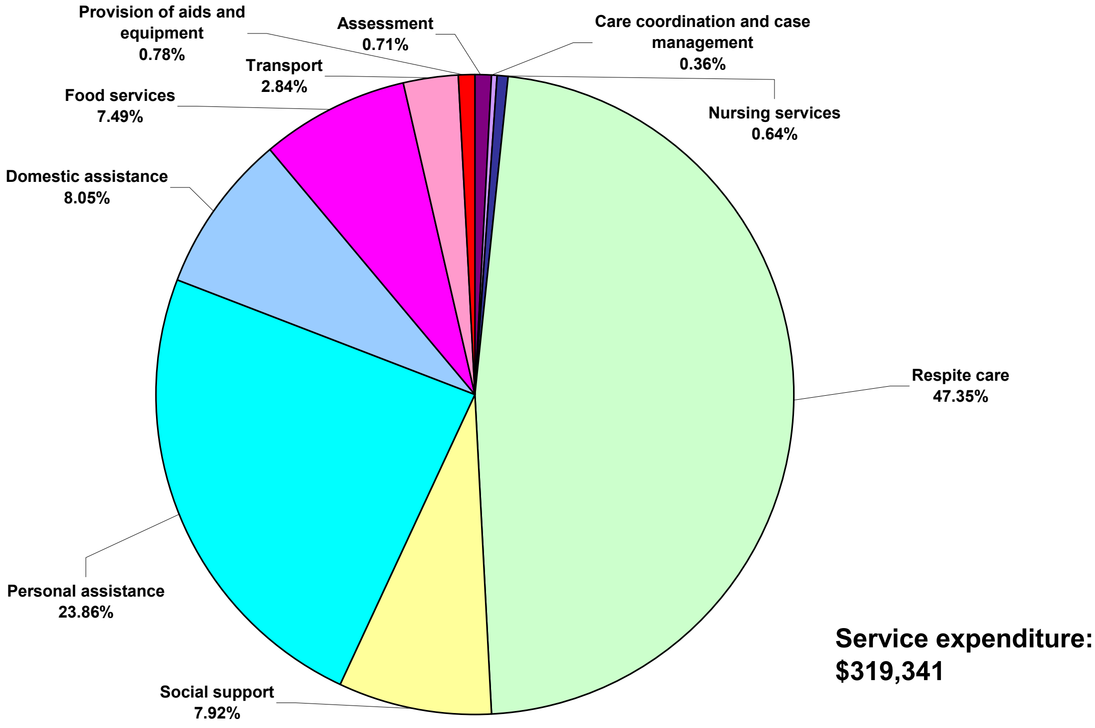
Respite care accounted for almost half of direct care expenditure in the 6 months from 1 July to 31 December 2004 (Figure B7.5).

Table B7.13 : Ozcare Innovative Dementia Care Packages, summary of services delivered per client per week.

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Respite (in-home and day)[(a)]	Hours	27	0.2	7.8	34.5	8.9	8.4
Personal assistance	Hours	25	0.1	2.4	16.9	4.1	4.4
Domestic assistance	Hours	23	0.0	1.0	4.4	1.2	1.2
Social support	Hours	19	0.1	1.1	3.6	1.4	1.1
Food service other	Hours	16	0.0	0.8	6.5	1.6	1.9
Nursing care	Hours	9	0.1	0.2	1.1	0.3	0.3
Allied health[(b)]	Hours	1	0.2	0.2	0.2	0.2	.
Follow-up needs assessment	No. contacts	14	0.1	0.2	2.0	0.4	0.5
Community transport	No. one-way trips	16	0.1	0.5	6.7	1.7	2.3
Delivered meals	No. meals	6	0.3	1.4	8.3	2.4	2.9
Overnight respite	No. nights	2	0.0	0.1	0.2	0.1	0.1
Carer support other than respite	No. contacts/events	2	0.2	0.2	0.2	0.2	0.0

(a) Assumes one day respite date is 6 hours

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.



Source: Appendix Table B26.

Figure B7.5: Ozcare Innovative Dementia Care Packages, expenditure on services, 6 months ending 31 December 2004

7.6 Accommodation outcomes

Ozcare conducted a follow-up of evaluation clients who were still with the project at 30 November 2004. Follow-up was completed between 24 February and 9 June 2005. Table B7.14 shows accommodation setting and government program support status for clients at time of follow-up (that is, between approximately 8 and 12 months since the start of the evaluation). By this time, three more clients had died and another five clients had entered residential care. Sixteen clients were still living in the community and being supported by the Ozcare project. Follow-up data are not available for the two clients who were discharged to hospital during the evaluation period.

Table B7.14: Ozcare Innovative Dementia Care Packages, client location and government-funded support at follow-up, June 2005

Location at follow-up	Number of clients
At home	
On Ozcare Innovative Dementia Care Packages	16
In care	
Residential aged care—high care	13
Total in care	*13*
Deceased	4
Not located	2
Total	**35**

8 Dementia Care in Alternative Settings

8.1 Project description

Southern Cross Care Western Australia received an allocation of 35 flexible care places to operate an Innovative Pool dementia service for eligible residents of the southern suburbs of Perth. Dementia Care in Alternative Settings (DCAS) was funded to operate for 2 years.

Southern Cross Care Incorporated in Western Australia is a not-for-profit provider of residential and community aged care services. Southern Cross Care WA operates eight dementia-specific units within its residential care facilities that accommodate up to 128 people in addition to two high care psychogeriatric residential units. The organisation also manages retirement village units. For approximately six years, Southern Cross Care WA has delivered community care programs including adult mental health (low level support), HACC services, CACP services, and two HACC-funded dementia-specific day centres. Its services extend to Bunbury and Broome. Southern Cross Care WA provides consultancy services, employing a dementia consultant, clinical nurse consultant, occupational therapy consultant, registered mental health nurse and occupational health and safety consultant to work with clients across the full range of Southern Cross Care WA programs.

A provisional allocation for the project of 25 places was increased to 35 places in June 2003 for a catchment area that covers the Local Government Areas of Cockburn, Fremantle, Canning, South Perth, Victoria Park, Belmont, Gosnells and Armadale. DCAS was established in October 2003 and accepted its first clients in November 2003. A steering committee comprising members of Southern Cross Care WA Incorporated, the Western Australia office of the Department of Health and Ageing, Bentley Aged Care Assessment Team, the Seniors Mental Health Service, and consumer representation provides guidance and monitoring.

Project objectives

DCAS is based on a philosophy that it is possible for people with severe dementia, including those who live alone and those with severe psychological and behavioural symptoms, to live at home provided there is sufficient flexibility to deliver truly client-focused care. The stated objective is to provide additional care options to members of an existing Southern Cross Care client base who were previously being supported on a high number of hours through the CACP service and to expand services to new clients in the community.

Target group

The project targets older people with moderate to severe dementia who wish to remain living in their own homes and who are not actively seeking residential care placement. Clients are those people whose needs cannot be met by provision of a CACP. Participation in

DCAS requires that the client and his/her family are committed to the client receiving care at home.

Care recipients with behavioural disturbances are accepted, provided that 24.5 hours of service per week is adequate to support them safely. Approximately 84% of clients received assistance through government support programs prior to entering DCAS, which is one of the higher rates of previous government-funded service use recorded by Innovative Pool Dementia Pilot projects.

ACAT approval for low or high level residential care is required and assessment processes must demonstrate that a client has moderate to severe dementia and/or behavioural symptoms of dementia.

Service environment

Flexible respite is an area of high unmet need, according to Southern Cross Care. Community respite services tend to offer respite for short periods of time, typically just a few hours, or for longer periods in short bursts of two to three days. Either model may not adequately assist a carer with other high demands time such as employment or other caring responsibilities, or a carer who needs longer periods of respite over a sustained period to help them cope with the demands of dementia care. Residential respite can be hard to access at short notice and is not the preferred respite service for many care recipients and their carers. The DCAS team believes that lack of flexibility in respite care delivery, and more generally, the limited hours of in-home care available through mainstream care packages contribute to people with moderate to severe dementia entering residential care prematurely despite a strong desire for care at home.

There are programs that support individuals who are at an equivalent level of hostel care and need approximately 4–8 hours per week of service delivery, for example, CACP. Programs that provide an equivalent level of nursing home care and provide approximately 12–17 hours are limited in their geographical allocation and number of places,for example, EACH.

DCAS is trialling a service model designed to deliver up to 24.5 hours per week to meet the observed higher needs of the target group.

Care model

DCAS comprehensive care packages provide for service on seven days per week and up to 3.5 hours per day. The Memorandum of Understanding between Southern Cross Care (WA) and the Department of Health and Ageing specifies that each care recipient will be allocated a maximum of a three-person team where possible, comprising a primary, secondary and relief support worker to ensure consistency of care and to minimise confusion for client and family carers. Services are tailored to individual client needs and may include personal care, medication management, meal preparation and assistance with feeding, domestic assistance, escorting for shopping and appointments, social support, respite care, therapy and behaviour management, continence management and carer support services.

The high number of hours and flexible rostering of DCAS to ensure a minimum number of staff delivering services to a client are key innovative features of the project.

Southern Cross Care uses Innovative Pool funding to offer day centre and emergency overnight respite care to complement the in-home respite service. Southern Cross Care contributes two adjoining units in a Southern Cross Care retirement village and uses Innovative Pool funding to run the respite care service. Day respite is available four days per week with two staff in attendance each day. DCAS respite clients normally spend 5 to 7.5 hours at the centre on each day of attendance. Residents in the retirement village assist staff on a volunteer basis and appear to enjoy the opportunity to contribute, while respite care clients benefit from the social atmosphere of the centre. Activities and lunch are included and transport to the centre can be arranged. The service allows DCAS to provide quality dementia-specific day respite services on an efficient basis. The provision of respite care in alternative settings provides for maximum flexibility which has met with high acceptance from care recipients and carers.

The project coordinator suggested a range of conditions which might signal that DCAS may no longer be able to adequately support a client:

- Maximum hours provided are insufficient to meet client needs.
- Client behaviour poses a risk of injury to support staff and behaviour management options have been exhausted.
- Unsafe care situation, for example, client wanders without supervision or other risk associated with severe cognitive decline.
- Deterioration in physical functioning that renders a client unable to manage at home alone.
- Carer breakdown to the point that having a partner at home is no longer sustainable despite extra support from the project.
- Client unable to safely transfer or mobilise with the assistance of one person.
- Nursing care needs exceed dementia care needs.

If a client is discharged to an aged care facility, DCAS support staff are available to visit for a reduced number of hours over a few weeks to assist with the settling-in process.

Staffing

At the time of the AIHW site visit, 17 salaried care workers were delivering in-home and respite centre services under the direction of one full-time coordinator/case manager. The one case manager is responsible for coordinating service delivery to all DCAS clients. The services of two care professionals are brokered for an average of two hours per week. Full-time administrative support was budgeted at a rate of 30 hours per week.

The case manager arranges for other experts to become involved in client assessment and management on a case-by-case basis. The Southern Cross Care dementia consultant and occupational therapist have a high input to the project.

Staff communication is facilitated by monthly meetings of support workers. Communication books are used to relay information to each support worker who comes into a client's home.

Delivering a highly flexible service has had some staffing implications and difficulties have been encountered, for example, finding staff for clients located over a large geographic area, staffing for a mix of substantial blocks of time and short periods both inside and outside normal working hours. In particular, expansion of the project to cover the local government areas of Fremantle and Cockburn was said to have had a major impact on service delivery due to staffing difficulties.

Early progress

The AIHW evaluation team visited the DCAS project team in July 2004. The project reached full occupancy within a short time of establishing. By mid-2004 the waiting list contained 26 names and the coordinator was receiving an average of two enquiries per week, either about the project or the waiting list. Thirty-nine clients had been accepted into the project and eight discharges had taken place in the year since November 2003.

Clients were either previously supported by family without formal services (14), receiving CACP services (21), or receiving HACC, nursing agency or similar services (four). Clients who were on a CACP before DCAS were referred to DCAS because they needed more hours or full-time case management, had become resistant or aggressive to existing support staff and needed dementia-specific care, or family had become unable to manage with CACP-level support. Discharges involved transfer to residential care either because of escalating nursing care needs, carer illness or refusal to accept support at home.

By 30 June 2004, five clients on the waiting list had entered permanent care and another two clients on the waiting list were actively seeking placement.

DCAS recorded information about clients on the waiting list to use as a basis for comparing accommodation outcomes with the evaluation group. It was intended that follow-up would occur at least 6 months after referral to facilitate a valid comparison; however only four of those not placed with the project were located 6 months or more after referral. Most follow-up was completed within just 3 months of referral. The waiting list data show that people who were unable to be placed on the project have similar living arrangement and core activity limitation profiles to the DCAS evaluation client group (see section 8.7).

Successes, challenges and lessons

The day respite centre is considered a major factor in the project's success. Clients have responded well to respite care in a home-like setting where their individual needs and preferences can be catered for. This model of respite is particularly well suited to clients who have an employed primary carer and who can benefit from a social form of care in a homely environment.

Support for carers has placed heavy demands on the project coordinator and support workers. It has been observed that in many cases, carers have managed without an adequate level of support from formal services so that by the time a client is accepted into DCAS, the carer can be experiencing severe strain. It is thought that earlier intervention for these carers may help to avoid some of the difficulties that the project has encountered in introducing higher levels of support.

Recruiting and keeping staff has been another challenge for the project, exacerbated by the project's large catchment area. This makes it difficult to achieve the goal of no more than three different care workers per client, although the goal has been achieved for some clients. The coordinator reported that staff need to be rotated more often for some clients with behavioural symptoms in order to avoid burn-out.

Severe mobility restriction, high risk of falls, and wandering behaviour in the absence of 24-hour supervision from a family member are the major risks for continuing care with DCAS. Southern Cross Care WA has a no lift policy, although the project has supported one client with the assistance of a hoist.

Case studies

DCAS provided three case studies.

Case study 1

'Client was referred to DCAS by the geriatric medicine team of a local health service in November 2003. At the time she had been receiving a Community Aged Care Package (CACP) that provided 7 hours of care a week.

The CACP care staff had been unable to provide the care required. Client was not taking her medications. She was not eating properly, and would not allow the care staff to cook, clean or assist her with personal care. Her food handling caused concern, as she would leave food out in the heat or defrost and then re-freeze food, putting herself at risk of food poisoning. She was not showering, and her clothes were old, dirty and ripped. If staff tried to carry out any personal care, she became very agitated and physically and verbally aggressive. Service times varied greatly which made it very difficult for any routine to be established.

Client was frail, stooped in posture and often wandered the grounds of the retirement complex she lived in. She was paranoid about people stealing her money and possessions, and would often approach the village administration staff about these concerns. Client presented as depressed, a condition that had persisted since the death of her husband several years before.

Client lacked insight into her abilities which made it very difficult for any successful interventions and she constantly complained about all the strangers entering her home and interfering with her possessions.

The CACP care staff found that they were unable to establish a rapport with the client, especially within the time constraints. She had no family support, and only one supportive friend. Client strongly wished to remain in her home, and was thus referred to DCAS.

Initially, the support workers offered companionship. Due to the client's reluctance to accept care, the priority was seen to be building rapport and a sense of trust. The client verbalised concerns at her initial assessment that DCAS was trying to put her in 'a home' and became quite distressed by this. Much reassurance was required to convince her that the priority was to assist her to stay in her home and to provide friendship rather than to take over her life.

Medication prompts and meal prompts were introduced. After about three months the support workers had developed a good relationship with the client, and she would allow them to assist her with personal care, including showering. Soon after that she decided to recommence day centre attendance.

Some other strategies included performing duties when she was not at home so that the client wouldn't become distressed, for example, doing the washing while she was having lunch with her friend. The hours of care were increased so that the support workers could take the client for outings and to the shops, which she loved. Domestic services were provided one day a week, while client was out with friends. The client's package was then increased to the full hours available.

Outcome

With the above care and services, the client coped well at home. She loved the social interaction provided by the visits from support workers. She especially loved a cup of tea, and this provided an important time for the relationship building to take place. Wandering virtually ceased. She was prescribed an antidepressant medication by her doctor and her mood continued to fluctuate, but showed an overall improvement. Her paranoia diminished, and she was no longer complaining to the village staff as often about things going missing. Her physical health improved greatly as she began eating regular, healthy meals.

Unfortunately, the building the client was living in was scheduled for demolition, and she was forced to relocate. Some of her behaviours began to escalate again as she felt under pressure from the village administration to go into residential care. Some of the alternative accommodation offered was inappropriate. An application was made for a public guardian to be appointed to assist in ensuring that the client's interests would be met.

In September 2004 the client moved to dementia-specific hostel accommodation. Some of her problems resurfaced following the move, but she has since settled into her new environment. Hostel staff members expressed surprise that she had been able to live alone at home for so long, given the severity of her dementia. Client is still able to enjoy the companionship of others along with regular outings and activities. An interim period of support was given by her community support workers to assist with her settling in process. However, if she had not been forced to relocate she would have been able to continue to live in her own home for longer with the assistance of her flexible care package.'

Case study 2

'Client was referred to the service by Fremantle Aged Care Assessment Team (ACAT) in August 2004. The client lived with her husband, who was physically frail and unwell. She had been receiving a Community Aged Care Package (CACP) of 7 hours per week. Her husband also received some respite support.

Client was doubly incontinent, and had mobility problems. She was paranoid about what her husband might do, for example, 'run off with someone'. This meant that she wouldn't let him out of her sight. Therefore, there was no break from caring for her husband, and he was becoming extremely worn down.

At the time of referral to the project, the situation was desperate as the client's husband was becoming increasingly stressed and unable to cope well. Although family lived next door they were providing little support due to a previous disagreement. The client's husband admitted that he had previously made a pact with his wife that they would never be separated and had considered ways of departing this world together. Despite having reached this point, the husband was initially reluctant to accept the full 24 hours of care per week that could be made available.

Services commenced within a few days to provide personal care and companionship along with respite for the client and daily assistance for domestic support for her husband. This made a big difference to his ability to cope.

In October, when the husband was diagnosed with a terminal illness, the situation again reached crisis point. He was strongly advised to access residential respite for his wife to give him some time to himself but when respite was arranged for his wife she began threatening that she no longer wished to live and that he had promised this would never happen. A crisis care intervention was arranged, whereby a carer stayed with the couple for 72 hours until the situation settled and the couple felt confident that they could stay at home safely.

Following the crisis intervention, care was provided in the couple's home, seven days a week. This included domestic assistance, personal care, assistance with meal preparation, and spending companionship time with the client to allow her husband a break. After this episode the client's husband was able to be convinced to reconsider her attending day centre care as this would give him full days of respite. The client agreed to start attending a day respite centre. She now attends four days a week, and loves it. She is picked up and dropped off by the centre's bus. She always enjoys her time there, and her husband reports that she sleeps much more soundly at night after the daytime stimulation. This is a great relief to him.

Outcome

Since the care workers have developed a trusting relationship with the client, they are able to support her in her grief on the occasions when she is lucid. The couple's family was encouraged and is now far more supportive. This is a great help. Grief counselling has been arranged for the couple through the Alzheimer's Association and plans are being made for residential care for the client due to her husband's failing health. The client's husband was reassured in knowing that appropriate arrangements are in place.

Currently the client's husband feels much stronger and able to cope with the day-to-day issues and he is no longer reluctant to ask for assistance. Family assists in the evenings to prepare the client for bed as her husband becomes exhausted from minimal effort.'

Case Study 3

'Client was referred to DCAS by the Fremantle Aged Care Assessment Team (ACAT) in February 2004. She was living alone and receiving support through Community Aged Care Packages (CACP) totalling 7 hours of care a week. Over a period of a year or so the client had become very depressed and withdrawn. She had isolated herself from everyone, even family. She did not leave the house and always kept the curtains and windows shut, so that she was sitting in the dark. She would binge eat, which was causing weight and health problems as she is diabetic. The client would wear soiled clothing over and over, did not attend to domestic duties, and was fast becoming reclusive.

DCAS services began slowly, with support workers simply visiting to start with, to build rapport and trust. The client would allow people in and speak with them, but maintained that she didn't need any help. Visits continued three times each day. After about two weeks the client began to allow the support workers to assist her with personal care. She began to wear clean clothes and use continence aids. She also allowed the support workers to prepare her meals and snacks. Medication prompts were given, as client had not been remembering to take her tablets. She accepted these prompts and took her medications as prescribed. The client enjoyed the social aspects of the visits, and the companionship they provided. She began to allow the curtains and the windows to be opened, slowly reconnecting her to the outside world.

After about two months the client began to go out grocery shopping with the support workers. She enjoyed these outings, when prior to this she had not left her house for over a year.

Outcome

Client has a supportive family who are astounded at her improvement. They had been so concerned before commencement of the service, but their attempts to help had been to no avail.

Now the client's GP has reported that her health has significantly improved. She has lost weight, and her diabetes is well managed. She loves going out, not only shopping, but to cafes and a theatre group as well. With prompting she will even attend her doctor's appointments by herself. She has been able to take the initiative to buy flowers for her daughter-in-law and arrange for them to be sent. She has been reading books and writing letters again with prompting. Support workers started accompanying her on walks around the river and now the client has purchased a pedometer, which she uses to make sure she gets enough exercise.

Now that she is taking her medication as prescribed, eating a healthy diet and enjoying a good level of social interaction the client's Mini-Mental State Examination score has improved by eight points, from 16 to 24. Correspondingly, her level of functioning has improved markedly, and she is certainly enjoying a much better quality of life. Her family is very pleased with her progress.'

A profile of DCAS evaluation clients during the reporting period 14 June to 30 November 2004 follows.

8.2 Client profiles

DCAS supplied data for 33 clients, including 10 men and 23 women.

Age and sex

Ages of evaluation clients ranged from 70 years to 94 years (mean 82.6 years). Twelve clients were aged 85 years or over (Table B8.1).

Table B8.1: Dementia Care in Alternative Settings, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
65–74	—	4	4
75–84	6	11	17
85+	4	8	12
Total	**10**	**23**	**33**
		(per cent)	
65–74	—	12.1	12.1
75–84	18.2	33.3	51.5
85+	12.1	24.2	36.4
Total	**30.3**	**69.7**	**100.0**

— Nil.

Language and communication

Seven clients had little or no effective means of communication. The remaining 25 clients in the evaluation could communicate effectively in spoken language. Four national languages were represented in the group (Table B8.2).

Table B8.2: Dementia Care in Alternative Settings, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	26	4	—	30
Eastern European [(a)]	2	1	—	3
Total	**28**	**5**	**—**	**33**

(a) Includes Croatian, Estonian and Polish.

— Nil.

Accommodation and living arrangement

Clients were living in private residences or a retirement villages (Table B8.3) and all were in their usual place of residence at time of referral.

Table B8.3: Dementia Care in Alternative Settings, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement			
Accommodation setting	**Alone**	**With family**	**Unknown**	**Total**
Private residence	14	13	1	28
Retirement village—independent living unit	1	4	—	5
Total	**15**	**17**	**1**	**33**

Years at usual place of residence ranged from less than one to 55 years. Four clients had been living in the same home for 30 or more years.

Carer availability

All 33 DCAS clients had a family carer and 14 carers were living with the care recipient (Table B8.4). Carers' ages ranged from 32 to 80 years, averaging 56.7 years (Table B8.5).

Table B8.4: Dementia Care in Alternative Settings, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Carer does not live with client	Not stated	Total
Spouse or partner	7	—	—	7
Son or daughter	6	16	1	23
Son- or daughter-in-law	—	1	—	1
Other relative	1	—	—	1
Friend or neighbour	—	1	—	1
Total clients with a carer	*14*	*18*	*1*	*33*
Total clients				**33**
Per cent of clients with a carer				100

— Nil.

Table B8.5: Dementia Care in Alternative Settings, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	2	3	5
45–54	4	6	10
55–64	5	4	9
65–74	1	4	5
75–84	2	2	4
Total	**14**	**19**	**33**

Income and concession status

Government pensions were the primary source of cash income for 32 clients (Table B8.6). Thirty-two clients held a health care concession card and 10 clients received a discounted weekly contribution rate for the DCAS due to financial hardship.

The majority of clients were contributing $5.43 per day towards the cost of services (rates varied from $1.43 to $5.57 per day).

Table B8.6: Dementia Care in Alternative Settings, number of clients by principal source of cash income, health care concession card status and project concession status

	Number of clients	Per cent
Principal source of cash income		
Age pension	25	75.8
DVA pension	7	21.2
Nil income	1	3.0
Total	**33**	**100.0**
Health care concession card holder	32	97.0
Project concession status	10	30.3

Previous use of government community care programs

Five clients were not receiving assistance from government community care programs before entering DCAS (Table B8.7). Twenty-eight clients had been receiving help prior to entering the project, 10 of whom were receiving assistance from multiple sources. Nineteen clients were receiving assistance through the CACP program, eight in conjunction with services funded by other programs. HACC had been providing assistance to six clients, Veterans' Home Care was assisting four clients and eight clients received services through Day Therapy Centres.

Of the 16 carers who had accessed any form of respite care in the 12 months prior to entering the project, 11 had used mainly residential respite and five had used mainly in-home respite. Eight carers reported that, despite having had a need for respite care in the 12 months prior to DCAS, they had not used a respite care service. Nine carers said they had not needed respite care services.

Table B8.7: Dementia Care in Alternative Settings, number of clients by use of government support programs prior to DCAS

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	11	33.3
Home and Community Care	4	12.1
Veterans' Home Care	2	6.1
Day Therapy Centre	1	3.0
Multiple programs (CACP & other)[(a)]	8	24.2
Other multiple programs[(b)]	2	6.1
Total clients with previous government program support	*28*	*84.4*
Clients without previous government program support	5	15.2
Total	**33**	**100.0**
Use of respite care in the 12 months prior to the project		
Respite care used	16	48.4
Respite care not needed	9	27.3
Respite care needed but not used	8	24.2
Total	**33**	**100.0**

(a) Other includes DTC, HACC and VHC.

(b) Other includes VHC with DTC and DTC with NRCP.

One client is reported to have been on a waiting list for residential aged care during the evaluation.

Assessment and referral

ACAT assessments are performed by Bentley Health Service, Armadale Health Service and Fremantle ACATs. During the evaluation period, nine of the 33 clients had been approved by an ACAT for residential low care and 24 clients had approval for high level residential care.

Twenty-four clients were referred to the project by an ACAT (Table B8.8). The other nine clients were referred by Southern Cross Care WA or another agency.

Table B8.8: Dementia Care in Alternative Settings, number of clients by source of referral.

Referral source	Number of clients
Aged Care Assessment Team	24
Southern Cross Care WA	5
Other agency	4
Total	**33**

Some clients on a Southern Cross Care CACP commenced services with DCAS a time after initial needs assessment, hence DCAS recorded service commencement date as distinct from referral or initial needs assessment date. Most clients had completed an ACAT assessment before commencing on a DCAS package (Table B8.9).

Table B8.9: Dementia Care in Alternative Settings, number of clients by days between completion of ACAT assessment and commencement of services

Completion date of ACAT assessment	Number of clients
Before commencement of DCAS services	
0–20 days	3
21–60 days	6
61–90 days	5
91–120 days	3
121–365 days	12
Total	*29*
After commencement of DCAS services	**4**
Total	**33**

A registered nurse managed the care of all clients.

The HACC Needs Identification instrument, Bristol Activities of Daily Living Scale and a 12-item Caregiver Strain Index are routinely used in DCAS for client and carer assessment and review, which facilitated adaptation to the evaluation data collection tools.

Health conditions and health status on entry

The number of health conditions that each client had at the time of entry to the project ranged from one to nine. Twenty-six clients had three or more health conditions. All DCAS clients have dementia recorded as the primary health condition—30 cases of dementia in Alzheimer's disease and three of vascular dementia.

Seventeen clients out of 33 were assessed as being at risk of falls due to impaired gait or balance and seven clients had diagnosed depression (Table B8.10).

Table B8.10: Dementia Care in Alternative Settings, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	17
Hearing impairment	12
Vision impairment	10
Diagnosis of depression	7
Total or partial paralysis	1

Clients were taking between zero and nine different medications. Nineteen clients were taking four or more different medications.

Clients were asked to rate client health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Twenty-four carers gave a proxy report and nine clients were able to self-report.

Eight clients were said to be in excellent or very good health. The remaining ratings were good (13 clients), fair (nine clients) and poor (two clients). Most raters said that the client's health was somewhat worse (23 clients) than one year earlier.

Level of core activity limitation

Most DCAS clients experienced mild to moderate activity limitation in the areas of self care, mobility and communication (Table B8.11). Twelve clients had a severe or profound activity limitation in at least one core activity.

Severe or profound activity limitation was most often found to be related to self-care.

Table B8.11: Dementia Care in Alternative Settings, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	1	9	12	11	**33**
Mobility	6	17	10	—	**33**
Communication	6	18	5	4	**33**

— Nil.

Use of medical and hospital services prior to entry

Of the 33 DCAS clients, 32 had visited a medical practitioner at least once in the 6 months before joining the project. The reported number of visits to a medical practitioner in this period varies from zero to 40 per client. One client reported 40 medical consultations outside hospital and in addition to two unplanned admissions to hospital in the 6 months prior to entering the project. Cumulatively, the 32 clients recorded 169 visits to a medical practitioner outside of a hospital setting over an estimated 5,760 person days.

Eleven clients contributed to a total of 18 hospital admissions in the 6 months before entry. One client had a planned admission only. The remaining 10 clients with one or more hospital admissions recorded unplanned or urgent admissions and most had visited a hospital emergency department. These clients collectively accumulated 124 unplanned hospital bed days over approximately 1,620 person days. Individually, they recorded between three and 28 days in hospital for unplanned admissions.

Conditions recorded as occasioning admissions to hospital for clients in the pre-entry period include:

- injuries to leg/knee/foot
- oedema
- fracture of the femur
- falls
- transient cerebral ischaemic attacks
- influenza and pneumonia
- blackouts, fainting, convulsions.

Three clients had experienced a serious medical emergency during the pre-entry period, all of whom had also suffered a fall with injury. Another five clients suffered a fall with injury, two of whom were rendered immobile and unable to summon assistance for more than 30 minutes. All but one client who had a medical emergency or fall were reported to have presented to an emergency department or had unplanned admissions to hospital.

8.3 Client assessment results

Cognitive function

MMSE scores were recorded for 28 clients when they entered the project (Table B8.12). Non-zero scores range from a minimum of 4 to a maximum of 24 out of a possible 30 points (mean 13.4).

Table B8.12: Dementia Care in Alternative Settings, number of clients by Mini-Mental State Examination score at entry

MMSE score	Number of clients
Zero	2
1–15	15
16–18	5
19–24	6
25–30	—
Missing	5
Total	**33**

— Nil.

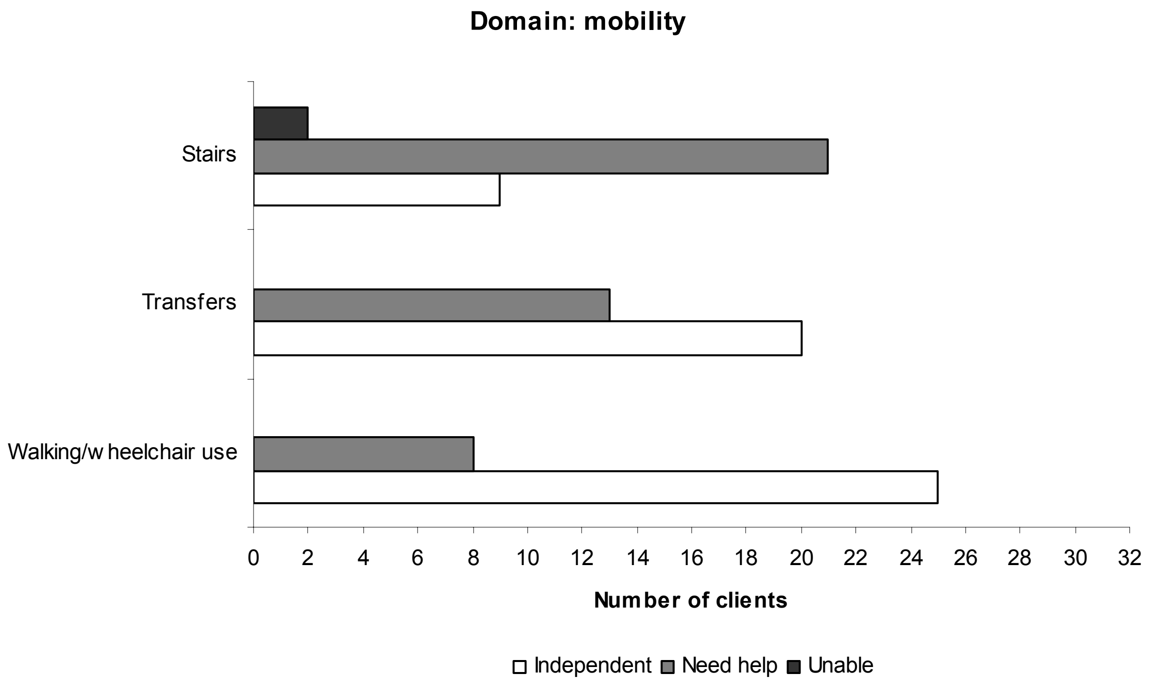
A score of 23 points or lower is usually taken as a positive screen for cognitive impairment, although 24 points is often used when higher sensitivity for screening mild impairment is required.

It is recommended that level of education is taken into account in the interpretation of MMSE scores. Cut-points to account for educational attainment were applied to the DCAS entry MMSE scores (see Uhlmann & Larson 1991), indicating that 27 of the 28 clients who completed the test screened positive for cognitive impairment. One client who recorded a score indicative of no cognitive impairment at time of entry to the project was re-tested at a final assessment and did not register as cognitively impaired at that time either.

On the basis of MMSE results, it is concluded that DCAS was targeting the intended client group.

Activities of daily living

MBI scores reveal that, at entry to the project, at least half of DCAS clients needed assistance in tasks involving self-care and mobility (Figure B8.1). MBI scores at entry ranged from zero to 20 out of a total 20 points. The mean score was 13.0 points.



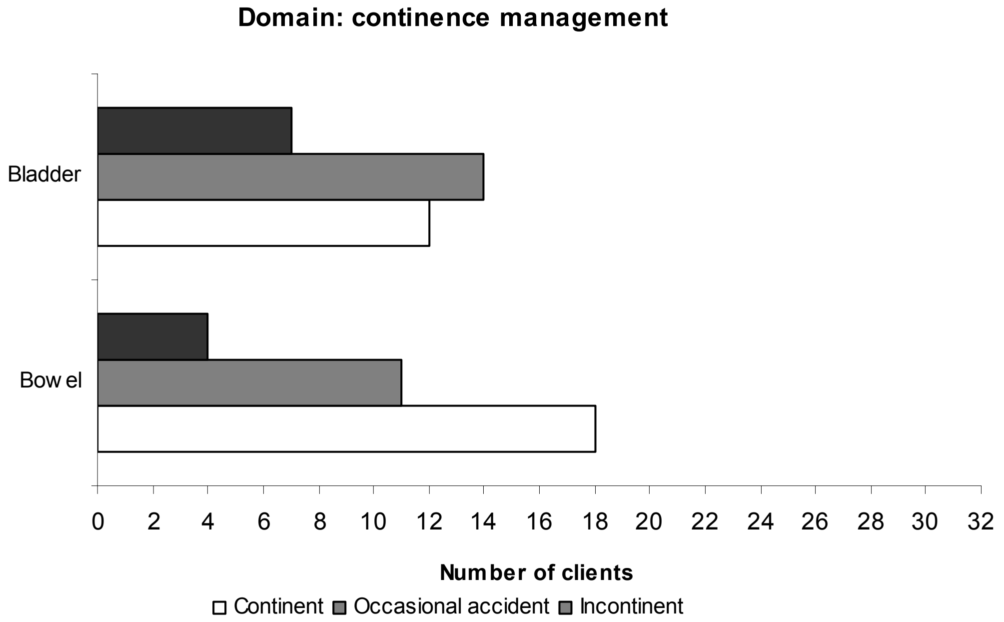
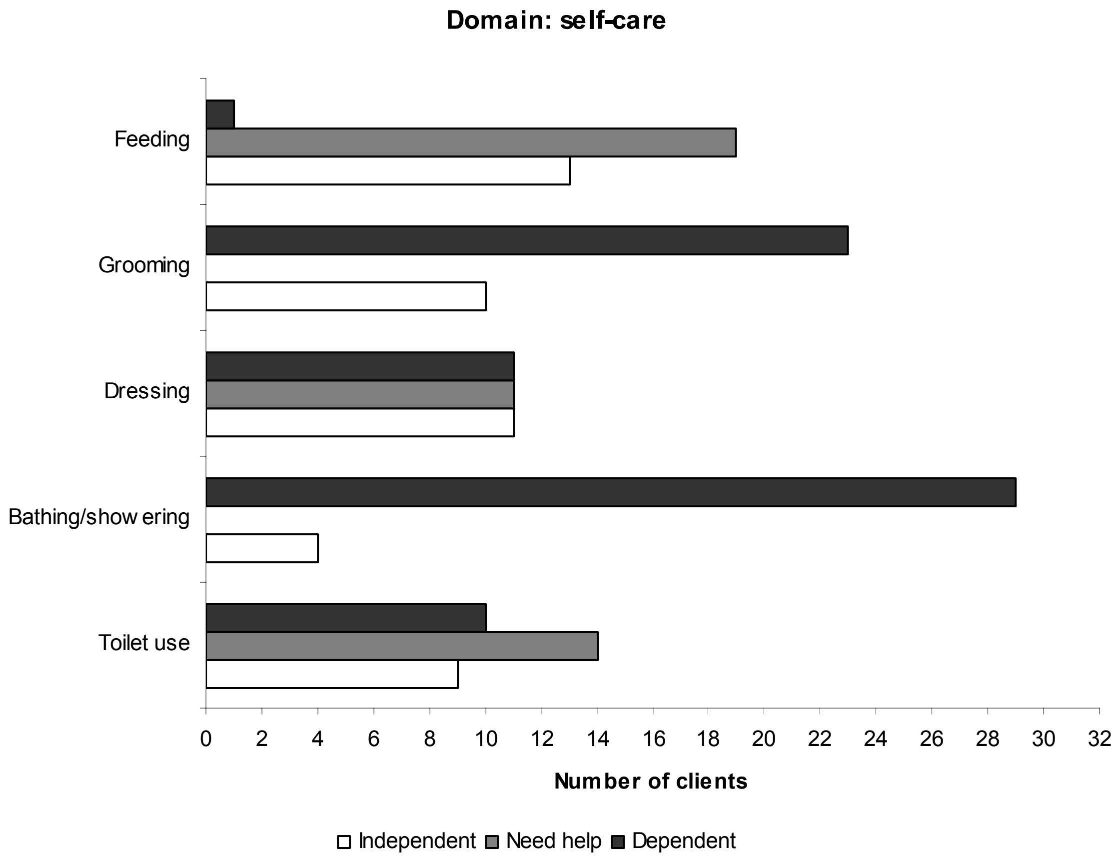


Figure B8.1: Dementia Care in Alternative Settings, number of clients by level of ADL function at entry

(continued)



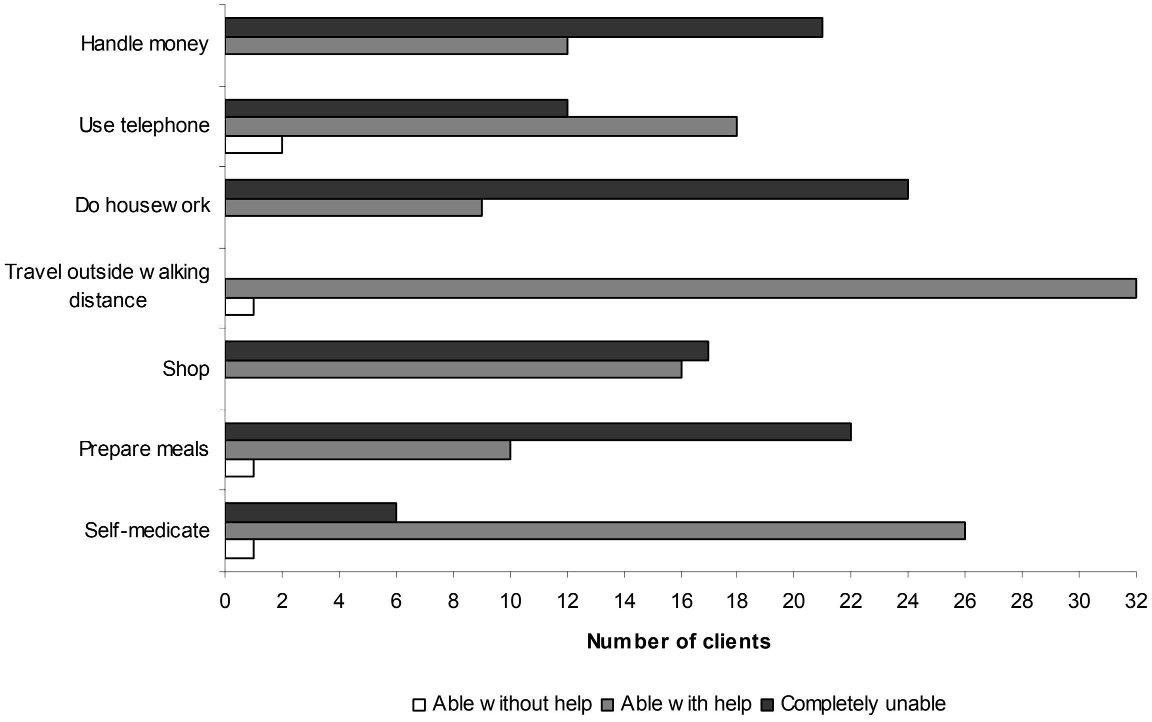
Source: Appendix Table B21.

Figure B8.1 continued: Dementia Care in Alternative Settings, number of clients by level of ADL function at entry

Using a classification scheme for the Barthel Index (Shah et al. 1989), 17 clients exhibited severe dependency in self-care and mobility at time of entry, 13 clients exhibited moderate dependency and two clients showed slight dependency. One client was independent in self-care and mobility at entry to DCAS, however this person needed help in all but one IADL.

Fourteen clients were doubly incontinent. Twenty-nine clients were unable to bathe or shower without assistance. Twenty-four clients needed help to use the toilet and 13 clients needed help with transfers. Most clients also needed help in the areas of dressing, grooming and feeding.

Most DCAS clients were highly dependent in IADL when they entered the project and travelling away from home without assistance was not a possibility for any client (Figure B8.2). On average, DCAS clients were completely dependent in three out of seven IADL at the time of entry. Three clients were totally dependent in six out of seven IADL.



Source: Appendix Table B22.

Figure B8.2: Dementia Care in Alternative Settings, number of clients by level of IADL function at entry

The project recorded two more assessments after baseline. In some cases only one additional assessment was possible. Figure B8.3 shows the MBI scores for clients at baseline, interim and final assessment by accommodation setting at follow-up. Clients in care at follow-up were either in residential high or low care, or in hospital. Clients in the community were either still on Dementia Care in Alternative Settings, in other community care or were not accessing government-funded care services.

There is no discernable overall difference in the pattern of functional change for clients who entered residential care versus clients who remained in the community at time of follow-up. Both groups include individuals who remained functionally stable or gained ADL function and others who lost ADL function over time. A wide range of MBI scores at the baseline and final assessments is seen in both groups.

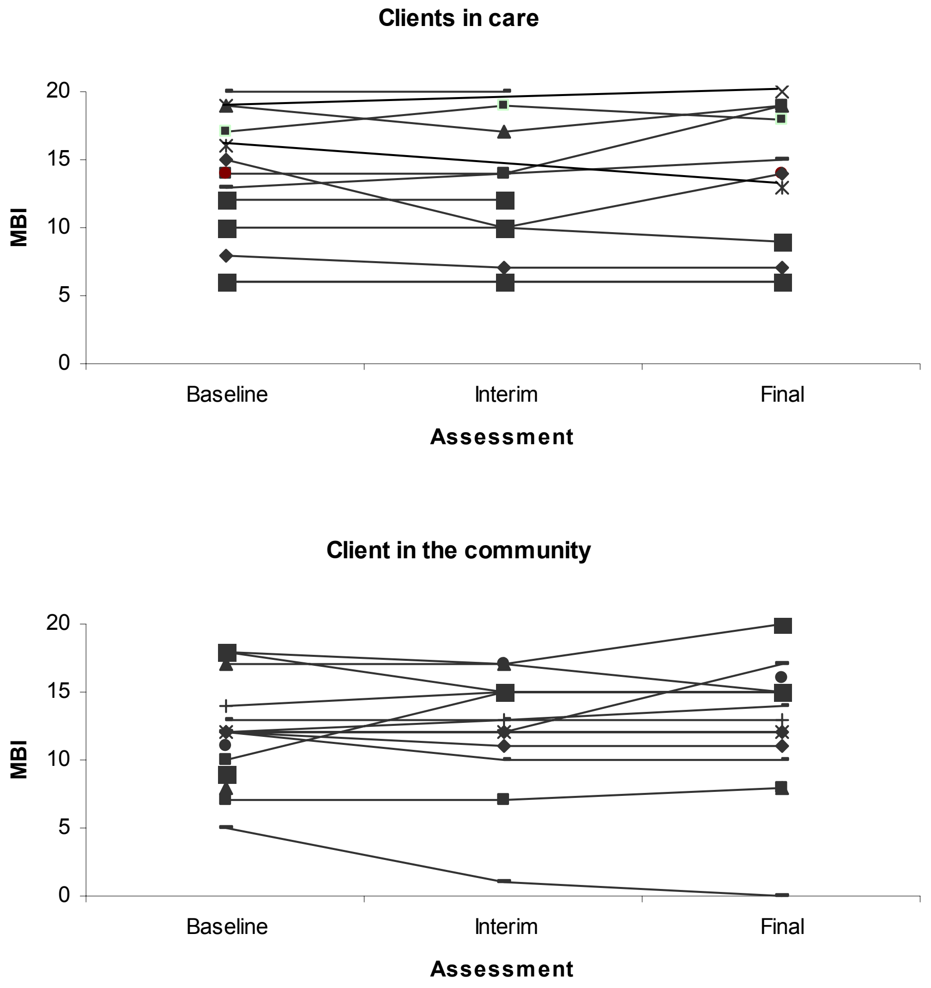


Figure B8.3: Dementia Care in Alternative Settings, baseline, interim and final MBI scores by follow-up accommodation setting (one symbol per client)

Psychological and behavioural symptoms

All clients showed signs of intermittent or extensive memory loss (Figure B8.4). Twenty-seven clients exhibited emotional or psychological symptoms of dementia on an intermittent or extensive basis. Twenty-six clients were reported to be a danger to themselves or others at least occasionally. Thirty-one clients exhibited two or more of psychological and behavioural symptoms on an intermittent or extensive basis and 24 of these clients exhibited two or more symptoms on an extensive basis.[13] Eighteen clients were reported as having other unspecified dementia-related intermittent or extensive behaviours.

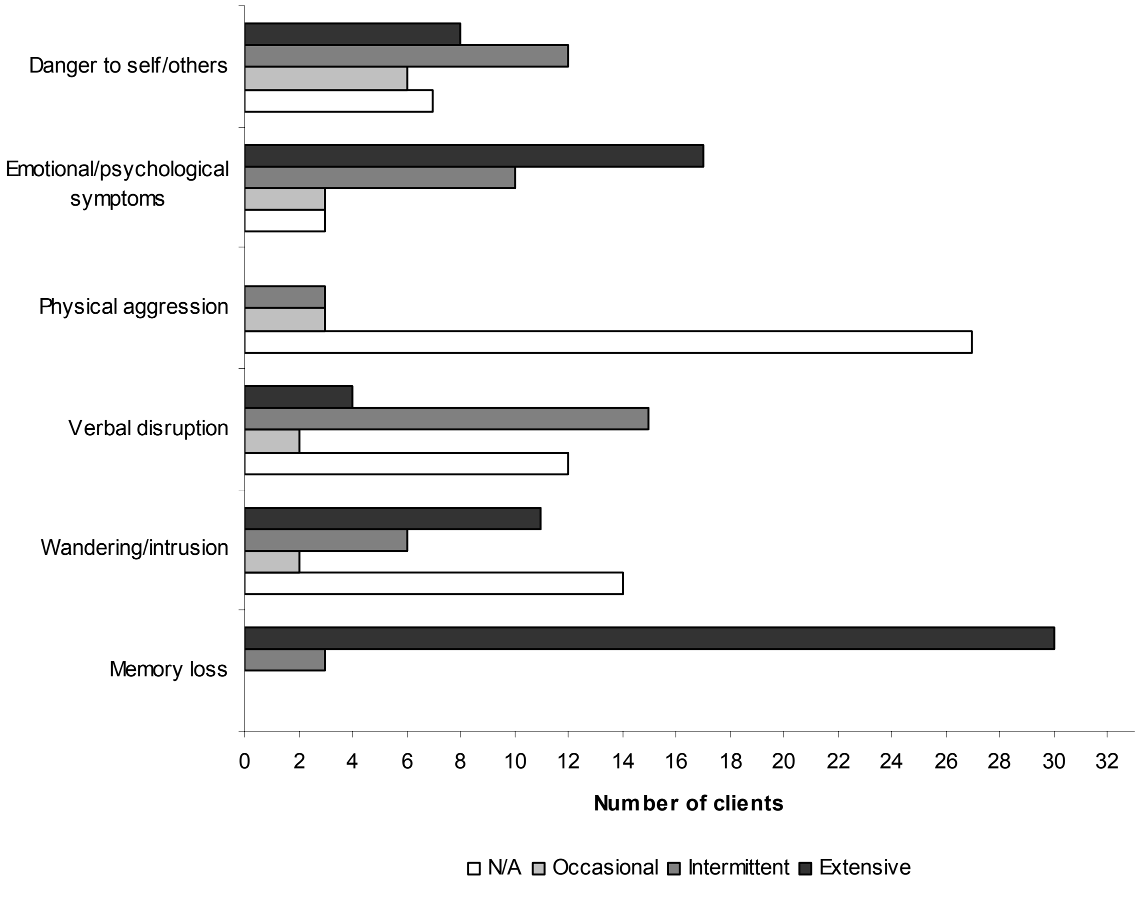


Figure B8.4: Dementia Care in Alternative Settings, number of clients by frequency of psychological and behavioural symptoms at entry

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[13] This includes data from a seventh category called ‘Other behaviour’.

8.4 Carer assessment results

Most carers reported that they were in good to excellent health (20 carers). Nine carers reported their health was fair, and four said that they were experiencing poor health.

Southern Cross Care WA uses a 12-item variant of the CSI as part of normal practice in assessment and care provision. Thus, assessments of carer strain had been performed at or around the time of entry to the project in most cases and assessments for the evaluation were readily incorporated into ongoing assessment and review.[14]

The DCAS baseline scores of carer strain ranged from 2 to 12 points, with a mean score of 8.4 (standard deviation 2.5). Twenty-four carers recorded scores above the threshold for carer strain, and five more carers scored one point below the case threshold.

Baseline and final CSI measures were recorded for 27 carers. Twenty-four of these carers registered at or above the threshold for carer strain at baseline; 17 recorded at or above the threshold on the final assessment. The median change score is the median of the paired differences between carers' final scores and baseline scores. This median, calculated across all carers with complete sets of scores, was –3 points (mean –2.9, standard deviation 2.4), indicating an average decrease in carer strain for DCAS carers between the two assessment points. CSI change scores range from –7 to 3 points. Twenty-one of the 27 carers who completed baseline and final assessments registered a reduction in carer strain.

Twenty-one carers also completed the GHQ-28. Nine carers scored 14 points or higher on at least one sub-scale. Five carers recorded scores of 14 points or higher for somatic symptoms; eight carers recorded scores of 14 points or higher for anxiety and insomnia, one of whom scored the maximum 21 points; six carers scored over 14 points for social dysfunction; and one carer scored over 14 points for severe depression. Two carers scored 14 or higher on one sub-scale; four carers scored 14 or higher on two sub-scales; two clients scored 14 or higher on three sub-scales; and one carer scored 14 or higher on all four sub-scales. According to these self-reports of psychological wellbeing, many carers were experiencing considerable disturbance or distress across a range of domains at the start of the evaluation.

Twenty-eight carers completed the GHQ-28 at a final assessment, of whom three scored above the 14-point threshold on at least one sub-scale. The number of carers reporting psychological symptoms associated with recent changes in circumstances was lower at final assessment than at the baseline assessment.

DCAS CSI and GHQ-28 data are included in an overall analysis of carer outcomes for the Innovative Pool Dementia Pilot long-term projects.

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[14] Clients who commenced on the DCAS before the beginning of the evaluation period were assessed using a 12-question abridged version of the Carer Strain Index. A case threshold of 6 has been used for these clients.

8.5 Service profile

Half to three-quarters of evaluation clients received personal assistance, domestic assistance, allied health care, food services, social support, transport and respite care during the evaluation period (Table B8.13). This project was able to deliver up to 24.5 hours of care per client per week, if required. Some clients received two or three visits daily, often to coincide with meal times so that the care assistant could help with meal preparation and provide companionship throughout the day.

High levels of respite care were observed, with a median of 4.6 hours per client per week but ranging up to 36.5 hours per week (including in-home respite and respite provided in the small group respite care unit). Carer support covered services other than respite such as counselling, information, advice and referral.

Specialist dementia care and memory and behaviour therapies are also featured in the DCAS service profile. These services draw on existing dementia care expertise within Southern Cross Care WA.

The project did not supply financial data to enable a breakdown of expenditure by service category.

Table B8.13: Dementia Care in Alternative Settings, summary of services delivered per client per week, June–November 2004

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Personal assistance	Hours	25	1.0	4.0	11.1	4.6	2.7
Domestic assistance	Hours	24	0.1	1.1	3.3	1.1	0.8
Allied health[(a)]	Hours	24	0.0	0.0	1.5	0.2	0.4
Food service other than delivered meals	Hours	24	0.3	4.6	22.7	5.2	4.7
Social support	Hours	19	0.2	2.0	9.7	2.8	2.5
Respite (in-home and day)[(b)]	Hours	13	0.3	4.6	36.5	8.9	10.4
Nursing care	Hours	3	0.1	0.2	0.4	0.2	0.2
Aids and equipment combined	Dollars	6	0.1	3.0	56.9	12.2	22.2
Dementia care, memory and behaviour management	No. contacts	13	0.0	0.1	5.6	0.7	1.6
Assistance—GP consult.	No. contacts	9	0.0	0.1	0.3	0.1	0.1
Assistance—geriatrician consult.	No. contacts	4	0.0	0.1	0.1	0.1	0.0
Nursing/medical other	No. contacts	3	0.1	0.1	0.6	0.3	0.3
Community mental health service	No. contacts	1	0.0	0.0	0.0	0.0	—
Overnight respite	No. days/nights	1	0.1	0.1	0.1	0.1	—
Carer support other than respite	No. events	23	0.0	0.2	0.9	0.3	0.2
Information advice and referral	No. events	19	0.0	0.2	0.5	0.2	0.1
Medication review	No. events	13	0.0	0.0	0.2	0.1	0.0
Personal other	No. events	12	0.2	0.9	13.5	3.3	4.6
Community service other	No. events	1	0.1	0.1	0.1	0.1	—
Delivered meals	No. meals	8	2.3	3.9	12.1	5.4	3.3
Community transport	No. one-way trips	16	0.1	0.7	4.8	1.2	1.3
Dietetics	No. referrals	1	0.0	0.0	0.0	0.0	—

(a) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(b) Assumes one-day respite date is 6 hours.

Note: DCAS did not provide services data for six clients, consequently this table reflects services provided to 27 of the 33 clients in the evaluation.

— Nil.

8.6 Accommodation outcomes

Follow-up of DCAS evaluation clients was completed by 7 June 2005. Table B8.14 shows accommodation setting and government support program status for all clients at follow-up (that is, approximately 11 months from the start of the evaluation period). Just over half of the original group were still with the project. Most discharges were to high level residential care.

Table B8.14: Dementia Care in Alternative Settings, number of clients by follow-up status, June 2005

Follow-up status	Number of clients
At home	
On DCAS	16
Home and Community Care	1
Total living in community	*17*
In care	
Residential aged care—high	12
Residential aged care—low	2
Total in residential aged care	*14*
Deceased	2
Total	**33**

One client who was with DCAS at time of follow-up had actually been discharged from the project in December 2004 to enter high level residential care. This client was subsequently discharged from the aged care facility to return home in January 2005 and recommenced DCAS services.

Twelve of the 24 clients with ACAT approval for high level residential care were still at home (and with DCAS) at follow-up (Table B8.15).

Table B8.15: Dementia Care in Alternative Settings, number of clients by type of ACAT approval at entry and follow-up status

	Follow-up status				
ACAT approval	At home	Residential low care	Residential high care	Deceased	Total
Low care	5	2	2	—	9
High care	12	—	10	2	24
Total	**17**	**2**	**12**	**2**	**33**

— Nil.

8.7 Wait list clients

DCAS supplied information about 33 people who were placed onto a waiting list for the project from December 2003 onwards. Nine of these individuals were eventually placed onto DCAS as places became available, leaving 24 on the waiting list as a potential basis for comparing DCAS client outcomes.

The waiting list group comprises 16 females (67%) and has an average age of 81 years. Twenty-four per cent (24%) of the group was aged over 85 years at the time of referral to DCAS. Thirty-six per cent (35%) were living alone. Fourteen waiting list clients had a co-resident carer and nine had an ex-resident carer (carer availability was not recorded in two cases). Thus, the waiting list group had a similarly high rate of carer availability, albeit with a slightly higher proportion of co-resident carers (56% of wait list clients versus 46% of evaluation clients).

At time of referral, nine of the 24 people in the waiting list group were not receiving assistance from government support programs. Home and Community Care was providing support to more people in the group than any other program (Table B8.16). The wait list group recorded a higher proportion (36%) of clients with no previous government program support compared to the DCAS group (15%).

A comparison was made of the wait list group and DCAS evaluation clients with respect to a selected number of dependency items:

- presence of severe or profound core activity limitation
- level of mobility limitation
- level of self-care limitation
- level of communication limitation
- bladder incontinence and bowel incontinence (Modified Barthel Index item)
- level of dependency in mobility (Modified Barthel Index item)
- need for assistance with meal preparation (OARS IADL item)
- need for assistance with medication administration (OARS IADL item).

Both the wait list and evaluation groups recorded 64% of people with a severe or profound level of core activity limitation. No significant differences were found between the groups in respect of incontinence, level of self-care limitation, or need for assistance with meal preparation and medication use. Proportions of DCAS and wait list groups on selected ADL items, respectively, were: 12% versus 12% bowel incontinent; 21% and 24% bladder incontinent; 36% versus 33% with a severe or profound self-care limitation; 67% versus 68% unable to prepare meals; 18% versus 44% unable to self-medicate. The wait list group recorded a higher rate of independent mobility (100% versus 76% of the DCAS client group) and a lower rate of severe communication limitation (no clients in the wait list group compared to 12% or four clients in the DCAS group); however a higher proportion (44%) of the wait list group experienced at least moderate communication restriction than the DCAS client group (27%, which includes clients severely limited in communication activities). To summarise, the wait list group reported to the evaluation is similar to the DCAS client group in many important respects.

The purpose of collecting minimal baseline data for a wait list group was to compare baseline characteristics of this group with the evaluation clients to facilitate a valid comparison of 6-month accommodation outcomes. Unfortunately, follow-up was not consistent and much of the follow-up of wait list clients was completed well within a 6-month time frame (one-third of the people were not located at follow-up). By the (varying) time of follow-up, all of those located alive were receiving one or more types of government-funded assistance (Table B8.16). The Home and Community Care Program, with or without other sources of assistance, was the most commonly accessed government community care program for people assessed as eligible for DCAS but who could not be placed onto DCAS. There is evidence of multiple program support, that is, use of HACC services together with assistance funded by other programs.

Three of the 16 people who were located had entered residential care.

Table B8.16: Dementia Care in Alternative Settings wait-list clients, government-program support at referral and follow-up: wait-list data recorded for national evaluation, 2004

	At home at follow-up							In care at follow-up						
	No government-funded support	With government-funded support												
		HACC	HACC+	DTC	CACP	EACH+	Total community	Low care	High care	Total residential	Deceased	Total follow-up	Not located	Total
Support program at date of referral														
No support program	—	2	—	1	—	1	*4*	1	1	*2*	—	6	3	**9**
HACC	—	2	—	—	—	—	*2*	—	1	*1*	—	3	—	**3**
HACC plus other	—	1	3	—	—	—	*4*	—	—	—	—	4	—	**4**
Veterans' Home Care	—	—	—	—	—	—	—	—	—	—	—	—	1	**1**
Day Therapy Centre	—	—	—	—	—	—	—	—	—	—	—	—	2	**2**
CACP	—	—	—	—	—	—	—	—	—	—	1	1	—	**1**
State program	—	—	—	—	1		*1*	—	—	—	—	1	1	**2**
Not stated	—	1	—	—	—	—	*1*	—	—	—	—	1	1	**2**
Total	**—**	**6**	**3**	**1**	**1**	**1**	**12**	**1**	**2**	**3**	**1**	**16**	**8**	**24**

— Nil.

9 The Sundowner Club

9.1 Project description

ECH Incorporated[15] received an allocation of 15 flexible care places under the Innovative Pool Dementia Pilot to establish The Sundowner Club, a new model of respite care and socialisation for people with dementia. The Sundowner Club began as a partnership between ECH and Eldercare Incorporated.

Both ECH and Eldercare operate on a not-for-profit basis. ECH is a large provider of residential aged care and retirement village accommodation in South Australia. ECH is an approved provider for the CACP program, operates community Day Therapy Centre services and is a collaborative partner within regional HACC programs. ECH also offers a range of food services to its own clients and those of other aged care providers. In parallel with The Sundowner Club, ECH has participated in the Australian Government Retirement Villages Care Pilot. Eldercare Inc. is a large provider of residential aged care including high and low care facilities and dementia-specific facilities. Retirement living is the other major area of business for Eldercare. In total, Eldercare provides 730 residential aged care beds and 180 retirement units across 10 metropolitan and rural locations. ECH and Eldercare operate secure dementia units within their residential care facilities.

The Sundowner Club was designed for people with dementia who live in the community and experience specific difficulties associated with 'sundowner' behaviours. 'Sundowning' is a term used to refer to behavioural symptoms associated with dementia that tend to manifest more intensely in the late afternoon and early evening, often causing distress to carers and families and risk of harm to the person with dementia.

The Sundowner Club commenced service delivery in April 2004, operating five nights per week based at two locations in metropolitan Adelaide.

Project objectives and target group

The objective of the project is to test the effectiveness of an evening respite and socialisation program for people with dementia-related behavioural symptoms that contribute to carer strain and social isolation for the person with dementia. In particular, the project aims to provide:

- appropriate social activities, encouraging ongoing community participation and maintenance of existing social and ADL skills for people diagnosed with dementia
- monitoring of the person with dementia who lives alone, for example, physical health, changes in capacity for self-care
- supervision of participants for whom late afternoon and early evening can be a period of acute disorientation, wandering and confusion

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[15] Formerly Elderly Citizens Homes of South Australia Incorporated.

- respite for carers of community-living people with dementia who are approved for residential high care placement (Sundowner Club Pilot Proposal, joint application by Elderly Citizens Homes of SA Inc. and Eldercare Inc., November 2002).

ECH and Eldercare expect The Sundowner Club to achieve the following key outcomes:

- respite for carers
- supervision of clients with dementia
- improved quality of life for clients and carers
- extended periods of independent living and thus delayed entry to residential care, especially by supporting carers
- improved management of client behaviours on participating nights
- education for carers and significant others on successful ways of managing behaviours associated with dementia.

The program was initially intended to provide services to existing ECH and Eldercare independent living unit residents with dementia who were at risk of placement into residential care, with a view to extending the service to community clients according to program capacity.

The Innovative Pool entry criteria for clients included a diagnosis of dementia and approval for residential care placement. Initially targeting people who had been approved for high care, Sundowner Club entry criteria were broadened to include low care approvals following negotiations between ECH and the Department of Health and Ageing in mid-2004. In addition, clients were required to need supervision in the early evening and to be physically able to leave their home environment safely.

Service model

The rationale for The Sundowner Club is to address a gap in mainstream service provision for people with dementia who have specific 'after hours' care needs, and those who find it difficult to access or are reluctant to use traditional forms of respite care. People who live alone, for example, may be excluded from respite services by virtue of not having a co-resident carer, adult day care programs are frequently rejected as 'childish' or as providing inappropriate activities by the intended service recipients, and men and younger people with dementia are observed to resist the idea of joining day programs where the 'very old' comprise the majority of participants (Sundowner Club—Pilot Proposal, ECH and Eldercare, November 2002).

Over time, the ECH supportive services coordinators in each of the three metropolitan service regions had become increasingly aware that people in the target group may be placed in residential care as a result of frequent complaints about sundowner behaviour. Yet, it is also apparent that most people in this situation are able to manage at other times of the day with appropriate formal and informal supports. The Sundowner Club was thus conceived as a means to overcome a general lack of formal support services that extend into evening hours.

Services provided include socialisation, meals, supervision of medication and transport. Service recipients are transported to a community facility from their home address and returned home at the end of the evening. An evening meal is served in a congregate setting with access to social activities. Recipients participate in meal preparation and clean-up. Activities are designed with the flexibility to meet the needs of different groups such as men and younger people with dementia. The Sundowner Club caters for up to eight people each evening over five evenings per week. Each participant is able to attend on multiple evenings in a week. The program operates between 3.30 pm and 8.00 pm, Monday to Friday, with two evenings based at a site in Norwood and three at a site at Henley Beach. Maximum capacity lies between 20 and 30 service recipients at any one time.

The Sundowner Club is unique among the Innovative Pool Dementia Pilot long-term care projects in that it is a stand-alone evening meal and socialisation program rather than a comprehensive care package service. Clients are expected to continue in any pre-existing support arrangements, with The Sundowner Club providing supplementary respite and socialisation. The project reports that around 80% of Sundowner Club clients receive assistance from other community care services and continue to do so while taking part in the evening program. Clients who require ongoing case management will access that support through another service since The Sundowner Club does not operate a case management model. These clients usually have a primary case manager, either through a CACP, ECH Support Coordination Service, or a HACC-funded service. Sundowner Club staff liaise with the primary care manager to address changes in the client's needs or status.

Staffing

In mid-2004, The Sundowner Club staff comprised one care manager (0.7 full-time equivalent) and two part-time care workers. In addition, the project receives a high level of support from the ECH senior support coordinator. At the same time ECH was in the process of recruiting a casual additional assistant coordinator to cover leave periods for permanent staff.

Recruitment of staff has proven to be more problematic than anticipated. Few applications were received for the advertised position of project coordinator and enquiring applicants indicated that the working hours were a disincentive. Attracting suitably experienced applicants also proved to be a challenge.

Filling the assistant coordinator positions was less difficult as the working hours are well suited to tertiary students and these positions offer the opportunity for health sciences students to consolidate practical skills.

Successes, challenges and lessons

The Sundowner Club highlights the positive features of a small group model in supporting community-living clients with advanced dementia. The model is an innovative form of respite and socialisation with significant benefits for clients and family carers, described below under 'Case studies—carer feedback'.

ECH reported that a major achievement of The Sundowner Club is the enriched social participation and increased service acceptance among recipients that takes place over time. Examples were cited of clients who had previously been resistant to the idea of formal services coming to accept assistance, initially through the Sundowner Club program and progressing to additional in-home services. It was noted that people with dementia who have led active social lives in the past do not stop enjoying social outings because they have dementia. The positive experience of an 'outing' and social interaction provides reassurance to clients that service providers support their desire to remain at home. Family members have reported to coordinators that The Sundowner Club provides them with valuable support, both in the form of respite and in the easing of care recipient behaviours. One carer said that her husband's aggressive behaviour had lessened significantly since he started attending Sundowner Club evenings to the extent that she felt able and willing to continue caring for him at home and was no longer considering residential placement for the foreseeable future.

It is often observed that a new client is initially apprehensive about attending The Sundowner Club. Many clients exhibit some degree of paranoia and suspicion, particularly in regard to new activities and activities initiated by ECH and Eldercare, which are viewed as manoeuvres to place people in residential care. Sundowner Club coordinators have had to make multiple home visits to build rapport and trust before a number of clients would agree to leave home to attend the program. Clients who agree to trial the program for one night have quickly settled into a pattern of regular attendance and some have requested more frequent attendance. Similarly, clients who initially required substantial assistance to leave their units are frequently now waiting to be picked up by staff (staff ring earlier in the afternoon to prompt clients and some clients are able to get ready independently despite significant levels of confusion).

During the evening sessions staff members have observed changes in clients' ability to interact with one another and with staff. One very confused client was initially unable to speak unless spoken to on a one-to-one basis. This client is now able to engage in appropriate, spontaneous conversation with other clients in response to activities occurring at the time and has developed a friendship with another person who attends on the same evening. Over time, clients begin to confide in staff about problems at home that they are unable to resolve. Information withheld during the assessment process is gradually divulged. Some clients have told staff that their Sundowner Club night(s) are the only occasions on which they eat a meal with other people. The opportunity for supported social interaction is observed to engender a heightened sense of self and has helped to encourage a greater interest in self-care and appearance in many clients.

The project reports that the behavioural symptoms of clients are somewhat different to what was anticipated. Clients generally show signs of self-neglect and/or aggressive behaviour instead of wandering and intrusive behaviour. Undiagnosed depression is suspected to be a factor for some clients. The process of introducing new clients has been modified as the importance of minimising disruption to the dynamics of a relatively cohesive group became evident. Some clients become agitated with changes to their familiar environment. This resulted in slower than anticipated recruitment of clients into the project to allow groups to settle before the introduction of a new client.

Issues encountered during the establishment of The Sundowner Club included recruitment of suitably experienced/qualified staff willing to work regular evening hours; education of referral sources to make appropriate referrals to the program (both within ECH/Eldercare and other service providers, ACAT, GPs, etc.); and waiting time for ACAT assessments (at the time the program commenced some clients waited a number of months after referral to ACAT before being ACAT assessed).

Project coordinators experienced difficulty in deciding whether to commence services for a client while they show a willingness to do so, or to wait for ACAT approval and risk client refusal of the service at a later date. Waiting times for ACAT assessments can be 3–6 months in some areas. Delays have also occurred because ACAT approvals have been given for respite and flexible care, but not residential care, as required. ECH reported that some ACATs appear to have assigned low priority to assessments for clients referred to The Sundowner Club and it is thought that this is because Sundowner Club referrals are competing for ACAT resources with referrals for clients seeking residential placement.

Sometimes clients contribute to assessment delays. Some clients refuse to sign the ACAT approval or refuse ACAT entry to their home. The assessment process undertaken by The Sundowner Club coordinator and/or ECH senior support coordinator is too lengthy to undertake in a single session and normally requires several in-home assessments, which makes the process expensive and resource intensive. Clients are frequently suspicious of the assessment process and gaining cooperation has been difficult in a number of cases. Clients recognise the Mini-Mental State Examination, which is used frequently by medical practitioners, specialists and other service providers and tend to be highly resistant to this type of assessment. They are often unwilling to share information that is perceived to increase the likelihood of residential placement and will thus deny the existence of problems such as incontinence, medication management and ADL difficulties. Often the real situation only emerges when a client feels comfortable with staff on their Sundowner Club evenings. Assessment issues are thought to be a particularly salient consideration when designing programs and working with members of the target group.

From the perspective of the Adelaide ACAT, by the time the ACAT conducts an assessment, ECH has already assessed the client and has mapped out a service plan. There is some feeling that the ACAT assessment is essentially a 'rubber stamp' by that point, however the team has found ECH assessments to be generally accurate and the proposed services appropriate. The ACAT enjoys a smooth working relationship with ECH. Adelaide ACAT has a benchmark of five days to conduct an assessment after receipt of a referral. If a service is immediately available the assessment is given priority status and the client is seen sooner, sometimes on the same day. Were The Sundowner Club service not available, clients without existing services would most likely be placed on a CACP waiting list, which at the time was running at between 6 and 24 months, depending on the provider. Most clients, particularly those with dementia, cannot remain in their homes and wait that long for services, so a move to residential aged care is often inevitable.

The key issues affecting placement for those Sundowner Club clients who subsequently moved into residential aged care appear to be the lack of available high care or dementia-specific case management services, lengthy waiting lists for CACP services, the lack of other community programs able to support clients with dementia and challenging behaviours on an ongoing basis, and the withdrawal of informal carer support (either spouse, family or friends). In most cases, withdrawal of support was by family members (son, daughters, niece and nephew) or a friend, whereas one client moved into residential care following the sudden death of her spouse who was her carer. In all but the latter case, carers had been actively seeking placement prior to the clients commencing with The Sundowner Club and most clients remained living in the community for some months after commencing with the Sundowner Club program.

Case studies—interviews with family carers

While the Sundowner Club program was not intended to replace case management or packaged services, the program has been effective in supporting clients and carers by providing regular respite which is valued by the client and carer. The importance to carers of receiving out of home respite for the person with dementia has been emphasised repeatedly by carers in feedback to Sundowner Club staff throughout the program and during follow-up evaluation in September 2005. Various carers have reported that being able to have regular time at home to themselves has been an important factor in enabling them to provide ongoing care. Likewise they have emphasised the importance of feeling that the person with dementia is enjoying the experience, with several reporting that they feel intensely guilty about receiving respite (and less likely to continue with the service) if they feel that the person with dementia is unhappy or doesn't enjoy attending a respite program.

ECH interviewed family members about their experiences. The stories highlight a strong desire for social participation in people with dementia, which becomes more difficult as the dementia advances, often leading to social isolation for both the person with dementia and their family carer. The impact of The Sundowner Club on people's quality of life and its potential to help sustain caring roles is described in selected interview transcripts below.

A daughter reported to staff that her mother (who has advanced dementia and is no longer able to speak English and only speaks in single words in her first language) came home with a smile on her face for the first time in months after her first visit to The Sundowner Club. Similarly, the daughter has reported to staff that her mother is 'happy all the next day even though she can't remember going to the Club, she is still happy' and that her mother has once been able to tell her daughter 'I had a good time'. One wife also spoke of her difficulty in finding activities which her husband would enjoy at home, stating that he gets bored when he is at home with her and needs his own 'normal' social outlet despite the extent of his dementia.

Two women caring for husbands with advanced dementia who attended The Sundowner Club were interviewed. Both showed signs of high levels of stress which they associated with their role as a carer. One spouse is still able and willing to actively support her husband to remain living at home however the other is actively seeking residential care placement for her husband in the near future due to his verbal and physical aggression towards her and other family members. This client's aggression is also evident to Sundowner Club staff who report sudden threatening movements, for example, sudden, unexpected hand gestures towards staff, threatening facial expressions, including verbalising aggressively through clenched teeth and verbally aggressive statements towards staff and other clients. These behaviours were observed during the period of re-assessment of clients in 2005, including some verbal and threatened physical aggression towards the assessor.

Both carers spoke of the isolating effects of Alzheimer's disease experienced by themselves and their husbands. One described her husband's experience as 'the slow torment of losing his mind' which she felt was particularly difficult for a man who had previously been extremely successful in business and a gifted artist and musician. Both reported that as their husbands' ability to participate in social activities has declined, the number and frequency of their longstanding social contacts has diminished.

One carer described having to restrict the number of people invited to attend luncheons (compared to previously regularly hosting large gatherings for lunch and dinner parties) due to her husband's difficulty coping with large groups and his withdrawal because he is no longer able to follow or participate in conversations to his satisfaction. She reported that a luncheon party of six people is feasible for him because in the smaller group there is usually only one conversation which he can follow and feel that he can contribute whereas once the group expands to eight people there are usually two conversations and her husband is unable to follow or participate in either conversation. They also choose to have luncheons because he is less tired and less likely to struggle socially at that time of the day. She commented about the irony of their peers (many of whom were medical practitioners like her husband) being unable to cope with her husband's diagnosis and the resulting constriction of their social network. Both she and her husband reported their ongoing sense of loss and grief at his diagnosis. His ability to be insightful fluctuates, however he is very aware that his illness is affecting his wife as well as him. He was also able to clearly describe his loneliness and frustration, including his word-finding difficulties which slows his participation in social situations. He commented repeatedly on the importance of The Sundowner Club to him, including a statement that 'I would certainly miss not having some contact with people'. His wife reports that he has previously been referred to other community-based groups, however his participation has been short-lived because he has been frustrated by the activities offered (which he felt were inappropriate and patronising) and by his difficulty coping with larger groups of people. She reported that she felt that the small number of clients attending The Sundowner Club was key to his willingness to continue to attend the group, along with the activities offered, which he enjoyed. She also reported that she felt that while The Sundowner Club offered her some respite, it was of greater importance to him because it enabled him to retain a valued social role with other people, whereas prior to attending he had become increasingly withdrawn.

The other carer reported that 'a carer goes through more hell than the patient' because the carer has to cope with their own sense of grief and cope with their partner's fluctuating insight and loss. She reported that she most missed being able to have a meaningful conversation with her husband and her difficulty coping with her husband's increasing egocentricity, especially during a recent period of illness when she needed support and he was unable to respond to her needs and placed extra demands on her. She talked of the importance of The Sundowner Club to her—'the beauty of it (The Sundowner Club) is that he leaves here and comes back' (door-to-door transport is provided) and 'I get about 5 precious hours to myself—I can watch the news without him constantly interrupting me because he can't follow what is happening on the TV anymore'. She fears that his mobility will deteriorate to the point that he is unable to board the Sundowner bus and that this will mean that he is no longer able to attend the evening. She also talked of the importance of the evening to her husband: '[her husband] gets bored at home with me' and 'he really enjoys the music. He has always loved music and singing, and [the coordinator] is able to bring out the best in him because she can just pick up a tune and play it on the piano while he sings. He gets a great deal of enjoyment from singing, but even that is slipping and her skill is that she can work out what he is singing so he still feels that he is doing well'. This carer feels that her husband's participation in The Sundowner Club has been valuable for him by enabling him to continue to participate in activities which he has previously enjoyed while also providing her with invaluable respite enabling her to pursue her own interests.

Both wives spoke of the importance to them of feeling that they could get out of the house on their own and resume their own interests and lives during the respite offered by The Sundowner Club. One uses the time to have coffee with her daughters, and more recently has joined an adult French language class for her own mental stimulation, whilst the other (older) carer enjoys being able to phone her adult children who live interstate without having constant interruptions from her husband. She reports that her children are a major source of support to her but that she can rarely speak to them freely when her husband is present. She also watches the evening news uninterrupted which she says 'on the surface is a small thing, but it means a lot to me because I am so isolated in the house with [her husband] and I need to know what is going on in the world or I feel even more isolated'.

The interviews with the carers highlighted the following issues and strengths of the small group model utilised by The Sundowner Club, including:

- their experiences of increasing social isolation, loss of meaningful social contacts and infrequent participation in valued community activities due to their responsibilities as a carer
- carers' desires to regain intellectual stimulation (and social activities) to replace the interaction with their partners which their partners are no longer able to sustain

- increasing social isolation for the person with dementia despite the desire on the part of the individual to maintain meaningful social contacts
- the importance of supporting the individual with dementia to retain their own valued social roles
- the difficulty experienced by people with dementia in coping in large group settings where they are overwhelmed by and unable to cope with or participate in multiple conversations or stimuli
- the importance of a small group model in enabling the client to participate and interact to the best of their abilities
- the importance to the client with dementia of being able to participate in a program which offers socially (and developmentally) appropriate activities and interaction
- the frustration experienced by clients with dementia of being expected to participate in programs which they perceive to be demeaning or infantile, resulting in reluctance to attend and/or service refusal
- the importance of staff being able to be respectful, flexible and responsive to individual needs in a group setting, adapting and changing activities to maximise each individual's participation.

9.2 Client profiles

Formal evaluation of the program commenced shortly after The Sundowner Club started operating. At this time the program was still being established, including promotion to other service providers and recruitment of clients. Just prior to commencement of data collection in 2004, eight of the initial group of Sundowner Club clients had entered residential aged care. Three of these clients were assessed and accepted into the project but took up a residential place before attending their first Sundowner Club evening. Another five clients were assessed and accepted into the project and attended one evening before moving to residential care. Evaluation data were not recorded for these clients, leaving 15 members of the early client intake to participate in the evaluation who tended to be a higher functioning group. This early pattern of rapid discharge to residential aged care suggests that the initial target group included people with high care needs who may not have had adequate support in addition to The Sundowner Club to remain at home and/or people who were actively seeking residential placement.

Since The Sundowner Club was a completely new program, client selection criteria were refined as experience with the target group increased. Data collected in 2004 reflect the profile of a program in its formative stages rather than a well-established program. ECH conducted a follow-up evaluation in September 2005 to report on the established service. These results are included where applicable to highlight changes in the profile of Sundowner Club clients that have taken place as the program matured. The main differences between project snapshots of mid-2004 and mid-2005 are that clients in the established program are more likely to come from a culturally and linguistically diverse background, more likely to live in the community with a co-resident carer, and more likely to score poorly on the MMSE or to be unable to be assessed due to language difficulties and/or highly confused state than the early client intake.

Age and sex

The mean age of the evaluation clients during the reporting period was 85.3 years (age ranges from 79 years to 92 years). Eight evaluation clients were aged 85 years or over (Table B9.1).

The 21 clients in September 2005 averaged 83 years of age.

Table B9.1: Sundowner Club, number of clients by age group and sex, 2004

Age (years)	Males	Females	Persons
		(number)	
75–84	2	5	7
85+	3	5	8
Total	**5**	**10**	**15**
		(per cent)	
75–84	13.3	33.3	46.7
85+	20.0	33.3	53.3
Total	**33.3**	**66.7**	**100.0**

Language and communication

During the formal evaluation all 15 clients used spoken language effectively and spoke English at home.

In September 2005, six out of 21 clients were from culturally and linguistically diverse backgrounds including Latvian, Serbian and Italian nationalities. One such client was living alone in an ECH independent living unit (with a non-resident family carer) while the remaining five clients were all living with family carers (either partners or sons/daughters and their respective partners). Generally, the clients from culturally and linguistically diverse backgrounds demonstrated more confused behaviours including frequent wandering, higher levels of agitation and frequently repetitive speech (often in a mixture of English and their first language) when attending The Sundowner Club. Four of these clients required extensive staff assistance for basic personal care tasks including eating and toileting.

Accommodation and living arrangement

All original evaluation clients were living in independent living units within retirement villages managed by ECH or Eldercare at the time of the evaluation (Table B9.2). One client was living in a private residence at the time of referral and subsequently moved into a retirement village. Years at usual accommodation range from 2 to 33. Eight clients had been living in the same home for 10 or more years.

Among the clients who participated in the evaluation in 2004, more were living alone (including those managing without carers) than had originally been anticipated by ECH. Changes in carer availability and carer co-residency profiles that occurred over the 12 months to September 2005 are described below and reflect a decrease over time in the proportion of Sundowner Club clients who live alone.

Table B9.2: Sundowner Club, number of clients by usual accommodation setting, living arrangement and accommodation setting at time of referral to project, 2004

	Usual living arrangement				
Accommodation setting	**Alone**	**With family**	**With others**	**Not stated**	**Total**
Retirement village—independent living	11	4	—	—	15
Total	**11**	**4**	**—**	**—**	**15**

— Nil.

As awareness of The Sundowner Club grew, the project received referrals from a greater number of sources and ECH reported that the majority of clients in the follow-up evaluation had been referred by service providers other than ECH or Eldercare.

Carer availability

The profile of carer availability and carer co-residency changed noticeably between the initial evaluation and follow-up in 2005. Nine of the original 15 evaluation clients (60%) had a carer and only four carers were reported to be living with the Sundowner Club client (Table

B9.3a). In September 2005, 81% of clients had a carer and most carers lived with the Sundowner Club client (Table B9.3b). Thus over the course of the evaluation, The Sundowner Club increasingly functioned as a respite program for co-resident carers as well as socialisation for clients.

Carers' ages in the original group ranged from 41 to 86 years, averaging 68 years, and four carers were aged 75 years or over (Table B9.4).

Table B9.3a: Sundowner Club, number of clients by carer availability, carer relationship to client and co-residency status, 2004

Relationship of carer to client	Carer lives with client	Carer does not live with client	Not stated	Total
Spouse or partner	4	—	—	4
Son or daughter	—	3	—	3
Other relative	—	1	—	1
Not stated	—	—	1	1
Total clients with a carer	*4*	*4*	*1*	*9*
Total clients				**15**
Per cent of clients with a carer				60

— Nil.

Table B9.3b: Sundowner Club, number of clients by carer availability, carer relationship to client and co-residency status, September 2005

Carer availability	Carer lives with client	Carer does not live with client	Total
Has a carer	12	5	17
Does not have a carer	. ..	. .	4
Total clients			**21**
Per cent of clients with a carer			81

. . Not applicable.

Table B9.4: Sundowner Club, number of carers by age group and sex, 2004

Age (years)	Males	Females	Not stated	Persons
25–44	—	1	—	1
45–54	1	1	—	2
55–64	—	—	—	—
65–74	—	—	—	—
75–84	—	3	—	3
85+	1	—	—	1
Not stated	—	1	1	2
Total	**2**	**6**	**1**	**9**

— Nil.

Income and concession status

Evaluation clients relied on the age pension or a DVA pension as their primary source of cash income. All clients held a health care concession card.

All clients make a co-payment of $1.50 per day to attend The Sundowner Club. This amount is recorded as the full co-payment that applies for the project.

Previous and concurrent use of government community care programs

Nine clients were not receiving assistance from government-funded community care before joining The Sundowner Club (Table B9.5). One client was receiving HACC-funded services, another received CACP services and one client was receiving services through another unspecified program. Previous source of assistance is unknown for three clients.

The three carers who had accessed respite care in the 12 months prior to entering the project had used mainly residential respite care. Two carers reported that, despite having had a need for respite care prior to the care recipient entering The Sundowner Club, they had not used a respite care service. Two carers reported that they did not need respite services. Use of respite services is unknown for two carers.

Since The Sundowner Club is not a case management/care package service, some clients continue to receive services funded by other programs while taking part in The Sundowner Club. In the original evaluation group one client was referred to The Sundowner Club from a Retirement Villages Care Pilot project operated by ECH and one client was referred to the ECH Retirement Villages Care Pilot project after commencing in The Sundowner Club. Two clients were receiving delivered meals five times a week through HACC, and one client had a CACP service. One other client began receiving delivered meals through HACC and was referred to Mental Health Services for Older People at the end of the evaluation.

Table B9.5: Sundowner Club, number of clients by previous use of government support programs, 2004

Previous use of government support programs	Number of clients	Per cent
Government support program		
Home and Community Care	1	6.7
Community Aged Care Packages	1	6.7
Other program	1	6.7
Total clients with previous government program support	*3*	*20.0*
Clients without previous government program support	9	60.0
Not stated	3	20.0
Total	**15**	**100.0**
Use of respite care in the 12 months prior to project		
Respite care used	3	37.5
Respite care not needed	2	25.0
Respite care needed but not used	2	25.0
Not stated	2	12.5
Total	**9**	**100.0**

Five clients were on a waiting list for residential aged care.

Assessment and referral

The majority of clients in the 2004 evaluation group were referred to the project by ECH or Eldercare (Table B9.6). By September 2005 The Sundowner Club was receiving referrals from other community service agencies and the majority of clients at that time had in fact been referred from the wider community.

Table B9.6: Sundowner Club, number of clients by source of referral, 2004

Referral source	Number of clients
ECH or Eldercare	9
Other community service agency	3
Aged Care Assessment Team	1
Other person	2
Total	**15**

The Innovative Pool entry criteria for clients include a diagnosis of dementia and approval for residential care placement. Initially, The Sundowner Club targeted people who had been approved for high care but entry criteria were broadened to include low care approvals following negotiations between ECH and the Department of Health and Ageing in mid-2004. In addition, clients were required to need supervision in the early evening and to be physically able to leave their home environment safely.

Five clients had completed an ACAT assessment on the same day or prior to referral to the project. For these clients, the time between completion of an assessment and referral to the project varies up to 255 days (Table B9.7). ACAT assessment was completed after referral to the project for nine clients, up to 191 days after referral.

ACAT assessment end date is not recorded for two clients. The project reported that one of these clients had had an ACAT assessment but the details are uncertain. The other client waited approximately 7 months for an ACAT assessment. The project had accepted this client prior to ACAT approval because of the uncertain waiting time for assessment which could have prevented the client from participation.

Thirteen clients are reported to have had one ACAT assessment in the 12 months prior to entering the project. Number of ACAT assessments is not reported for two clients.

Table B9.7: Sundowner Club, number of clients by days between completion of ACAT assessment and date of referral to project, 2004

Completion date of ACAT assessment	Number of clients
Before referral to project	
0–30 days	2
31–60 days	2
61–90 days	—
91–180 days	—
181–365 days	1
Total	*5*
After referral to project	
Between 6 and 191 days post-referral	9
Not stated	1
Total	**15**

— Nil.

Health conditions and health status on entry

The number of health conditions recorded for The Sundowner Club clients at entry to the project ranges from one to six. Seven of the 15 clients had four or more health conditions. Table B9.8 shows the primary health conditions recorded on the Aged Care Client Records for clients in the initial evaluation group. Fifteen of the 21 clients in the follow-up evaluation had a primary health condition of dementia.

Table B9.8: Sundowner Club, number of clients by primary health condition, 2004

Primary health condition	Number of clients
Dementia in Alzheimer's disease	7
Heart disease	3
Skin cancer	1
Parkinson's disease	1
Deafness/hearing loss	1
Hypertension	1
Diseases of the musculoskeletal system	1
Total	**15**

Seven clients in the initial group were assessed as being at risk of falls due to impaired gait or balance and seven had a diagnosis of depression (Table B9.9). Two clients presented with both hearing and vision impairment.

Table B9.9: Sundowner Club, number of clients by selected sensory, mental and physical conditions, 2004

Health condition	Number of clients
Impaired gait or balance—at risk of falls	7
Diagnosis of depression	7
Vision impairment	4
Disorientation/confusion	3
Hearing impairment	2

Eight clients were taking between one and nine different types of medication at the time of reporting. Four of the eight clients were taking four or more different medications.

Clients and carers of clients were asked to rate client health status and change in health status over the past twelve 12 using a five-point Likert scale (Short-Form 36). Seven clients gave a self-report, a carer responded on behalf of five clients, and a care worker responded for one client. Health status is not recorded for two clients. Health status was rated as very good (four), good (four), fair (four) or poor (one).

Change in health status was recorded for 12 clients. Nine clients were reported to be in about the same state of health as 12 months earlier. The health of two clients was rated as somewhat worse than 12 months earlier, and one client was said to be in a much worse state of health than one year earlier.

Level of core activity limitation

Most Sundowner Club clients are recorded as experiencing no difficulty or mild difficulty in the areas of self-care and mobility (Table B9.10). Two clients are recorded as having a severe or profound limitation in at least one core activity. While this is one of the lower rates of severe or profound core activity limitation recorded by Innovative Pool Dementia Pilot projects, the core activity limitation profile of Sundowner Club clients is likely to have changed given the results of cognitive function assessments in September 2005 that reveal a more highly impaired client group. Assessments of physical and ADL function were not performed in September 2005 due to time constraints.

Table B9.10: Sundowner Club, number of clients by level and area of core activity limitation, 2004

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	4	7	3	1	**15**
Mobility	5	6	3	1	**15**
Communication	8	4	2	1	**15**

Use of medical and hospital services prior to entry

Baseline profiles contain information about client use of medical and hospital services in the 6 months prior to entering the project —the 'pre-entry period'. Of the 13 clients for whom these data were recorded, 11 had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner in this period varied from zero to 12 per client. Cumulatively, the 11 clients recorded 55 visits to a medical practitioner outside of a hospital setting over an estimated 1,980 person days.

Three clients used hospital services in the 6 months prior to entering the project, one of whom attended an emergency department but was not admitted to hospital. The other two clients had planned admissions only; reasons for admission were not recorded. The project recorded no unplanned or urgent hospital admissions for clients in the 6 months before entry.

9.3 Client assessment results

Cognitive function

MMSE scores were recorded for all 15 Sundowner Club clients in the original evaluation group. Scores on entry ranged from 3 to 30 points out of a possible total of 30 points (mean 19.9; standard deviation 6.85; median 21). One client scored 3 points and the remaining 12 clients scored between 14 and 30 points.

Cut-points to account for educational attainment were applied to the entry scores (Uhlmann & Larson 1991). The results suggest that nine of the 15 clients had probable cognitive impairment and six clients did not display cognitive impairment on the basis of entry MMSE scores. During program implementation The Sundowner Club targeted a mixed group of older people, including some without MMSE indication of cognitive impairment.

ECH reported that clients who attended The Sundowner Club in its early days differed from the anticipated client profile by scoring higher on the MMSE and showing greater independence in personal care and instrumental activities of daily living (higher ADL and IADL scores). The higher functioning client profile found in the original evaluation is thought to reflect a number of factors including:

- the number of independent living unit clients with mild–moderate cognitive impairments who 'self-neglect', who are perceived to be at risk of placement into residential care due to those behaviours
- the inability to measure behaviours which place community-living clients at risk of residential care placement, for example, inability to initiate activity or passivity, but which do not include aggression, wandering or intrusiveness. The RCS behavioural questionnaire tool chosen for the evaluation reflects behaviours difficult to manage in a residential care setting where residents live in close proximity to others
- the small numbers of clients with dementia who are able to be supported to remain in independent living without extensive case management and services once 'disruptive' behaviours (for example, intrusiveness and wandering) become evident
- the number of clients who present as having cognitive deficits and poor functioning in activities of daily living who may be experiencing depression and who respond positively to opportunities for supportive socialisation provided by The Sundowner Club

- recognition by staff that these clients could benefit from support in the evening
- early confusion amongst referral sources about entry criteria for the program
- acceptance of early referrals into the program to boost client numbers and establish the program quickly, without adequate screening of referrals.

On this advice, the AIHW suggested a reassessment of clients, which was completed in September 2005. Seven of the original 15 evaluation clients were still attending The Sundowner Club. Six clients who were able to be reassessed (one client was in hospital) recorded a median decline of 2.5 points on the MMSE score since entry to the project. The median score at reassessment was 18 points (range 15 to 23 points).

Counting new clients, ECH administered the MMSE to a total of 14 clients for the follow-up evaluation. Seven clients could not be assessed due to hospitalisation, difficulty comprehending or responding in English and/or a highly confused state (ECH described the circumstances in each case). An MMSE score indicative of cognitive impairment was recorded for all reassessed clients (Table B9.11). Eight clients scored 16 points or below, which has been found to be an indicator of the onset of rapid loss of ADL function. Three clients scored under 10 points, indicating severe cognitive impairment and eight clients scored in the range of moderate cognitive impairment.

Table B9.11: Sundowner Club, number of clients by Mini-Mental State Examination score, September 2005

MMSE score	Number of clients
Zero	—
1–15	7
16–18	4
19–24	3
25–30	—
Not assessable	7
Total	**21**

— Nil.

Activities of daily living

At entry to the project, at least half of Sundowner Club clients needed assistance in tasks involving self-care and mobility (Figure B9.1). MBI scores at entry ranged from 10 to 20 out of a possible 20 points. The mean score was 17.2 points with a standard deviation of 2.8 (median 17 points).

A classification scheme for Barthel Index scores (Shah et al. 1989) indicates that four clients were independent in self-care and mobility, three clients showed slight dependency, seven were moderately dependent and one client exhibited severe dependency on entry to the project. Around 50% of clients were fully or partially dependent in two or fewer ADL. Nine of the 15 clients required continence management and four clients were doubly incontinent. Three clients were unable to bathe or shower without assistance and four clients needed assistance to use the toilet. Fourteen clients were able to mobilise independently. Around one in four clients needed help in the areas of dressing, grooming and transfers.

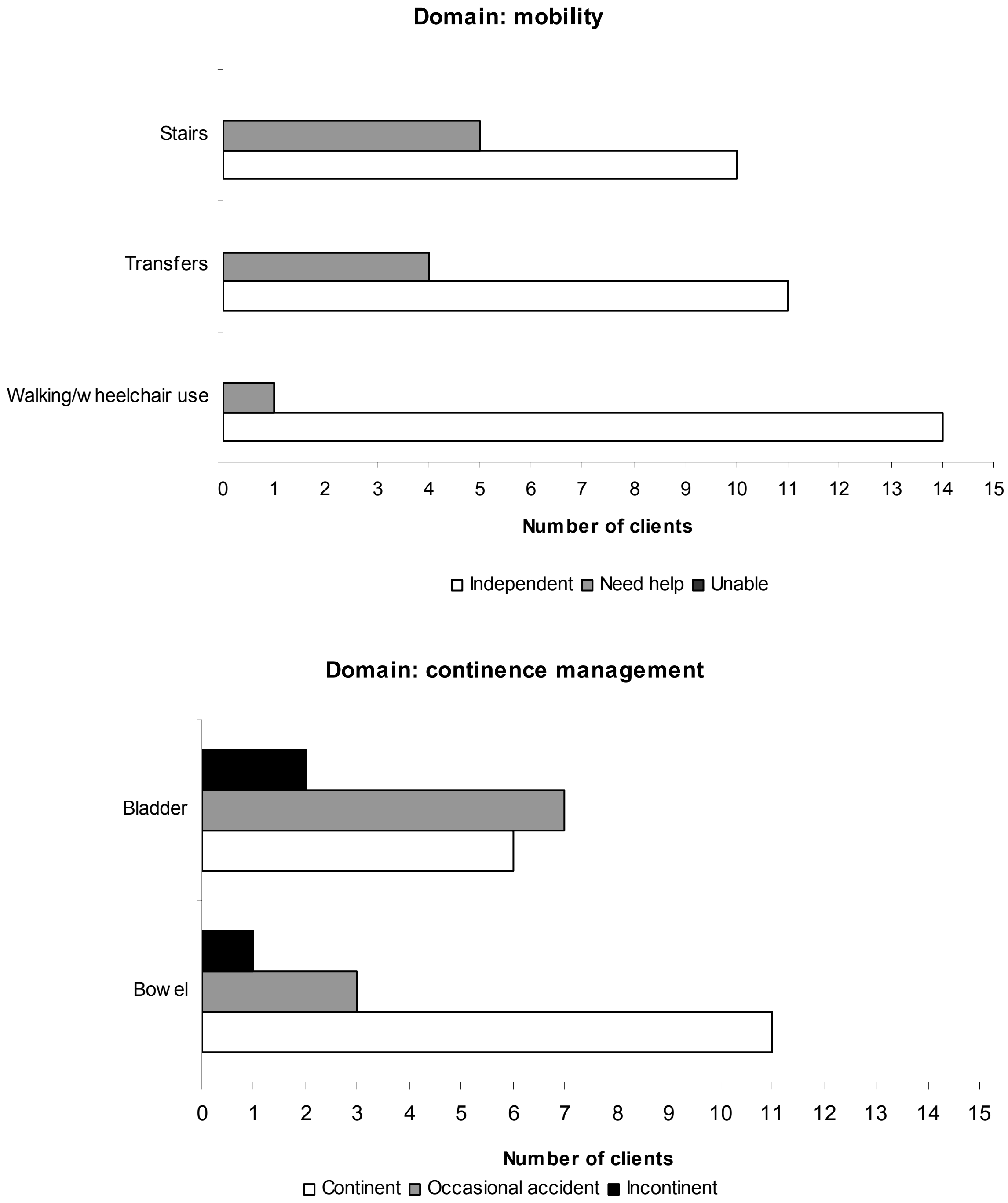

Figure B9.1: The Sundowner Club, number of clients by level of ADL function at entry to project

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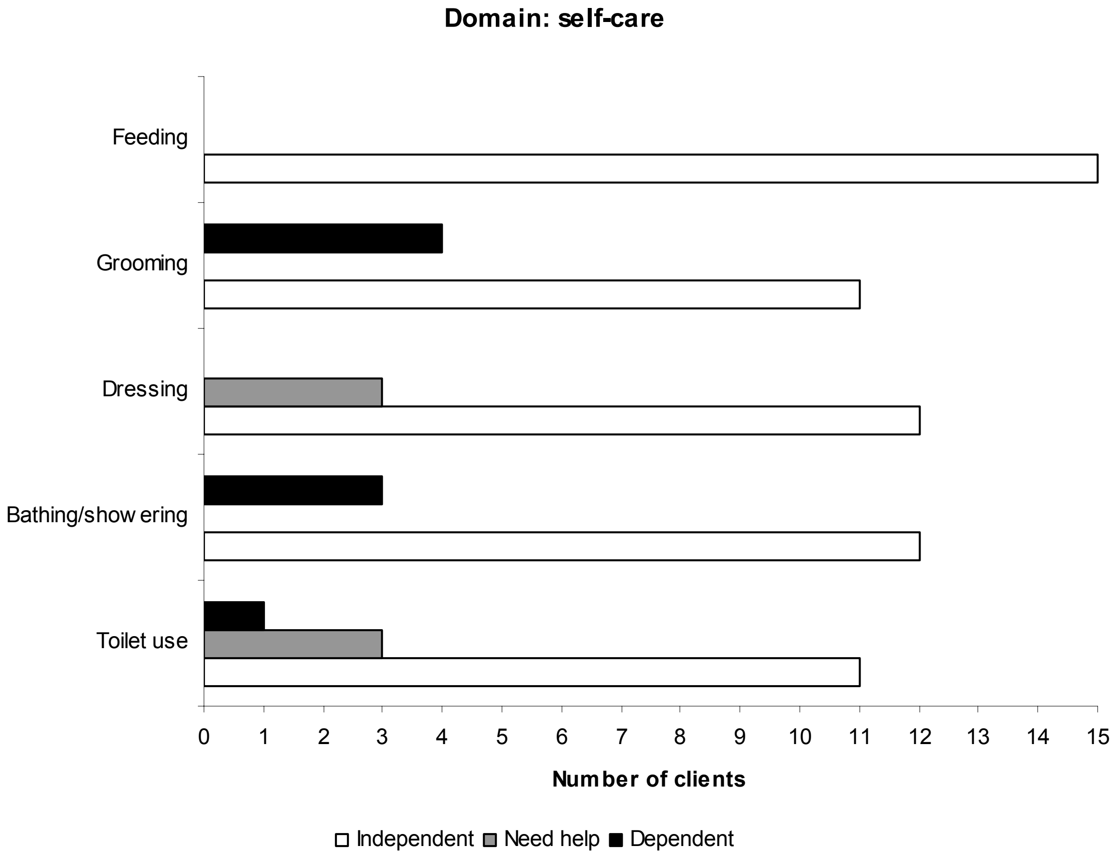
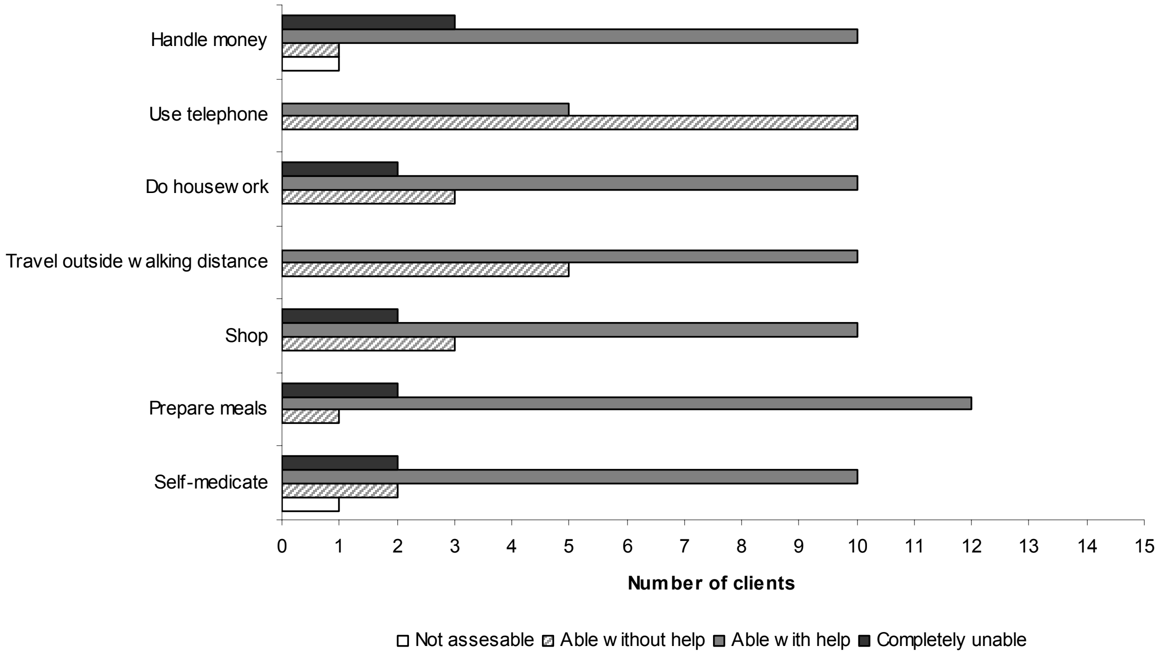


Source: Appendix Table B23.

Figure B9.1 continued: The Sundowner Club, number of clients by level of ADL function at entry

IADL data were recorded for evaluation clients in 2004. Apart from telephone use, most clients needed assistance in IADL when they entered the project (Figure B9.2). Clients were totally dependent in between zero and three IADL. Five clients were independent in all seven IADL. No client was unable to travel to places outside of walking distance, reflecting the requirement that clients are able to travel to a central location via minibus with the assistance of staff.



Source: Appendix Table B24.

Figure B9.2: The Sundowner Club, number of clients by level of IADL function at entry

ECH was asked to record the results of three assessments in total. In some cases only one further assessment was taken. Figure B9.3 shows the MBI scores for clients at baseline, interim and final by accommodation setting at follow-up. Clients in care were either in residential high or low care, or in hospital. Clients in the community were either still in The Sundowner Club, in other community care, or were not accessing formal care.

Patterns of ADL functioning over time for Sundowner Club clients are distinctive from those of other Innovative Pool Dementia Pilot client groups in the clustering around and above 15 points on the MBI. The overlap of ADL scores for clients with different follow-up outcomes as seen in other projects is also evident.

These results are thought to reflect the higher functioning profile of the initial evaluation group. ADL assessments of the follow-up evaluation group were not performed due to time constraints. ECH reported that clients in the established program tended to need higher levels of personal assistance and support in IADL compared with the group in 2004. The lower cognitive function profile of The Sundowner Club in 2005 provides further indication that the ADL support needs profile is likely to have changed over time.

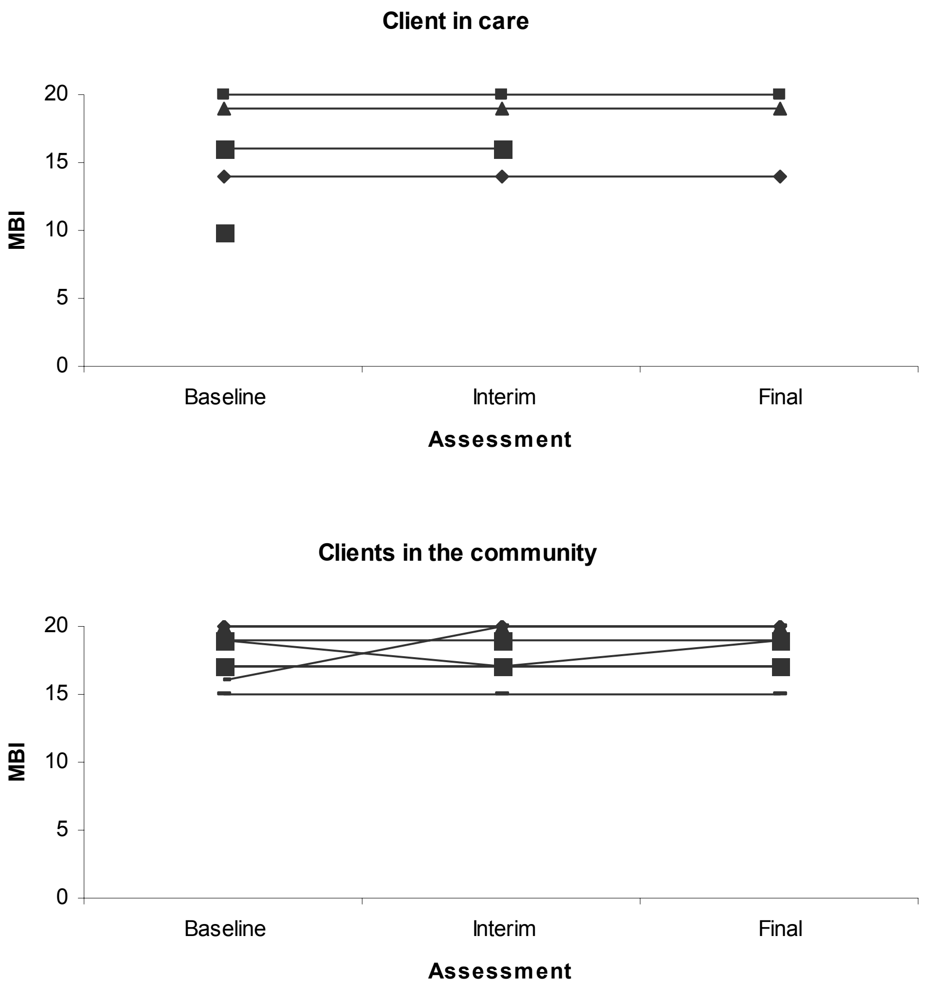


Figure B9.3: The Sundowner Club, baseline, interim and final MBI scores by follow-up accommodation setting, 2004 evaluation group (one symbol per client)

Psychological and behavioural symptoms

All of the initial evaluation clients displayed signs of memory loss and most showed emotional or psychological symptoms on an occasional or intermittent basis (Figure B9.4). Few members of the 2004 client group exhibited wandering or intrusive behaviour, verbally disruptive behaviour, or high risk behaviours. Five clients showed two or more behaviours on an intermittent or extensive basis; two of these clients displayed two behaviours on an extensive basis.

In the follow-up evaluation of September 2005, several clients exhibited verbal aggression and one client was physically aggressive towards family members and staff. ECH reported that client behaviours were a major factor in the decisions for some clients to move to residential care.

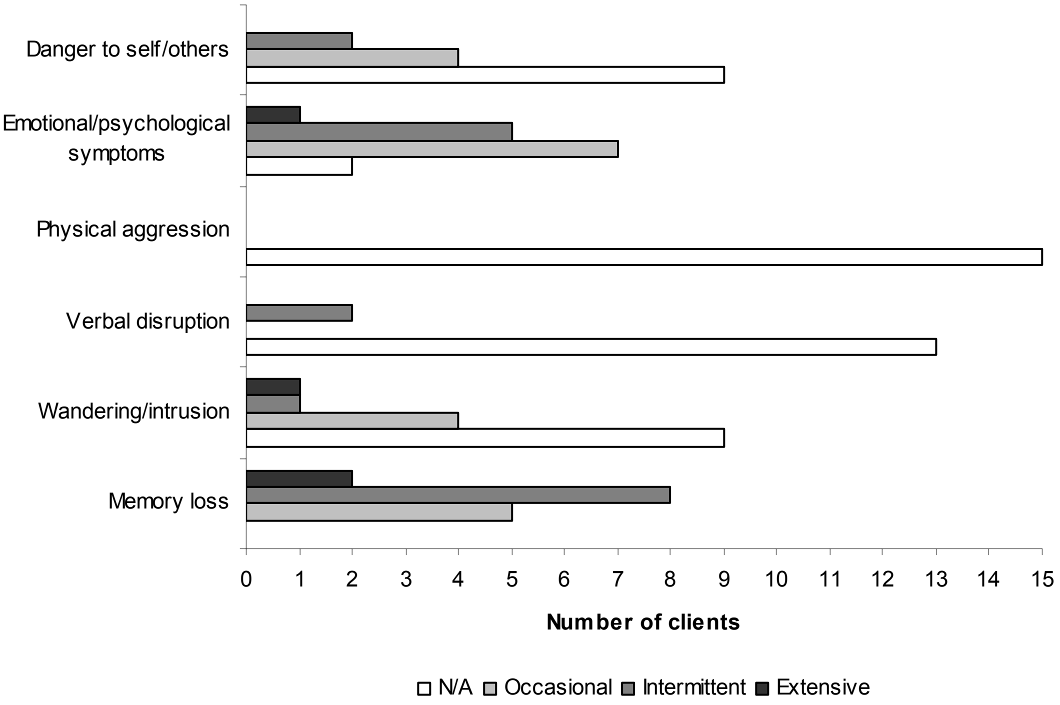


Figure B9.4: The Sundowner Club, number of clients by frequency of psychological and behavioural symptoms at entry

9.4 Carer assessment results

All carers gave a self-report of health status when their care recipient entered the project. Six reported excellent or very good health, and three reported good health.

Eight carers completed the CSI at a first assessment. Three of these carers scored on or just above the threshold for high carer strain.

Carer strain assessments were not repeated in 2005 when the project was servicing a higher number of clients with a co-resident carer.

All carers completed the GHQ-28. The GHQ-28 is designed to measure the appearance of psychological symptoms that are associated with recent changes in circumstances. Scores recorded for the evaluation cover four sub scales: somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. A four-point Likert scale is used to generate a score between zero and 21 points for each sub scale. A sub scale score of between 14 and 21 points would indicate that the respondent reported feeling worse or much worse than usual on a significant proportion of the sub scale items. No carers scored above the case threshold on any of the GHQ-28 sub scales at the first or final assessment.

Analysis of change in CSI and GHQ-28 scores was performed across the projects due to small sample sizes in individual projects.

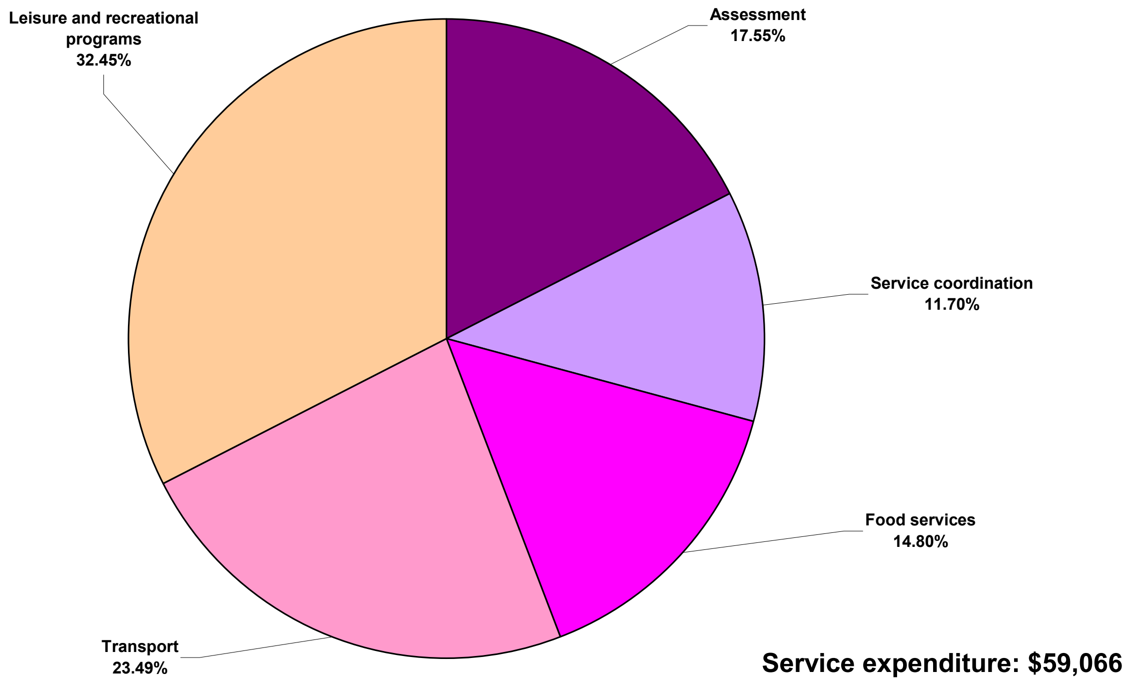
9.5 Service profile

Service provision involves transport, food service and programmed activities (Table B9.12). On average a client would attend The Sundowner Club twice per week.

Table B9.12: Sundowner Club, summary of services delivered per client per week, 2004

Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Recreation/leisure programs	No. days/nights	15	1.0	2.8	5.6	2.8	1.5
Community transport	No. one-way trips	15	1.5	2.8	5.6	2.9	1.4
Delivered meals	No. meals	14	1.0	2.4	5.6	2.8	1.5

Activity programs and transport comprised approximately one-third and one-quarter respectively of direct care expenditure between 1 July and 31 December 2004 (Figure B9.5).



Source: Appendix Table B26.

Figure B9.5: The Sundowner Club, expenditure on services, 6 months ending 31 December 2004

9.6 Accommodation outcomes

The Sundowner Club reported accommodation status of 14 evaluation clients in mid-April 2005 and of one client in early June 2005 (Table B9.13). By this time, five clients had entered high level residential care. Three clients were receiving CACP services and one client was receiving support from a Day Therapy Centre while continuing with The Sundowner Club. Accommodation outcomes, however, are not especially relevant in the context of The Sundowner Club as a stand-alone evening meal and activity program and the residential outcomes of people attending the program depend to a large extent on other support arrangements.

Table B9.12: Sundowner Club, client accommodation setting and government program support at follow-up in June 2005 (2004 evaluation group)

Location at follow-up	Number of clients
At home	
Sundowner Club, no other formal support program	6
Sundowner Club plus CACP	3
Sundowner Club plus Day Therapy Centre	1
Total living at home	*10*
In care	
Residential care—high	3
Residential care—low	2
Total	*5*
Total	**15**

ECH provided the following update on original Sundowner Club evaluation clients to highlight the importance of access to care packages and/or care from family for members of the Sundowner Club target group:

> 'On follow up, a number of the original Sundowner Club clients who participated in the evaluation were attending the program, while eight others (including participants and non-participants in the evaluation) have moved into residential aged care or been referred to more suitable programs meeting their needs. Four clients transferred to residential high care, one to a low care secure facility, one to low care and one into residential care with care level unknown. Of those seven original Sundowner Club clients who have moved into residential care, four lived within the eastern metropolitan area of Adelaide, including three living within one local government region where there are currently no high care or high care dementia-specific package services available and the sole CACP service operates a 2-year waiting list. It was felt that all clients could have been supported at home in the community for longer, and in one case the crisis which precipitated admission to residential care might have been avoided if a care package had been available.
>
> Three previous Sundowner clients (who have subsequently left The Sundowner Club program) were living on ECH independent living unit sites in the western suburbs and were able to access package services via the Retirement Villages Care Pilot, including one client who received a high care package before moving into a high care residential placement. Another client was supported at home from March 2004 (when placement was first sought by family) until July 2005 during which time her carer went overseas for 2 months and she was hospitalised and returned to her independent living unit with ongoing Sundowner Club and Retirement Villages Care Pilot low level supports. She was finally placed into low care when her son (carer and guardian) obtained a permanent bed. By contrast, one client whose wife (carer) was actively seeking placement due to his aggressive behaviours prior to his Sundowner Club attendance (which was initiated as a 'stop gap' to tide her over until placement could be found for him) was able to be discharged and referred to a community group for less disabled clients and remains living at home in the community with his wife after his behaviour improved and his aggression

> stopped. It was felt that his ‘dementia’ might have been an undiagnosed depression which improved when he was supported to resume social contact outside the home (he had been unable to get out of their home due to his poor mobility and medical conditions).’

Accommodation outcomes for clients are in part a reflection that The Sundowner Club has accepted clients who, or whose families, are actively seeking a residential placement. The project has demonstrated that some decisions can be reversed when appropriate formal supports for family carers are put in place. The Sundowner Club model of respite and socialisation has met with high acceptance from clients and carers and represents a truly novel approach to service provision for the target group. The project experience highlights that an adequate supply of care packages needs to operate alongside innovative respite services if members of the target group are to be supported in the community for longer periods.

Appendix tables for Part A

Table A1: All projects, number and per cent of evaluation clients by main source of cash income

Source of cash income	Number	Per cent
Age Pension	194	77.9
DVA pension	28	11.2
Superannuation	10	4.0
Disability pension	4	1.6
Primary cash	1	0.4
Property cash	3	1.2
Income of spouse or partner	2	0.8
Other government payment	1	0.4
Other income	3	1.2
Nil income	2	0.8
Not stated	1	0.4
Total	**249**	**100.0**

Table A2: All projects, number and per cent of clients by frequency of selected behavioural and psychological symptoms of dementia

	Frequency of behavioural symptoms				
Behaviour	**Not applicable**	**Occasional**	**Intermittent**	**Extensive**	**Total**
			(number)		
Memory loss	3	36	54	134	227
Problem wandering or intrusive behaviour	98	49	27	53	227
Verbally disruptive or noisy behaviour	108	45	46	28	227
Physical aggression	155	42	18	12	227
Emotional or psychological symptoms	45	48	68	66	227
Danger to self or others	99	42	44	42	227
			(per cent)		
Memory loss	1.3	15.9	23.8	59.0	100.0
Problem wandering or intrusive behaviour	43.2	21.6	11.9	23.3	100.0
Verbally disruptive or noisy behaviour	47.6	19.8	20.3	12.3	100.0
Physical aggression	68.3	18.5	7.9	5.3	100.0
Emotional or psychological symptoms	19.8	21.1	30.0	29.1	100.0
Danger to self or others	43.6	18.5	19.4	18.5	100.0

Table A3: Innovative Pool Dementia Pilot short-term care projects, number and per cent of carers by level of distress reported in association with selected client behavioural or psychological symptom of dementia at baseline assessment

	Level of distress reported by carer					
Psychological or behavioural symptom	**No distress or N/A**	**A little**	**Moderate**	**Very much**	**Extreme**	**Total[(a)]**
			(number)			
Memory loss	24	9	25	22	16	96
Problem wandering or intrusive behaviour	21	8	7	15	11	62
Verbally disruptive or noisy behaviour	23	9	12	6	8	58
Physical aggression	22	6	4	7	3	42
Emotional or psychological symptoms	26	11	17	17	19	90
Danger to self or others	25	10	9	15	12	71
			(per cent)			
Memory loss	25.0	9.4	26.0	22.9	16.7	100.0
Problem wandering or intrusive behaviour	33.9	12.9	11.3	24.2	17.7	100.0
Verbally disruptive or noisy behaviour	39.7	15.5	20.7	10.3	13.8	100.0
Physical aggression	52.4	14.3	9.5	16.7	7.1	100.0
Emotional or psychological symptoms	28.9	12.2	18.9	18.9	21.1	100.0
Danger to self or others	35.2	14.1	12.7	21.1	16.9	100.0

(a) Total includes carers of clients who were recorded as displaying the symptom on an occasional, intermittent or extensive basis in the week prior to the baseline assessment.

Table A4: Innovative Pool Dementia Pilot long-term care projects, number and per cent of carers by level of distress reported in association with selected client behavioural or psychological symptom of dementia at baseline assessment

	Level of distress reported by carer					
Psychological or behavioural symptom	No distress or N/A	A little	Moderate	Very much	Extreme	Total[(a)]
			(number)			
Memory loss	13	18	29	32	18	110
Problem wandering or intrusive behaviour	15	12	9	13	11	60
Verbally disruptive or noisy behaviour	20	12	11	8	5	56
Physical aggression	7	12	3	2	3	27
Emotional or psychological symptoms	9	18	17	20	19	83
Danger to self or others	8	6	10	14	10	48
Other symptoms	5	7	14	16	5	47
			(per cent)			
Memory loss	11.8	16.4	26.4	29.1	16.4	100.0
Problem wandering or intrusive behaviour	25.0	20.0	15.0	21.7	18.3	100.0
Verbally disruptive or noisy behaviour	35.7	21.4	19.6	14.3	8.9	100.0
Physical aggression	25.9	44.4	11.1	7.4	11.1	100.0
Emotional or psychological symptoms	10.8	21.7	20.5	24.1	22.9	100.0
Danger to self or others	16.7	12.5	20.8	29.2	20.8	100.0
Other symptoms	10.6	14.9	29.8	34.0	10.6	100.0

(a) Total includes carers of clients who were recorded as displaying the symptom on an occasional, intermittent or extensive basis in the week prior to the baseline assessment.

Table A5: All projects combined, number of clients by severity of BPSD of dementia at baseline (adapted from Brodaty et al. 2003)

Model tier	Number	Per cent
Tier 2	37	14.9
Tier 3	28	11.2
Tier 4	25	10.0
Tier 5	159	63.9
Total	**249**	**100.0**

Table A6: All clients with repeated BPSD measures: number and per cent of clients by severity of BPSD at baseline and final assessments (Brodaty et al. 2003)

Baseline assessment	Last assessment				
	Tier 2	Tier 3	Tier 4	Tier 5	Total
			(number)		
Tier 2	6	3	4	6	18
Tier 3	4	9	—	9	22
Tier 4	6	2	3	10	21
Tier 5	12	11	16	95	134
Total	**28**	**24**	**23**	**120**	**195**
			(per cent)		
Tier 2	3.1	1.0	2.1	3.1	9.2
Tier 3	2.1	4.6	—	4.6	11.3
Tier 4	3.1	1.0	1.5	5.1	10.8
Tier 5	6.2	5.6	8.2	48.7	68.7
Total	**14.4**	**12.3**	**11.8**	**61.5**	**100.0**

— Nil.

Table A7: DBAMS clients: number of clients by severity of BPSD (Brodaty et al. 2003) at baseline and final assessments

Baseline assessment	Last assessment				
	Tier 2	Tier 3	Tier 4	Tier 5	Total
			(number)		
Tier 2	—	—	—	—	**—**
Tier 3	1	—	—	—	**1**
Tier 4	—	—	1	—	**1**
Tier 5	3	1	4	25	**33**
Total	**4**	**1**	**5**	**25**	**35**

— Nil.

Table A8: Innovative Pool Dementia Pilot short-term care projects, time spent on initial needs assessment per client by project, June–November 2004

		Time spent on initial needs assessment per client (hours)				
Project	Number of records	Minimum	Median	Maximum	Mean	Standard deviation
DBAMS	39	1.5	3.0	4.5	3.3	0.7
DRAH	31	11.0	18.0	29.5	19.5	5.1
FCS	24	1.0	2.0	3.0	1.9	0.6
NEDID	14	2.0	3.3	6.0	3.6	1.0
Total	**123**	**1.0**	**3.0**	**29.5**	**7.0**	**7.8**

Table A9: Innovative Pool Dementia Pilot long-term care projects, time spent on initial needs assessment per client by project, June–November 2004

		Time spent on initial needs assessment per client (hours)				
Project	Number of records	Minimum	Median	Maximum	Mean	Standard deviation
RSL Care Pilot	32	2.0	4.0	16.0	5.0	3.7
South Brisbane & Gold Coast Pilot	23	2.0	8.0	24.0	9.4	5.3
Ozcare Packages	35	1.0	2.25	6.5	2.6	1.3
DCAS	27	1.5	3.0	4.0	3.2	0.8
Sundowner Club	15	1.5	3.0	4.0	2.7	0.8
Total	**132**	**1.0**	**3.0**	**24**	**4.5**	**3.8**

Table A10: Innovative Pool Dementia Pilot short-term and long-term care package projects, minimum, maximum and percentiles of weekly average hours of assistance per client excluding case management, clinical work-up and ancillary services(a)

Project	Count	Minimum	25th percentile	50th percentile	75th percentile	Maximum
DRAH	31	1.2	5.5	10.2	14.5	21.3
FCS	23	2.9	5.2	9.2	12.9	18.9
NEDID	14	5.3	12.2	19.8	29.0	47.7
RSL Care Pilot	32	0.6	2.3	4.3	7.1	20.9
SBG Pilot	21	3.1	8.1	11.7	23.1	34.7
Ozcare Packages	32	1.0	6.5	11.3	18.3	38.3
DCAS	27	4.1	8.8	14.6	21.6	39.0

(a) Minimum estimates of hours of assistance cover personal assistance, nursing and allied health care, domestic assistance, food preparation other than delivered meals, social support, in-home and centre-based respite care.

Table A11: Innovative Pool Dementia Pilot care package projects, minimum, maximum and percentiles of weekly respite care (in-home and day centre respite) per client

Project	Count	Minimum	25th percentile	50th percentile	75th percentile	Maximum
DRAH	24	0.0	4.7	7.4	9.8	20.0
FCS	23	2.0	3.8	5.6	9.4	15.0
NEDID	13	1.0	3.5	5.9	15.5	24.0
RSL Care Pilot	22	0.0	1.6	2.8	5.9	9.0
SBG Pilot	20	0.0	0.9	2.5	8.6	16.0
Ozcare Packages	27	0.0	2.5	7.9	13.1	35.0
DCAS	13	0.0	1.7	4.6	12.2	37.0

Table A12: Innovative Pool Dementia Pilot long-term care projects, per cent of clients by quarter in which Pilot services were commenced, by project

Project	1 Jul–30 Sep 03	1 Oct–31 Dec 03	1 Jan–31 Mar 04	1 Apr–30 Jun 04	1 Jul–30 Sep 04	1 Oct–31 Dec 04	Total
Ozcare	0.0	34.3	14.3	20.0	28.6	2.9	100.0
RSL Care	3.1	3.1	15.6	25.0	46.9	6.3	100.0
South Brisbane & Gold Coast	0.0	42.3	23.1	11.5	19.2	3.9	100.0
DCAS	0.0	24.2	33.3	21.2	18.2	3.0	100.0
The Sundowner Club	0.0	0.0	0.0	53.3	33.3	13.3	100.0
Total	**0.7**	**22.7**	**19.2**	**23.4**	**29.1**	**5.0**	**100.0**

Table A13: Innovative Pool Dementia Pilot short-term care projects, total place days, client service days, new income, total expenditure and expenditure on services per client service day by project. 1 July–31 December 2004

Project	Allocated place days	Client service days	Mean weekly hours of service per client[(a)]	Income[(b)] per client service day ($)	Total service expenditure ($)	Total expenditure ($)
DRAH	2,760	2,660[(c)]	10.2	230,708	226,980	274,207
NEDID	1,891	1,691	20.9	201,592	94,437	201,378
FCS	3,680	3,680	9.9	355,692	160,824	415,500
DBAMS	2,944	2,938	. .	724,163	855,845	855,846

Note: DBAMS—average hours of service per week per client not included due to residential component of project.

(a) Includes personal assistance, nursing care, domestic assistance, social support, food service other than delivered meals, allied health care. Excludes transport, delivered meals and other services not measured in time units. Calculated from evaluation client data.

(b) Includes Australian Government Innovative Pool subsidies, client co-payments and income from other sources. Excludes funds carried forward from previous financial quarter.

(c) Project A client service days includes 2,033 days of active service and 627 'maintenance days', as reported by the project.

. . Not applicable.

Source: Project financial reports.

Table A14: Innovative Pool Dementia Pilot long-term care projects, available funds and expenditure by project (dollars), 1 July–31 December 2004

	Income					Expenditure			
Project	Flexible care subsidy[(a)]	Other income	New income	Funds carried forward	Total available funds	Total service expenditure	Non-service expenditure	Total expenditure	Surplus/ deficit
RSL Care	592,839	20,487	613,326	—	613,326	259,025	95,110	354,135	259,191
SBGC	. .	. .	. .	. .	. .	. .	. .	. .	. .
Ozcare Packages	442,873	21,870	464,743	—	464,743	319,341	-1,023	318,319	146,424
DCAS	. .	. .	. .	. .	. .	. .	. .	. .	. .
Sundowner Club	81,776	647	82,422	—	82,422	59,066	12,641	71,707	10,715

(a) As reported by the projects. May be different from official figures.

Source: Project financial reports.

Table A15: Innovative Pool Dementia Pilot short-term care projects, available funds and expenditure by project (dollars), 1 July–31 December 2004

	Income					Expenditure			
Project	Flexible care subsidy[(a)]	Other income	New income	Funds carried forward	Total available funds	Total service expenditure	Non-service expenditure	Total expenditure	Surplus/ deficit
DBAMS	269,984	454,179	724,163	827	724,990	855,845	1	855,846	-130,856
DRAH	228,499	2,208	230,708	43,500	274,208	226,980	47,227	274,207	—
FCS	355,692	—	355,692	78,000	433,692	160,824	254,676	415,500	18,192
NEDID	194,965	6,628	201,592	99,054	300,646	94,437	106,941	201,378	99,268

(a) As reported by the projects. May be different from official figures.

— Nil.

Source: Project financial reports.

Appendix tables for Part B

Table B1: DBAMS community clients, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	8	3	5	**16**
Bladder management	6	6	4	**16**
Toilet use	4	7	5	**16**
Bathing/showering	2	. .[(a)]	14	**16**
Dressing	3	12	—	**15**
Grooming	6	. .[(a)]	10	**16**
Feeding	10	6	—	**16**
Mobility (level surface)	15	1	—	**16**
Transfers	11	4	1	**16**
Stairs	7	9	—	**16**

(a) Scored on a two-point scale scoring system, independent and needs help with personal care.

. . Not applicable.

— Nil.

Table B2: DBAMS community clients, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	1	15	—	**16**
Shop for groceries or clothes	—	13	3	**16**
Prepare meals	—	8	8	**16**
Household chores	1	12	3	**16**
Correctly administer own medications	—	13	3	**16**
Monetary transactions (e.g. pay bills)	—	9	7	**16**
Use the telephone	3	11	2	**16**

— Nil.

Table B3: DBAMS residential high care clients, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	3	4	5	**12**
Bladder management	—	4	8	**12**
Toilet use	1	6	5	**12**
Bathing/showering	—	. .(a)	12	**12**
Dressing	—	5	7	**12**
Grooming	—	. .(a)	12	**12**
Feeding	7	4	1	**12**
Mobility (walking on a level surface)	10[b]	1	1	**12**
Transfers	7	4	1	**12**
Stairs	1	5	6	**12**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes one client who is wheelchair independent.

. . Not applicable.

— Nil.

Table B4: DBAMS residential high care clients, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	9	3	**12**
Shop for groceries or clothes	—	—	12	**12**
Prepare meals	—	1	8	**9**
Household chores	—	3	9	**12**
Correctly administer own medications	—	4	8	**12**
Monetary transactions (e.g. pay bills)	—	—	12	**12**
Use the telephone	—	4	7	**11**

— Nil.

Table B5: DBAMS residential low care clients, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	5	3	3	**11**
Bladder management	4	5	2	**11**
Toilet use	3	6	2	**11**
Bathing/showering	—	. .[(a)]	11	**11**
Dressing	1	8	2	**11**
Grooming	1	. .[(a)]	10	**11**
Feeding	5	4	2	**11**
Mobility (walking on a level surface)	11	—	—	**11**
Transfers	6	4	1	**11**
Stairs	3	5	3	**11**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

. . Not applicable.

— Nil.

Table B6: DBAMS residential low care clients, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	11	—	**11**
Shop for groceries or clothes	—	5	6	**11**
Prepare meals	—	1	8	**9**
Household chores	—	1	7	**8**
Correctly administer own medications	—	8	3	**11**
Monetary transactions (e.g. pay bills)	—	4	7	**11**
Use the telephone	1	5	5	**11**

— Nil.

Table B7: DBAMS clients, number of clients by extent of behavioural and psychological symptoms of dementia at baseline, interim and final assessments and usual accommodation setting

	Baseline assessment					Interim assessment					Final assessment				
Client group	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**
Community clients															
Memory loss	—	4	4	8	16	5	1	4	6	16	—	3	6	7	16
Wandering/intrusion	2	6	4	4	16	5	6	4	1	16	7	5	1	3	16
Verbal disruption	6	3	6	1	16	11	2	2	1	16	9	4	1	2	16
Physical aggression	7	3	5	1	16	13	3	—	—	16	11	1	2	2	16
Emotional/psychological symptoms	1	5	6	4	16	6	5	5	—	16	7	2	5	2	16
Danger to self/others	2	2	6	6	16	10	3	1	2	16	8	5	2	1	16
Other behaviour	4	2	7	3	16	11	2	2	1	16	9	3	3	1	16
RAC high care															
Memory loss	—	2	1	9	12	5	—	2	5	12	2	—	2	8	12
Wandering/intrusion	1	1	—	10	12	5	2	1	4	12	4	2	2	4	12
Verbal disruption	1	1	3	7	12	5	2	2	3	12	4	2	4	2	12
Physical aggression	1	2	4	5	12	7	1	4		12	3	5	4		12
Emotional/psychological symptoms	—	1	3	8	12	5	2	1	4	12	2	5	4	1	12
Danger to self/others	1	2	1	8	12	5	2	4	1	12	3	3	4	2	12
Other behaviour	—	2	5	5	12	5	—	2	5	12	6	1	2	3	12

(continued)

Table B7 continued: DBAMS clients, number of clients by extent of behavioural and psychological symptoms of dementia at baseline, interim and final assessments and usual accommodation setting

	Baseline assessment					Interim assessment					Final assessment				
Client group	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**	**N/A**	**Occ.**	**Int.**	**Ext.**	**Total**
RAC low care															
Memory loss	—	—	2	9	11	3	—	1	7	11	2	—	4	5	11
Wandering/intrusion	1	1	1	8	11	5	1	3	2	11	2	2	3	4	11
Verbal disruption	1	3	3	4	11	5	3	1	2	11	4	2	4	1	11
Physical aggression	2	3	4	2	11	6	2	2	1	11	4	5	1	1	11
Emotional/psychological symptoms	1	—	4	6	11	4	2	3	2	11	3	2	3	3	11
Danger to self/others	—	2	3	6	11	4	4	2	1	11	3	3	3	2	11
Other behaviour	—	1	4	6	11	4	2	3	2	11	6	1	2	2	11

Notes

1. N/A: Not applicable, includes clients for whom no assessment was recorded.
2. Occ.: occasional.
3. Int.: intermittent.
4. Ext.: extensive.

— Nil.

Table B9: Dementia Rehabilitation at Home, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	26	3	2	**31**
Bladder management	17	10	4	**31**
Toilet use	18	9	4	**31**
Bathing/showering	12	. .[(a)]	19	**31**
Dressing	14	14	3	**31**
Grooming	17	. .[(a)]	14	**31**
Feeding	24	7	—	**31**
Mobility (level surface)	27[(b)]	3	1	**31**
Transfers	20	9	2	**31**
Stairs	14	13	4	**31**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes one client who is wheelchair independent.

. . Not applicable.

— Nil

Table B10: Dementia Rehabilitation at Home, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	5	16	10	**31**
Shop for groceries or clothes	2	10	19	**31**
Prepare meals	3	14	14	**31**
Household chores	—	12	19	**31**
Correctly administer own medications	3	18	9	**30**
Monetary transactions (e.g. pay bills)	2	8	20	**30**
Use the telephone	8	15	8	**31**

— Nil.

Table B11: Flexible Care Service, number of clients by level of ADL function at entry

	Dependency level				
	Independent	Partially dependent	Fully dependent	Not stated	Total
Bowel management	6	11	6	1	**24**
Bladder management	3	4	16	1	**24**
Toilet use	—	16	7	1	**24**
Bathing/showering	2	. .[(a)]	21	1	**24**
Dressing	2	14	7	1	**24**
Grooming	2	. .[(a)]	21	1	**24**
Feeding	2	18	3	1	**24**
Mobility (level surface)	19	4	—	1	**24**
Transfers	8	14	1	1	**24**
Stairs	7	8	8	1	**24**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

. . Not applicable.

— Nil.

Table B12: Flexible Care Service clients, number of clients by level of IADL function at entry

	Capability				
	Help not needed	Help needed	Completely unable	Not stated	Total
Get to places out of walking distance	—	19	4	1	**24**
Shop for groceries or clothes	—	14	9	1	**24**
Prepare meals	—	7	16	1	**24**
Household chores	—	—	23	1	**24**
Correctly administer own medications	—	13	10	1	**24**
Monetary transactions (e.g. pay bills)	—	—	23	1	**24**
Use the telephone	1	10	11	2	**24**

— Nil.

Table B13: North East Dementia Innovations Demonstration, number of clients by level of ADL function at entry

	Dependency level			
	Independent	**Partially dependent**	**Fully dependent**	**Total**
Bowel management	4	4	6	**14**
Bladder management	2	5	7	**14**
Toilet use	3	7	4	**14**
Bathing/showering	4	. .(a)	10	**14**
Dressing	3	7	4	**14**
Grooming	4	. .(a)	10	**14**
Feeding	6	7	1	**14**
Mobility (level surface)	8(b)	3	3	**14**
Transfers	5	9	—	**14**
Stairs	2	5	7	**14**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes one client who is wheelchair independent.

. . Not applicable.

— Nil.

Table B14: North East Dementia Innovations Demonstration, number of clients by level of IADL function at entry

	Capability			
	Help not needed	**Help needed**	**Completely unable**	**Total**
Get to places outside of walking distance	—	10	4	**14**
Shop for groceries or clothes	—	5	9	**14**
Prepare meals	—	1	13	**14**
Household chores	—	2	12	**14**
Correctly administer own medications	—	2	12	**14**
Monetary transactions (e.g. pay bills)	1	3	10	**14**
Use the telephone	1	8	5	**14**

— Nil.

Table B15: RSL Care Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

	Dependency level			
	Independent	**Partially dependent**	**Fully dependent**	**Total**
Bowel management	7	10	14	**31**
Bladder management	5	9	17	**31**
Toilet use	4	11	16	**31**
Bathing/showering	4	. .(a)	27	**31**
Dressing	6	14	11	**31**
Grooming	7	. .(a)	24	**31**
Feeding	5	21	5	**31**
Mobility (level surface)	24(b)	4	3	**31**
Transfers	11	18	2	**31**
Stairs	9	12	10	**31**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes two clients who are independent with the use of a wheelchair.

. . Not applicable.

Table B16: RSL Care Innovative Dementia Care Pilot, number of clients by level of IADL function at entry

	Capability			
	Able without help	**Able with help**	**Completely unable**	**Total**
Get to places outside of walking distance	1	21	9	**31**
Shop for groceries or clothes	—	14	17	**31**
Prepare meals	—	4	27	**31**
Household chores	—	5	26	**31**
Correctly administer own medications	—	19	12	**31**
Monetary transactions (e.g. pay bills)	—	3	28	**31**
Use the telephone	—	8	23	**31**

— Nil.

Table B17: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	3	14	6	**23**
Bladder management	5	9	9	**23**
Toilet use	4	9	10	**23**
Bathing/showering	1	. .[(a)]	22	**23**
Dressing	2	13	8	**23**
Grooming	5	. .[(a)]	18	**23**
Feeding	3	14	6	**23**
Mobility (level surface)	10[(b)]	7	6	**23**
Transfers	3	14	6	**23**
Stairs	2	11	10	**23**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes four clients who are independent with the use of a wheelchair.

. . Not applicable.

Table B18: South Brisbane and Gold Coast Innovative Dementia Care Pilot, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	11	12	**23**
Shop for groceries or clothes	—	6	17	**23**
Prepare meals	—	3	20	**23**
Household chores	—	2	21	**23**
Correctly administer own medications	1	8	14	**23**
Monetary transactions (e.g. pay bills)	3	6	14	**23**
Use the telephone	5	9	9	**23**

— Nil.

Table B19: Ozcare Innovative Dementia Care Pilot, number of clients by level of ADL function at first assessment

	Dependency level			
Activity of daily living	**Independent**	**Partially dependent**	**Fully dependent**	**Total**
Bowel management	16	9	9	**34**
Bladder management	10	8	16	**34**
Toilet use	9	16	9	**34**
Bathing/showering	4	. .(a)	30	**34**
Dressing	5	21	8	**34**
Grooming	5	. .(a)	29	**34**
Feeding	11	18	5	**34**
Mobility (walking on a level surface)	24(b)	8	2	**34**
Transfers	17	16	1	**34**
Stairs	8	20	6	**34**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

(b) Includes two clients who are independent with the use of a wheelchair.

. . Not applicable.

Table B20: Ozcare Innovative Dementia Care Pilot, number of clients by level of IADL function at first assessment

	Capability			
Advanced activity of daily living	**Help not needed**	**Help needed**	**Completely unable**	**Total**
Get to places outside of walking distance	—	29	5	**34**
Shop for groceries or clothes	—	14	20	**34**
Prepare meals	—	17	17	**34**
Household chores	—	9	25	**34**
Correctly administer own medications	1	13	19	**33**
Monetary transactions (e.g. pay bills)	1	7	26	**34**
Use the telephone	2	14	18	**34**

— Nil.

Table B21: Dementia Care in Alternative Settings, number of clients by level of ADL function at entry

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	18	11	4	**33**
Bladder management	12	14	7	**33**
Toilet use	9	14	10	**33**
Bathing/showering	4	. .[(a)]	29	**33**
Dressing	11	11	11	**33**
Grooming	10	. .[(a)]	23	**33**
Feeding	13	19	1	**33**
Mobility (level surface)	25	8	—	**33**
Transfers	20	13	—	**33**
Stairs	9	22	2	**33**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

. . Not applicable.

— Nil.

Table B22: Dementia Care in Alternative Settings, number of clients by level of IADL function at entry

	Capability			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	1	32	—	**33**
Shop for groceries or clothes	—	16	17	**33**
Prepare meals	1	10	22	**33**
Household chores	—	9	24	**33**
Correctly administer own medications	1	26	6	**33**
Monetary transactions (e.g. pay bills)	—	12	21	**33**
Use the telephone	3	18	12	**33**

— Nil.

Table B23: The Sundowner Club, number of clients by level of ADL function at entry

	Dependency level			
	Independent	**Partially dependent**	**Fully dependent**	**Total**
Bowel management	11	3	1	**15**
Bladder management	6	7	2	**15**
Toilet use	11	3	1	**15**
Bathing/showering	12	. .[(a)]	3	**15**
Dressing	12	3	—	**15**
Grooming	11	. .[(a)]	4	**15**
Feeding	15	—	—	**15**
Mobility (level surface)	14	1	—	**15**
Transfers	11	4	—	**15**
Stairs	10	5	—	**15**

(a) Scored on a two point scale scoring system, independent and needs help with personal care.

. . Not applicable.

— Nil.

Table B24: The Sundowner Club, number of clients by level of IADL function at entry

	Capability			
	Help not needed	**Help needed**	**Completely unable**	**Total**
Get to places outside of walking distance	5	10	—	**15**
Shop for groceries or clothes	3	10	2	**15**
Prepare meals	1	12	2	**15**
Household chores	3	10	2	**15**
Correctly administer own medications	2	10	2	**14**
Monetary transactions (e.g. pay bills)	3	10	1	**14**
Use the telephone	10	5	—	**15**

— Nil.

Table B25: Innovative Pool Dementia Pilot short-term care projects, expenditure on services by project, 1 July–31 December 2004

	Project			
Service type	**DBAMS**	**DRAH**	**FCS**	**NEDID**
Assessment	4,648	—	1,500	8,265
Care coordination and case management	7,452	136,701	35,220	23,580
Nursing services	658,798	—	2,930	1,655
Medical services	11,451	—	—	—
Physiotherapy/occupational therapy	1,631	—	1,200	1,125
Behaviour management therapy	6,846	—	—	—
Counselling and support (client and carer)	26,451	—	200	10,101
Other allied health care	1,716	—	4,372	1,183
Personal assistance	38,134	12,583	24,268	30,128
Social support	—	—	—	395
Domestic assistance	—	15,390	8,015	3,802
Food services	—	2,900	—	—
Home maintenance	—	1,239	11,204	189
Home modifications	—	873	272	483
Pilot program residential accommodation	54,483	—	11,265	—
Accommodation assistance	—	—	—	679
Transport	99	8,467	1,391	—
Provision of aids and equipment	—	3,675	10,457	4,612
Interpreter and translation service	—		225	701
Leisure and recreational programs	4,760	1,342	—	—
Centre-based day care	—	—	1,465	1,560
Respite care	—	38,865	46,842	22,103
Carer support and education	—	3,429	—	—
Staff training	—	1,516	—	—
Pharmaceuticals	13,524	—	—	—
Medical supplies	1,863	—	—	—
Special service supplies	2,058	—	—	—
Repair and maintenance	21,931	—	—	—
Total	**855,845**	**226,980**	**160,824**	**110,561**

Note: DRAH—care coordination and case management includes assessment and case management of the following types: nursing, medical, physiotherapy and occupational therapy, behaviour management therapy, counselling and support, and other allied health.

— Nil.

Source: Project financial reports.

Table B26: Innovative Pool Dementia Pilot long-term care projects, expenditure on services by project, 1 July–31 December 2004

	Project				
Service type	**RSL Care Pilot**	**South Brisbane & Gold Coast Pilot**	**Ozcare Packages**	**DCAS**	**Sundowner Club**
Assessment	—	. .	2,279	. .	10,367
Care coordination and case management	17,342	. .	1,150	. .	6,911
Nursing services	6,302	. .	2,059	. .	—
Counselling and support (client and carer)	2,085	. .	—	. .	—
Other allied health care	1,295	. .	—	. .	—
Personal assistance	75,361	. .	76,180	. .	—
Social support	—	. .	25,300	. .	—
Domestic assistance	49,453	. .	25,697	. .	—
Food services	1,005	. .	23,928	. .	8,744
Transport	—	. .	9,070	. .	13,875
Provision of aids and equipment	1,513	. .	2,475	. .	—
Leisure and recreational programs	—	. .	—	. .	19,169
Respite care	104,669	. .	151,203	. .	—
Total	**259,025**	**. .**	**319,341**	**. .**	**59,066**

Note: DCAS and South Brisbane & Gold Coast Pilot did not provide financial reports.

— Nil.

. . Not applicable.

Source: Project financial reports.

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Attachment
Functional assessment instruments

Modified Barthel Index (adapted)

The Barthel Index measures functional independence in personal care and mobility. Please rate the client's level of need for assistance on each personal care and mobility item and record ratings directly onto the *Client Profile and Assessment Form* where indicated at *Section B.6 Client Functional Assessment* for Baseline, Interim and Final Assessments.

Bowels (preceding week)

0 = incontinent (or needs to be given enemata)

1 = occasional accident (once/week)

2 = continent

Bladder (preceding week)

0 = incontinent (or catheterised and unable to manage)

1 = occasional accident (maximum once per 24 hours)

2 = continent (for over 7 days, or catheterized and can completely manage the catheter alone)

Grooming (preceding 24–48 hours)

0 = needs help with personal care

1 = independent face/hair/teeth/shaving (implements can be provided)

Toilet use

0 = dependent

1 = needs some help, but can do some things alone

2 = independent (can reach toilet/commode, undress sufficiently, clean self, dress and leave)

Feeding

0 = unable

1 = needs help cutting, spreading butter etc.

2 = independent (able to eat any normal food, not only soft food, cooked and served by others but not cut up).

Please turn over and continue on the next page

Transfer (from bed to chair and back)

0 = unable –- no sitting balance

1 = major help (one strong/skilled or two people, physical, can sit)

2 = minor help (verbal or physical, one person easily can assist if necessary)

3 = independent

Mobility

0 = immobile

1 = wheelchair independent including corners etc.

2 = walks with help of one person (verbal or physical)

3 = Walks with use of a walker, crutches or aid other than stick

4 = Independent (may use stick)

Dressing

0 = dependent

1 = needs help, but can do about half unaided

2 = independent (can select and put on all clothes, which may be adapted, including buttons, zips, laces etc.).

Stairs

0 = unable

1 = needs help (verbal, physical, help to carry walking aid)

2 = independent up and down, carries own walking aid if applicable.

Bathing

0 = dependent

1 = Needs help to get in or out of bath or shower but can bathe without supervision

2 = Independent. Can get in and out unsupervised and wash self.

Source: Collin C, Wade DT, Davies S, Horne V, 1988. The Barthel ADL Index: a reliability study. International Disability Studies 1988 (adapted). In: McDowell & Newell 1996. Measuring health: a guide to rating scales and questionnaires. 2nd edn. New York: Oxford University Press.

OARS Instrumental Activities of Daily Living (adapted)

The OARS IADL (adapted) measures personal functioning status for some important activities of daily living. Please rate the client's level of functioning for each activity and record ratings directly onto the *Client Profile and Assessment Form* where indicated at *Section B.6 Client Functional Assessment* for Baseline, Interim and Final Assessments.

Can the client use the telephone…

0 = completely unable to use the telephone

1 = with some help (can answer phone or dial in an emergency, but needs a special phone or help in getting the number or dialling)

2 = without help, including looking up numbers and dialling

9 = unable to assess

Can the client get to places outside of walking distance…

0 = unable to travel unless emergency arrangements are made for a specialised vehicle such as an ambulance

1 = with some help (needs someone to help him/her or go with him/her when travelling)

2 = without help (drives own car, or travels alone on buses or in taxis)

9 = unable to assess

Can the client go shopping for groceries or clothes (assuming he/she has transportation)…

0 = completely unable to do any shopping

1 = with some help (needs someone to go with him/her on all shopping trips)

2 = without help (can take care of shopping needs him/herself, assuming he/she has transportation)

9 = unable to assess

Can the client prepare his/her own meals…

0 = completely unable to prepare any meals

1 = with some help (can prepare some things but is unable to cook full meals him/herself)

2 = without help (can plan and cook full meals for him/herself)

9 = unable to assess

Please turn over and continue on the next page

Can the client do his/her housework

0 = completely unable to do any housework

1 = with some help (can do light housework but needs help with heavy work)

2 = without help (can clean floors etc.)

9 = unable to assess

Can the client take his/her own medicine…

0 = completely unable to take his/her medicines

1 = with some help (can take medication if someone prepares it for him/her and/or reminds him/her to take it)

2 = without help (can take the right dose at the right time)

9 = unable to assess

Can the client handle his/her own money…

0 = completely unable to handle money

1 = with some help (can mange day-to-day buying but needs help managing chequebook and paying bills)

2 = without help (writes cheques, pays bills etc.)

9 = unable to assess

Source: Fillenbaum G 1988. Multidimensional Function Assessment of Older Adults: the Duke Older Americans Resources and Services procedures. New Jersey, USA: Lawrence Erlbaum Associates.

Mini-Mental State Examination

MiniMental, LLC holds the Copyright for the Mini-Mental State Examination. The instrument was last published in 2001 by *Psychological Assessment Resources Incorporated* in the USA. The AIHW obtained permission to use and purchased forms from the Australian Council for Educational Research, the authorised distributor in Australia (www.acer.edu.au).

Client behaviour and psychological symptoms (adapted from the Resident Classification Scale)

Behaviour management clients only

The Behaviour Scale rates the frequency with which behaviour management clients exhibit ‘problem’ behaviours. Please rate the frequency of the following behaviours **over the last week** and record ratings directly onto the *Client Profile and Assessment Form* where indicated at *Section B.6 Client Functional Assessment* for baseline, interim and final assessments. Please note there is a separate worksheet to be completed by carers (Behaviour Scale—Carer Reactions).

Memory Loss – relates to the care recipient forgetting information sch as the names of family members, location of personal items, or recent activities.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Problem wandering or intrusive behaviours – relates to the care recipient wandering, absconding or interfering with other people or their belongings whilst wandering.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Verbally disruptive or noisy behaviours – includes abusive language and verbalised threats directed at a care recipient, visitor or member of staff.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Physically aggressive – includes any physical conduct that is threatening and has the potential to harm a care recipient, visitor or member of staff.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Please turn over and continue on the next page

Emotional or psychological symptoms – This question includes active and passive resistance (other than physical aggression), attention seeking and manipulative behaviour, and depressive symptoms such as withdrawal and loss of sense of self.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Danger to self or others– covers high risk behaviour requiring supervision or intervention and strategies to minimise the danger.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Other behaviour– covers behaviour not already covered in the above questions 6.22 – 33 which require staff to spend time and effort in addition to support for daily activities.

0 = Not applicable (does not require monitoring)

1 = Occasionally (requires monitoring but not regular supervision)

2 = Intermittently (requires monitoring for recurrence then supervision on a less than daily basis)

3 = Extensively (requires monitoring for recurrence and supervision on a daily basis)

Source: Adapted from the Resident Classification Scale (items 9–14), Australian Government Department of Health and Ageing.

Caregiver Strain Index

Here is a list of things that other people have found to be difficult when caring for someone who needs support. Please circle **YES** if they apply to you or **NO** if they do not apply to you.

1.	My sleep is disturbed (e.g. because the person I care for is in and out of bed or wanders around all night).	YES / NO
2.	It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)	YES / NO
3.	It is a physical strain (e.g. because of lifting in and out of chair; effort of concentration is required)	YES / NO
4.	It is confining (e.g. helping restricts my free time or I cannot go visiting)	YES / NO
5.	There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)	YES / NO
6.	There have been changes in personal plans (e.g. had to turn down a job; could not go on holiday)	YES / NO
7.	There have been other demands on my time (e.g. from other family members)	YES / NO
8.	There have been emotional adjustments (e.g. because of severe arguments)	YES / NO
9.	Some behaviour is upsetting (e.g. incontinence, trouble remembering things, or accusing people of taking things)	YES / NO
10.	It is upsetting to find the person I care for has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)	YES / NO
11.	There have been work adjustments (e.g. because of having to take time off)	YES / NO
12.	It is a financial strain	YES / NO
13.	Feeling completely overwhelmed (e.g. because of worry about the person I care for; concerns about how I will manage)	YES / NO
Total score (count YES responses):		

Transfer total score to section B.6 as indicated on the Client Profile and Assessment Form for Baseline, Interim and Final Assessments

Source: Robinson BC 1983. Validation of a caregiver strain index. Journal of Gerontology 38(3): 344–48.

General Health Questionnaire–28

The GHQ—28 was used to record carer self-reported psychological wellbeing. The AIHW obtained permission to use and purchased forms and manuals from the Australian Council for Educational Research, the authorised distributor in Australia (www.acer.edu.au).