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.

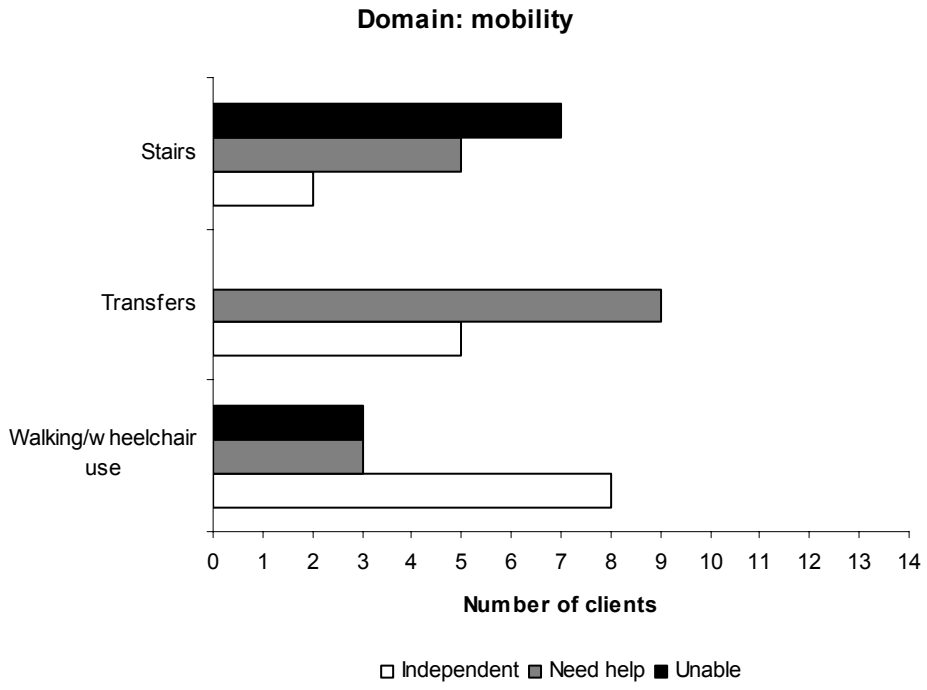
On the basis of reported MMSE scores, it is concluded that NEDID has targeted people with cognitive impairment.

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.



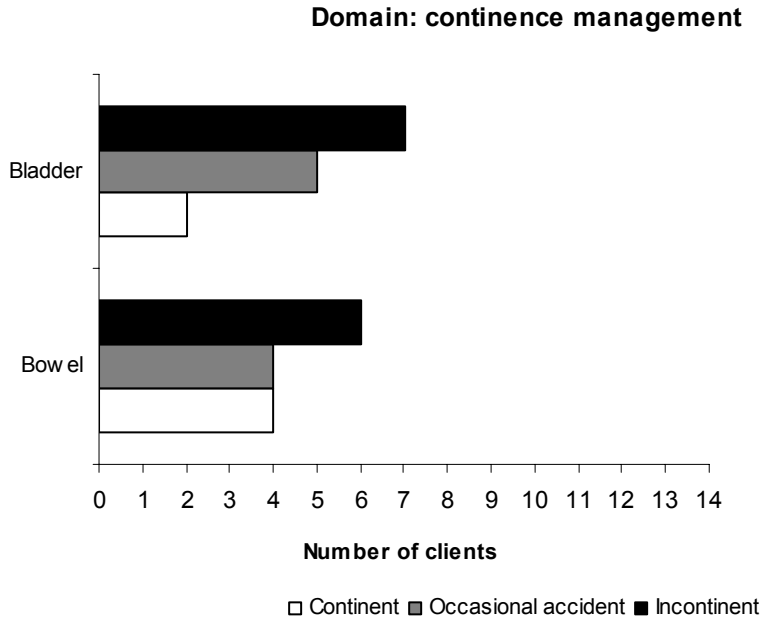
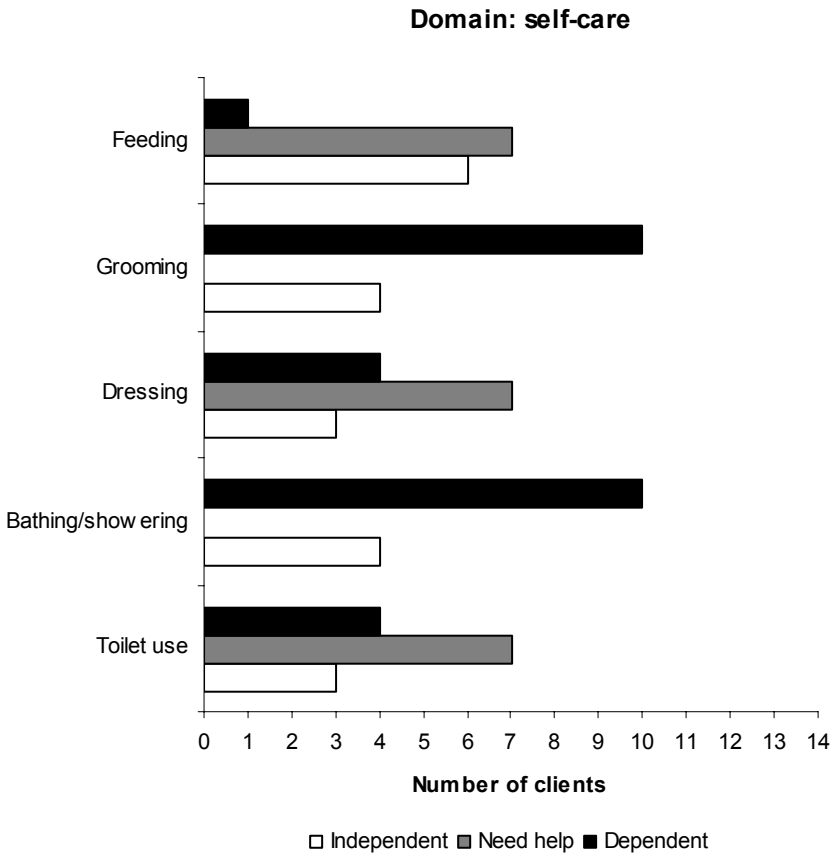


Figure B4.1: North East Dementia Innovations Demonstration, number of clients by level of ADL function at entry

(continued)



Source: Appendix Table B13.

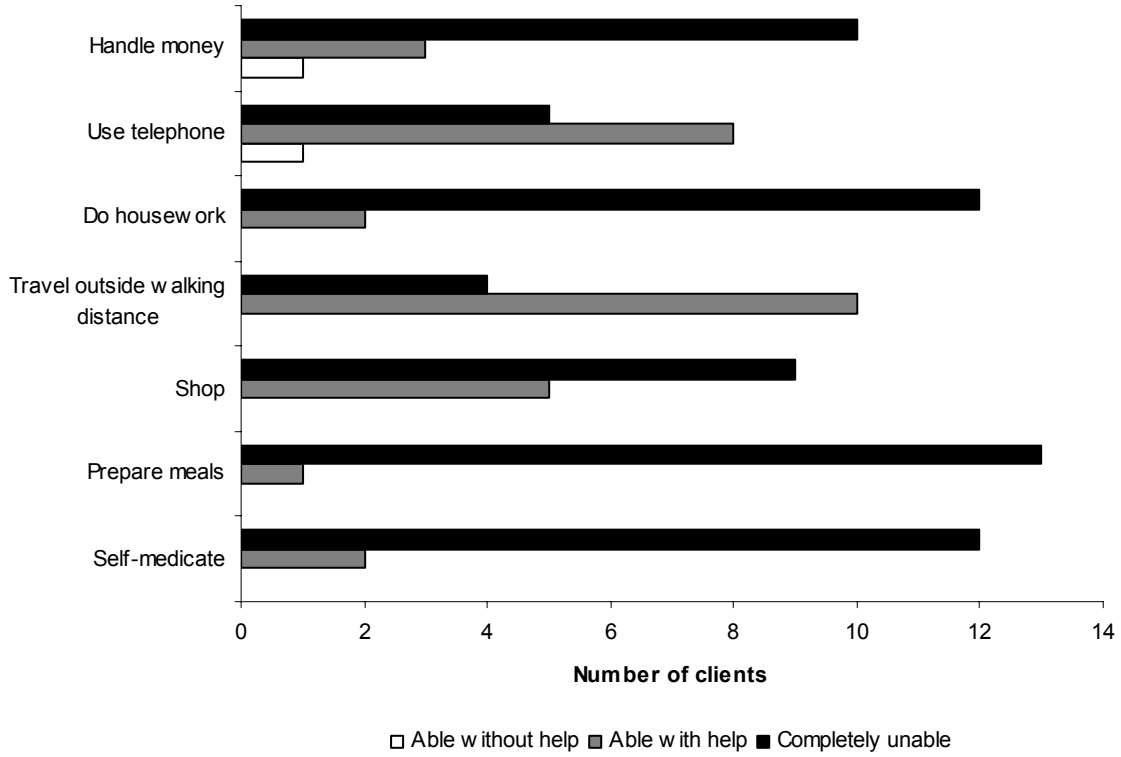
Figure B4.1 continued: North East Dementia Innovations Demonstration, number of clients by level of ADL function at entry

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.

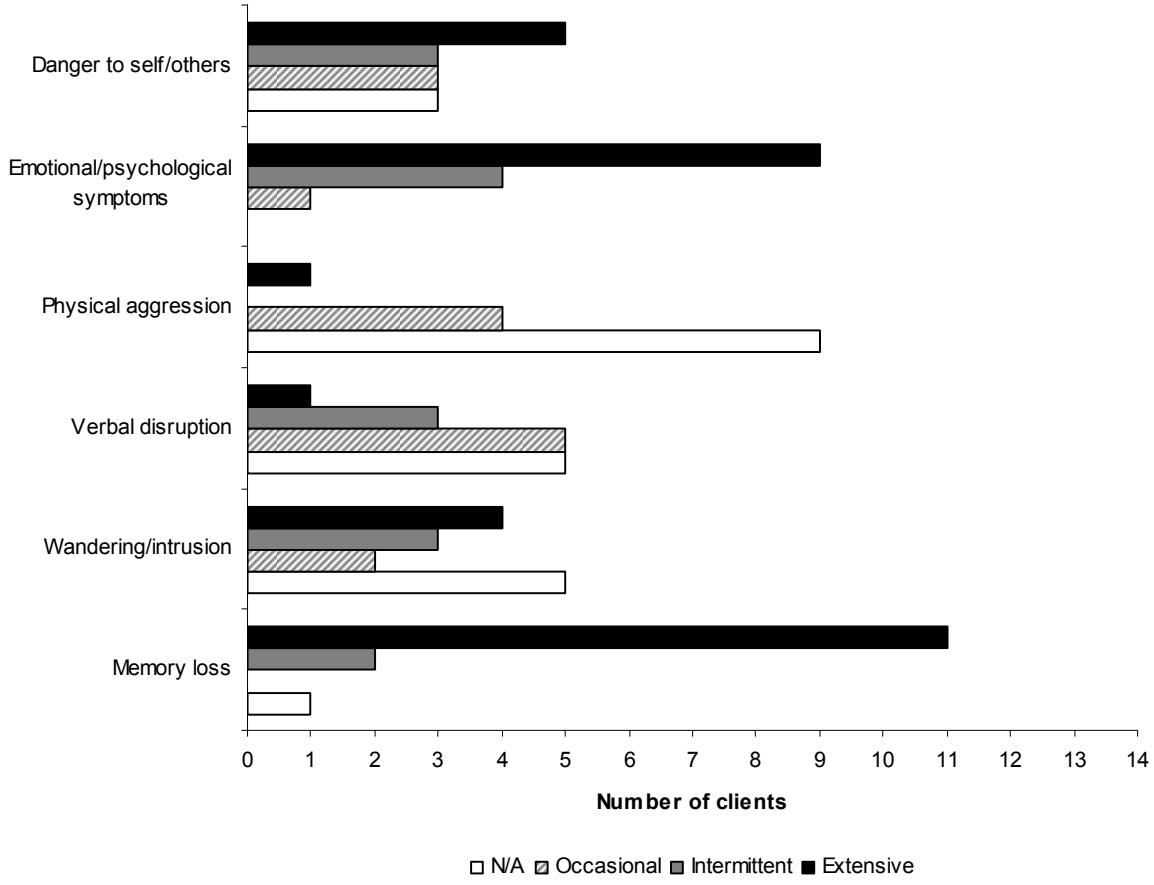


Figure B4.3: North East Dementia Innovations Demonstration, number of clients by frequency of psychological and behavioural symptoms at entry to project

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

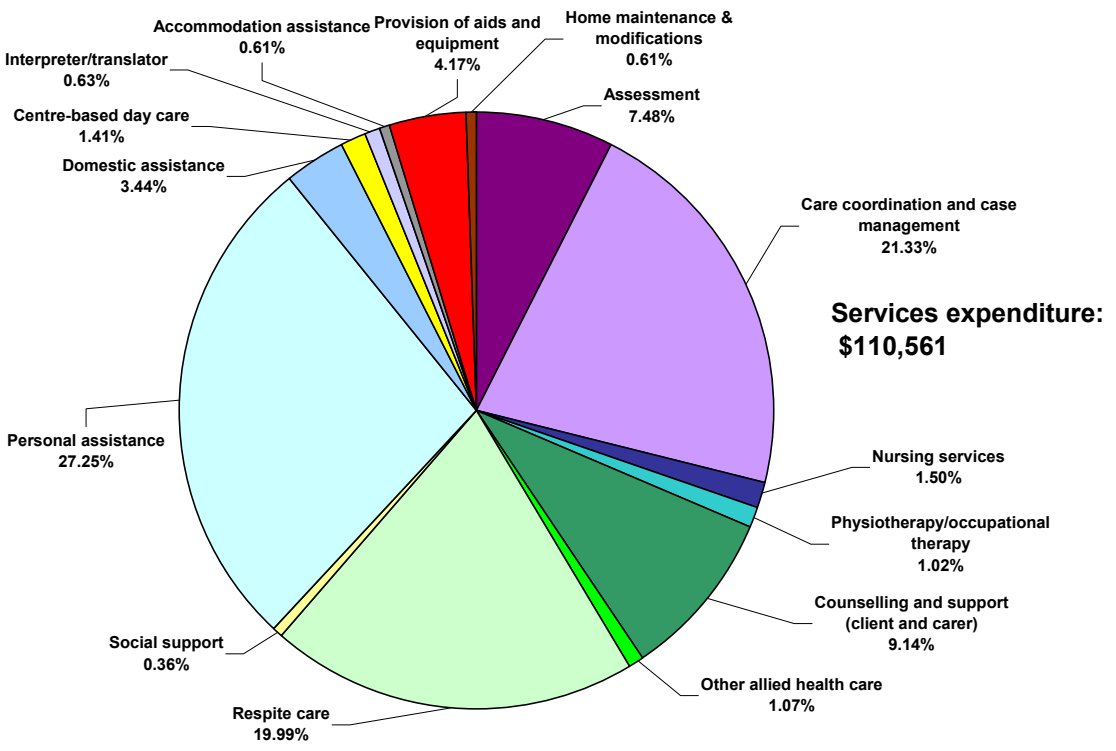
Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Personal assistance	Hours	13	1.9	8.6	29.2	10.8	8.1
Allied Health[(a)]	Hours	13	0.1	0.4	12.8	1.5	3.4
Respite (in-home and day)[(b)]	Hours	13	0.5	5.8	23.7	9.5	7.9
Domestic assistance	Hours	4	0.1	0.9	2.1	1.0	0.9
Nursing care	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

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).

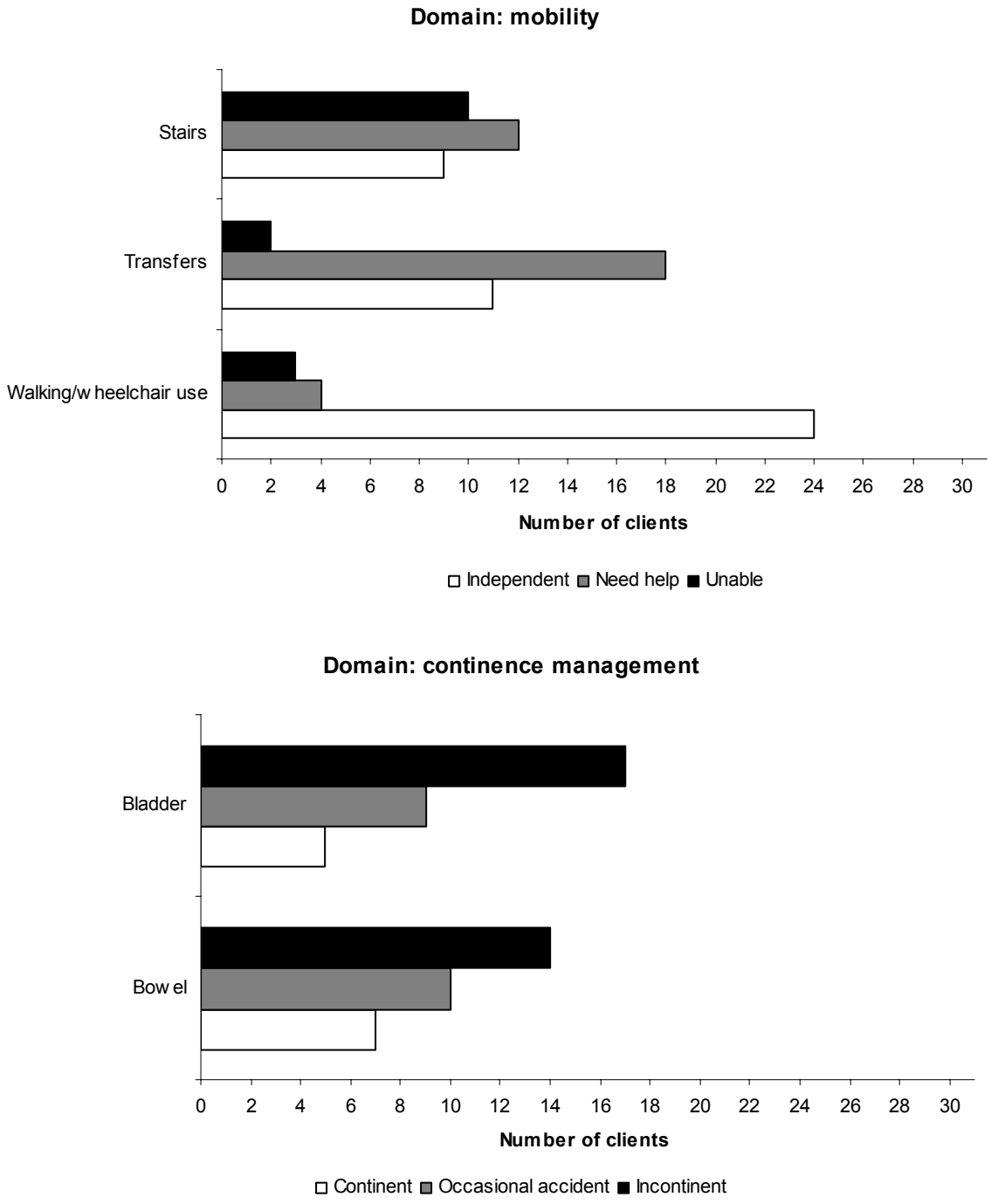
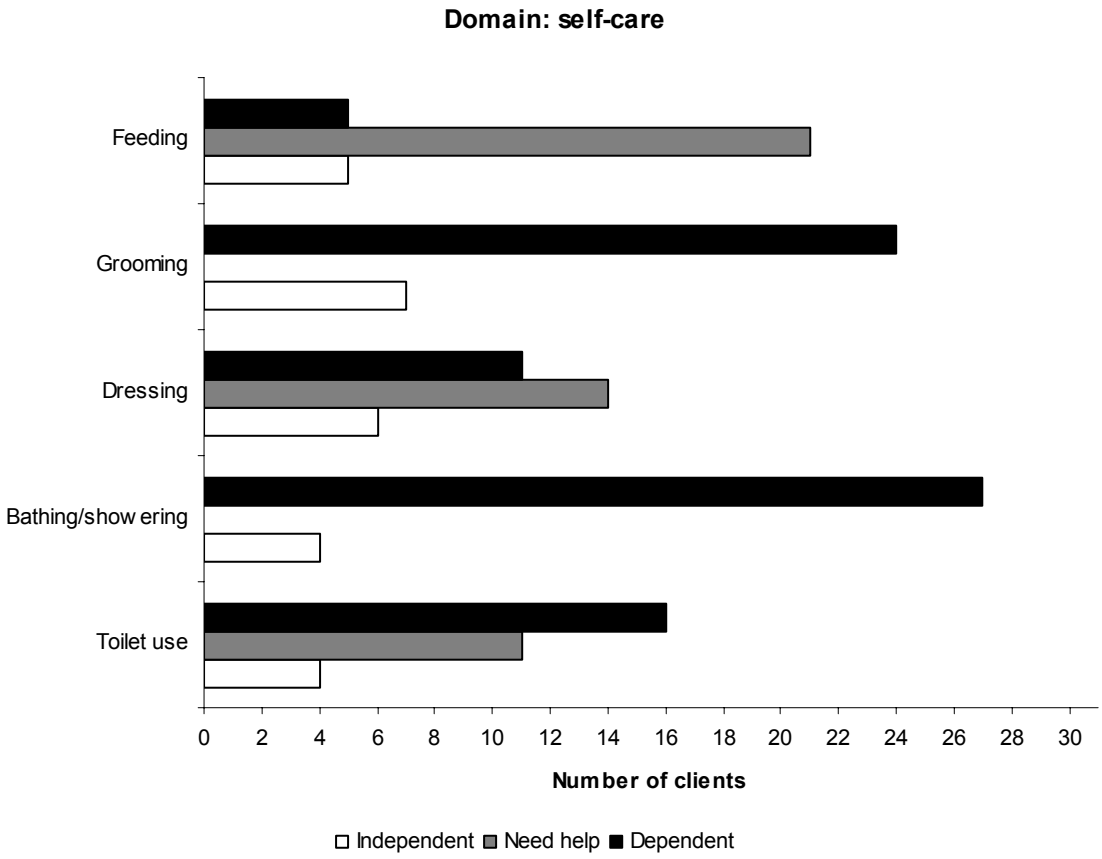


Figure B5.1: RSL Care Innovative Dementia Care Pilot, number of clients by level of ADL function at entry

(continued)

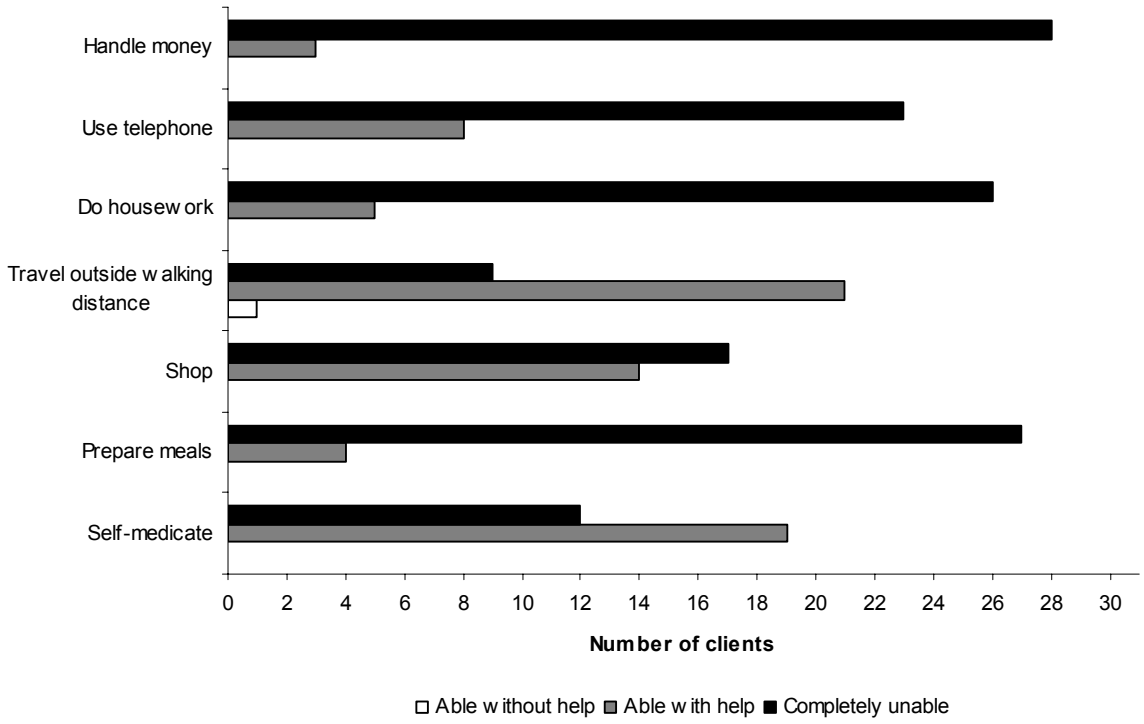


Source: Appendix Table B15.

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.

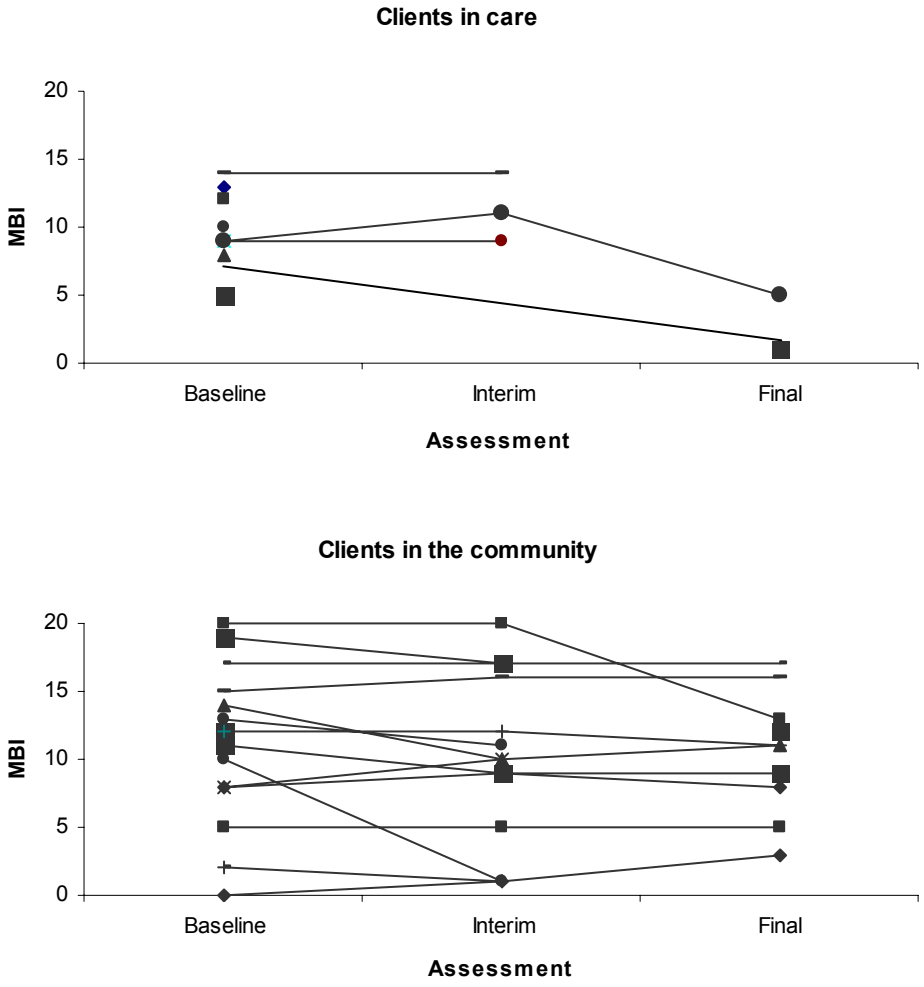


Figure B5.3: RSL Care Innovative Dementia Care Pilot, MBI at baseline, interim and final assessment by follow-up accommodation setting (one symbol per client)

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.

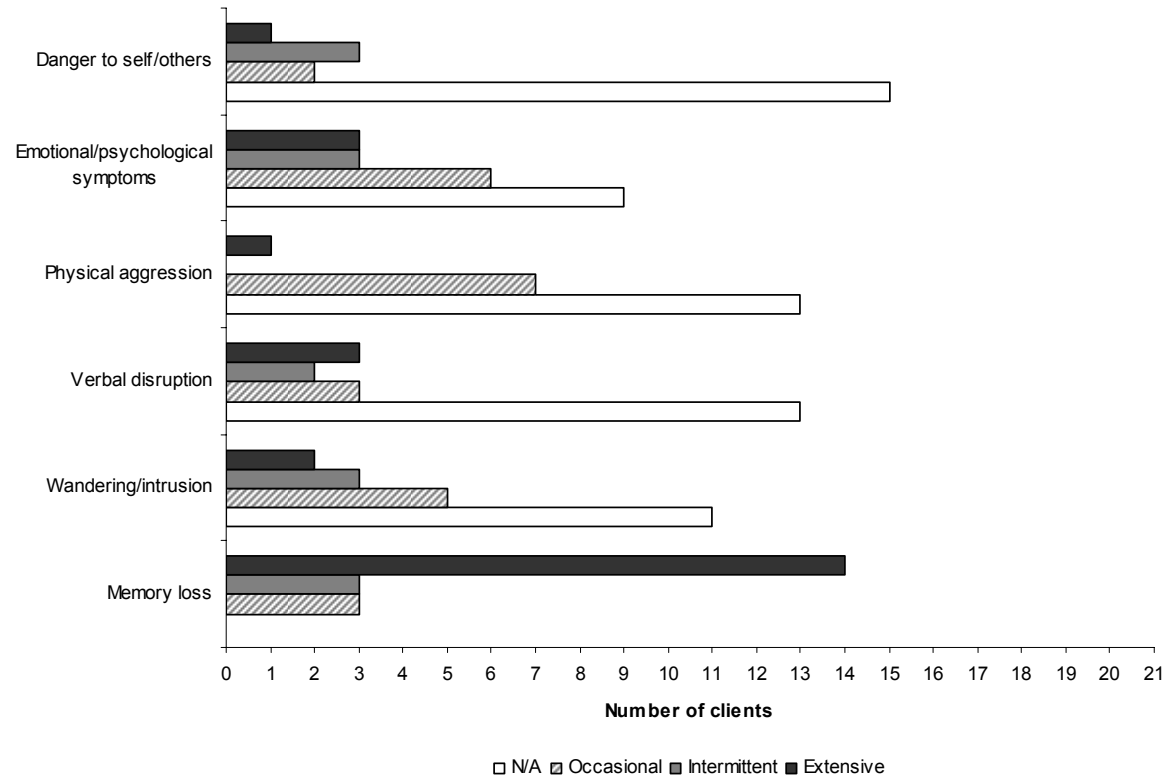


Figure B5.4: RSL Care Innovative Dementia Care Pilot, frequency of psychological and behavioural symptoms at entry

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).

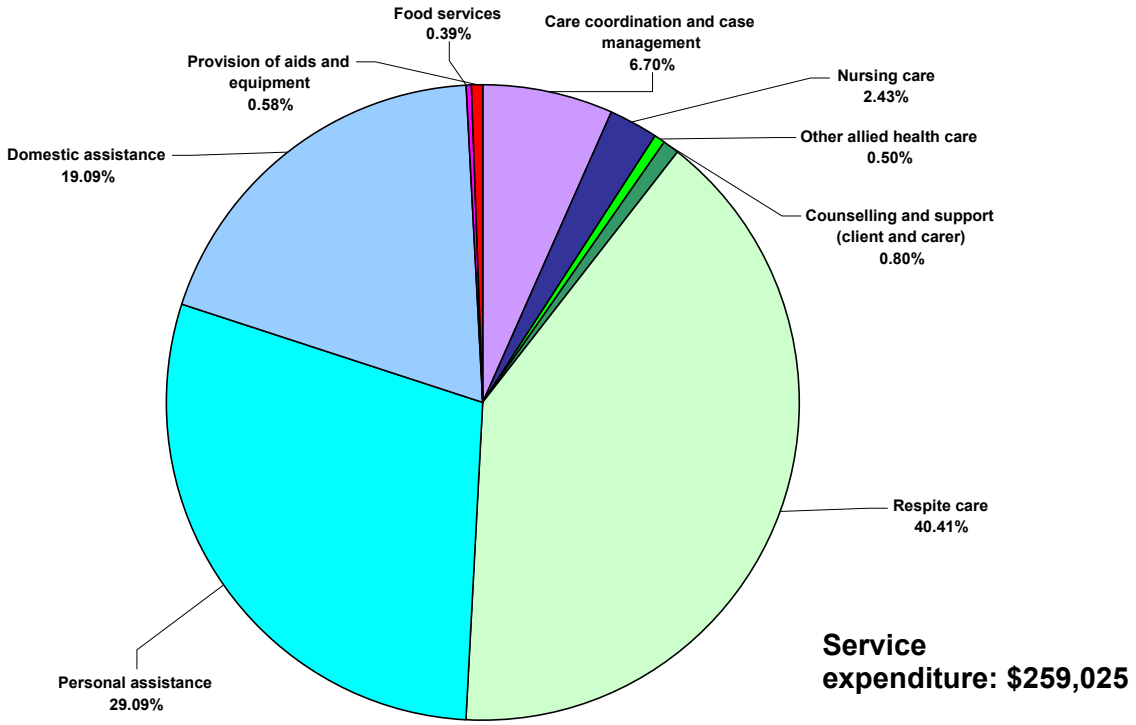
Table B5.15 : RSL Care Innovative Dementia Care Pilot, summary of services delivered per client per week, 14 June–29 November 2004

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**