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

— 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

Excludes 23 DBAMS clients living in an aged care facility on entry to DBAMS.

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.

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			Residential-care at follow-up						
support on discharge	Number of clients	Measure	Valid observations	Minimum	Median	Maximum	Mean	Number	Per cent
		Entry MBI	3	6	18	19	14.3		
None	3	Discharge MBI	3	5	17	18	13.3	_	_
None	· ·	Entry MMSE	3	12	12	19	14.3		
		Entry MBI	17	3	14	20	13.9		
HACC/VHC/other	17	Discharge MBI	15	2	13	19	13.1	4	23.5
TIN CON VITO/OUTCE	.,	Entry MMSE	15	4	17	28	17.8		
		Entry MBI	12	6	11.5	20	12.6		
Multiple program	12	Discharge MBI	12	5	14	20	12.6	2	16.7
support ^(a)	12	Entry MMSE	11	3	17	23	14.4		
		Entry MBI	10	9	16.5	19	14.3		
CACP	10	Discharge MBI	10	9	17.5	20	16.3	1	10.0
0/101	10	Entry MMSE	9	2	23	26	18.8		
		Entry MBI	8	3	9	12	8.3		
EACH	9	Discharge MBI	8	2	7.5	11	7.4	1	11.1
L/ (0/)	3	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).

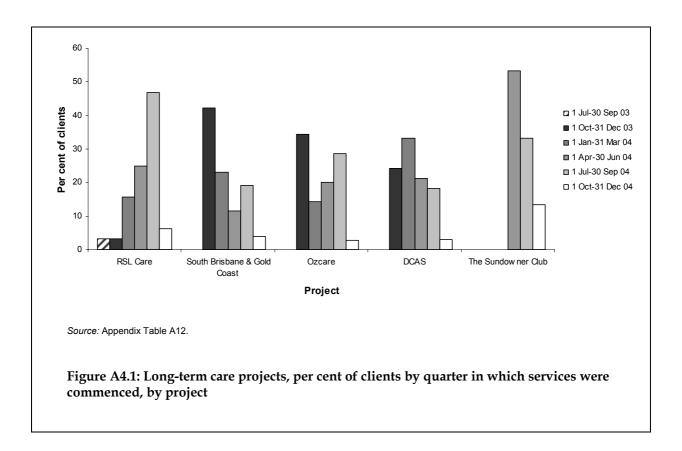
Table A4.3: Long-term care projects, number and per cent of clients by accommodation status and program support at follow-up

		At	home			Residen	Residential aged care				
Project	Continuing client	No program support	насс	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.



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.

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.

^{..} Not applicable.

[—]Nil.

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 <u>at home</u> 7 x 24 [sic], doing <u>everything</u> 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

		Daily payments		
Project	Flexible care subsidy ^(a)	Client co-payment min–max (mean)	Average combined per person payment ^(c)	
Short-term care packages				
Dementia Behaviour Assessment and	\$92.46	Nil (community)	\$92.46 (community)	
Management Service (DBAMS)		\$37.00 (intermediate care) ^(b)	\$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.

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).

⁽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.

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

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 p	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 soci	ialisation 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.

Source: Project quarterly financial reports.

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

n.r. Not reported.

[—] Nil.

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 car	e 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	e 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.

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.

^{..} Not reported

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.