2 Dementia Rehabilitation At Home

2.1 Project description

NSW Health received an allocation of 15 flexible care places to operate a Pilot project for a period of 2 years. The project, Dementia Rehabilitation at Home (DRAH) offers service to eligible residents of the Northern Rivers region of New South Wales for a period of 8 to 12 weeks.

DRAH has a strong clinical focus with primary aims of achieving accurate medical diagnosis of physical and behavioural symptoms, and of linking clients and carers into the formal service network. This project is perhaps best described as extending the ACAT service model to intensive case management, including the capacity to facilitate specialist assessment and diagnosis for ACAT clients with dementia, suspected dementia or other causes of cognitive impairment.

Clients and carers are assisted to identify up to 16 rehabilitation goals, the achievement of which is intended to facilitate a successful 'transition' at a key milestone on the care continuum. In this context, 'transition' might be the passing from an unawareness or uncertainty of the presence of dementia through clinical diagnosis, education and counselling. Alternatively, it could involve a client's progression from an unstable care situation due to social isolation or behavioural symptoms of dementia to a more managed environment through the diagnosis and treatment of behavioural symptoms and establishment of in-home services.

Client care is developed and reviewed by a multidisciplinary team comprising a clinical nurse consultant, registered nurses (including psycho-geriatric nurse), geriatrician and psycho-geriatrician specialists, occupational therapist, social worker and gerio-psychologist.

Tele-health technology plays a central role in the DRAH clinical work-up model.

Partnerships

DRAH operates as a partnership between the North Coast Area Health Service[5] and Clarence Valley Council Community Services[6] in northern New South Wales. The Aged Care Assessment Team in Grafton auspices the project and the council is a partner for community care delivery.

Clarence Valley Council is a local government provider of services for Home and Community Care, Community Aged Care Packages, the Commonwealth–State/Territory Disability Agreement and various New South Wales Government programs.

DRAH is one of the first partnerships between health and community services to be piloted in the region.

---

5 The Northern Rivers Area Health Service, the original auspice, was subsumed into the North Coast Area Health Service as part of a restructuring of New South Wales health service administration.

6 The Maclean Shire Council Community Services, the original partner, was subsumed into the Clarence Valley Council Community Services on council amalgamation.

Service environment

The project services four Local Government Areas that comprise the Clarence Valley, covering a region of 10,097 square kilometres (now amalgamated as one—Clarence Valley Council). Approximately 16.9% of the population is aged over 65 years, which is well above the state average. It is estimated that over 700 people in the Valley have dementia.

The service environment of Clarence Valley Council is characterised as having a relatively low level of service provision, poor access to medical specialists and mental health services, and a large service area.

Older people in the service region have limited access to geriatric and psycho-geriatric services. Tele-health enables DRAH to access a geriatrician (2 hours per fortnight) and psycho-geriatrician (up to 4 hours per fortnight). DRAH recipients are also assisted to travel to Coffs Harbour and Lismore to consult with specialists there, though the waiting period is generally around 4 months. The 8–12 week DRAH intervention is designed to achieve medical diagnosis or resolution of medical conditions, the establishment of appropriate in-home services, and support for carers and families who are adjusting to living with a person who has dementia.

Prior to the establishment of DRAH, six areas of unmet need are said to have existed in the Valley:

- lack of support for carers to decrease the burden of dementia care
- lack of post-hospitalisation support to reduce the length of hospital stay and services to help people avoid hospitalisation—hospital can be a very unfavourable environment for people with dementia
- a lack of attention to delirium in older hospitalised patients compounded by a drive within acute care settings for early discharge of patients to the community
- poor access to diagnostic services in the community that help to prevent inappropriate admission to aged care facilities and hospitals
- lack of flexible, client-centred service models for people with dementia who want to and can be cared for at home
- a lack of carer and family education programs that specifically address aspects of dementia care.

Polypharmacy is a major issue impacting on members of the target group and, in addition to diagnosis of dementia, is a principal reason for requiring increased access to medical specialists.

In the past, members of the target group are reported to have experienced difficulty accessing community care packages, Home Care, medical specialists (especially psycho-geriatricians) and carer support services.

Project objectives

Specific objectives of DRAH are to:

- assess the effectiveness of short-term post-hospitalisation support to increase or maintain functional independence at home for people with dementia or dementia-related challenging behaviours and their carers
- prevent inappropriate and premature admission to residential aged care or hospital

- decrease the burden of care for carers of people with dementia or dementia-related challenging behaviours.

According to the project proposal, DRAH was designed to test the effectiveness of:

1. short-term access to in-home, multidisciplinary, community-based, therapeutic interventions post-hospitalisation in improving the long-term functional capacity of individuals—dementia as a co-morbidity often rules a client out of rehabilitative type service provision
2. a mobile response team, in close partnership with general practitioners, with capacity to provide short-term, in-home support to maintain or improve levels of functioning for people with dementia or behavioural symptoms associated with dementia
3. a program of services to be tailored to individuals' service needs aimed at improving their long-term functioning
4. inter-agency cooperation and governance between NSW Health, Clarence Valley Council Community Services and the Australian Government.

Increased access to specialist medical diagnosis of dementia and dementia-related medical problems via tele-health evolved as a key feature of the DRAH service model, as is the integration of assessment and service coordination through a partnership of the Area Health Service and Clarence Valley Council.

Target group

The target group is people with cognitive impairment or dementia-related behavioural symptoms and their carers, living in their own homes, who would benefit from the provision of a time-limited period of intensive support and case management.

Eligible participants are those assessed by Clarence Valley ACAT as requiring high level flexible care. Clinicians further evaluate client needs and a care plan is developed and given to the service coordinator to commence an 8-week program targeted at improving or maintaining functional independence.

At the conclusion of a DRAH care plan, the client's progress is assessed and assistance is given to return the client to usual levels of integrated community service support, where appropriate.

Referrals have been accepted for care recipients with a somewhat different profile to that expected of the target group. Acute care and post-acute care needs have been less prominent than anticipated at the outset. The ACAT remarked that general practitioners and other service providers seemed to be referring clients earlier as awareness of the project increased. A higher than expected proportion of clients was referred from home (versus hospital) and it is thought that, in many cases, the project has helped people avoid hospital admission (in a survey of both hospitals in the area, the discharge planners and nurse unit managers reported a decrease in hospital admission of psycho-geriatric and dementia patients).

Service model

DRAH integrates intensive clinical assessment and work-up with community-based, in-home services. The ACAT provides overall case management and direction, covering clinical and community services.

A multi-disciplinary team comprising physiotherapist, gero-psychologist, specialist nurses, social worker and occupational therapist develops diagnostic plans, reviews client progress through weekly case conferences and contributes to the planning of community-based services. Geriatric and dementia specialist services in Sydney are accessed via tele-health when necessary. Two geriatricians in the Northern Rivers area also consult with DRAH clients. A person accepted into the project requiring confirmation of dementia or another investigation such as medication review or gero-psychiatric examination will typically undergo a period of intensive clinical work-up, possibly involving medical specialists, a clinical nurse consultant, and allied health professionals.

Weekly case conferences are held to review the progress of every care recipient. Calculated over the entire episode of care, this activity runs to an average of approximately 2 hours per client per week. This 'behind the scenes' clinical management activity is in addition to initial needs assessment and follow-up contact between the project coordinator and clients. Data recorded for the evaluation reflect the high 'assessment' component of DRAH services, which is in reality a mix of needs assessment and case management for the purposes of delivering community care and clinical work-up for medical diagnosis and management.

Care plans are designed to address up to 16 rehabilitation goals that are agreed between the care recipient, family and ACAT team.

Complementing clinical services, the community service arm of the project focuses on physical management (for example, personal and domestic assistance, food services), and social management (for example, social support, respite care, carer/family support and education). These services are delivered by Clarence Valley Council Community Services as specified in the client's care plan.

The DRAH carer support program aims to create an environment for carers and family members to better understand dementing illnesses. DRAH contracts with Community Programs Incorporated to deliver the 5-week program. Facilitated learning and discussion covers the causes, symptoms and stages of dementia, the impact on carers and families of living with a person who has dementia, management and coping strategies to use at home, and ways that carers can care for themselves. A major spin-off is the opportunity for participants to join carer networks that have arisen through the education program and which continue to provide support long after the period of DRAH service.

Care recipients in the first 6 months of DRAH operation averaged 8.2 weeks of service. A breakdown of the delivery of clinical services during this period is given in Table B2.1. The ACAT is heavily involved not just in the eligibility assessment, but also in weekly case reviews of all DRAH care recipients. The ACAT guides recipients through the program to ensure that clinical outcomes are reviewed regularly and achieved to the greatest possible degree. In addition to clinical services, care recipients and their carers receive a tailored package of 'ancillary services'—personal assistance, home help, respite care, aids and equipment, diversional therapies, transport service and carer education and home modifications and relocation. A total of 1,680 hours of ancillary services were delivered to 25 care recipients who completed their programs in the first 6 months of the project. Project coordination and administration consumed 1,344 person hours in this period (Dementia Rehabilitation At Home, 6-monthly report, 1 February – 31 July 2003).

Table B2.1: Dementia Rehabilitation At Home, clinical service delivery in the first 6 months

Clinical service	Hours per occasion of service	Number of clients in receipt of service (N = 39)	Total hours over 6 months
Service hours client in attendance			
Specialist geriatric work-up	5	16	80.0
Psycho-geriatrician consultation	1.5	10	15.0
Gero-psychologist	1.5	11	16.5
Geriatrician	1.5	5	9.0
Occupational therapist	2–3	7	20.0
Dietician	2	5	10.0
Physiotherapist	2	1	2.0
Speech therapist	1.5	1	1.5
Service hours client not in attendance			
Psycho-geriatric clinical nurse consultant	n.a.	n.a.	214.0
Social work	n.a.	n.a.	219.0
ACAT clinician registered nurse (1 fulltime equivalent)	n.a.	n.a.	227.0
Registered nurse part-time	n.a.	n.a.	99.0
Occupational Therapist part-time	n.a.	n.a.	157.0
Total			**1,070.0**

— n.a. not applicable.

Source: Dementia Rehabilitation At Home 6-monthly report:, 1 February–31 July 2003.

This pattern was repeated in the second 6 months, from 1 August 2003 to 31 January 2004. Approximately 960 hours of clinical services were delivered to 37 clients admitted in the period. The project delivered a total of 4,561 hours of ancillary services in the 6 months (it is assumed this figure covers newly admitted and established clients). Respite care made up approximately 48% of ancillary service hours; personal assistance, domestic assistance, transport and carer education each accounted for between 10% and 12% of total hours.

Staffing

In 2003, DRAH increased ACAT capacity by one fulltime equivalent clinician and administrative support three person days per week. In 2004 this was increased to one extra fulltime equivalent clinician and increased administrative support to full time.

Clarence Valley Council Community Service employed one fulltime coordinator to manage the service provision side of the project and 12 part-time support workers.

The usual case management load is one care manager per 15 care recipients.

Early progress

During the first 6 months of operations, 51 referrals were received from hospitals (15), family, friends or neighbours (14), community service providers (10), general practitioners (six), psychologists (three), community nurses (two) and one aged care facility,

reflecting a widespread awareness of DRAH in the community. Twelve referrals were not accepted for various reasons including care needs that were too high to be adequately supported by the project (three), no rehabilitation goal (two), person refused or deferred services (three), a CACP was a more appropriate type of service (two), and person took up a place in an aged care facility (two).

Twenty-five care recipients were discharged during the first 6 months and 21 of these people were discharged to home with support services (Table B2.2).

Table B2.2: Dementia Rehabilitation at Home, discharge outcomes from project commencement to 31 July 2003

Discharge outcome	Number of clients
To home	
With CACP	9
With HACC	3
DVA Home Care	4
With Clarence Community Programs	2
With respite service (including DVA respite care)	3
Total at home	*21*
To care facility	
Hospital	1
Residential respite care	2
Residential low care	—
Residential high care	1
Total in care	*4*
Deceased	—
Total	**25**

— Nil

Source: Dementia Rehabilitation At Home, 6-monthly report, 1 February 2003–31 July 2003.

It is estimated that 97 hospital patient days were saved through early supported discharge as a result of DRAH in its first six months of operation. In addition, eight people received DRAH services as a complete alternative to hospital.

The project also reported a high rate of goal attainment during the first 6 months. The 25 care recipients who were discharged in the first 6 months collectively identified 88 rehabilitation goals, of which 64 goals were fully achieved, 15 partially achieved and eight goals were not achieved during the periods of care.

The 12-monthly report indicates that of the 58 clients who completed their program of care in the first year of the project, only seven had entered permanent care. Key achievements in the second 6 months included:

- an estimated saving of 204 acute care patient days through supported early discharge and hospital avoidance
- 16 carers trained in brain and behaviour, nutrition, self-care strategies, the importance of touch, and community service awareness

- a review of the carer program and launch of a new education program in February 2004
- 14 care workers from Clarence Valley Council trained in the management of dementia and dementia-related behavioural symptoms.

A major challenge faced during this period was the lack of community services for clients on discharge from DRAH. The Valley saw significant periods of time in which Home Care, CACP and dementia programs funded by non-government organisations were unable to accept new clients. DRAH allowed clients ready for discharge to continue on a maintenance program while they awaited community services. Several clients were discharged to multiple services in order to ensure continuity of care.

The general shortage of community care options is said to have affected not just DRAH clients, but all ACAT clients, since fee-for-service organisations were the only referral option for people needing personal and domestic assistance, in-home respite care and other standard care services.

Clarence Valley ACAT reported that the project has enhanced awareness and increased the clinical experience of its members. In particular, delirium is assessed more competently and it is believed that interventions for decreasing the intensity and duration of delirium are put into place more effectively. Fifteen DRAH recipients showed signs of delirium at referral. Thirteen clients are reported to have experienced a lessening of delirium symptoms while with DRAH.

Achievements, challenges and lessons

The DRAH model has demonstrated how tele-health technology can be used to increase access to specialist medical services for people with dementia and their families who live outside major metropolitan centres. Carers have attested to the relief that comes from firm diagnosis and information on how they can plan for the future.

Multidisciplinary team work has produced benefits for clinicians involved in the project, increasing knowledge and information exchange. The ACAT reports that the project has been a highly positive experience for its members through the partnership forged between local health and community services and geriatric specialists further afield and the way that the partnerships have facilitated client-centred coordinated care.

DRAH has experienced difficulty in discharging some clients and some compromises have been necessary in making discharge support arrangements due to a shortage of appropriate long-term community care options in the region. Nine clients discharged during the evaluation period are thought to have been placed into the best possible program. Table B2.3 compares actual discharge outcome with optimal discharge support as indicated by the DRAH team for the remaining 22 clients. Extended Aged Care at Home was thought to have been the best support program for 17 clients discharged to home with support from other programs or without formal support.

Four of the five clients discharged to CACP were assessed to have required an EACH service. Similarly, seven clients discharged to a HACC or Veterans' Home Care(VHC) service would have been more appropriately placed with an EACH service.

Table B2.3: A comparison of actual and optimal discharge outcomes for DRAH evaluation clients

	Optimal discharge support						
Discharge outcome	**EACH dementia specific**	**EACH**	**CACP**	**NSW Homecare**	**DVA care package**	**Higher intensity respite**	**Total**
Unable to discharge	—	1	—	—	—	—	**1**
Home without services or with services unspecified	2	2	1	—	—	—	**5**
HACC or VHC	4	1	—	—	1	—	**6**
HACC or VHC with Day Therapy Centre service	1	1	—	—	1	1	**4**
CACP	2	2	—	1	—	—	**5**
Residential care	1	—	—	—	—	—	**1**
Total	**10**	**7**	**1**	**1**	**2**	**1**	**22**

Note: New South Wales Homecare was recorded as a suitable alternative to EACH or CACP in six cases.

— Nil

Source: Dementia Rehabilitation at Home.

Case studies

The following case studies were supplied by the project.

Case study 1

'A referral was received from a neighbour for an 87 year old man (Mr F) caring for his 94-year-old wife who is hearing and sight impaired. They have no children and no contactable relatives. They have refused all services in past. The neighbour reported Mr F had gone for a drive and got lost 2 kilometres from home. A stranger had driven him home. The stranger reported this to the neighbour. Mr F's GP had not seen him for some time.

DRAH visited Mr F in his home, a two-storey house with a very narrow internal staircase. At the time he was giving his wife cold leftover potato chips for lunch. Mr F did not remember the incident with the driving and getting lost but he would accept help at home with meals.

Goals for the DRAH care plan included: acceptance of services; pursue diagnosis; maintenance of skills; environmental safety; and improve nutritional status.

Services commenced daily, although Mr F would often not let staff in. DRAH pursued diagnosis through his GP and geriatrician. Care workers helped transport Mr F to these appointments. In addition, DRAH facilitated the wife's visits to the GP which led to diagnosis of dehydration and malnutrition.

DRAH organised emergency respite care for Mrs F as Mr F had an episode where he did not recognise his wife and locked her out of the house. In addition, guardianship was organised with a family member as Mr F was no longer able to manage his finances (for example, he had tried to withdraw $25,000 from the bank to pay for a car battery).

Mr F also received 2 weeks respite care but was very agitated and returned home early. The hostel advised that Mr F would not be suitable in their Dementia Unit and would need

nursing home dementia care. Mrs F is in hostel respite care awaiting nursing home placement. Mr F has refused placement.

Mr F is awaiting an EACH package as this would be a better alternative at the present time to a nursing home placement. He is orientated in his own home with support workers attending to meals and taking him to visit his wife.'

Case study 2

'An 84-year-old woman was referred by her family for ACAT assessment for respite to enable her elderly carer to have a break (client could not be left alone). Dementia and hypertension were listed as diagnoses on the referral.

The ACAT assessment referral stated that the client could not be left alone, had been seen by a geriatrician for agitation and anxiety 3 months prior to assessment, and was taking an antidepressant and a cholinesterase inhibitor. The client had six presentations to the emergency department and hospital in the 12 months prior to assessment.

DRAH assessment revealed that the client had features of delirium, a high risk of falls due to decline in mobility (frequent falls had been reported), was unsafe in the shower (and did not like having help) and was reluctant to go to day care. The carer was stressed due to constant demands and having to provide personal care assistance.

The client was admitted to DRAH with the goals of:

1. safety and compliance with medications;
2. acceptance of services/care;
3. reduced carer stress;
4. improved environmental safety.

DRAH services included a review by a geriatrician, which resulted in a change of medications (fewer), staff assistance with personal hygiene once daily and in-home respite care, a psychologist visit for the carer (for anxiety management strategies) and carer education sessions, and an occupational therapy assessment and home modifications. In addition, the client and carer were referred for a 'Care For U Holiday'[7] and to a dementia outreach service for ongoing support.

Outcome

On discharge from DRAH, the delirium had resolved, and the client's mobility had improved (transferring and mobilising independently). The client received a CACP which supported the carer and provided day respite three days a week. In addition the client had no falls or presentations to the emergency department or hospital since discharge from program.'

7 Care for U Holidays provide specifically designed short break holidays for people with dementia and related disorders and their carers. Holidays are four days & three nights (Monday-Thursday) at the Rainforest Resort, Byron Bay. Respite care staff provide 24-hour support and recreational activities for the person with dementia, and there are activity programs for carers. All transport is provided from the carer and client's home. Holidays are funded by the New South Wales Department of Health and Aged Care, with participants making a contribution of $40 per person.

Case study 3

'A 79-year-old woman (Mrs C) was referred by her daughter who had concerns about her mother's forgetfulness and increasing difficulty with ADL tasks at home. To compound matters, Mrs C's carer, her husband, was awaiting major surgery. Family were keen to have residential respite organised and plan for future support.

Mrs C had been physically well despite being diagnosed with diabetes and arthritis. Mr and Mrs C were both concerned about her short-term memory loss, evident for about 6 months. Mrs C queried 'am I going mad?'. They had only recently discussed it with their family, although close knit, because of concerns about what it would mean for the future. Their children had observed that Mr C was now cooking or prompting his wife with food preparation and housework, and monitoring insulin management. She tended to 'shadow' him and his role as carer was becoming increasingly onerous and impacting on his health. The closest family were about a three hours drive away.

Mrs C could walk around the block alone. The couple tend to shop locally in a familiar environment rather than travelling to the provincial city one hour away, as they had done previously.

Mr and Mrs C attended the ACAT assessment along with their son and daughter. It was found that Mrs C was aware of her short-term memory loss and her reliance on Mr C and was concerned about the impact on him. Along with memory loss she was found to have trouble with concentration and orientation, and accessing the bath. Mr C was quite distressed at the changes in Mrs C and sad to be 'losing' the person he had known for 60 years. He was worried about the seriousness of his impending surgery and how Mrs C would manage. Mr C was a well organised, caring, capable man. He was missing opportunities to pursue his previous interests.

DRAH commenced services with goals of: supporting the carer through illness, relieving carer stress, pursuing accurate diagnosis, ensuring safety and compliance with medications and having the clients accept services.

An accurate diagnosis was achieved by a tele-health appointment with a geriatrician, through which a diagnosis of Alzheimer's disease was made and the implications of the disease and medication options were discussed with Mr and Mrs C. Mrs C's GP was sent a copy of this report. In addition a referral was made to a diabetic educator, so Mrs C could attend a local diabetes clinic for regular monitoring and support. Day respite was organised, and DRAH implemented in-home respite and domestic assistance during Mr C's hospital stay and recovery period. Mr C also attended DRAH education sessions.

Outcome

An early intervention was possible and therefore residential respite and hospitalisation was avoided. Diagnosis and education were obtained enabling planning for future possibilities (the family renovated the bathroom for easy showering and are now aware of resources available). Mr C is now able to pursue his own interests knowing that his wife is safe at day club or having in-home respite care. Short- and long-term services are in place.'

Case study 4

'A referral was received from hospital for an 82-year-old woman with a diagnosis of dementia and a carer who was unable to cope. The client had presented to the emergency department four times in 8 months. She had recently commenced on anti-cholinesterase medication for treatment of Alzheimer's disease. Confirmation of diagnosis was made by a consultant physician or psychiatrist to prescribe medication, however, DRAH found inconsistencies in her MMSE score between physicians (one score indicated no cognitive impairment). Following commencement of medication the client became disorientated and confused. Her elderly husband was afraid to take her home from hospital.

DRAH implemented services with the following goals: reducing carer stress; pursuing diagnosis; ensuring adequate socialisation; maintenance of skills; acceptance of services; and ensuring environmental safety.

An urgent consultation via tele-health with a psycho-geriatrician was made to confirm the diagnosis of Alzheimer's disease, with the client's GP in attendance. The client was diagnosed with a major depressive episode, not dementia. The psycho-geriatrician recommended changes to medications including ceasing anti-cholinesterase medications. She was discharged from hospital straight after the consultation and service commenced immediately. Services were implemented daily to provide support to the client's husband. All medications were put in a webster pack and extra medications taken to the chemist to avoid confusion. In addition, DRAH assisted with contact with social day care groups and referred the client to an occupational therapist and physiotherapist due to unsteady gait.

Outcome

The client was discharged to DVA Homecare and the GP was very happy with the outcome, stating that he wished referral had happened earlier.'

2.2 Client profiles

DRAH supplied evaluation data for 31 clients (12 men and 19 women).

Age and sex

The mean age of clients at the time of the evaluation was 79 years (ages ranged from 59 years to 94 years). Six clients were aged 85 years or over (Table B2.4).

Table B2.4: Dementia Rehabilitation at Home, number of clients by age group and sex

Age (years)	Males	Females	Persons
		Number	
Less than 65	1	—	1
65–74	3	1	4
75–84	7	13	20
85+	1	5	6
Total	**12**	**19**	**31**
		Per cent	
Less than 65	3.2	—	3.2
65–74	9.7	3.2	12.9
75–84	22.6	41.9	64.5
85+	3.2	16.1	19.4
Total	**38.7**	**61.3**	**100.0**

— Nil.

Language and communication

Two clients had little or no effective means of communication and the remaining clients could communicate effectively in spoken language. All participants in the evaluation were from an English-speaking background.

Accommodation and living arrangement

Most clients were living in private residences (Table B2.5). One client was in hospital at the time of referral to the project.

Table B2.5: Dementia Rehabilitation at Home, number of clients by usual accommodation setting and living arrangement

	Usual living arrangement				
Accommodation setting	**Alone**	**With family**	**With others**	**Not stated**	**Total**
Private residence	7	22	1	—	30
Short-term crisis accommodation	—	1	—	—	1
Total	**7**	**23**	**1**	**—**	**31**

— Nil.

Years at usual accommodation ranged from less than one to 60 years. Eight clients had been living in the same home for 20 years or longer. Three clients had changed place of residence in the 2 years prior to entering DRAH.

Carer availability

Twenty-six clients had a carer, 18 of whom were living with the care recipient (Table B2.6). Carers' ages ranged from 47 to 85 years, averaging 64.4 years. Eight carers were aged 75 years or over (Table B2.7).

Table B2.6: Dementia Rehabilitation at Home, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	**Carer lives with client**	**Carer does not live with client**	**Total**
Spouse or partner	15	—	15
Son or daughter	3	8	11
Total clients with a carer	*18*	*8*	*26*
Total clients			**31**
Per cent of clients with a carer			83.9

— Nil.

Table B2.7: Dementia Rehabilitation at Home, number of carers by age group and sex

Age (years)	**Males**	**Females**	**Persons**
45–54	4	3	7
55–64	—	5	5
65–74	1	3	4
75–84	4	3	7
85+	1	—	1
Not stated	1	1	2
Total	**11**	**15**	**26**

— Nil.

Income and concession status

Evaluation clients were in receipt of Australian Government pensions as their primary source of income: age pension (29 clients), disability pension (one client), and the DVA pension (one client). All clients held a health care concession card.

DRAH does not charge client fees.

Previous use of government community care programs

Twenty-four clients were not receiving assistance from government community care programs when they entered DRAH. One client was receiving a CACP, four clients were receiving assistance through the HACC program, and one client received support through the National Respite for Carers Program (Table B2.8).

Of the seven carers who had accessed any form of respite in the 12 months prior to entering the project, three had accessed mainly in-home respite and four had accessed mainly residential respite. Nine carers reported that, despite having had a need for respite care in the 12 months prior to DRAH, they had not used a respite care service (Table B2.8).

Table B2.8: Dementia Rehabilitation at Home, number of clients by previous use of government support programs

Previous use of government support programs	Number of clients	Per cent
Government support program		
Community Aged Care Packages	1	3.2
Home and Community Care	4	12.9
National Respite For Carers	1	3.2
CACP and NRCP	1	3.2
Total clients with previous government program support	*7*	*23.1*
Clients without previous government program support	24	77.4
Total	**31**	**100.0**
Use of respite care in the 12 months prior to DRAH		
Respite care not needed	9	34.6
Respite care used	7	26.8
Respite care needed but not used	9	34.6
Not known	1	3.8
Total	**26**	**100.0**

Two clients were reported to be on a waiting list for residential aged care when they entered DRAH.

Assessment and referral

All DRAH clients were referred from different sources to ACAT for intervention and assessment; consequently ACAT were the identifiers of the need for DRAH in particular. ACAT recommended 23 clients for the project (Table B2.9).

Twelve clients had completed an ACAT assessment on the same day or prior to referral. For these clients, the time between completion of an assessment and referral to the project varied up to 13 days (Table B2.10). ACAT assessment was completed after referral to the project for 19 clients. Twelve clients are reported as having had two ACAT assessments in the 12 months prior to entering the project, and one client is reported as having three ACAT assessments in the same period.

ACAT assessment time is included in clients' initial needs assessment hours because of the central role of ACAT in the service model. 'Clinical work-up', which involves a weekly multidisciplinary case conference on each client, has been recorded separately and appears in the DRAH services summary.

Table B2.9: Dementia Rehabilitation at Home, number of clients by source of referral

Referral source	Number of clients
Multiple other sources of referral with final DRAH recommendation from ACAT	23
Hospital	3
Other community service agency	2
Other agency	1
Family	1
General practitioner	1
Total	**31**

Table B2.10: Dementia Rehabilitation at Home, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral to DRAH	
0–20 days	12
Total	*12*
After referral to DRAH	
0–60 days post-referral	16
61–300 days post-referral	3
Total	*19*
Total	**31**

The care of DRAH clients is managed by a registered nurse (21 clients), an occupational therapist (three clients) or a social worker (seven clients). In addition, the progress of all clients is reviewed by a multidisciplinary team of clinicians.

Health conditions and health status on entry

The number of health conditions recorded for DRAH clients as at entry ranged from one to eight. Fourteen of the 31 clients had five or more health conditions. Table B2.11 shows the primary health conditions recorded on the Aged Care Client Records for clients.

Table B2.11: Dementia Rehabilitation at Home, number of clients by primary health condition at entry

Primary health condition	Number of clients
Dementia (Includes Alzheimer's and other types of dementia)	23
Delirium	1
Psychoses and depression/mood affective disorders	1
Mental and behavioural disorders due to alcohol and other psychoactive substance use	1
Transient cerebral ischaemic attacks	1
Heart disease	1
Cerebrovascular disease	1
Osteoporosis	1
Amnesia	1
Total	**31**

Eighteen clients were assessed as being at risk of falls due to impaired gait or balance (Table B2.12). Five clients were both vision and hearing impaired.

Table B2.12: Dementia Rehabilitation at Home, number of clients by selected sensory, mental health and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	18
Vision impairment	10
Diagnosis of depression	7
Hearing impairment	7
Disorientation/confusion	6
Vision and hearing impairment	5
Total or partial paralysis	3
Missing or non-functional limbs	1

Clients were taking between one and 11 different types of medication. Thirteen clients were taking seven or more different medications.

Clients and carers were asked to rate the client's health status and change in health status over the past 12 months using a five-point Likert scale (Short-Form 36). Self-reported health status was reported by three clients, by carers on behalf of clients in 21 instances, and by a care worker for six clients. Respondent identity was not reported in one case. Clients rated their present state of health as good, fair or poor. Seventeen clients were rated (by another person) as being in fair health, seven as being in good health, one as being very good, and one as excellent. Two clients were rated as being in poor health. Ten raters believed that the

client's health was about the same as it was a year earlier, and one rater reported that the client's health was somewhat better. Fifteen raters believed the client's health was somewhat worse and five raters stated that the client's health was much worse than 12 months earlier.

Level of core activity limitation

Most DRAH clients experienced mild or moderate activity limitation in the areas of self-care (22 clients), mobility (20 clients) and communication (22 clients) (Table B2.13). Eight clients recorded a severe or profound limitation in at least one core activity.

Table B2.13: Dementia Rehabilitation at Home, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	4	13	9	5	**31**
Mobility	8	15	5	3	**31**
Communication	5	18	4	4	**31**

Use of medical and hospital services prior to entry

All of the 31 clients had visited a medical practitioner at least once in the 6 months before starting with DRAH. The reported number of visits to a medical practitioner in this period varied from one to 24 per client. Cumulatively, clients recorded 159 visits to a medical practitioner outside of a hospital setting over an estimated 5,580 person days.

Around two-thirds of clients recorded use of hospital services in the 6 months prior to entering DRAH. Sixteen clients contributed to a total of 31 hospital admissions in the pre-entry period. Forty-eight per cent of clients recorded unplanned or urgent hospital admissions and collectively accumulated 183 unplanned patient days over approximately 2,700 person days. Individually, they recorded between 3 and 29 days in hospital for unplanned admissions in the 6-month period.

Some of the admissions were directly associated with dementia or other cause of cognitive impairment such as delirium or dementia-related psychosis. Three clients recorded these types of admissions to hospital prior to entering DRAH (six admissions in total).

Altogether, conditions recorded as occasioning admission to hospital prior to entry to DRAH were either dementia-related or unrelated medical conditions:

- dementia
- delirium
- influenza and pneumonia
- acute upper respiratory tract infection
- osteoporosis
- fracture of the wrist
- dizziness
- nausea and vomiting

- pain
- diseases of the intestinal tract and other diseases of the digestive system
- heart disease
- hypertension
- other diseases of the circulatory system
- psychoses and depression/mood affective disorders.

That only three evaluation clients had been hospitalised for dementia or delirium suggests that DRAH has been helping people with dementia to avoid hospitalisation where possible, because given the lack of alternative means of accessing specialist services in the region it is likely that more of the high needs clients would have sought assistance from a hospital for dementia-related conditions.

Prior to entering DRAH, seven clients recorded a fall with injury, four clients were rendered immobile and without assistance for more than 30 minutes, and 11 clients suffered another serious medical emergency. Thus, DRAH services a client group in which a significant proportion of people are at increased risk of hospitalisation if assistance and monitoring at home is not available.

2.3 Client assessment results

Cognitive function

The MMSE scores recorded for clients when they entered DRAH range from a minimum of 6 to 28 points out of a possible 30 points (mean 19.9). Twelve clients scored around or below 16 points (Table B2.14).

Table B2.14: Dementia Rehabilitation At Home, number of clients by MMSE score at entry

MMSE score	Number of clients
1–15	5
16–18	7
19–24	12
25–30	6
Missing	1
Total	**31**

Cut-points to account for educational attainment were applied to the raw scores (Uhlmann & Larson 1991), indicating that 17 out of 30 clients showed probable cognitive impairment at date of entry to DRAH.

Of the 13 clients with a score that does not indicate cognitive impairment at baseline, three showed probable cognitive impairment at their final assessment. On the basis of recorded MMSE scores, it can be concluded that the DRAH is targeting a mixed group of clients, some of whom exhibited probable cognitive impairment on entry to the project, as might be expected for a project that targets people in need of assessment and diagnosis. All but five

clients are reported as displaying behavioural symptoms at entry to the project (see Figure B2.3).

Activities of daily living

At least half of the clients needed assistance in tasks involving self-care and mobility (Figure B2.1). The MBI was used to record levels of ADL function on entry. Scores ranged from 6 to 20 out of a total 20 points. The mean score was 15.3 points, indicating that the middle of the MBI distribution for DRAH clients was in the range of moderate dependency in ADL (Table B2.15).

Using a classification system for the Barthel Index (Shah et al. 1989), the results indicate that seven clients were severely dependent and 14 clients were moderately dependent in ADL at time of entry. Five of the evaluation clients were slightly dependent and five were independent in ADL.

Five clients were sometimes or always doubly incontinent. Nineteen clients were unable to bathe or shower without assistance and 13 clients needed assistance to use the toilet. Twenty-six clients were able to walk independently and one was independently mobile with the use of a wheelchair. Around one-third of clients needed help in the areas of feeding and transfers, and around half of the clients needed assistance in grooming and dressing (Figure B2.1).

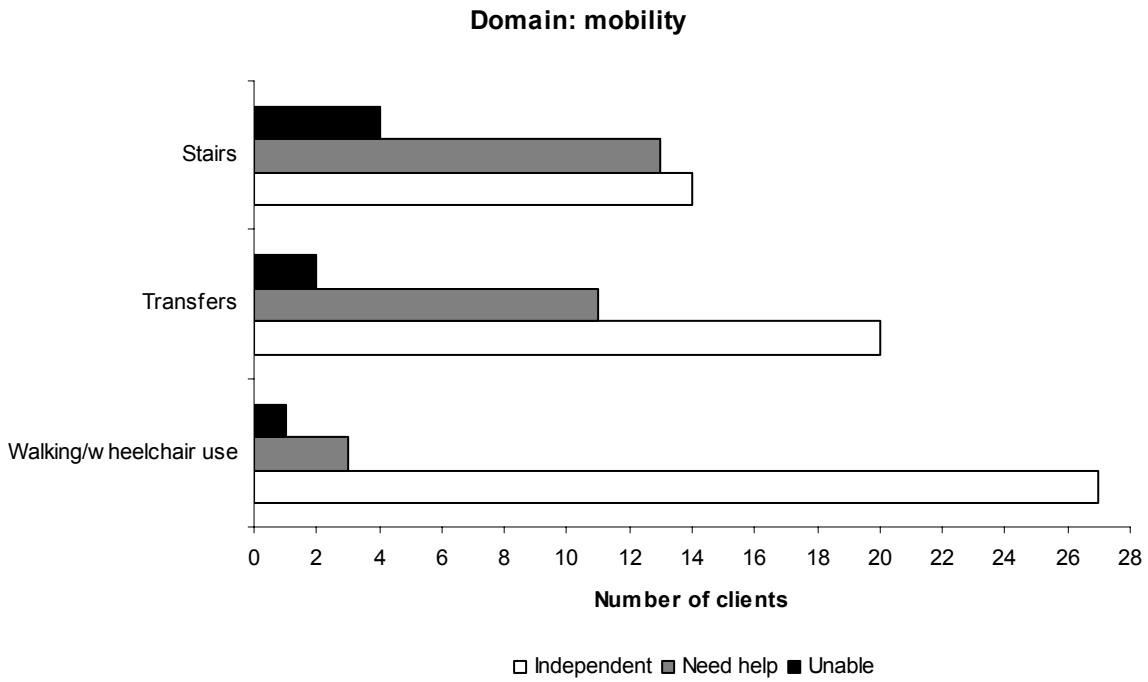
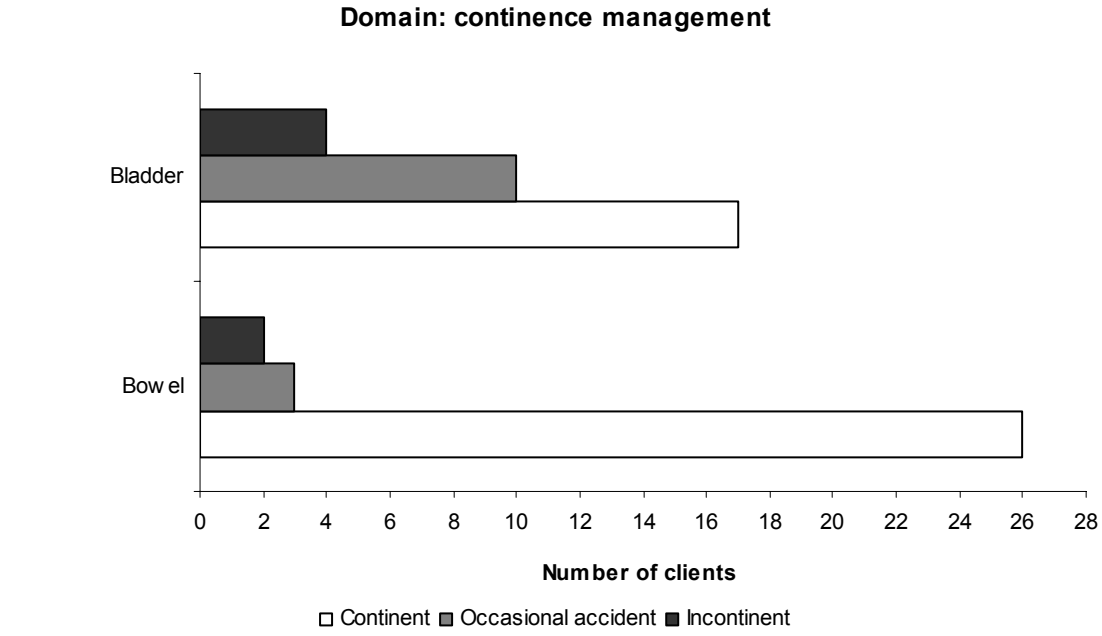
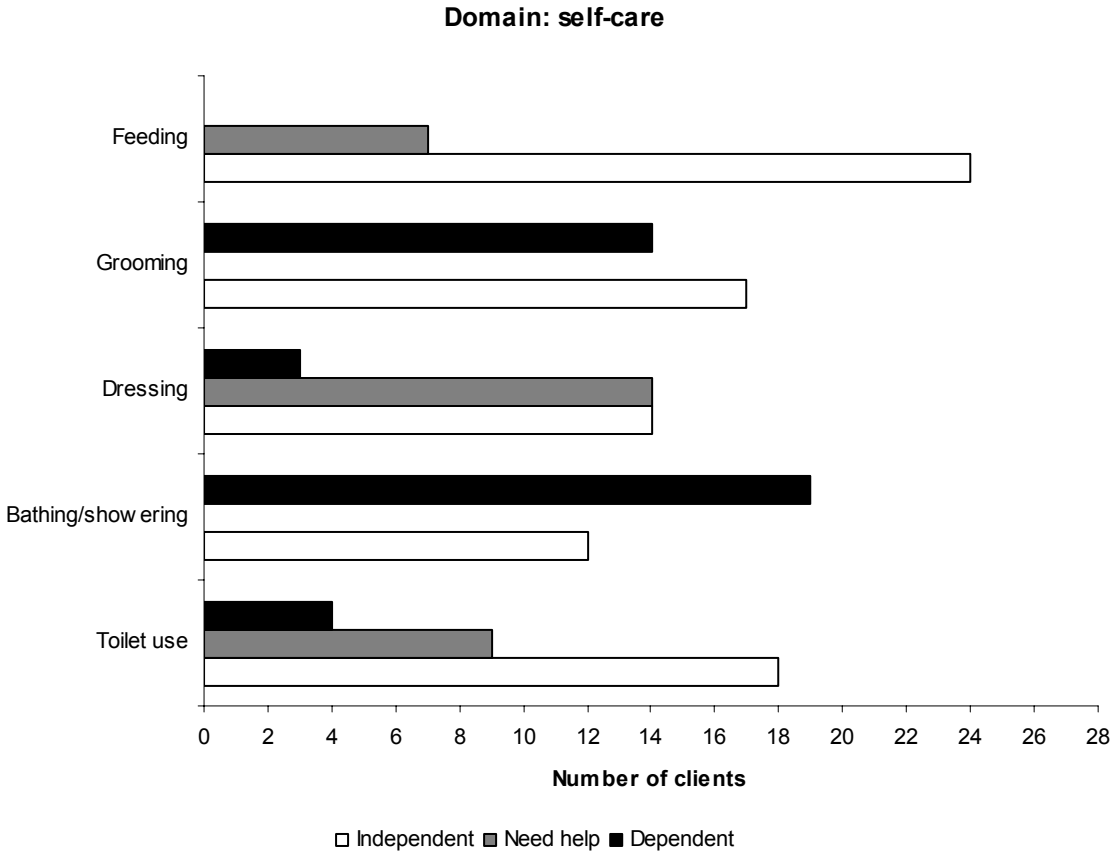


Figure B2.1: Dementia Rehabilitation at Home, number of clients by level of ADL function at entry to DRAH

(continued)



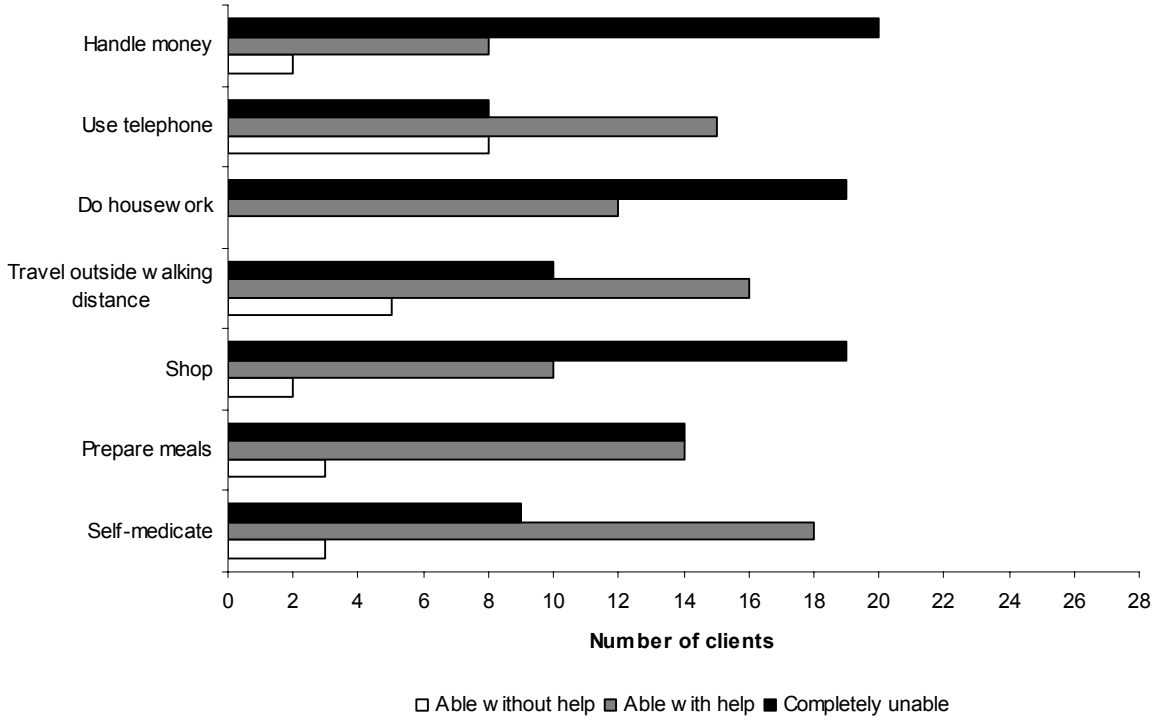


Source: Appendix Table B9.

Figure B2.1 continued: Dementia Rehabilitation at Home, number of clients by level of ADL function at entry to DRAH

The median baseline IADL score was 3 points, with scores ranging from zero to 12 out of a possible maximum of 14 points. Baseline results indicate that all DRAH clients had lost some IADL function by the time they joined the project.

DRAH clients were completely dependent in between zero and seven of the seven IADL at the time of entry (Figure B2.2). Three clients were unable to perform tasks in any of the seven IADL. Although 26 clients registered as being able to walk or use a wheelchair independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all but five cases, independent mobility was limited to the home environment.



Source: Appendix Table B10.

Figure B2.2: Dementia Rehabilitation at Home, number of clients by level of IADL function as at entry

Final assessments were conducted on average 77 days after entry.

Changes in the ADL scores between baseline and final assessments ranged from –7 (a 7-point decline in function) to 7 points (a 7-point improvement in function). The median change score was zero (Table B2.15), that is, on average the level of functioning in ADL was the same at baseline and final assessments. Of the 16 clients with a non-zero change score, nine changed to a different level of dependency, representing a mixture of cases of deterioration and improvement in ADL functioning.

The median IADL change score (between baseline and final assessments) was zero, with variation within the range of –7 to 3 points (Table B2.15). Thirty-three per cent of clients registered a decrease in IADL function between baseline and final assessments.

Table B2.15: Dementia Rehabilitation at Home, summary measures for ADL and IADL baseline[a] and change scores[b]

	Count	Minimum	Median	Maximum	Mean	Standard deviation
ADL						
Baseline MBI	27	6	15	20	14.7	4.0
Change in MBI	27	–7	0	7	0.4	3.2
IADL						
Baseline IADL	27	0	3	12	4.2	3.4
Change in IADL	27	–7	0	3	–0.5	2.0

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Of the 26 clients with baseline behaviour measures, 21 showed signs of memory loss on an intermittent or extensive basis (Figure B2.3). Seventeen clients showed intermittent or extensive signs of emotional or psychological symptoms of dementia. Seven clients were reported at time of entry to the DRAH to be sometimes physically aggressive. Four clients wandered or displayed intrusive behaviour and nine were verbally disruptive on an intermittent or extensive basis. Eleven clients were a danger to themselves or others either intermittently or extensively. Around half of the clients exhibited other unspecified types of behaviour, either intermittently or extensively, and four clients exhibited three or more psychological and behavioural symptoms on an extensive basis.

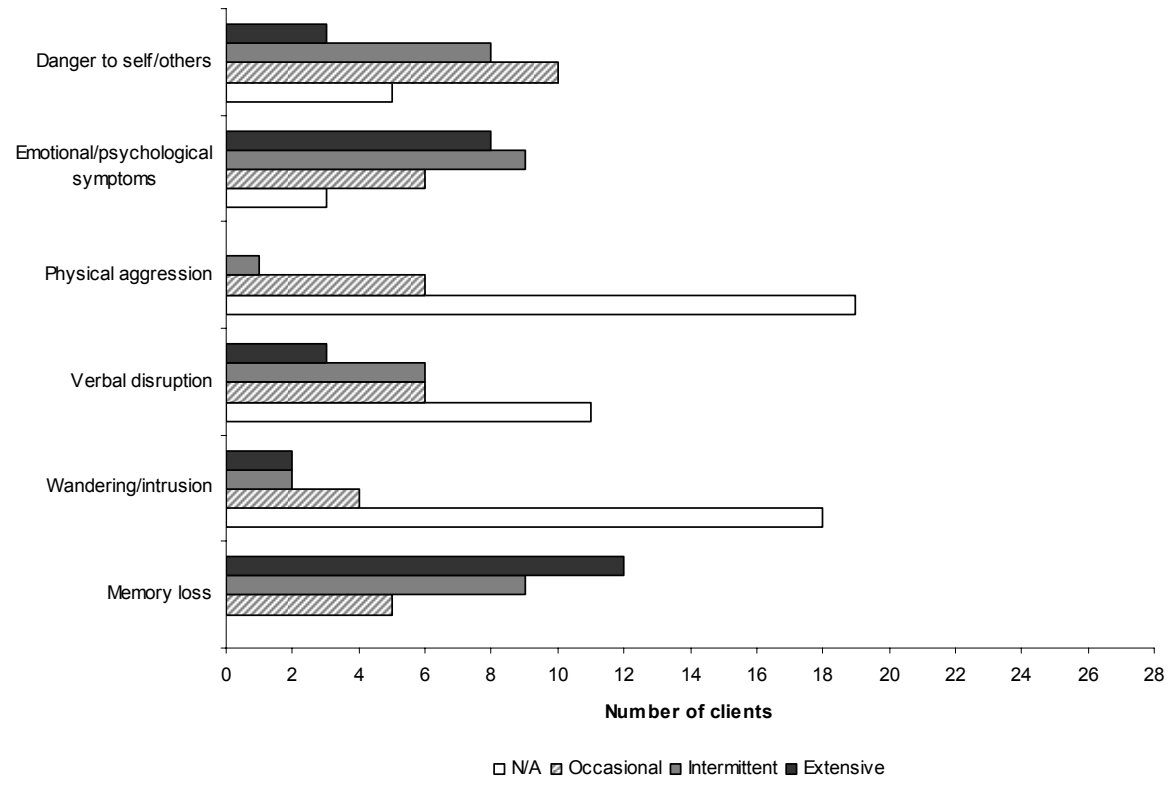


Figure B2.3: Dementia Rehabilitation at Home, number of clients by frequency of psychological and behavioural symptoms at entry

Other assessments

DRAH provided results of additional assessments for six to eight clients in addition to standard evaluation assessments. These data are summarised below.

Geriatric Depression Scale

The Geriatric Depression Scale is a 30-item questionnaire used to measure depression in older people, including those who are medically ill or mildly to moderately cognitively impaired. The scale has been used extensively in community, acute and long-term care settings (Kurlowicz 1999). Scores between zero and 9 points are considered normal, scores between 10 and 19 points indicate mild depression, and scores of 20 to 30 points indicate severe depression (Yesavage et al. 1983).

DRAH provided Geriatric Depression Scale scores for eight clients at entry. Seven of these clients scored within the normal range; three clients scored zero out of a possible 30 points and four clients scored between 1 and 6 points. One client scored 38 points (above the maximum allowable on the scale). This client was also recorded as having a diagnosis of depression on entry to the project. This client scored 14 out of 30 at the final assessment, which indicates mild depression at that time. The scores were not recorded for any other client at the final assessment.

Clock-face drawing test

The clock-face drawing test is a quick screening test for cognitive dysfunction secondary to dementia, delirium, or a range of neurological and psychiatric illnesses, to be used in conjunction with other tools and clinical assessment. There are numerous versions of the clock-face drawing test, all of which involve asking the patient to draw the face of a clock with the hands showing a particular time (Braunberger 2001).

A number of cognitive abilities, motor skills and perceptual functions are required simultaneously for a client to successfully draw a clock-face showing the appropriate time. These include orientation, conceptualisation of time, visual spatial organisation, memory and executive function, auditory comprehension, visual memory, motor programming, numerical knowledge, semantic instruction, inhibition of distracting stimuli, concentration and frustration tolerance. A well-drawn clock-face therefore suggests that a number of functions are intact and contributes to the weight of evidence that, for example, the patient's independent living skills may be intact. Abnormalities in the drawing may indicate potential problems warranting further investigation or resource allocation (Braunberger 2001).

There are a number of variations on scoring the clock-face drawing test. Most scoring systems are highly correlated with well-established measures including the MMSE, Dementia Rating Scale and the Global Deterioration Scale. DRAH scored the test using the Sunderland method, which allocates the client a single score from zero to 10 based on the completeness and accuracy of the drawing (Sunderland et al. 1983). This scoring method is not diagnostic (that is, the score cannot be used to establish whether or to what extent a client is cognitively impaired), but results can inform the overall clinical assessment of the client.

Sunderland scores were provided for six clients at baseline. One client scored zero out of 10 points, indicating that no attempt was made to complete the task. This client had a baseline MMSE score of 17 points. Five clients scored between 6 and 9 points, producing a clock-face with circle and numbers generally intact.

Sunderland scores were provided for eight clients at the final assessment (none of these clients had scores recorded at baseline). Four clients scored between 2 and 5 points, indicating that their drawings did not contain an intact circle and numbers. Three clients scored between 6 and 8 points, producing a clock-face with circle and numbers generally intact. One client did not make a recognisable attempt to complete the test and scored zero points.

There was general agreement between MMSE scores and scores derived from the clock-face test in all but two cases. One client recorded a baseline MMSE score of 27 but was unable to complete the clock-face test, scoring zero points. One client produced a clock-face with circle and numbers mostly intact at the final assessment but scored only 3 points on the MMSE.

Confusion Assessment Method

The Confusion Assessment Method is an assessment instrument that screens for overall cognitive impairment and distinguishes delirium or reversible confusion from other types of cognitive impairment (Waszynski 2001). DRAH conducted the test for seven clients at baseline and one client at final assessment. All clients scored zero points, meaning no signs of confusion or delirium were recorded during the assessments.

Nutritional Risk Screening and Monitoring Tool

The Nutritional Risk Screening and Monitoring Tool was developed by the Victorian Department of Human Services Home and Community Care Program as a method of screening older and vulnerable adults for nutritional risk and to identify the factors contributing to nutritional risk to inform care planning and intervention. Clients' height, weight and body mass index are recorded and a 10-item risk tool is used to generate a score of between zero and 10 points. If nutritional risk is identified (that is, the client scores 1 or above), a general needs assessment covering 23 factors which may contribute to nutritional risk is conducted. Results are used to inform care planning (VDHSHACC 2001).

DRAH provided nutritional risk scores for six clients at baseline. No nutritional risk was identified for four of these clients (scores of zero out of 10); two clients were identified to be at some nutritional risk (scores of 2 out of 10 and 3 out of 10). One client was assessed using the tool at the final assessment only, and scored 7 out of 10 suggesting nutritional risk which would be addressed in the client's care plan.

2.4 Carer assessment results

Eight out of the 26 carers reported that they were in very good or good health. Seven carers said they were in fair health and four reported poor health. Responses were not recorded for the remaining seven carers who took part in baseline assessments.

Twenty-three carers completed the CSI on entry to the DRAH, generating a mean score of 6.3 (median 6) with a standard deviation of 2.8 points. Scores ranged from 1 to 11 out of 13 points. Twelve carers recorded scores above the threshold for carer strain of 7 points.

Eighteen carers completed the CSI at the final assessment. Changes in the CSI between baseline and final assessments ranged from –8 (an 8-point reduction in carer strain), to 4 points (a 4-point increase in carer strain). The median change score was –1.0.

Of the 18 carers who completed both baseline and final assessments, eight scored over the threshold of high carer strain at baseline. Five of these clients recorded a lower CSI score at the final assessment that was sufficiently lower to no longer be considered as experiencing carer strain at that time; the other three carers continued to report high carer strain at the final assessment. One client who was below the threshold for high strain at baseline had exceeded the threshold by final assessment.

DRAH did not administer the GHQ-28 to carers on the basis that the instrument would cause undesirable response burden.

2.5 Service profile

DRAH combines multidisciplinary assessment and ongoing review (including medication review and allied health care) with in-home ADL support, respite care and other forms of carer support. The project service profile thus includes a long list of service types covering those of a clinical nature and others of a community service nature (Table B2.16). 'Multidisciplinary clinical work-up' includes ACAT assessment time and all specialist assessment and diagnostic activity that emanates from ACAT assessment. The case management capability of ACAT under the DRAH service model means that high ACAT involvement continues throughout the DRAH episode of care, as the ACAT is the central

point of coordination of other health care providers involved in client care for example, geriatrician, psycho-geriatrician, general practitioner and allied health professionals.

On the community services side, Clarence Valley Council delivers in-home ADL support, transport and respite care. This project reported relatively high levels of transport and respite care hours per week.

Table B2.16: DRAH summary of services, average number of service units per client per week
Results for period 14 June – 29 November 2004

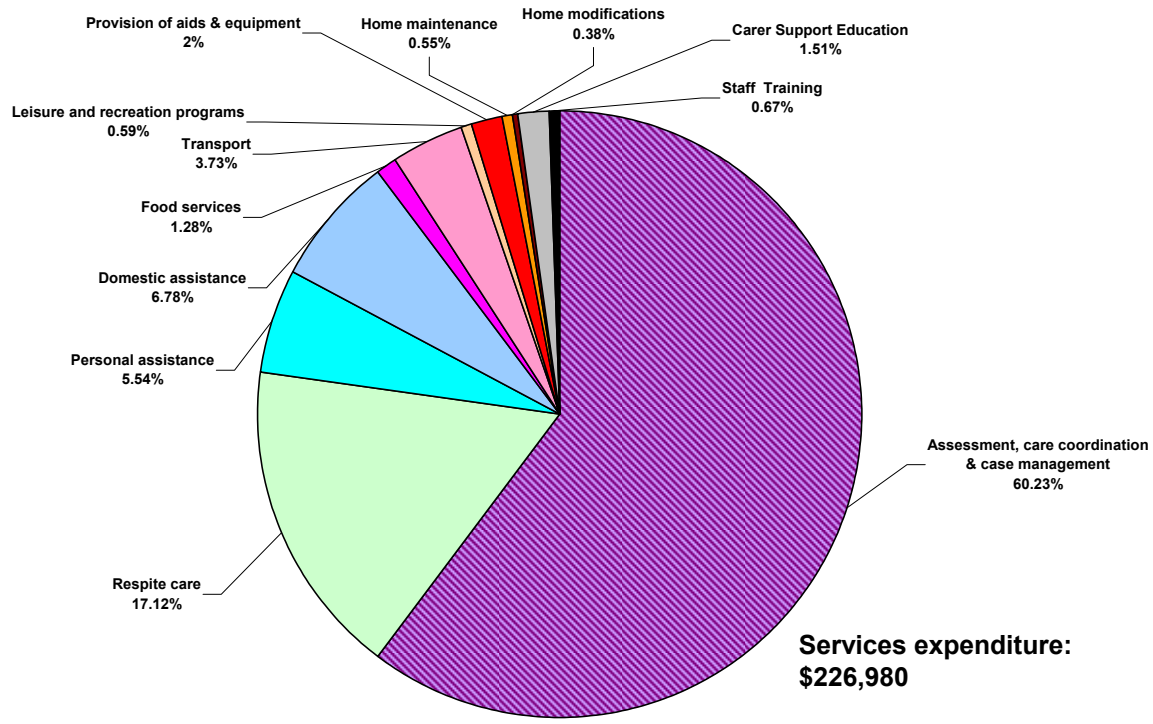
Service type	Service unit	Clients	Minimum	Median	Maximum	Mean	Standard deviation
Multidisciplinary clinical work-up	Hours	31	0.1	1.8	4.2	1.9	0.9
Domestic assistance	Hours	24	0.0	0.8	9.0	2.2	2.9
Allied health[(a)]	Hours	24	0.1	0.3	1.3	0.3	0.3
Respite (in-home and day)[(b)]	Hours	24	0.5	7.4	19.7	7.6	4.5
Personal assistance	Hours	19	0.1	1.3	6.4	1.7	1.6
Social support	Hours	17	0.1	1.3	6.6	1.8	2.0
Food service other	Hours	14	0.1	0.4	2.9	0.7	0.8
Nursing care	Hours	9	0.0	0.4	0.8	0.3	0.2
Linen service	No. of deliveries	2	1.3	1.4	1.4	1.4	0.1
Home modifications and maintenance combined	Dollars	9	6.4	42.9	149.4	64.6	52.4
Aids and equipment	Dollars	7	10.0	35.0	47.3	26.8	15.5
Follow-up needs assessment	No. contacts	31	0.4	1.5	4.7	1.7	1.1
Dementia care, memory and behaviour management	No. contacts	24	0.2	1.1	6.4	1.9	1.7
Geriatrician	No. contacts	20	0.1	0.1	0.3	0.2	0.1
Nursing/medical other	No. contacts	5	0.1	0.2	0.5	0.2	0.2
GP consultation	No. contacts	2	0.4	0.6	0.7	0.6	0.2
Overnight respite	No. days/nights	2	0.3	2.5	4.6	2.5	3.0
Recreation/leisure programs	No. days/nights	1	1.2	1.2	1.2	1.2	—
Carer support other than respite	No. events	26	0.1	0.4	3.0	0.6	0.7
Medication review	No. events	25	0.1	0.2	0.6	0.2	0.2
Information advice and referral	No. events	19	0.1	0.3	2.8	0.5	0.6
Allied health other	No. events	7	0.1	0.2	1.6	0.4	0.5
Personal other	No. events	1	0.2	0.2	0.2	0.2	.
Delivered meals	No. meals	9	0.1	1.0	8.1	1.8	2.5
Community transport	No. one-way trips	23	0.5	1.8	10.2	2.2	2.2
Dietetics	No. referrals	3	0.1	0.1	0.2	0.1	0.1

(a) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

(b) Assumes one-day respite equivalent to 5 hours.

— Nil.

Figure B2.4 gives a breakdown of direct care expenditure in DRAH between 1 July and 31 December 2004. The high clinical work-up component of DRAH means that 'Assessment, care coordination and case management' includes all of the clinical activity involved in referral to medical and nursing specialists, case conferencing and review, which is different to assessment and case management in most other projects. In the six months from 1 July to 31 December 2004, DRAH salaries expenditure included $87,926.98 for clinical case management (38% of salaries bill). The 'wedge' representing expenditure on assessment, care coordination and case management in Figure B2.4 is exploded in Figure B2.5 by clinical department. Nursing and allied health assessment and work-up and counselling services constitute a significant portion of expenditure on assessment, care coordination and case management. Clinical service delivery in DRAH was discussed in section 2.1 (Service model).



Source: Appendix Table B25.

Figure B2.4: Dementia Rehabilitation At Home, expenditure on services, 1 July–31 December 2004

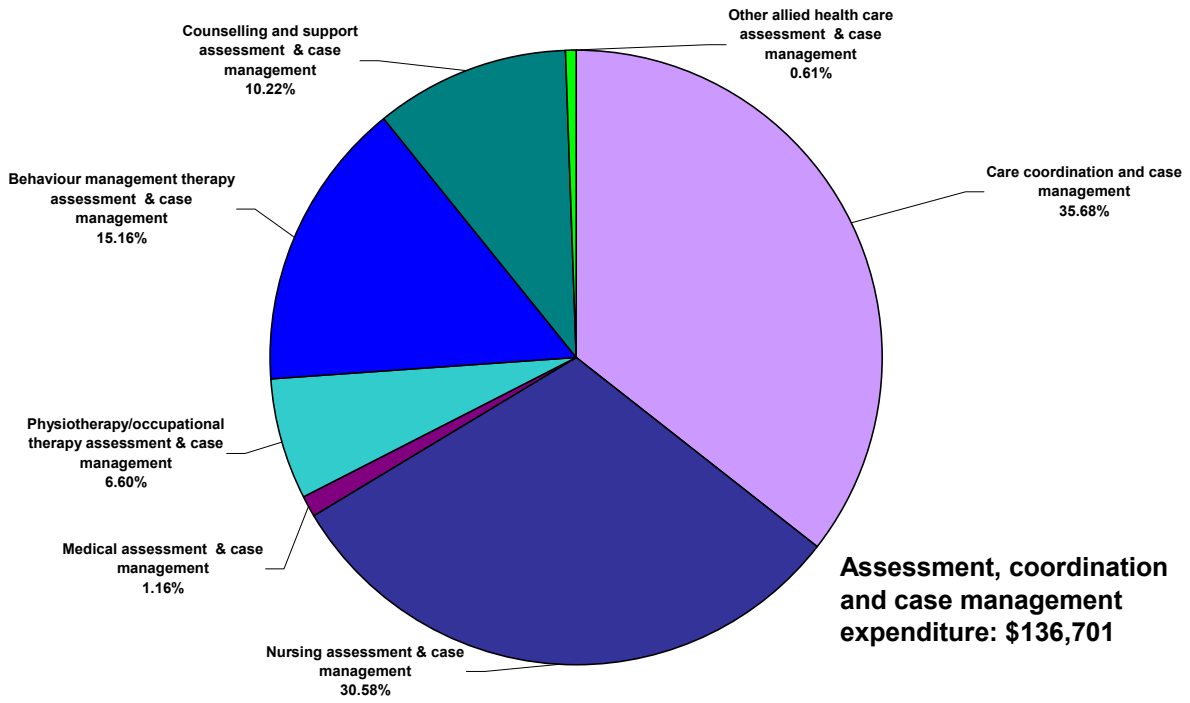


Figure B2.5: Dementia Rehabilitation At Home, expenditure on assessment, coordination and case management by activity type, 1 July–31 December 2004

2.6 Accommodation outcomes

Twenty-eight clients were discharged from DRAH during the evaluation. Two clients were discharged to high level residential aged care and one client was discharged to hospital (Table B2.17). The project indicated that an EACH package was the preferred discharge destination of one client who had entered an aged care facility (see Table B2.3). The remaining 25 clients who had completed their DRAH episode were at home following discharge from the project. Two clients continued with a DRAH maintenance plan because there was no appropriate program support available at the time of discharge.

The most common form of government program support for clients in the community on discharge from DRAH was CACP (seven clients), followed by HACC (five clients) and multiple program support, for example, HACC and Day Therapy Centre services or Veterans' Home Care plus HACC.

Five clients who were discharged during the evaluation had been in the project for over 100 days (112–142 days). During the AIHW site visit, project staff reported that difficulty in making suitable discharge support arrangements could result in clients remaining in the project for longer than the planned maximum length of stay of approximately 90 days.

Table B2.17: Dementia Rehabilitation at Home client discharge destination, number of clients by government program support on discharge and length of stay

Discharge destination/status	No. of clients	Length of stay (min – max days)
At home		
Without government program support	3	51–137
Community Aged Care Packages	7	39–142
Home and Community Care	5	55–112
Veterans' Home Care	1	44
National Respite for Carers Program	2	58–90
Multiple programs	5	64–91
Total discharged	*23*	*39–142*
DRAH maintenance—unable to discharge	2	88–90
Total at home	*25*	*39–142*
In care		
Hospital	1	87
Residential aged care—high	2	88–90
Total in care	*3*	*88–90*
Total	**28**	**39–142**

DRAH completed a follow-up of evaluation clients between 14 February and 27 April 2005. Table B2.18 shows the accommodation setting and government program support for all clients at follow-up, that is, approximately 11 months from the start of the evaluation period.

Between the end of the evaluation and the conclusion of follow-up, 15 community-dwelling clients had changed their formal support arrangements. Two clients who were discharged with no government program support and one client whose program support was unknown at discharge were receiving HACC services, and one client whose program support was unknown had begun HACC and NRCP services. One client who was discharged with no government program support and another whose program support was unknown at discharge were receiving a CACP. Two clients who were discharged onto CACPs were receiving HACC services in addition to the CACP. One HACC client transferred to a CACP, and one NRCP client began receiving HACC services in addition. Four clients receiving services from multiple sources at discharge were receiving HACC services only at the time of follow-up.

Table B2.18: Dementia Rehabilitation at Home, number of clients by accommodation setting and government program support at follow-up, April 2005

Location at follow-up	No. of clients
At home	
Without government program support	3
Home and Community Care[(a)]	10
Veterans' Home Care[(a)]	1
Community Aged Care Packages[(a)]	6
Multiple programs[(a)]	5
Not stated	1
Total at home	*26*
In care	
Residential aged care–high	3
Total in care	*3*
Deceased	1
Not located at follow-up	1
Total	**31**

(a) Clients on multiple program support included two clients on CACP plus HACC;
two clients on HACC plus NRCP;
one client on VHC plus Day Therapy Centre.

These results are indications of the instability of support arrangements following discharge which helps to confirm the advice of project staff that discharge outcomes were not always ideal. However, 84% of evaluation clients were still living in the community at the time of follow-up.

3 Flexible Care Service

3.1 Project description

annecto – the people network received an allocation of 20 flexible care places to operate a 2-year pilot project called Flexible Care Service (FCS). FCS provides home-based care of a finite term with an intended average length of stay of around 12 weeks. The project operates from offices in Canterbury, Melbourne, to service the eastern metropolitan region.

annecto is an established service provider for the CACP and HACC programs and the National Respite for Carers Program. Job Connections and the Supported Accommodation Assistance Program also fund *annecto* to deliver community services. Prior to its renaming to *annecto*, WiN Support Services had been providing community care for over 20 years and was operating in four metropolitan and two rural regions of Victoria. *annecto* (and formerly WiN Support Services) ordinarily provides case management and care coordination for people with complex care needs, including those with dementia and dementia-related behaviours.

The organisation delivers dementia-specific respite care services with funding from the Australian Government; the establishment of Flexible Care Service was a logical extension of these services using existing expertise and infrastructure.

Project objectives

Flexible Care Service aims to:

- provide a range of community service options for older people with dementia and/or dementia-related behaviours, to help improve functioning and stabilise behaviour
- increase the number of people with dementia and an Aged Care Assessment Service (ACAS)[8] approval for high level care who are able to remain in their own homes
- enable clients to remain at home wherever possible, or to enter residential aged care from the project with a higher level of functioning and independence than would otherwise have been possible
- test the effectiveness and efficiency of innovative service funding to provide short-term dementia care in the home.

This project, originally proposed as a long-term dementia care program, was implemented as a short-term intervention at the suggestion of the State Office of the Australian Department of Health and Ageing.

8 Aged Care Assessment Service is equivalent to Aged Care Assessment Team in other jurisdictions.

Target group

The target group is people living in the community with dementia-related high care needs. Acceptance into the project requires ACAS approval for residential high care. Prior to the launch of FCS, *annecto* targeted mainly people with low level care needs. FCS is therefore targeting a substantially different group from *annecto's* traditional clientele. It was originally envisaged to target people who present with high care needs but who have not previously used formal services in order to link them into the formal service network. Identifying people with no or minimal established services proved difficult and the project has found that the majority of people accepted into FCS have been using council HACC services at the least.

All FCS evaluation clients were referred from the community and remained in a private residence for the period of FCS service. FCS requires all care recipients to have a family carer.

The Department of Health and Ageing State Office directed *annecto* to develop clear selection criteria with a view to achieving good client outcomes. For example, the project needs to determine whether a potential client is seeking nursing home placement. If a placement is offered shortly after a client starts in the project, the client and family needs to make an immediate and significant decision on long-term care. Given the shortage of nursing home beds, people often feel that there is little alternative than to accept an offer of placement. For this reason, a person/family who is actively seeking placement would not normally be accepted into FCS.

Referrals have been sourced mainly from ACAS (the Peter James and Outer East ACAS accept referrals in the FCS service area). ACAS indicated that the types of clients referred to the project would otherwise be referred as a client in urgent need of a CACP, mainly because there are rarely vacant Linkages packages in the area. For this type of client, the ACAS often takes on a case management role that is outside the scope of its brief. Some community service providers have been observed to 'give up' on high care clients with very complex needs, leaving ACAS to pick up the pieces (although some day care centres offer quasi-case management, which provides valuable relief to the ACAS).

After receiving a referral from ACAS and checking that the client is approved for residential high care and high level respite care, the FCS coordinator initiates contact via a telephone screening assessment.

The needs of people in the target group are perhaps less likely to be temporary compared to client needs targeted by a post-acute/sub-acute service model. Approximately 75% of FCS care recipients have required personal care for continence management. Emotional and psychological symptoms of dementia and resistance to formal services are observed in many care recipients. People referred to FCS can be characterised as having experienced a crisis in care, as opposed to a recent medical event or recent diagnosis of dementia. FCS clients tend to have moderate to severe dementia and are at the point of no longer having access to care at home as a result of carer death, illness or burnout.

Implementation of a short-term intervention model for people with long-term high care needs has presented certain difficulties.

Entry criteria

Initial screening of referrals makes an assessment against the following criteria:

- ACAS approval for residential high care for a client with dementia

- there is a family or friend carer who makes daily contact with the client (there is no requirement for the carer to reside with the FCS client)
- the client is not on a waiting list for an EACH package (department State Office advice)
- the client is unlikely to require more than 2 weeks of respite care or acute care during the FCS service episode (department State Office advice)
- no palliative clients.

Service model

FCS is a full brokerage model. If a client has community services in place, such as a council HACC service, the aim is to leave these arrangements in place by taking over the funding and providing supplementary services to meet the assessed level of need.

Respite care is viewed as a core service for the target group, reflecting a primary aim of reducing levels of carer strain, stabilising care environments and introducing appropriate ongoing supports. Personal and domestic assistance services are other key features of the service model.

Care recipients have access to *annecto*'s Support Emergency After Hours Response Service (EARS). EARS is unique in Victoria and is available to clients of all *annecto* programs as well as being brokered by other agencies.[9] Clients/carers may not need to access EARS during their time in the project but knowing it is available increases confidence that support is available at any future time of need when no other help can be found.

Achievements, challenges and lessons

FCS has demonstrated considerable success in working with one of the higher needs groups in the Innovative Pool Dementia Pilot, despite a number of operational difficulties.

At time of follow-up, 50% of evaluation clients accepted into the project between June and October 2004 were found to be at home with support from government programs (25% deceased and 25% in high level residential care). A survey conducted by *annecto* in November–December 2004 of care recipients who had moved through the project between November 2003 and July 2004 revealed that approximately 47% had entered residential high care. The remaining people were at home (33%) or deceased (19%).

There is evidence that longer term outcomes in FCS have as much or more to do with services received after discharge as with the impact of FCS service. Evaluation clients discharged onto an EACH package were still at home with an EACH service at time of follow-up. Clients discharged to a HACC service were less likely to be at home with a HACC service at follow-up. A number of clients were discharged from FCS with support from multiple programs. This solution to a lack of high care community options appears to maintain people at home over the medium term but may not represent an efficient allocation of services that are perhaps better targeted at people with lower care needs. The number of people in each category is too small to report meaningful percentages; however, the trends are apparent and are consistent with the observations of FCS care managers.

---

9 For example, EARS is available to clients in the other Victorian Innovative Pool dementia project, North East Dementia Innovations Demonstration at the Austin and Repatriation Medical Centre, under a purchaser–provider agreement.

An important contribution of the project has been the level of support given to carers, many of whom experience high levels of strain associated with the caring role. The project has acted as a source of referral for people in crisis. Nineteen of the 22 carers who completed a carer strain assessment on entry to the project exceeded the recognised threshold for carer strain. Eight carers experienced a reduction in carer strain during the FCS service episode and five carers above the threshold for high carer strain when they entered the project registered below the threshold by completion of the FCS episode. The mean change in carer strain score between two assessments, averaged over all carers, is –1.4 points that is, on average, the level of carer strain has reduced during FCS service episodes. While an association between reduced carer strain and FCS intervention is speculative, it is clear that around half of evaluation clients previously faced an elevated risk of admission to residential care because of excessive levels of carer strain. Moreover, the results suggest that for a proportion of dementia carers, a short-term intervention may be insufficient to reduce symptoms of strain to within coping capacity.

During the first 6 months of operation *annecto* found it difficult to meet the occupancy target of 20 clients with only one case manager to manage existing clients and assess and establish clients from new referrals. The appointment of a second case manager greatly improved matters and reduced the load on staff to a more manageable level. It is thought that a ratio of no less than one coordinator per 10 clients is required to work effectively with this target group.

The early days proved to be a learning experience. *annecto* revised the client selection protocol and the Department of Health and Ageing was receptive to changes made. Occupancy-based funding arrangements have proved to be the biggest hurdle for the project to overcome. Managing occupancy in a program of 8 to 12 weeks service intervention involves intensive case management. The project team likens its role to 'crisis management' because there is so little time to establish a client with complex care needs and their carer in the project before it is time to commence discharge planning. Discharge planning is usually a complicated exercise for the type of client accepted into the project. It is rarely possible to reach a stage of stabilised care needs within 8 weeks, yet this is necessary in order to reliably assess maintenance of effort prior to discharge.

Discharge planning was further complicated by the limited availability of appropriate discharge options. FCS coordinators see Extended Aged Care at Home (EACH) and HACC Linkages packages as the best forms of ongoing support for the majority of clients discharged from FCS. The department's State Office instructed *annecto* that referrals for people already on a waiting list for an EACH package should not be accepted on the rationale that this is consistent with the Innovative Pool Guidelines 2002–03 which state:

> Criteria should address the particular people within the broader target group who would be most likely to benefit from the proposed service and cannot access the care they require through other appropriate means.

Hence, the insertion of a clause in the Memorandum of Understanding between the department and *annecto* which states that the project is 'not intended to replace Extended Aged Care in the Home Packages (EACH) for those who are eligible for EACH'. It is not clear that an FCS package could substitute for an EACH package because of the time-limited nature of FCS. Moreover, there is a definite advantage in being able to offer time-limited service to people in crisis who, because of waiting lists for EACH packages, face an immediate risk of admission to permanent residential care.

It is overly optimistic to equate eligibility to mainstream high level community-based aged care services with timely access in areas where demand for such services currently exceeds

supply. Further, it seems illogical that a care recipient and their carer would enrol in an 8–12 week service if they were hopeful of being able to access an EACH package. Lengthy waiting lists for EACH packages proved to be a barrier to one potential effective discharge option and the said scarcity of Linkages packages ruled out the other most desirable option for many clients. The typical outcome following FCS was a long waiting period to achieve the best form of ongoing care during which time a significant proportion of clients accessed multiple program sources of funding, possibly with multiple service providers, to piece together something close to a high level care package.

Flexibility in the provision of respite care is a main objective of the project but FCS has encountered difficulty in accessing overnight respite services. If a client takes leave from the project to access residential respite care, *annecto* is unable to extend the client's stay beyond 12 weeks to make up the time. In some cases it has been possible to use a state government-funded Supported Residential Service to get around this problem but these services offer low level care and very limited access to registered nurses, which is not an ideal form of respite care for many people with severe dementia. Limited access to respite care is a major problem for the project because (a) respite care is a core component of the program that aims to reduce levels of carer stress and (b) many clients and carers have not used respite care before coming into the project and FCS offers an opportunity to introduce respite care services to help sustain the caring relationship over the longer term.

Reasons for rejecting referrals have mainly had to do with the entry criteria that exclude clients with ACAS approval for EACH; clients in hospital at time of referral; clients in permanent care; clients at risk at home; and case management not being required.

The project team is of the opinion that the FCS model does not lend itself to mainstreaming. It is thought that FCS services a specific target group that, at the time the project was established, was not adequately serviced by any other community service agency in the Eastern Metropolitan Region. Standard EACH packages are seen as unable to provide the required level of support to carers. Advanced dementia requires a unique program, which demands a level of expertise and flexibility that is not normally available through general package offerings. [The introduction of dementia-specific EACH packages was announced subsequent to these observations from the FCS team.]

annecto recommends that programs designed to meet the needs of older people with dementia should offer a flexible range of services tailored to meet the needs of the person with dementia and their carer. It is thought that dementia sufferers who are assessed at the high end of low level care should have access to this type of service to avoid the all too common scenario of a crisis marking the first contact that a client or carer has with a comprehensive case management service.

3.2 Client profiles

FCS supplied evaluation data for 24 clients, including eight men and 16 women. One client did not participate in functional assessments. Two care recipients who were active during the evaluation period opted not to take part in the evaluation.

Age and sex

The estimated mean age of FCS clients at the time of the evaluation was 80 years (ages of evaluation clients ranged from 69 years to 95 years). Four clients were aged 85 years or over (Table B3.1).

Table B3.1: Flexible Care Service, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
65–74	3	2	5
75–84	4	11	15
85+	1	3	4
Total	**8**	**16**	**24**
		(per cent)	
65–74	12.5	8.3	20.8
75–84	16.7	45.8	62.5
85+	4.2	12.5	16.7
Total	**33.3**	**66.7**	**100.0**

Language and communication

Five clients had little or no effective means of communication. Seven national languages are represented in this client group (Table B3.2).

Table B3.2: Flexible Care Service, number of clients by language spoken at home and English proficiency

	How well does client communicate in English?			
Language spoken at home	Very well or well	Not well	Not at all	Total
English	12	3	—	15
Southern European[(a)]	1	3	2	6
Eastern European[(b)]	1	1	—	2
Japanese	—	—	1	1
Total	**14**	**7**	**3**	**24**

(a) Includes Italian, French and Spanish.

(b) Includes Hungarian and Serbian.

— Nil.

Accommodation and living arrangement

All clients were living in their usual place of residence (private residence) at time of referral. Years at usual residence ranged from less than one to 56 years. Seven clients had been living in the same home for over 40 years.

Carer availability

Carer availability is a requirement of the project; all evaluation clients had a co-resident carer (Table B3.3). Carers' ages ranged from 42 to 87 years, averaging 69.7 years. Thirteen carers were aged 75 years or over (Table B3.4).

Table B3.3: Flexible Care Service, number of clients by carer availability, carer relationship to client and co-residency status

Relationship of carer to client	Carer lives with client	Total
Spouse or partner	16	16
Son or daughter	5	5
Other relative	2	2
Friend or neighbour	1	1
Total clients with a carer	*24*	*24*
Clients without a carer		—
Total clients		**24**
Per cent of clients with a carer		100.0

— Nil.

Table B3.4: Flexible Care Service, number of carers by age group and sex

Age (years)	Males	Females	Persons
25–44	1	—	1
45–54	1	3	4
55–64	1	—	1
65–74	—	5	5
75–84	10	2	12
85+	1	—	1
Total	**14**	**10**	**24**

— Nil.

Income and concession status

Government pensions were the primary source of cash income for 19 clients (Table B3.5). Twenty clients held a health care concession card. FCS does not charge client fees in the belief that Australian Government flexible care subsidy covers costs and for a short-term intervention the overhead of administering client payments would be unsustainable. A co-payment would most likely be levied if FCS operated as a long-term program.

Table B3.5: Flexible Care Service, number of clients by principal source of cash income and health care concession card status

	No. of clients	Per cent
Principal source of cash income		
Age pension	19	79.1
Superannuation	2	8.3
Other income	1	4.2
Nil income	1	4.2
Not stated	1	4.2
Total	**24**	**100.0**
Health care concession card holder	20	83.3
Project concession status	N/A	N/A

Previous use of government community care programs

Twelve clients were not receiving assistance from government community care programs before FCS (Table B3.6). Six clients were receiving HACC-funded assistance prior to joining FCS.

Fourteen carers reported that, despite having had a need for respite care in the 12 months prior to FCS, they had not used a respite care service. Of the carers who had accessed any form of respite in the previous 12 months, four out of five had used mainly residential respite. Five carers stated that they did not need to access respite services in the 12 months prior to entering the project.

Table B3.6: Flexible Care Service, number of clients by use of government support programs prior to FCS

Previous use of government programs	No. of clients	Per cent
Government support program		
Home and Community Care	6	26.1
National Respite for Carers Program	2	8.7
Day Therapy Centre	1	4.4
Multiple (NRCP & DTC)	1	4.4
Other program	1	4.4
Not stated	1	4.4
Total clients with previous government support	*12*	*50.0*
Clients without previous government program support	12	50.0
Total	**24**	**100**

Twenty-two clients were not on a waiting list for residential aged care when they entered the FCS, and the waiting list status on entry of the remaining two clients is unknown.

Assessment and referral

Twenty-one clients had completed an ACAT assessment on the same day or prior to referral to the FCS. For these clients, the time between completion of an assessment and referral to the FCS varied up to 260 days (Table B3.7). ACAT assessment was completed after referral to the FCS for three clients. Four clients had had two ACAT assessments in the 12 months prior to entering the project.

Table B3.7: Flexible Care Service, number of clients by days between completion of ACAT assessment and date of referral to FCS

Completion date of ACAT assessment	No. of clients
Before referral to FCS	
0–20 days	11
21–30 days	3
31–60 days	2
61–90 days	2
91–120 days	1
181–365 days	2
Total	*21*
After referral to FCS	
1 and 5 days post-referral	3
Total	**24**

FCS receives most of its referrals from an ACAS (Table B3.8).

The care of FCS clients is managed by a social worker.

Table B3.8: Flexible Care Service, number of clients by source of referral

Referral source	No. of clients
Aged Care Assessment Service	15
Hospital	5
annecto (other programs)	1
Other health or community service	1
Other agency	1
Family	1
Total	**24**

FCS provided additional information regarding referrals for clients who could not be accepted into the project in the 6 months from June to December 2004, that is, referrals of clients who did not meet the eligibility criteria or who were otherwise deemed unsuitable for FCS (Table B3.9).

Table B3.9: Flexible Care Service, rejected referrals, June–December 2004

Reason for not accepting client	No. of clients
Client had valid EACH approval[(a)]	2
Client living in permanent care	2
Client in hospital at time of acceptance	1
Home environment unsafe/inappropriate for client	1
Client deceased before package available	1
Insufficient needs to warrant FCS package	1
Total	**8**

(a) FCS was instructed by the DoHA program manager that clients on the waiting list for an EACH package are not eligible for FCS services.

Source: Letter from FCS coordinator dated 18 January 2005.

Health conditions and health status on entry

The number of health conditions recorded for FCS clients ranges from one to eight. Eighteen of the 24 clients had three or more health conditions at entry. Dementia was the primary health condition for the majority of clients at the time of entry to FCS (Table B3.10).

Table B3.10: Flexible Care Service, number of clients by primary health condition

Primary health condition	No. of clients
Dementia (Includes Alzheimer's disease & other dementias)	21
Other disease[(a)]	3
Total	**24**

(a) Includes infections and parasitic diseases, heart disease and cerebrovascular disease.

Sixteen clients were assessed as being at risk of falls due to impaired gait or balance (Table B3.11).

Table B3.11: Flexible Care Service, number of clients by selected sensory, mental and physical conditions

Health condition	No. of clients
Impaired gait or balance—at risk of falls	16
Disorientation/confusion	3
Total or partial paralysis	1
Diagnosis of depression	1

The 24 clients with recorded medication use were taking between zero and 15 different types of medication. Twelve clients were taking four or more medications.

Carers were asked to report on client health status and change in health status over the 12 months prior to entry using a five-point Likert scale (Short-Form 36). Twenty-three carers reported on their care recipient's health status.

One client was reported to be in very good health; the remaining ratings were good (13 clients), fair (eight clients) and poor (one client). Thirteen carers said that the client's health was somewhat worse than a year earlier. Eight carers reported no change over the 12-month period and one carer reported that their care recipient's health was much worse than a year ago. One carer reported that their care recipient's health was much better than one year ago.

Level of core activity limitation

Most FCS clients experienced moderate to profound activity limitation in the area of self-care (20 clients) and mild to moderate activity limitation in the areas of mobility (18 clients) and communication (21 clients) (Table B3.12). FCS has recorded one of the higher rates of severe or profound limitation in self-care among the projects (38%).

Table B3.12: Flexible Care Service, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	4	11	9	**24**
Mobility	2	10	8	4	**24**
Communication	—	11	10	3	**24**

— Nil.

Use of medical and hospital services prior to entry

Use of medical and hospital services in the 6 months before starting with FCS was recorded for 23 clients. All but one of these clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner varied up to 20 per client. Cumulatively, the 22 clients recorded 143 visits to a medical practitioner outside of a hospital setting over an estimated 3,960 person days.

Ten clients had been admitted to hospital in the 6 months prior to entering the FCS. Information on hospital admissions and number of unplanned days in hospital is available for nine clients, who contributed to a total of 15 hospital admissions in the pre-entry period. All 10 clients reported unplanned admissions to hospital. Nine clients had also visited a hospital emergency department. These 10 clients collectively accumulated 151 unplanned patient days over approximately 1,620 person days. Individually, they recorded between one and 30 days in hospital for unplanned admissions. Thus, although FCS has not operated as a post-acute/sub-acute model, a proportion of FCS clients are high users of hospital services and hospital leave will often need to be managed in the project.

Conditions recorded as occasioning admission to hospital for FCS clients in the pre-entry period include:

- diseases of the urinary tract
- heart disease

- disease of the respiratory system
- fractures
- injuries to arm/hands/shoulder
- unspecified urinary incontinence.

Two clients had experienced a serious medical emergency in the 6 months before joining FCS, one of whom had a fall with injury and was rendered immobile and without assistance for more than 30 minutes. Both clients had spent at least 2weeks in a rehabilitation facility. Five other clients had experienced a fall with injury, two of whom were rendered immobile and without assistance for more than 30 minutes and spent 14 and 30 days respectively in a rehabilitation facility.

A fairly high proportion of FCS clients are thus at high risk of fall-related injury or medical emergency, hospitalisation and, therefore, admission to permanent care following an acute episode. Recovery from illness or injury may be complicated by dementia and may present special difficulties for family carers.

3.3 Client assessment results

Cognitive function

Baseline MMSE scores were recorded for 16 clients. Three further clients were unable to be assessed and five clients had MMSE scores recorded by the Outer East ACAS which did not make MMSE scores available to the evaluation. The 16 recorded scores range from a minimum of 2 to 24 out of a possible 30 points (mean 11.8).

Table B3.13: Flexible Care Service, number of clients by Mini-Mental State Examination score at entry

MMSE score	No. of clients
1–15	11
16–18	2
19–24	3
25–30	—
Missing	8
Total	**24**

— Nil.

Cut-points proposed by Uhlmann & Larson (1991) to account for educational attainment were applied to the scores, indicating that 14 clients who completed the test had probable cognitive impairment at date of entry. Two clients scored on the threshold of probable cognitive impairment.

On the basis of reported MMSE scores, FCS was found to be appropriately targeting people with moderate to severe cognitive impairment.

Activities of daily living

As at entry to the project, FCS clients present as one of the lowest functioning groups in the Innovative Pool Dementia Pilot.

MBI scores for 22 clients reveal that most clients either needed assistance or were completely dependent in self-care tasks (Figure B3.1). Baseline scores ranged from 2 to 17 out of a total 20 points. The mean score was 10.5 points with a standard deviation of 3.4 (median 11), indicating that the middle of the MBI distribution for FCS clients at the time of the evaluation was in the range of severe dependency in ADL (Table B3.14).

Using a classification for the Barthel Index (Shah et al. 1989), the MBI results indicate that three clients were completely dependent on entry, 18 clients exhibited severe dependency and three clients exhibited moderate dependency in ADL.

Seventeen of the 23 clients for whom the MBI is recorded were doubly incontinent. Most clients were unable to bathe or shower, groom, dress, feed or use the toilet without assistance. Most clients were independently mobile.

Most FCS clients showed high IADL dependency when they entered FCS (Figure B3.2). IADL scores were recorded for 23 clients, although data on one client are incomplete. On average, FCS clients were completely dependent in four out of seven IADL. One client was totally dependent in all seven IADL. No clients were able to perform household duties or manage their finances, even with assistance.

Although 18 clients registered as being able to walk independently, the mobility item on the IADL scale (travelling outside walking distance) reveals that in all cases, independent mobility was limited to the home environment. FCS clients were insufficiently mobile to get into or out of a car without assistance, and either incapable of using public transport or needed help to do so. The median baseline IADL score for the 20 clients with complete records was 3 points. Scores ranged from 1 to 4 out of a possible maximum of 14 points. Baseline results indicate that all FCS clients had lost a significant amount of IADL function before entering the project (Table B3.14).

Final assessments were conducted on average 73 days after entry.

Changes in the MBI between baseline and final assessments ranged from –6 (a 6-point decline in ADL function) to 2 points (a 2-point improvement). The median change was –1 point (Table B3.14), indicating that on average, level of functioning ADL dropped by 1 point between the baseline and final assessments. Of the clients with a non-zero change score, three clients changed level of ADL dependency: two clients moved from severe to total dependency and one client improved from severe to moderate dependency.

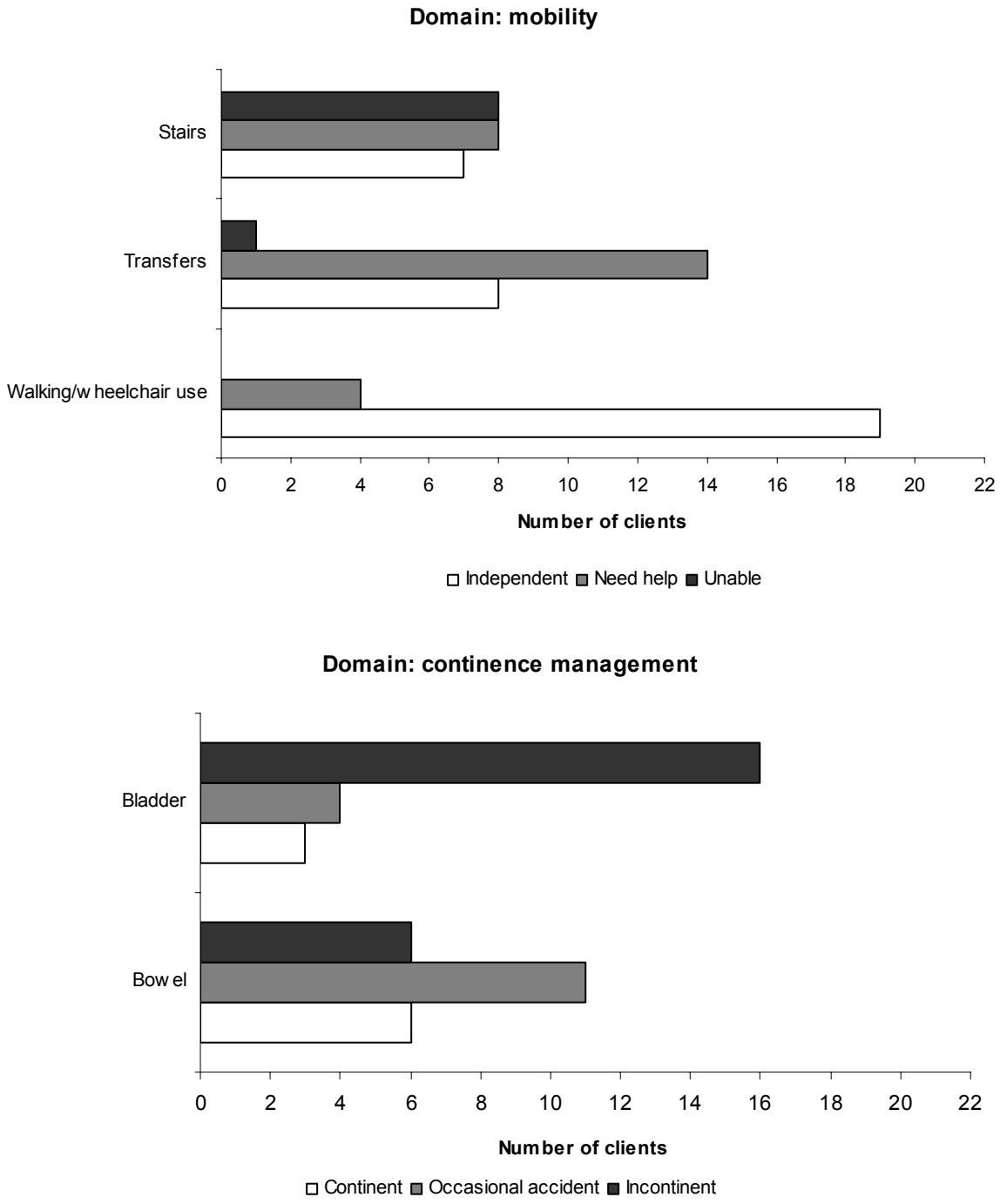
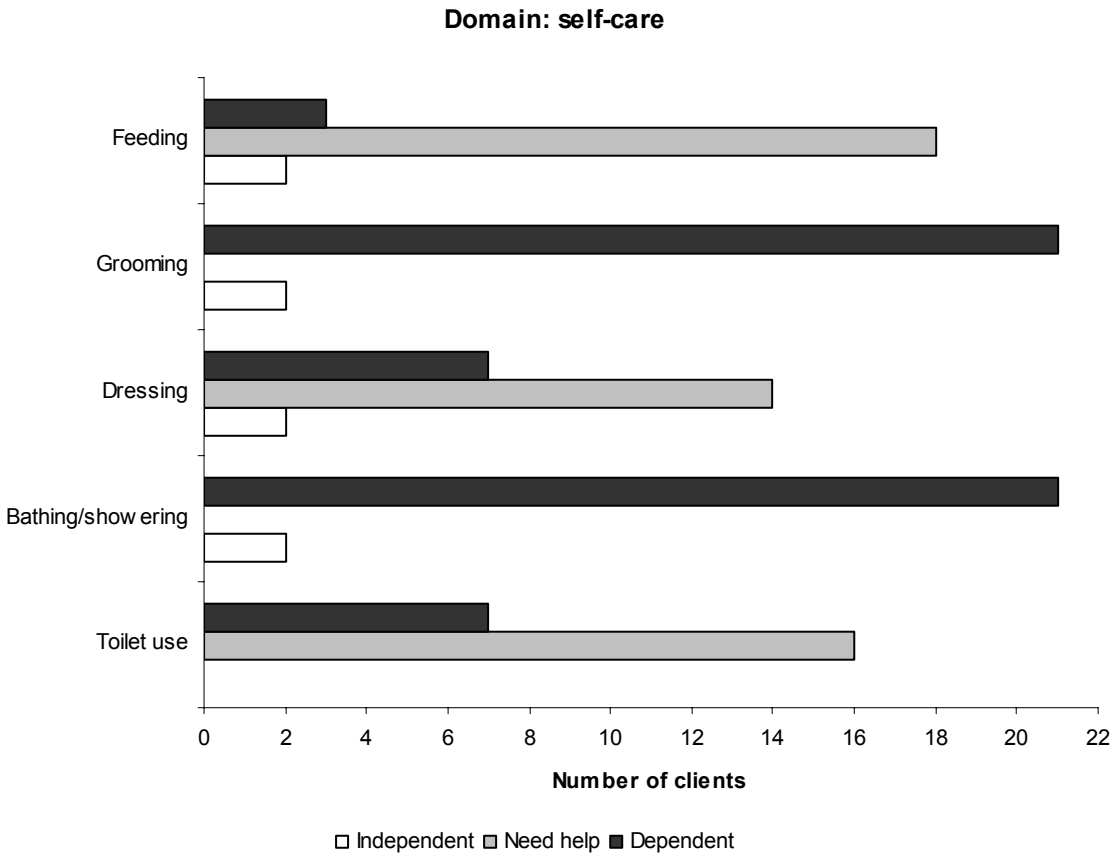


Figure B3.1: Flexible Care Service, number of clients by level of ADL function at entry

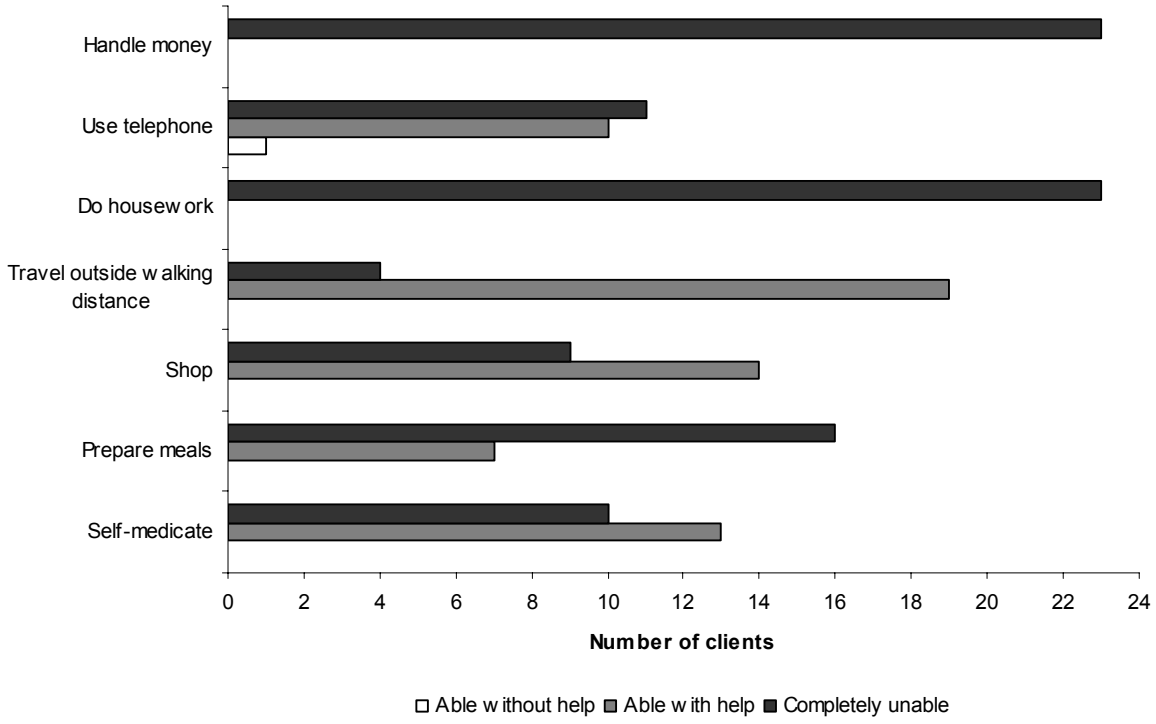
(continued)



Source: Appendix Table B11.

Figure B3.1 continued: Flexible Care Service, number of clients by level of ADL function at entry

The median IADL change score between baseline and final assessments was zero, with variation within the range of –3 to 1 point (Table B3.14). Thirty-five per cent of clients registered a decrease in IADL function between baseline and final assessments.



Source: Appendix Table B12.

Figure B3.2: Flexible Care Service, number of clients by level of IADL function at entry

Table B3.14: Flexible Care Service, summary measures for baseline[(a)] and change[(b)] in ADL and IADL

	Count	Min.	Median	Max.	Mean	Standard deviation
ADL						
Baseline MBI	21	2	11	17	10.5	3.4
Change in MBI	21	–6	–1	2	–1.5	2.4
IADL						
Baseline IADL	20	1	3	4	3.1	0.9
Change in IADL	20	–3	0	1	–0.7	1.1

(a) Clients with complete (baseline and final assessment) records.
(b) Score at final assessment minus score at baseline for an individual client.

Psychological and behavioural symptoms

Information on psychological and behavioural symptoms was recorded for 22 clients. Eighteen clients showed signs of memory loss and 13 clients showed signs of emotional or psychological symptoms of dementia on an intermittent or extensive basis (Figure B3.3). Wandering or intrusive behaviour was present in 10 cases. Fifteen clients exhibited two or more psychological and behavioural symptoms on an intermittent or extensive basis, two of whom exhibited two or more symptoms extensively.

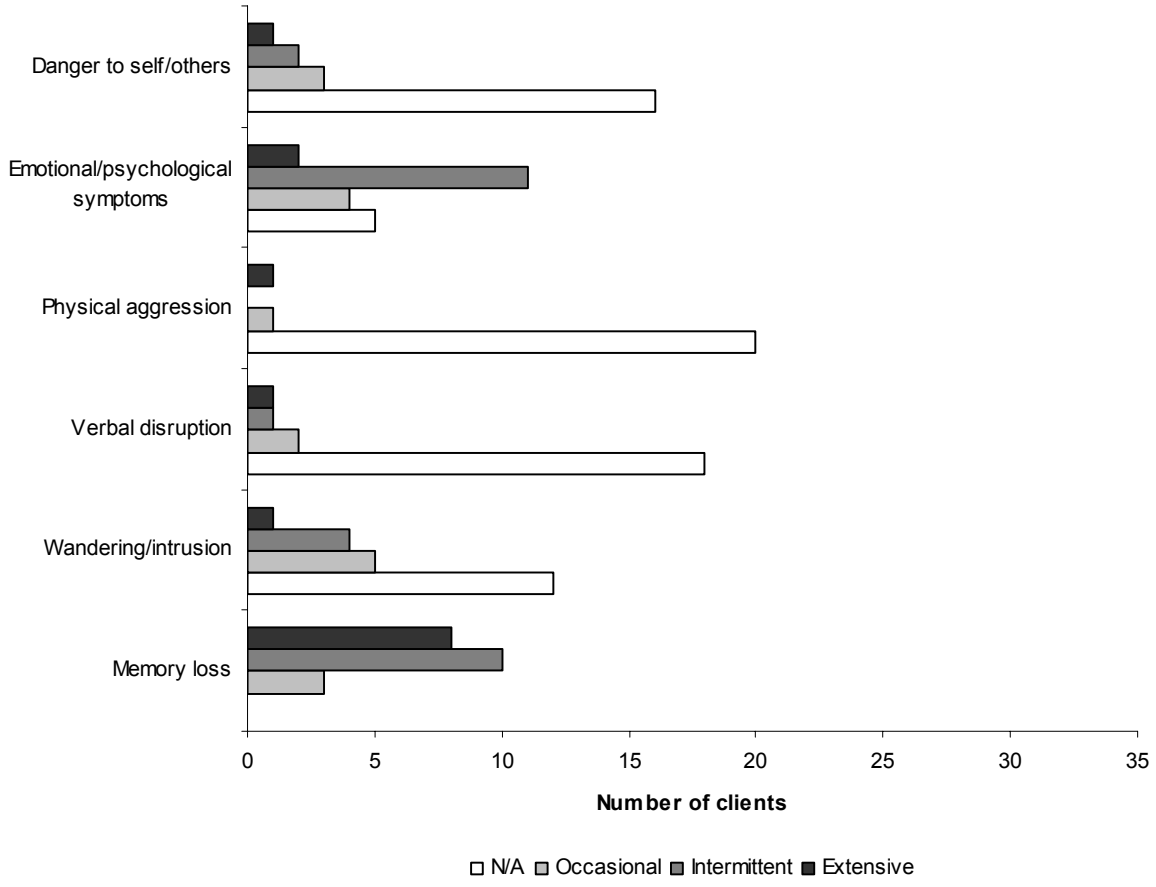


Figure B3.3: Flexible Care Service, number of clients by frequency of psychological and behavioural symptoms

3.4 Carer assessment results

Seventeen carers reported that they were in good health at the time that their care recipient entered FCS. Three carers reported they were in fair health and three reported that they were in very good health.

Twenty-two carers completed the CSI on entry to the FCS to generate a mean score of 8.6 (median 9) with a standard deviation of 3.5 points. Scores ranged from zero to 13. Eight carers recorded modal scores of 8 or 9 points. Nineteen carers recorded scores above the threshold for high carer strain.

Twenty-one carers completed the CSI at a final assessment. Changes in the CSI between baseline and final assessments ranged from –11 (an 11-point reduction in carer strain), to 3 points (a 3-point increase in carer strain). The median change score was zero (mean –1.4; standard deviation 3.4). Eight carers recorded a reduction in carer strain during the FCS service episode; 10 carers recorded no change; two carers recorded slight increases in carer strain. Five carers experienced a reduction in symptoms from above the threshold to below the threshold for carer strain. Twelve carers registered high carer strain at their final assessment.

Twenty-three carers completed the GHQ-28 at a baseline assessment. Five of these carers scored 14 to 21 points on at least one sub-scale. Two carers recorded scores of 14 or higher for somatic symptoms and four carers recorded scores of 14 or higher for anxiety and insomnia. One carer exceeded the 14 points on the social dysfunction subscale. No carer scored 14 or above on the severe depression sub-scale. Three carers scored highly on one out of four sub-scales, and two clients exceeded the case 14-point threshold on two out of the four sub-scales.

Twenty-one carers completed the GHQ-28 at the final assessment, of whom three scored above on at least one sub-scale. Analysis of change in GHQ-28 scores over time is included in the overall profiles for the Innovative Pool Dementia Pilot.

3.5 Service profile

Compared to other types of assistance, respite care, personal assistance, domestic assistance, aids and equipment and minor home modifications were recorded for higher numbers of FCS clients during the evaluation (Table B3.15). Information, advice and referral, carer support other than respite care, and dementia care/behaviour management also feature in the FCS service profile. This project has delivered high levels of in-home respite care and a number of carers received overnight respite. FCS reported that more carers could have benefited from overnight respite had it been easier to source.

The FCS service expenditure profile shows an extensive range of services were delivered during the evaluation. Almost 70% of expenditure on client services in the reporting period comprised combined expenditure on respite care (29.1%), care coordination and case management (21.9%), and personal assistance (15.1%) (Figure B3.4). Expenditure on care coordination and case management takes in staff time for discharge planning in addition to coordination of FCS services (including the management of brokerage arrangements for pre-existing services). The complexity and cost of discharge planning was underestimated at the

outset. Expenditure on pilot program accommodation services was associated with the use of supported residential services for overnight respite care.

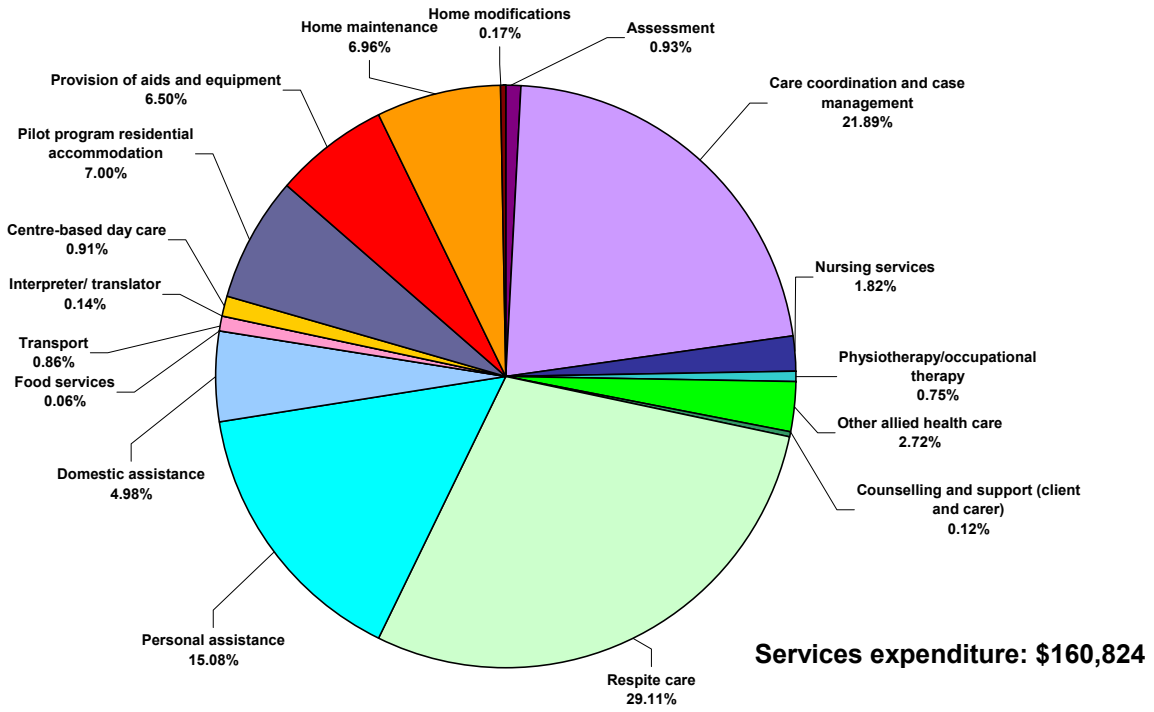
Table B3.15: Flexible Care Service summary of services delivered per client per week, results for the period 14 June–29 November 2004

Service type	Service unit	No. of Clients	Minimum	Median	Maximum	Mean	Standard deviation
Respite (in-home and day) [(a)]	Hours	23	2.0	5.6	14.6	6.7	4.0
Personal assistance	Hours	20	0.4	2.0	8.5	2.5	2.0
Domestic assistance	Hours	17	0.2	1.1	3.3	1.2	0.9
Nursing care	Hours	1	1.0	1.0	1.0	1.0	. .
Allied health [(b)]	Hours	8	0.1	0.2	0.5	0.2	0.1
Social support	Hours	2	0.1	0.1	0.1	0.1	0.0
Aids and equipment	Dollars	16	8.0	63.7	437.2	86.3	103.4
Home modifications and maintenance	Dollars	11	17.0	50.0	437.5	90.3	123.7
Residential services (e.g. SRS)	Dollars	1	73.3	73.3	73.3	73.3	. .
GP consultation	No. contacts	3	0.1	0.1	0.3	0.1	0.1
Geriatrician	No. contacts	2	0.1	0.1	0.1	0.1	0.0
Nursing/medical other	No. contacts	1	7.1	7.1	7.1	7.1	. .
Overnight respite	No. days/nights	6	0.3	1.2	2.1	1.3	0.6
Recreation/leisure programs	No. days/nights	3	0.8	1.1	1.1	1.0	0.2
Rehabilitation service	No. days/nights	1	1.0	1.0	1.0	1.0	. .
Information advice and referral	No. events	13	0.1	0.3	0.5	0.3	0.1
Carer support other than respite	No. events	9	0.1	1.1	1.5	0.9	0.6
Dementia care, memory and behaviour management	No. events	7	0.1	0.1	1.0	0.2	0.3
Community transport	No. one-way trips	5	1.6	2.5	4.9	2.9	1.2

(a) Assumes one day respite date is 5 hours.

(b) Includes physiotherapy, occupational therapy, social work, psychologist assessment and counselling, podiatry and alternative therapies where applicable.

. . Not applicable



Source: Appendix Table B25.

Figure B3.4: Flexible Care Service, expenditure on services, 1 July–31 December 2004

3.6 Accommodation outcomes

Twenty clients were discharged from FCS during the evaluation (Table B3.16). Clients discharged to the community were most often placed onto multiple support programs, for example, HACC plus Day Therapy Centre plus National Respite for Carers Program services. Three clients received an EACH package upon discharge, two clients were discharged onto CACP and three clients received HACC services.

FCS reported great difficulty in discharging a number of clients because of a lack of appropriate high care packages through Linkages (otherwise known as HACC Community Options) and the imposed eligibility criterion that clients should not have been approved for an EACH package prior to entry to FCS. However, only one client who was discharged during the evaluation had been in the project for over 100 days. Thus, despite reported difficulty finding suitable discharge destinations and support programs for clients, FCS appears to be maintaining the planned length of stay of approximately 90 days.

Table B3.15: Flexible Care Service evaluation clients, number of clients by discharge destination and government program support for clients discharged during the evaluation

Discharge status	No. of clients	Length of stay (days) (min– max)
At home		
Community Aged Care Packages	2	50–97
Extended Aged Care at Home	3	50–97
Home and Community Care	3	86–103
Multiple	5	76–95
Total discharged to community	*13*	*50–103*
In care		
Hospital	3	48–51
Residential aged care—high	2	0–83
Total deceased, hospital, RAC	*5*	*0–83*
Deceased	2	22–26
Total	**20**	**0–103**

FCS completed a follow-up of evaluation clients by 3 June 2005. Table B3.16 shows accommodation setting and government program support for all clients at this time (that is, 6 to 12 months from initial needs assessment). Six more clients had entered high level residential care in the intervening period. Three of these clients were initially discharged from the project onto HACC services, two were receiving services from multiple programs on discharge, and one was receiving a CACP after leaving FCS.

The three clients who were discharged from FCS onto EACH packages continued to be maintained on this program at follow-up. In total, half of the clients were still living at home when followed up.

Table B3.16: Flexible Care Service evaluation clients, accommodation and government program support status at follow-up

Location and support program at follow-up	No. of clients
At home	
Community Aged Care Packages	1
Extended Aged Care at Home	4
Home and Community Care	1
Multiple programs	5
Unknown	1
Total at home	*12*
In care	
Residential aged care—high care	8
Total in care	*8*
Deceased	4
Total	**24**

annecto conducted its own follow-up survey in November and December 2004 of care recipients who were in FCS between September 2003 and July 2004. Results are summarised in Table B3.17, showing one-third of clients still living at home.

Table B3.17: Flexible Care Service, accommodation setting at exit and at follow-up survey for care recipients in FCS between September 2003 and July 2004

Accommodation setting	No. of care recipients on exit from FCS	No. of care recipients at time of survey
At home	***20***	***12***
In care		
Residential aged care	10	17
Hospital	5	—
Total in care	*15*	*17*
Deceased	2	7
Total	**37**[(a)]	**36**

(a) Survey counts (unable to identify).

— Nil

Source: annecto.

annecto also asked about government program support in the community for care recipients at home following discharge and at the time of the survey. The results show the number of care recipients receiving different types of services, which sum to more than the number of care recipients at home because some recipients were receiving services from multiple programs. Table B3.18 summarises known services for clients in the community. Care recipients in an unknown program could be accessing one or more of NRCP, residential respite, day centre program and/or other services. Care recipients in a known program may be also accessing one or more of these services. Clients who left FCS and commenced with an EACH package service were still at home and receiving EACH services. Of the 15 clients discharged from FCS onto a HACC service, only four were still at home at follow-up.

Table B3.18: Flexible Care Service, government program support at exit and at follow-up survey for care recipients in FCS between September 2003 and July 2004 discharged to the community

Government program support in the community	No. of care recipients on exit from FCS	No. of care recipients at time of survey
Community Aged Care Packages	1	—
Extended Aged Care at Home	2	3
Home and Community Care	15	4
Linkages	1	1
Unknown	1	4
Total	**20**	**12**

Source: annecto.

— Nil.

The numbers of clients in either the evaluation or *annecto* surveys, broken down by program support at time of follow-up, are too small to draw general conclusions about the success or otherwise of different programs for maintaining high care clients with dementia at home and providing an adequate level of support to family carers. Evaluation data suggest that high care clients who would be best supported by an EACH or EACH-type package are being supported by HACC plus additional services and it is not known to what extent this might place an unreasonably high case management and service coordination on already strained family carers. There are indications that HACC and multiple support programs do not maintain high care clients for the longer periods observed for clients discharged directly to an EACH service.

The evaluation has concluded that the time-limited nature of FCS is not suited to the care model of FCS and that FCS would have been better established as a long-term care pilot for the types of service it delivers. Based on ADL measures and behaviour measures, there is no evidence of marked reduction in the support needs of FCS clients during the FCS service episode (and no reason to expect that this would occur given the characteristics of the target group). The transitioning of clients and their carers from a flexible package service onto lower levels of support or multiple program support perhaps without overall care management and service coordination seems to carry a risk of service disappointment. As a short-term care intervention, a service such as FCS could provide a solution to long waiting lists for EACH packages but that possibility was specifically excluded from this trial.