

3 New choices in dementia care

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

3.1 Sources of assistance before the Pilot

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

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

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

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

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

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

(b) CACP or EACH.

— Nil.

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

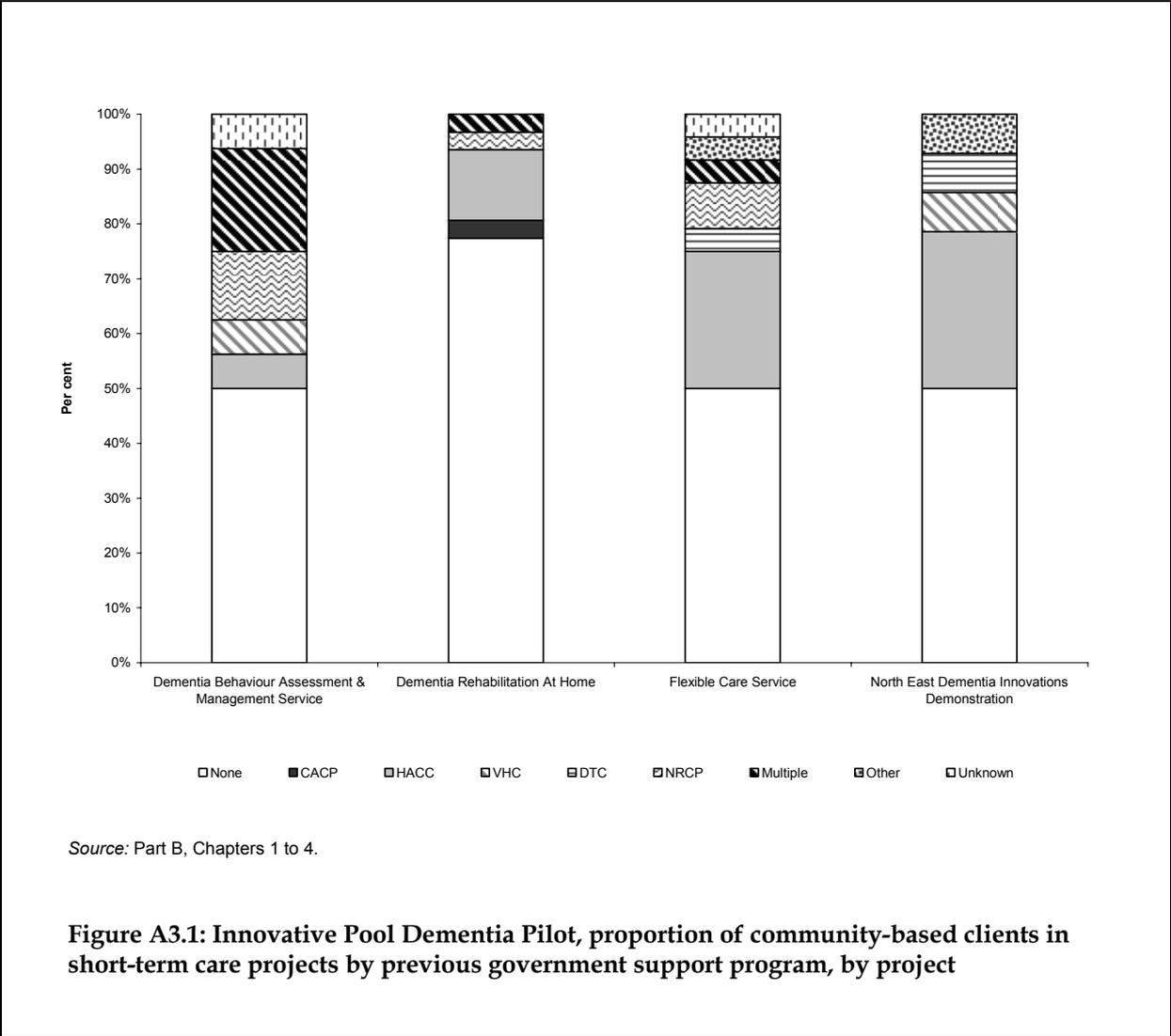
Table A3.2: Innovative Pool Dementia Pilot, number and per cent of community-based care recipients by previous formal assistance through government support programs, by program

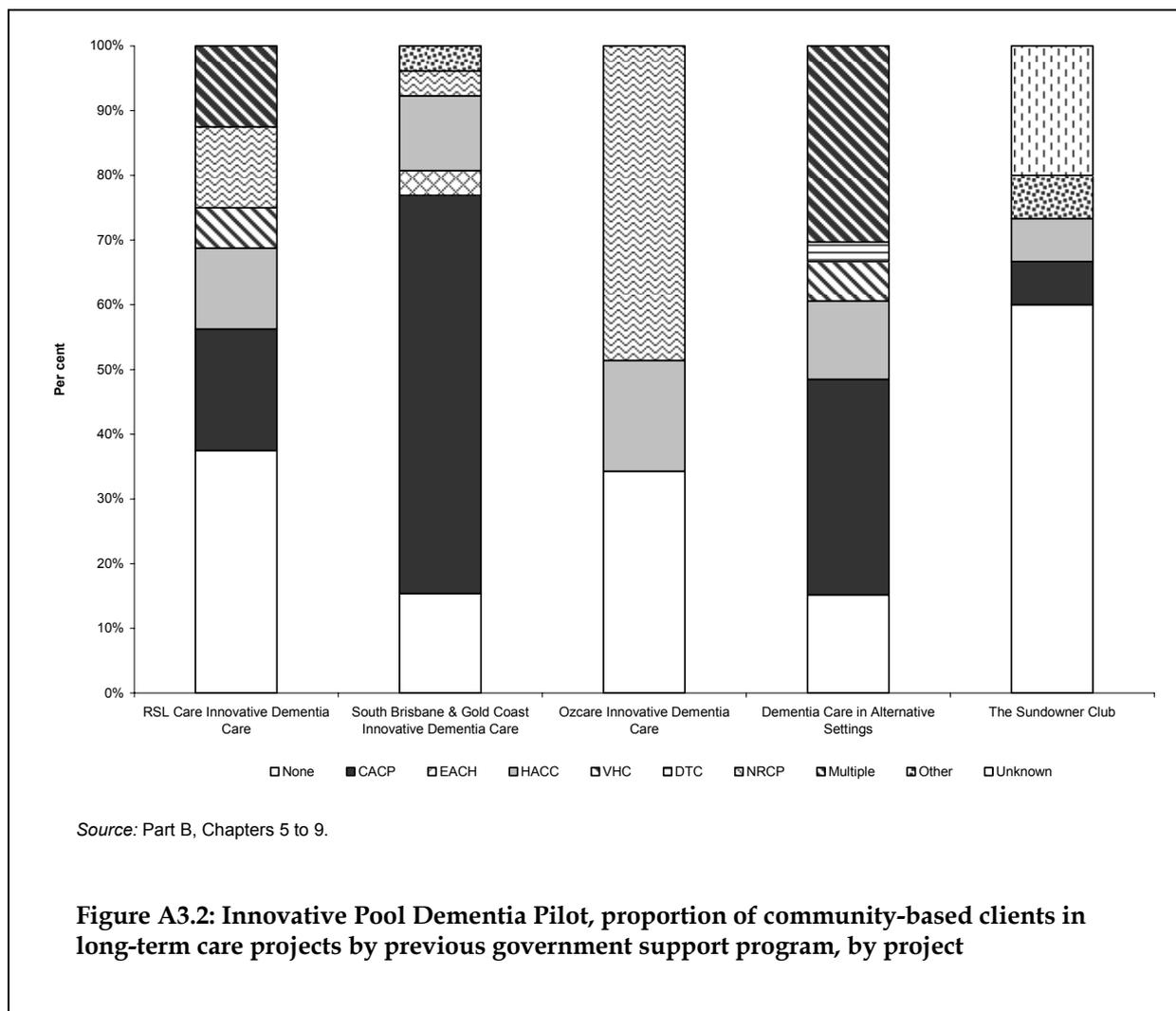
Previous government support program	Short-term care		Long-term care		All projects	
	Number	Per cent	Number	Per cent	Number	Per cent
No previous Government program support	51	60.0	42	29.8	93	41.2
Single program						
HACC	16	18.8	18	12.8	34	15.0
Veterans' Home Care	2	2.4	4	2.8	6	2.7
National Respite for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

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

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

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





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

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

3.2 New care choices

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

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

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

The projects are described in more detail below.

3.2.1 Models of short-term intervention

Dementia Behaviour Assessment and Management Service

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

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

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

Community outreach

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

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

Intermediate care

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

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

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

Dementia education

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

Client profiles

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

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

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

Key outcomes

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

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

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

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

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

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

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

Dementia Rehabilitation at Home

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

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

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

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

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

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

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

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

Client profiles

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

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

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

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

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

Key outcomes

Beneficial outcomes for clients include:

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

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

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

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

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

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

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

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

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

Flexible Care Service

Flexible Care Service (FCS) offers short-term intensive support for people with dementia-related high care needs. FCS was established at a time when EACH packages were not

available in the northern and eastern suburbs of Melbourne. Referring Aged Care Assessment Services² (ACAS) reported that FCS has accepted ACAS clients who previously would have been referred to service agencies as 'urgent CACP' because there are rarely vacant Linkages packages in the service region (prior to the availability of EACH packages in the region, 'Linkages' packages funded under the HACC program were the only community care equivalent of high level residential care). For this type of client, ACAS often takes on a case management role that is beyond the scope of its brief. ACAS observed that some community service providers 'give up' on high care clients with complex needs, leaving ACAS to pick up the pieces. Thus, FCS presented a new referral option for ACAS to place high care dementia clients.

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

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

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

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

2 Equivalent of ACAT in other jurisdictions.

Client profiles

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

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

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

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

Nineteen carers registered very high levels of carer strain.

Key outcomes

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

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

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

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

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

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

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

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

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

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

care determines whether a person with dementia-related high care needs is able to avoid or delay residential placement.

North East Dementia Innovations Demonstration

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

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

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

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

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

NEDID offers a flexible model for an innovative dementia care service in the community setting. NEDID provides a strong focus on case management, individual needs assessment,

counselling and education, and a tailored package of community services that can comprise nursing care, allied health, personal and domestic assistance, home respite, equipment hire, planned activity group programs, carer support and education, a brokered after-hours response service, and access to a specialist Dementia Care Team.

Innovative features of the service include:

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

Client profiles

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

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

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

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

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

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

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

Key outcomes

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

Much of the success is attributed to the high skill levels of the multidisciplinary team and the level of case management that facilitates a holistic approach to addressing the needs of both client and carer. NEDID has accepted clients on the verge of admission to residential aged care, but has been able to stabilise care needs and modify behaviours, enabling the client to remain at home for a period of time while helping to significantly reduce carer strain.

NEDID reported that in situations where a client has entered an aged care home, the NEDID experience has helped to make the placement decision an informed one. In some cases, a new Aged Care Client Record has been required to reflect the improvements that have occurred.

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

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

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

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

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

3.2.2 Models of long-term intervention

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

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

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

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

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

RSL Care Innovative Dementia Care Pilot

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

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

The objectives of the RSL Care Pilot were to:

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

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

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

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

Packages delivered high level coordination and management, and a multidisciplinary approach to assessment which is not generally available in mainstream low care packages. Prior to establishment of the Innovative Dementia Care Pilot, RSL Care clients with dementia were being supported through CACP with supplementation from dementia-specific respite care services, often funded by the National Respite for Carers Program. RSL Care reported that the Pilot enabled more efficient and longer term support of high care clients than a set of services designed for low care clients cobbled together under different funding arrangements. The ability to address the needs of care recipient and carer under the one funding arrangement is seen as a major benefit of the Pilot. It was suggested that innovative funding arrangements should be geared to more proactive care management for the target group. A widespread gap in service knowledge among older people and the confusion caused by different eligibility and funding requirements add to confusion about what is the most appropriate service for a client. RSL Care recommends flexible service delivery at an earlier stage of the care continuum for people with dementia so that supports are in place to avoid crisis situations from developing.

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

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

Client profiles

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

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

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

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

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

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

Key outcomes

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

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

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

South Brisbane and Gold Coast Innovative Dementia Pilot

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

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

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

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

Project coordinators remarked on the scarcity of culturally-specific care services for older people. A small number of residential facilities cater to the needs of people from culturally

and linguistically backgrounds but they generally service a limited geographic area. Culturally-specific community care is very hard to access. The Gold Coast was said to have had no multicultural aged care services at the time apart from the South Brisbane and Gold Coast Dementia Pilot.

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

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

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

Client profiles

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

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

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

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

Key outcomes

South Brisbane and Gold Coast Innovative Dementia Care Pilot made considerable progress in assisting family carers to look after themselves and in reducing carer strain and social

isolation. Bilingual support for care recipients facilitated the introduction of formal assistance or increased assistance from outsiders. This eases pressure on family carers.

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

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

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

Ozcare Innovative Dementia Care Packages

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

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

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

Ozcare reported on past experience in servicing high care community clients with dementia. A typical pattern would involve referral of a person with ACAT approval for high level residential care who is already on waiting lists at aged care homes. Many family carers would prefer their partner or parent to remain living (with them) in the community, however, limited hours of care and limited access to respite care can leave the carer believing there is no alternative but to actively pursue permanent placement, particularly when faced with increasing difficulties in managing behavioural symptoms. Thus, the primary area of unmet need in the target group was access to high hours of care with flexible delivery and in

this respect, the project was not a major departure from Ozcare's existing service model. Rather, the Pilot enabled Ozcare to deliver a higher level of service to an existing client base more effectively and efficiently through flexible funding.

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

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

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

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

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

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

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

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

Client profiles

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

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

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

Key outcomes

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

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

Ozcare identified late referral and intervention as a major challenge to assisting people in the target group. At the start of the evaluation 19 out of 30 family carers (63%) recorded high levels of carer strain. At their final assessment, 11 out of 21 carers (52%) scored above the threshold for high carer strain. Although the average measured level of carer strain in the group decreased over the assessment period and some carers showed marked reductions, a high proportion continued to report negative effects of their caring role, providing evidence of the ongoing high level of support that family carers need if informal care is to be

sustained. Project coordinators remarked that in too many cases this was because formal assistance was sought and received too late. Many people reach crisis point by the time of their first ACAT assessment, so that it can be difficult or impossible for the families to consider community-based care. Alternatively, a package may be accepted as a perceived solution to the waiting period for residential care placement. Many people in this situation expect that residential care is the only viable long-term care option.

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

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

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

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

Dementia Care in Alternative Settings

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

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

The objective of Dementia Care in Alternative Settings was to provide additional care options to members of an existing Southern Cross Care client base who were previously being supported on a high number of hours through the CACP service and to expand

services to new clients in the community. The DCAS team suggested that the constrained level of service provision from more widely available mainstream care packages – limited hours of in-home care and lack of flexibility in respite care delivery – contributes to people with moderate to severe dementia entering residential care prematurely despite a strong preference of many for care at home.

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

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

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

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

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

Client profiles

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

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

the threshold of cognitive impairment. Levels of cognitive impairment ranged from mild to severe.

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

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

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

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

Key outcomes

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

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

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

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

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

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

The Sundowner Club

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

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

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

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

Over time, ECH Support Services Coordinators in each of the three metropolitan service regions had become increasingly aware that people in the target group may be placed in residential care as a result of frequent complaints from neighbours and others about sundowner behaviour ('sundowning' refers to behavioural symptoms associated with dementia that tend to manifest more intensely in the late afternoon and early evening, often

causing distress to carers and families and risk of harm to the person with dementia). Yet, it was also apparent that most people in this situation are able to manage at other times of the day with appropriate formal and informal supports. The Sundowner Club was thus conceived as a means to overcome a general lack of formal support services that extend into evening hours.

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

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

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

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

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

Client profiles

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

formative program from June to September 2004, and in the more mature program of September 2005 were recorded for the evaluation.

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

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

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

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

Key outcomes

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

The Sundowner Club provides regular respite at a time of day when few other services are readily available to assist carers, to maintain the client's involvement in socially appropriate activities outside the home, to monitor clients who live alone for changes in self-care or health status, and to provide supervision for clients with 'sundowning' behaviours such as

wandering and agitation. This project highlights the positive features of a small group model in supporting community living clients with advanced dementia.

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

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

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

to continue to participate in activities that he previously enjoyed while also providing her with invaluable respite enabling her to pursue her own interests.

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

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

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

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

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

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

3.3 Condensed summary of project objectives and operational focus

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

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

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

It can be seen in Table A3.3 that FCS aligns closely with the long-term care projects in terms of objective and service model. Originally designed as a long-term project, the short-term nature of FCS presents special problems in relation to discharge. The rationale for offering high level ADL support and case management to people with dementia-related high care needs for just 12 weeks is somewhat elusive. Whereas the other short-term care projects have

a very specific purpose of specialist diagnosis or transition care, the focus of FCS is intensive case management, social work, in-home ADL support, flexible respite care and 24-hour rapid response. These are the domains of ongoing dementia care. Respondents to the Care Experience Survey were unanimous in their praise of the service and all wanted it to continue.

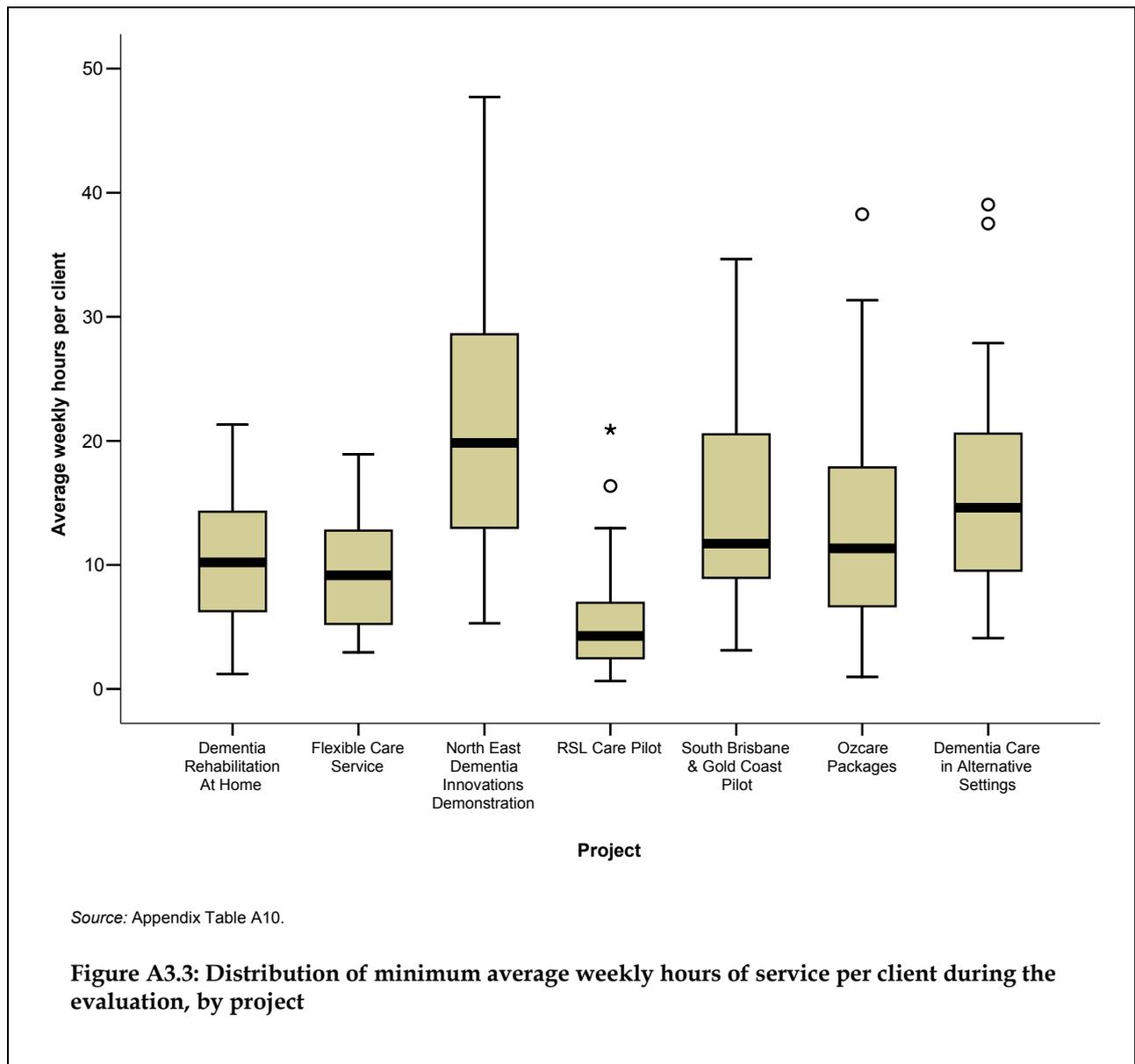
The flow-through concept whereby clients receive a short-term intervention is best suited to specialist interventions or transitioning between care settings. There is little evidence in this evaluation that many people in the target group would experience a reduction in care needs over a period of 8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

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

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

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

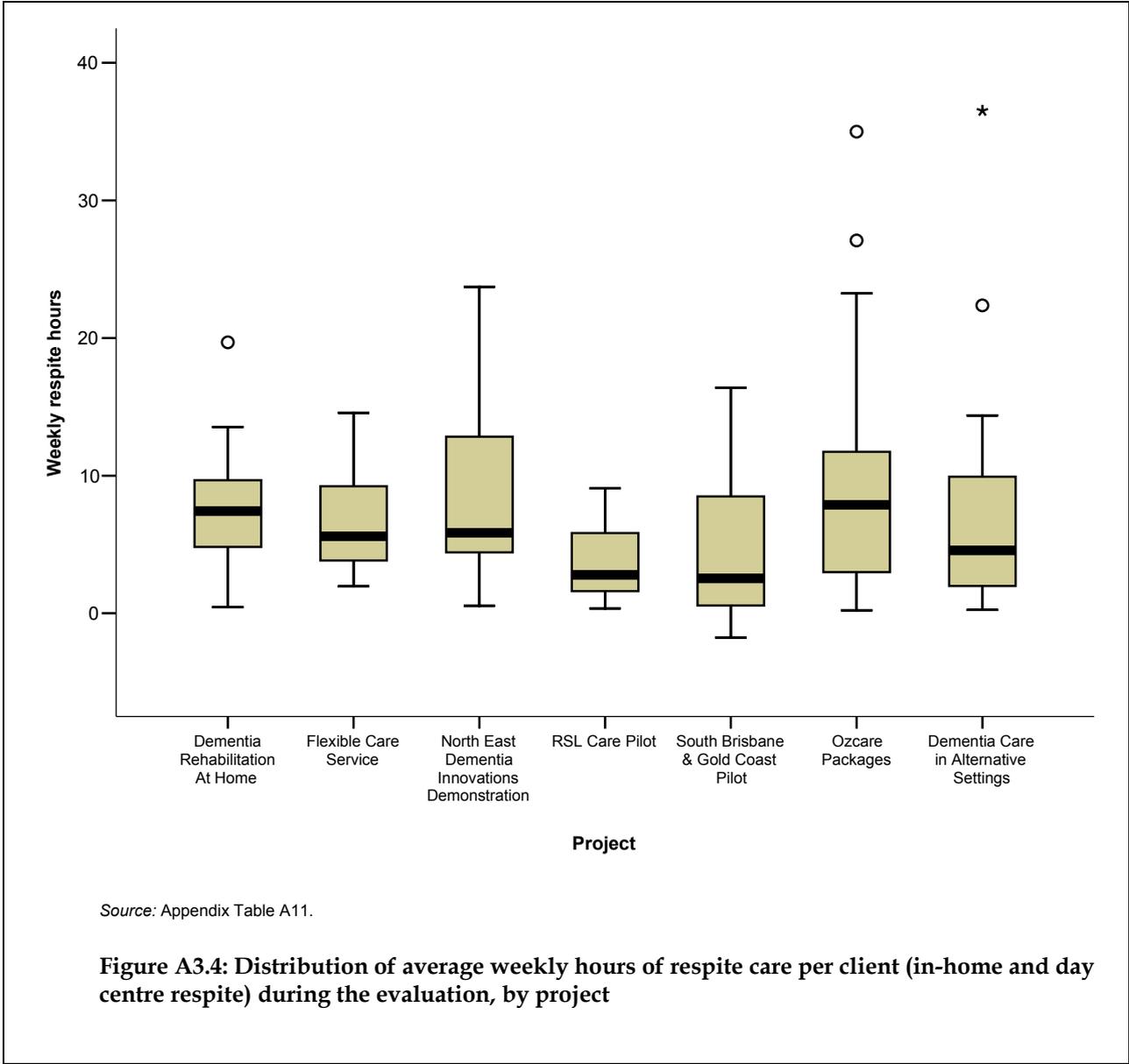
	Short-term care projects				Long-term care projects					
	DBAMS NSW	DRAH NSW	FCS Vic	NEDID Vic	RSL Care Qld	Ozcare Qld	SB&GC Qld	Sundowner Club SA	DCAS WA	
Dementia-specific client care										
High level case management and coordination	✓	✓	✓	✓		✓	✓	✓		✓
ADL/IADL with social support		✓	✓	✓		✓	✓	✓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



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

Respite care was a large component of service delivery in terms of both the proportion of weekly care hours and proportion of service expenditure. Figure 3.4 shows the distribution of average weekly hours of respite care per client for each project during the reporting period. Projects that delivered day centre respite services recorded some very high respite care users, that is, in situations where a client attended a day respite centre on multiple days per week for 5–6 hours per day. In a number of projects 50% or more clients received an average of more than typical CACP hours (6–7 hours per week) in respite care alone, in addition to any other services received. Project coordinators emphasised the importance of

high respite care in the weeks immediately after a client is accepted into a project to help stabilise the home situation and provide relief to family carers so that they are better able to contribute towards the planning of other services.



The proportion of service expenditure used for the delivery of respite care is reflected in expenditure pie charts in Part B of the report for those projects that submitted financial results. The short-term comprehensive care package services (NEDID, FCS and DRAH) reported between 17% and 29% of service expenditure on respite care delivery. RSL Care and Ozcare reported approximately 40% and 47% of service expenditure respectively for respite. Average levels of service (hours or number of events) for the range of service types offered by each project are given in the project reports in Part B.

3.4 Consumer perspectives

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

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

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

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

Older couple living at home:

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

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

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

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

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

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

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

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

Older couple living at home:

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

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

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

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

Older couple living at home:

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

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

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

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

Older couple living at home:

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

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

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

An older client receiving care from younger family members:

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

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

An older client receiving care from younger family members:

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

Hopes and expectations: 'Help understand dementia'.

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

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

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

Older couple living at home:

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

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

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

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

Client with husband as primary carer:

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

Client with employed family carer:

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

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

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

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

North East Dementia Innovations Demonstration, Victoria (Austin Health)

An older couple, wife providing care at home:

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

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

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

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

Older client with a younger family carer:

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

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

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

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

Older client with a younger family carer:

Client needed extensive help across a broad range of ADLs and before NEDID all help came from the client's daughter who hoped NEDID would provide 'daily carer support to daughter who is primary carer – who works fulltime and is not in good health. Client lives alone in own home and for 2 months daughter was required to move in with father to nurse him and manage acute pain and medication'.

Before NEDID the client had received support and assistance from the Aged Care Assessment Team, physiotherapist and occupational therapist at Austin Health; their assistance was highly valued: 'The Aged Care Assessment Team (A.K.) was very professional and respectful in her contact with client and family. The occupational therapist (A.S.) was of invaluable assistance in her professional approach and respect for client and primary carer.'

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

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

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

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

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

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

Older client with younger family carers:

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

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

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

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

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

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

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

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

Ozcare Innovative Dementia Care Packages, Queensland

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

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

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

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

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

Client with a daughter who is primary carer:

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

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

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

Family members commenting on the experience of their elderly parents:

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

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

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

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

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

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

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

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

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

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

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

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

An existing CACP client who transferred to a Pilot package:

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

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

An existing CACP client who transferred to a Pilot package:

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

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

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

RSL Care Innovative Dementia Care Pilot

An older couple, husband is primary carer:

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

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

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

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

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

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

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

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

A client with spouse as primary carer:

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

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

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

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

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

The Sundowner Club, South Australia (ECH Incorporated)

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

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

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

'Interaction with others.'

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

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

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

'Had no idea what to expect.'

And benefits of Sundowner Club to clients:

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

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

'Getting out [and] interacting with others.'

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

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

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

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

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

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

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

Before the Pilot the client was serviced by two providers:

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

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

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

'The greater number of hours has been a godsend. Mum's condition has improved markedly – no longer depressed, feels more in control because the carers "lead from behind" – that is, they help but in a way that Mum thinks she is doing it herself.'

'Staff seem carefully selected for aptitude and well trained. Also, they are very well presented and handle liaison with family very tactfully.'

Family particularly liked:

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

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

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

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

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

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

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

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

'One, or at most two, carers being allocated to each client would be beneficial. The client's short-term memory problems make it difficult for the client to cope with multiple carers – client still does not know four regular carers after 6+ months. By the time changes for holiday/sick leave are included, the client is very distressed at all the people who she does not know, coming in and out of her house. She does not know who to let in the front door. Having a business type card with name, photograph and organisation name on it which relief carers (that is, not the regular carers) can give to the client to keep each time the relief carer comes to the client's door may help reduce stress and confusion and uncertainty.

I realise that funding is a major factor in staffing and, on the other hand, I consider that when clients have dementia, they would greatly benefit by having a consistent carer.

Please could this be considered in the evaluation of the pilot program by the Department.'
[emphasis original]

Ensuring staff continuity is not always an easy task in community care. Difficulties can arise when clients are spread over a large geographic area and there are only a handful of clients in any one 'pocket' who can be serviced by one or two workers while also providing each

worker with enough hours of employment per week within the area in which they are prepared to travel. High travel costs associated with the escalating cost of fuel impact on the amount of travel time that workers are prepared to build into paid hours. Thus, number of packages and travel distances come into play besides staff sickness and holiday leave. Staff working for Ozcare Innovative Dementia Care Packages in Queensland are paid for travel time and are encouraged to use fleet vehicles, demonstrating one provider's initiative in minimising the impact of travel on take-home pay.

3.5 Main findings

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

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

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

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

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