

Part A

Main report

1 Introduction

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

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

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

1.1 Purpose of the national evaluation

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

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

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

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

1.2 Overview of Dementia Pilot projects

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

Box 1.1: Two categories of Innovative Pool Dementia Pilot proposal

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

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

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

Target group

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

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

Dementia care in alternative settings through flexible places

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

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

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

Target group

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

Eligibility

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

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

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

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

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

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

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

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

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

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

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

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

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

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

— Nil.

1.3 Context for an evaluation of dementia care

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

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

et al. 2003; Edelbrock et al. 2003; Edelman & Hughes 1990). As a group, people with dementia in aged care homes have been found to have higher care needs than residents without dementia (AIHW 2004a).

There is a strong association between dementia and rate of functional decline in activities of daily living (ADL) in old age. Dementia is often diagnosed when deterioration in cognitive function is sufficient to cause ADL impairment (WHO 2001). ADL have been defined as the most basic competencies in gerontology and 'central to stability of residence' at older ages (Lawton 1983, Gill et al. 1996, and Miller et al. 1999 cited in Lichtenberg et al. 2000).

Derouesne et al. (2002) reported that people with early stage dementia in Alzheimer's disease are likely to first experience reduced social and leisure participation and then a reduced ability to manage finances and shop. People with severe dementia show more marked loss of ADL function that over a 12-month period is estimated to involve family caregivers in an average of 14 additional hours of ADL assistance per fortnight (in addition to an established level of ADL assistance plus supervision and help with other tasks and demands).

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

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

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

Treatment of dementia focuses on establishing an early, accurate diagnosis, early institution of recommended pharmacological and non-pharmacological interventions, treatment of medical and psychological co-morbidities, provision of appropriate formal services and

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

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

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

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

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

1.4 Evaluation methods, strengths and limitations

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

Ethics approval

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

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

Timeframe and conduct of the evaluation

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

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

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

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

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

Guidelines issued to the projects specified key milestone dates (Table A1.5). Most projects supplied interim data soon after 30 September 2004 and the AIHW liaised with coordinators in the ensuing weeks on data quality and completeness. Final client-level data were required by 20 December 2004 and December quarter financial results by 14 February 2005. These

targets were not met in all cases. The AIHW worked with project coordinators throughout the first half of 2005 to clean the data and complete a follow-up of evaluation participants. The AIHW released draft reports on individual projects to project coordinators in July 2005.

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

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

Data storage and analysis

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

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

Methods

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

In this way the evaluation was designed to identify:

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

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

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

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

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

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

Strengths and limitations of the national evaluation

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

Design strengths and limitations

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

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

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

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

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

Data strengths and limitations

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

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

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

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

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

achieved in approximately 60% of cases, over 80% of care recipients have at least two repeat measures recorded including an entry/baseline measure. The CSI data give good coverage of participating carers.

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

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

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

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

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

— Nil.

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

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

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

2 Target group profiles

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

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

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

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

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

2.1 Key socio-demographic characteristics

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

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

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

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

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

— Nil.

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

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

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

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

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

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

Usual living arrangement	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)								
Lives alone	4	12	16	15	28	43	19	40	59
Lives with family	2	64	66	—	95	95	2	159	161
Lives with others	9	17	26	—	2	2	9	19	28
Unknown	—	—	—	—	1	1	—	1	1
Total	15	93	108	15	126	141	30	219	249
	(per cent)								
Lives alone	3.7	11.1	14.8	10.6	19.9	30.5	7.6	16.1	23.7
Lives with family	1.9	59.3	61.1	—	67.4	67.4	0.8	63.9	64.7
Lives with others	8.3	15.7	24.1	—	1.4	1.4	3.6	7.6	11.2
Unknown	—	—	—	—	0.7	0.7	—	0.4	0.4
Total	13.9	86.1	100.0	10.6	89.4	100.0	12.0	88.0	100.0

— Nil.

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

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

— Nil.

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

2.2 Targeting people with cognitive impairment

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

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

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

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

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

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

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

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

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

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

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

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

.. Not applicable.

2.3 Indicators of support need

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

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

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

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

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

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

Support need measures are summarised below.

2.3.1 Levels and areas of core activity limitation

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

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

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

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

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

their care, people with dementia who are just entering the formal care system and people with an established diagnosis of dementia who have reached a milestone on the care continuum.

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

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

2.3.2 Activities of daily living

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

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

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

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

Notes

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

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

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

.. Not applicable.

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

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

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

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

Notes

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

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

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

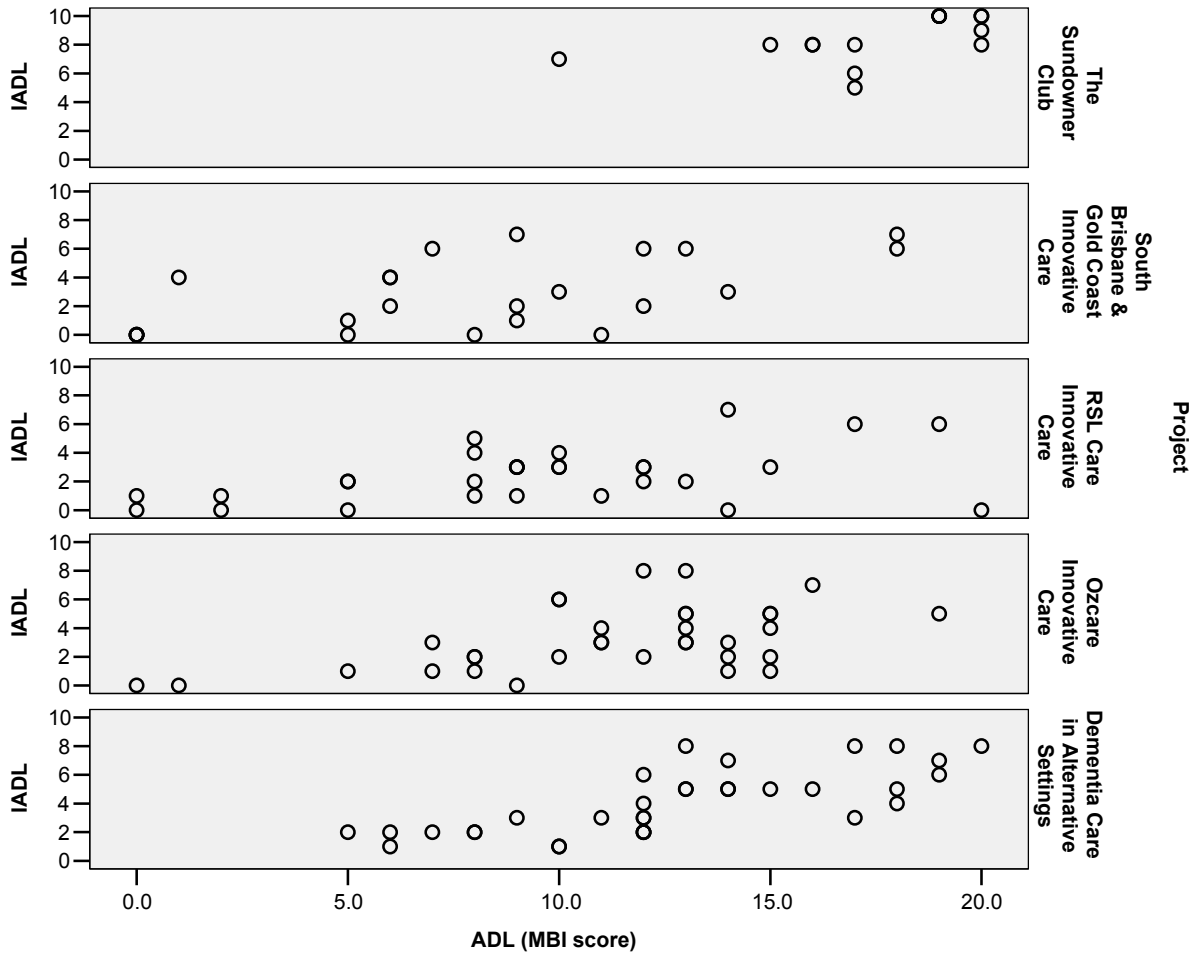


Figure A2.1: Innovative Pool Dementia Pilot, scatter plot of baseline IADL score by baseline ADL score for care recipients in long-term care projects, by project

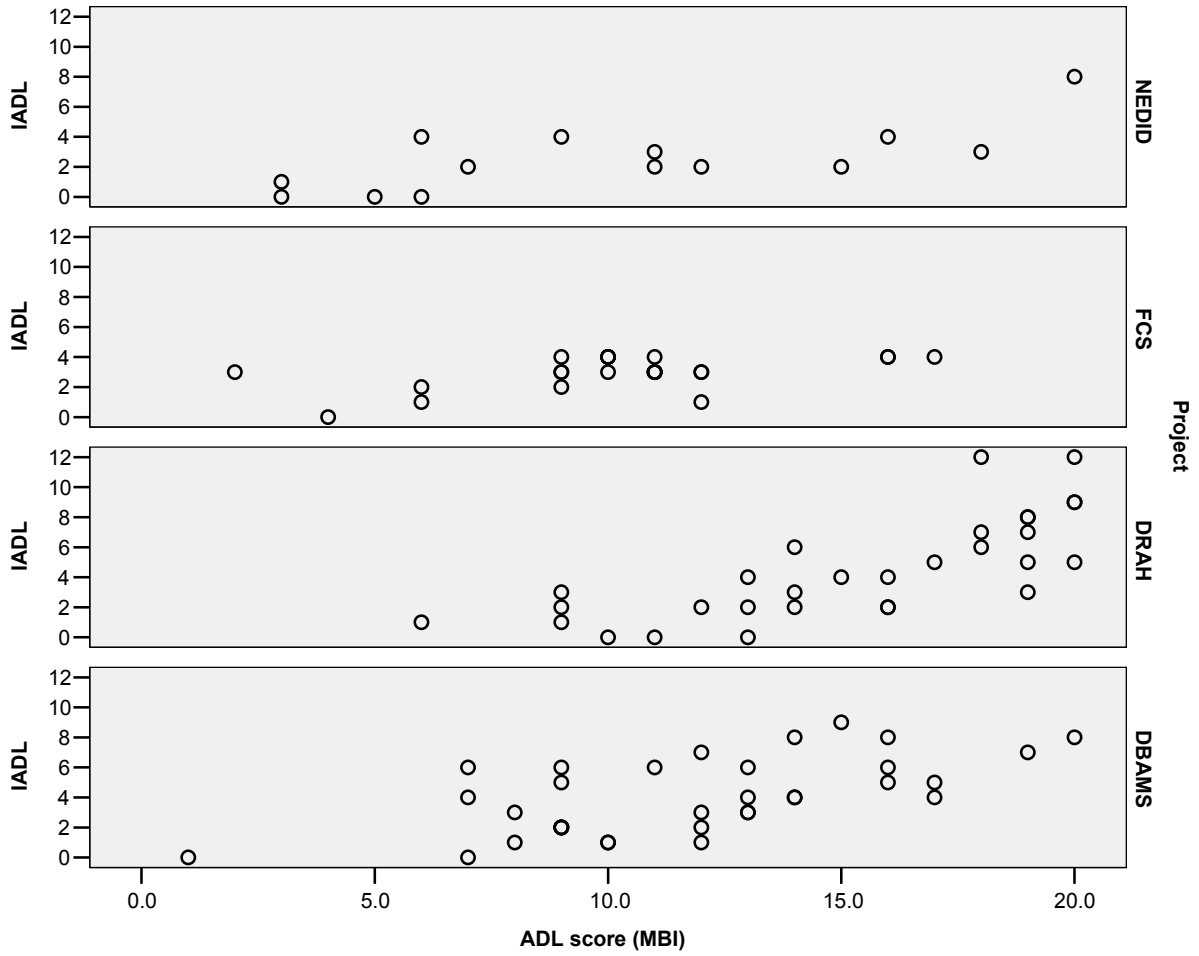


Figure A2.2: Innovative Pool Dementia Pilot, scatter plot of baseline IADL score by baseline ADL score for care recipients in short-term care projects, by project

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

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

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

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

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

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

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

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

2.3.3 Behavioural and psychological symptoms of dementia

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

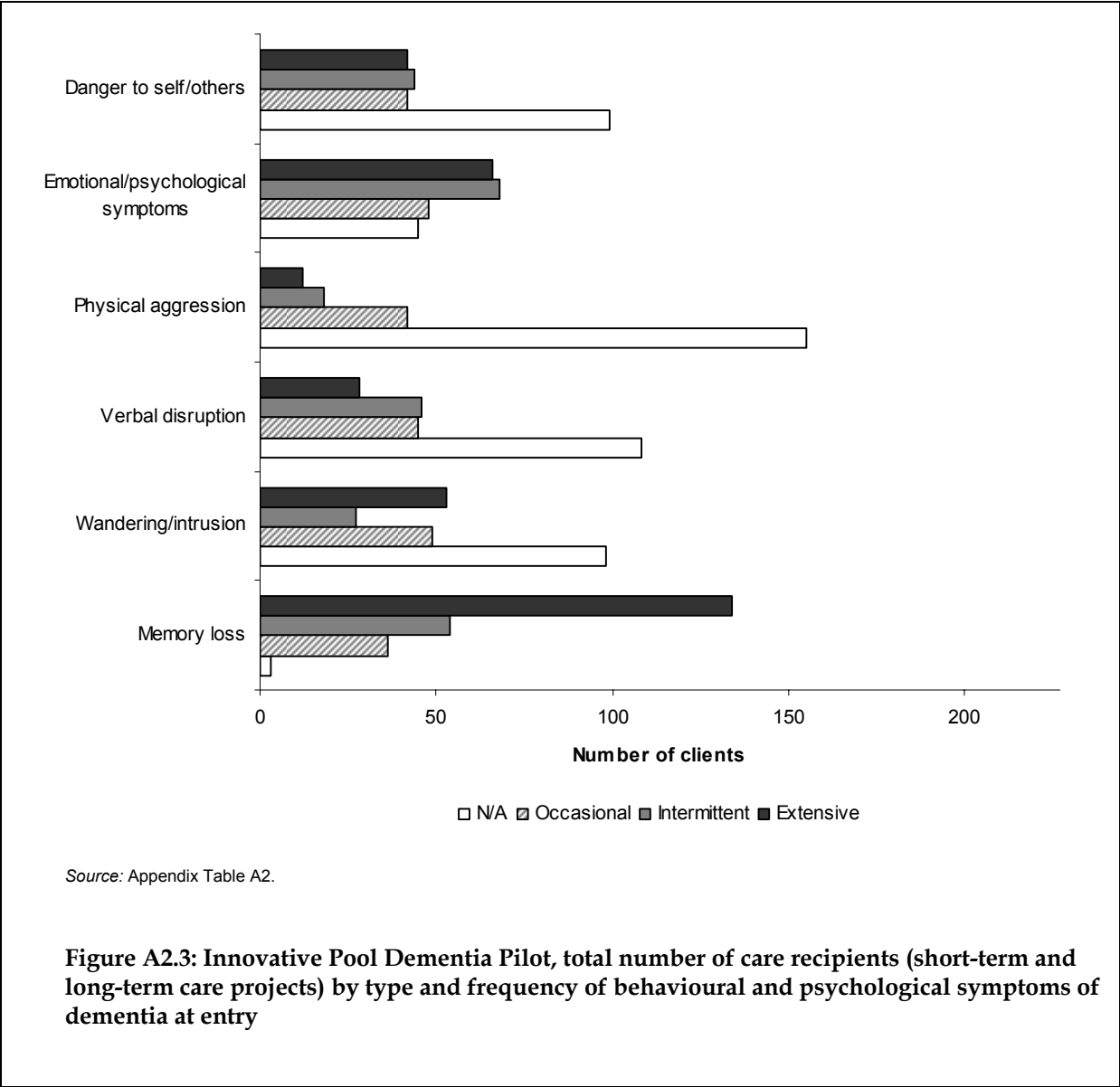
- Memory loss – relates to the care recipient forgetting information such as the names of family members, location of personal items, or recent activities.
- Problem wandering or intrusive behaviours – relates to the care recipient wandering, absconding, or interfering with other people or their belongings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

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

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

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

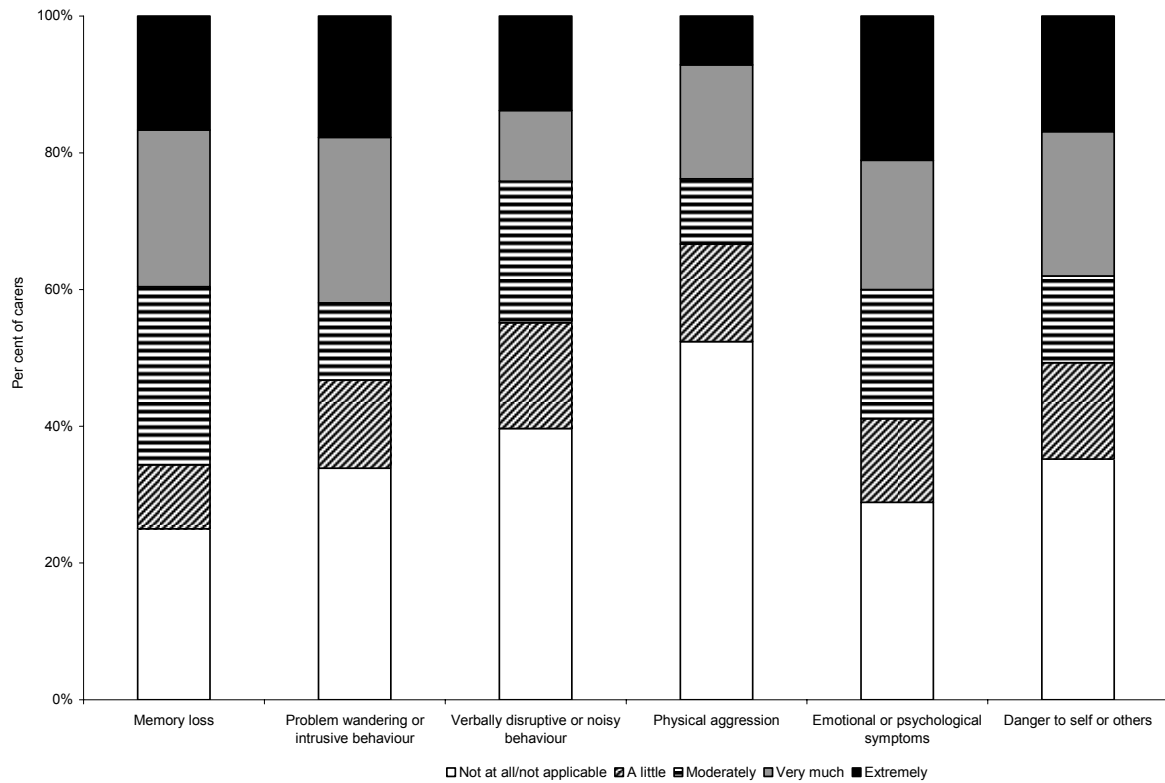
Virtually all care recipients for whom BPSD data were recorded exhibited memory loss, with emotional and psychological symptoms the next most prevalent class of symptom (Figure A2.3). Wandering or intrusive behaviour, verbally disruptive behaviour, presenting a danger to self or others, on at least an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



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

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

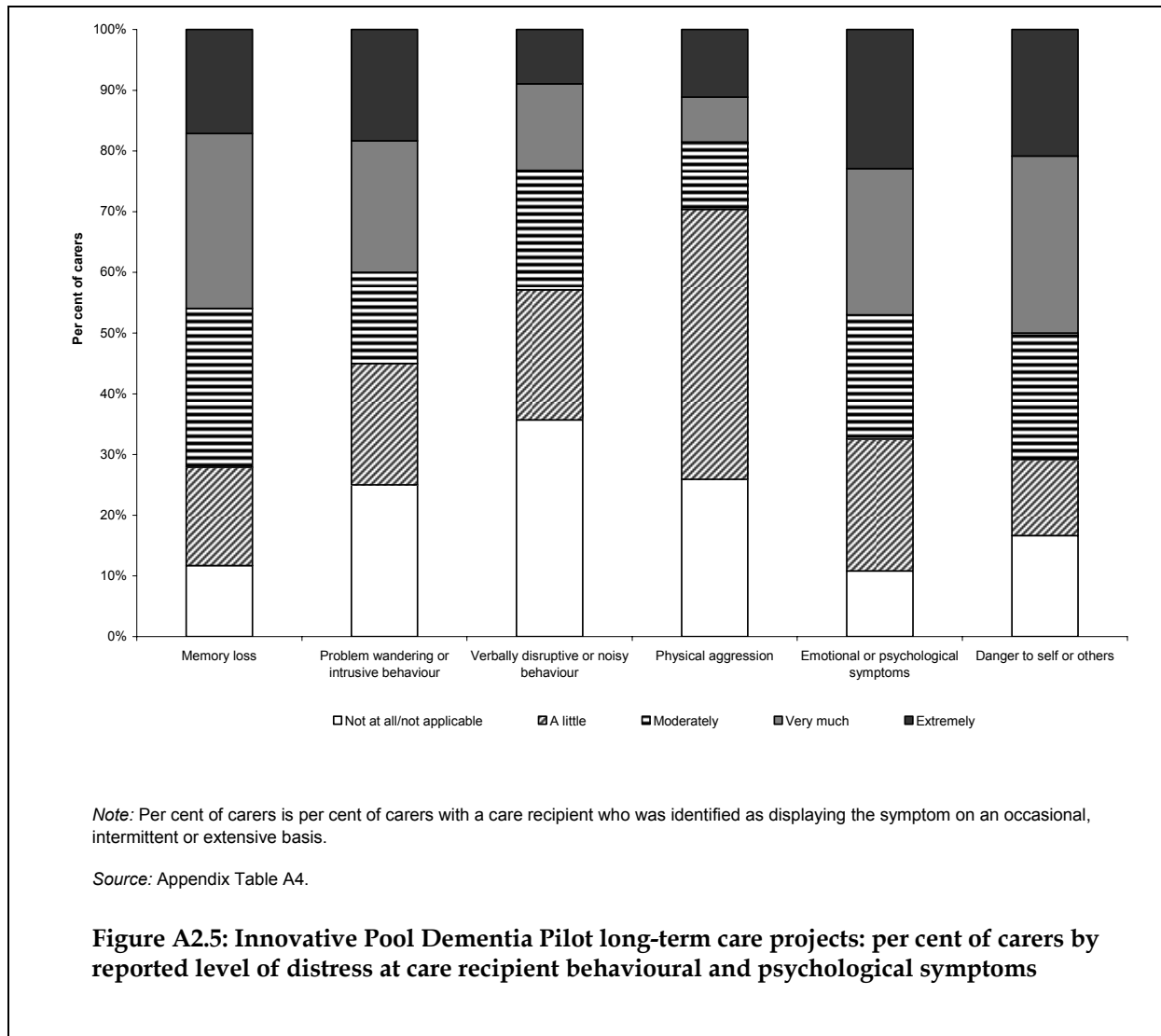
For each type of BPSD surveyed, at least 50% of carers reported some level of distress (Figures A2.4 and A2.5). Over 60% of carers with a care recipient who exhibited memory loss, emotional or psychological symptoms, and wandering or intrusive behaviour reported moderate to extreme distress as a result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



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

Source: Appendix Table A3.

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



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

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

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

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

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

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

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

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

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

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

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

Tier 1 *No dementia.*

Tier 2 *Dementia with no behavioural and psychological symptoms.*

Tier 3 *Dementia with mild behavioural and psychological symptoms, for example, apathy, mild depression, repetitive questioning and ‘shadowing’ (closely following other people). Symptoms may respond to distraction and reassurance or be ameliorated by altering interactions or the environment.*

Tier 4 *Dementia with moderate behavioural and psychological symptoms, for example, major depression, verbal aggression, low-level (non-dangerous) physical aggression, psychosis, sexual disinhibition and wandering. Generally people in tier 4 require specialist consultation and specifically targeted interventions such as behaviour management programs.*

Tier 5 *Dementia with severe behavioural and psychological symptoms, for example, severe depression, aggression and marked agitation. People in tier 5 may not be able to be managed within mainstream aged care services and may require tailored intervention programs administered by a specialist multidisciplinary team.*

Tier 6 *Dementia with very severe behavioural and psychological symptoms, that is, people with severe behavioural disturbance complicating their dementia such as dangerous physical aggression which cannot be managed by family or residential care staff, even with the assistance of other specialist services. Such people require placement in special-care facilities, for example, psycho-geriatric or aged care neurobehavioural units.*

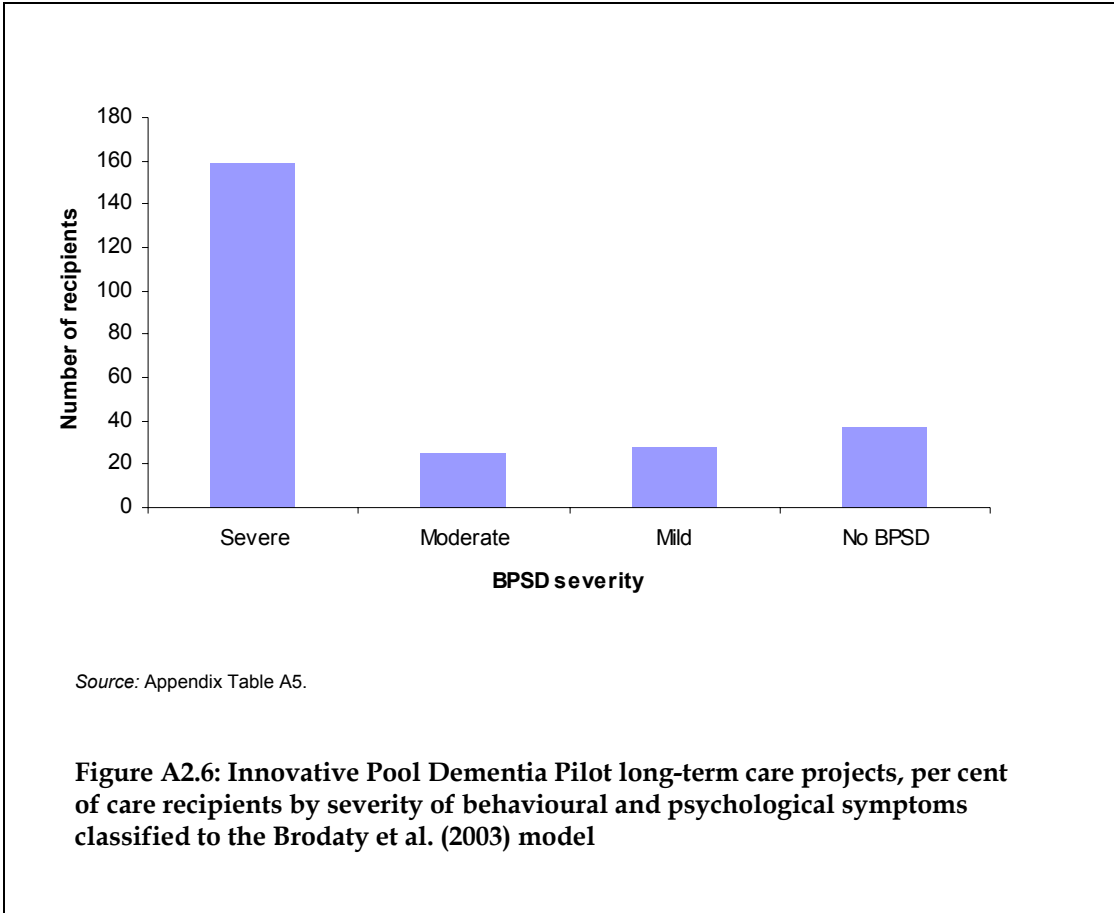
Tier 7 *Dementia with extreme behavioural and psychological symptoms, that is, people who are so violent that they have harmed other residents or staff. Management in hospital or special-care facilities may be unsuccessful and a high-security specialist care unit is required.*

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

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

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

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



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

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

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

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

2.4 Family carers

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

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

social support and respite services that offer opportunity for social interaction. Examples of Innovative Pool respite services that meet the varied needs of carers include:

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

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

2.4.1 Carer profiles

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

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

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

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

— Nil.

Indicators of carer wellbeing

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

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

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

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

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

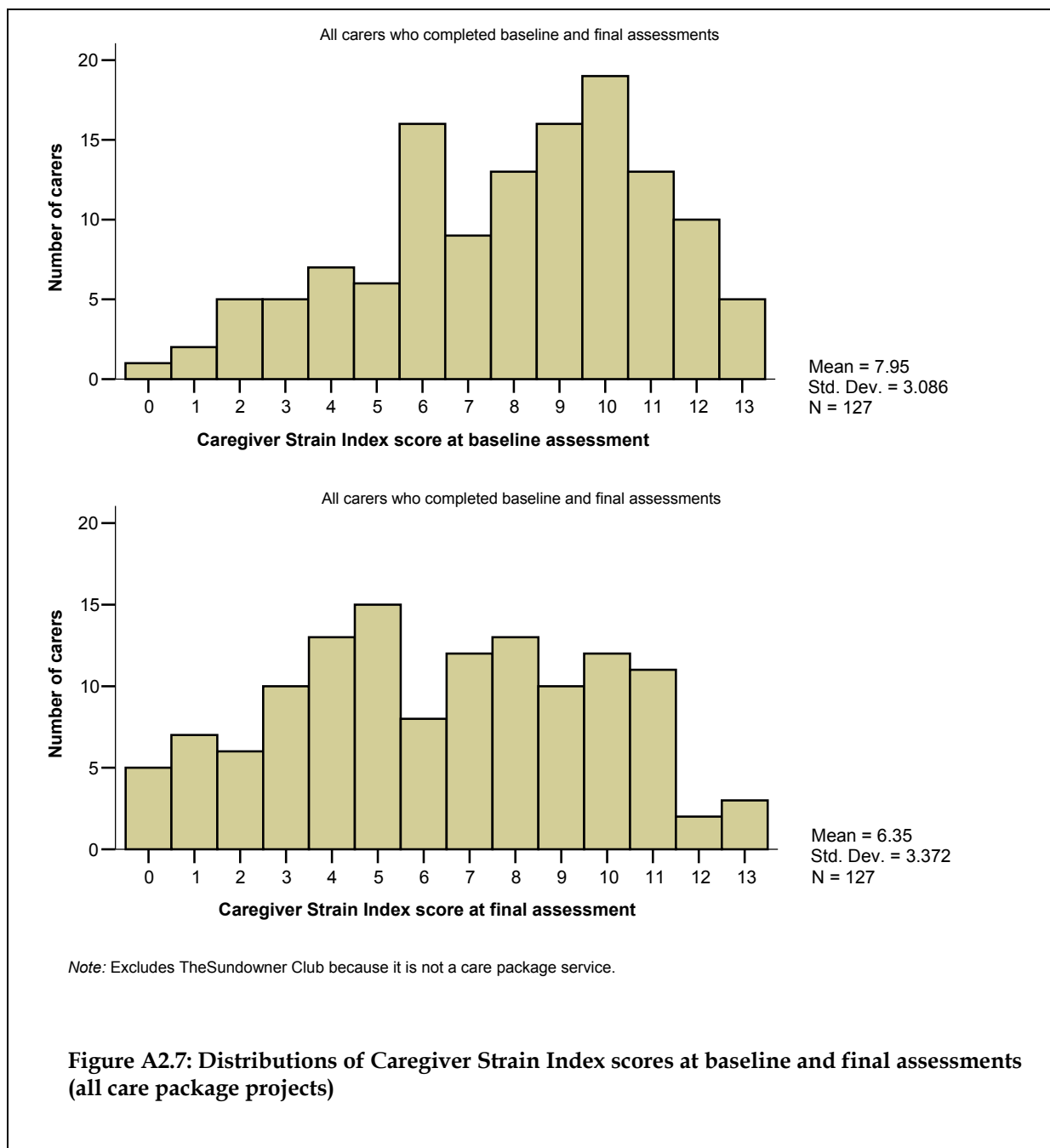
Carer strain (CSI) scores were recorded for 178 carers at the baseline assessment. Scores ranged from zero to 13 (Table A2.16). Almost three-quarters of carers scored above the threshold of high carer strain, revealing that projects have targeted clients whose conditions present significant challenges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

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

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

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

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



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

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

indicating significant personal risk for those people. Approximately 12% of carers in short-term care projects scored 14 points or higher on somatic symptoms, and 5% scored above the threshold for social dysfunction.

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

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

— Nil.

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

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

Measure	Number of records	Minimum	Mean	Maximum
Baseline CSI (0–13 points)	149	0	8.4	13
Baseline GHQ-28 (0–84 points)	149	6	27.6	71

Pearson's correlation coefficient: 0.52

Forty-nine carers of clients in short-term care projects and 68 carers of clients in long-term care projects completed the GHQ-28 at a final assessment as well as a baseline assessment. Comparison of baseline and final GHQ-28 scores for these clients indicates that, for the group as a whole, psychological symptoms relating to recent events and recently changed circumstances had reduced by the final assessment. The average change in scores on each of the sub-scales was negative (overall reduction in negative impact of caring) in both long-term and short-term care projects. The highest average reduction in symptoms was recorded on the anxiety and insomnia sub-scale (average decrease of 2.5 points in long-term projects

and 1.8 points in short-term projects). The proportion of carers who scored 14 points or higher was reduced on all sub-scales.

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

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

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