

# **National evaluation of the Aged Care Innovative Pool Dementia Pilot**

**Final report**

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AGED CARE SERIES

Number 10

# **National evaluation of the Aged Care Innovative Pool Dementia Pilot**

**Final report**

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**2006**

**Australian Institute of Health and Welfare  
Canberra**

AIHW cat. no. AGE 48

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This publication is part of the Australian Institute of Health and Welfare's Aged Care Series. A complete list of the Institute's publications is available from the Business Promotion and Media Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

ISBN 1 74024 589 X

ISSN 1325-6025

### **Suggested citation**

Australian Institute of Health and Welfare (AIHW): Hales C, Ross L & Ryan C 2006. National evaluation of the Aged Care Innovative Pool Dementia Pilot: final report. Aged Care Series no. 10. AIHW cat. no. AGE 48. AIHW: Canberra.

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Published by Australian Institute of Health and Welfare  
Printed by Pirion Printing

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# Acknowledgments

The national evaluation of the Innovative Pool Dementia Pilot was made possible through the cooperation of staff, care recipients and family members in pilot projects around Australia and referring Aged Care Assessment Team members. In particular, the AIHW evaluation team wishes to thank past and present representatives of service provider organisations, and their support staff, for assistance in the collection and reporting of data for the evaluation:

- Aged & Extended Care Services, Southern Area Health Service, Wagga Wagga – Mary Saligari and Isabelle Baker
- North Coast Aged Care Assessment Team, Grafton – Jenny Fitzpatrick and Helen Fletcher
- *annecto – the people network*, Melbourne – Lando Antonelli, Jo Debrincat, Talitha Daley
- Austin Health, Melbourne – Juliet Thorn, Adele Lee and Sue Salter
- RSL Care, Brisbane – Penny Holcombe, Monica Murphy, Anne-Maree Rossi, Darolyn Harris and Karen Constant
- Islamic Women’s Association (Queensland) and Gold Coast Multicultural Communities Council – Galila Abd Elsalam and Luisa Fuller
- Ozcare, Rockhampton and Bundaberg – Lanna Ramsay, Lyn Manning and Linda Scott
- Southern Cross Care WA, Perth – Wendy Silver and Sandy Crowe
- ECH Incorporated, Adelaide – Colin Ireland and Eleanor Kennett-Smith.

Aged Care Queensland invited the AIHW to participate in scheduled service provider teleconferences. We would like to thank Anne Livingstone, Aged Care Queensland, for allowing us to join in this forum for updates on the projects in Queensland.

The evaluation team thanks Dr Julie Winstanley and Osman Consulting Pty Ltd for assistance with the analysis of Care Experience Survey data.

David Martin, Tom Goff, Naomi Rogers and other staff of the Department of Health and Ageing provided guidance on the objectives and conduct of the evaluation.

Thanks to our colleagues at the Australian Institute of Health and Welfare: Ann Peut, Jo Broad, Phil Anderson and Diane Gibson.

# Abbreviations

|        |  |
|--------|--|
| ABS    | Australian Bureau of Statistics  |
| ACAS   | Aged Care Assessment Service (the name used for ACAT in Victoria)  |
| ACAT   | Aged Care Assessment Team  |
| ADL    | Activities of daily living (for example, eating, bathing/showering, dressing, grooming, toilet use, bladder and bowel continence management, walking or wheelchair use, transfers, negotiating stairs) |
| AIHW   | Australian Institute of Health and Welfare   |
| BPSD   | Behavioural and psychological symptoms of dementia   |
| CACP   | Community Aged Care Packages   |
| CSI    | Caregiver Strain Index   |
| DBAMS  | Dementia Behaviour Assessment and Management Service   |
| DCAS   | Dementia Care in Alternative Settings  |
| DRAH   | Dementia Rehabilitation at Home  |
| DTC    | Day Therapy Centre   |
| DVA    | Australian Government Department of Veterans' Affairs  |
| EACH   | Extended Aged Care at Home   |
| EARS   | Emergency After Hours Response Service   |
| FCS    | Flexible Care Service  |
| GHQ-28 | General Health Questionnaire (28-item version)   |
| GP     | General practitioner   |
| HACC   | Home and Community Care Program  |
| IADL   | Instrumental activities of daily living (for example, shopping, housework, travelling away from home, medication use, using the telephone, managing personal finances)                                 |
| MBI    | Modified Barthel Index   |
| MMSE   | Mini-Mental State Examination  |
| NEDID  | North East Dementia Innovations Demonstration  |
| NGO    | Non-government organisation  |
| NRCP   | National Respite for Carers Program  |
| OARS   | Older American Resources and Services (IADL scale)   |

|      |  |
|------|--|
| RAC  | Residential aged care  |
| RCS  | Resident Classification Scale                                |
| SBGC | South Brisbane and Gold Coast Innovative Dementia Care Pilot |
| VHC  | Veterans' Home Care  |

# Summary of findings

The Aged Care Innovative Pool Dementia Pilot became operational across Australia in the two years 2003–2004 as a set of projects under the administration of the Australian Government Department of Health and Ageing. This made available a pool of flexible care places outside the annual Aged Care Approvals Round to trial new approaches to care for older people with dementia. Operational management of projects has been the responsibility of the respective State Offices of the Department of Health and Ageing. Pilot services are administered according to the requirements of the *Aged Care Act 1997*.

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. Findings from the AIHW evaluation are to inform the Department’s broader review of the Dementia Pilot. The Hammond Care Group commissioned its own evaluation of the Short Term Intensive Community Care Service and that report is available upon request from The Hammond Care Group.

National evaluation commenced in June 2004 and data collection was completed in mid-2005. Approval for the evaluation was given by the AIHW Ethics Committee (Register Number 353 and 354).

Three questions were set for the evaluation to address:

- 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)?**

In addition, this report discusses a range of issues highlighted by the Pilot that could help to inform policy on community care for people with dementia.

Quantitative and qualitative methods were used to collect relevant data and information about clients, family carers and pilot projects. In total, 249 care recipients and 219 family carers contributed to the evaluation.

The nine projects were found to be offering a variety of dementia-specific, short-term interventions of a planned duration of 8 to 12 weeks and longer term interventions that continue for the duration of the project or until a care recipient can no longer benefit from the type of care offered.

*Short-term care interventions:*

1. Dementia Behaviour Assessment and Management Service (DBAMS), Wagga Wagga, New South Wales (Southern Area Health Service)
2. Dementia Rehabilitation At Home (DRAH), Northern Rivers area, New South Wales (North Coast Area Health Service)
3. Flexible Care Service (FCS), Melbourne, Victoria (*annecto* – the people network, formerly WiN Support Services)
4. North East Dementia Innovations Demonstration (NEDID), Melbourne (Austin Health)

*Long-term care interventions:*

5. RSL Care Innovative Dementia Care Pilot, Brisbane and Ipswich/West Moreton, Queensland (RSL Care Queensland)
6. South Brisbane and Gold Coast Innovative Dementia Care Pilot, Queensland (Islamic Women's Association of Queensland in partnership with the Queensland Multicultural Communities Council and Queensland Transcultural Mental Health Centre)
7. Ozcare Innovative Dementia Care Packages, Rockhampton/Gladstone and Bundaberg, Queensland (Ozcare, formerly St Vincent's Community Services)
8. Dementia Care in Alternative Settings (DCAS), Perth, Western Australia (Southern Cross Care WA)
9. The Sundowner Club, Adelaide, South Australia (ECH Incorporated in partnership with Eldercare Incorporated).

## **Service delivery context**

Projects have targeted people with very high care needs. Eligibility for Pilot services requires Aged Care Assessment Team (ACAT) approval for residential aged care and, in all but one project, approval for high level residential care was required.

The average age of clients during the evaluation was 81 years and one in three clients was aged 85 years or over. The average Mini-Mental State Examination (MMSE) score, a measure of cognitive function, on entry to a project was 15 points out of 30. A score of 16 on the MMSE has been reported to be a key transition point that often marks the onset of rapid functional decline in activities of daily living (Feldman et al. 2005). Scores below 12 points are used in practice to indicate severe cognitive impairment (see for example Holmes & Lovestone 2003; Huusko et al. 2000). Severe cognitive impairment was indicated at entry to a project for 26% of care recipients for whom a baseline MMSE score was recorded.

Cognitive impairment contributed to the observed high levels of impairment in activities of daily living and social functioning. Most care recipients had experienced significant loss of function in the instrumental activities of daily living (IADL include housework, shopping, meal preparation, travelling away from home, medication use, and managing personal



finances). In addition, 95% of care recipients had lost a degree of self-care and/or mobility function, including 80% with moderate or severe impairment in activities of daily living (ADL) involving self-care and mobility. Over 60% of care recipients were reported to be experiencing severe behavioural and psychological symptoms associated with dementia.

Support arrangements before joining a project varied across the group. Care from family was the main source of assistance for the majority of clients before and during the Pilot. Ninety-one per cent (91%) of community-based clients in the evaluation had a carer (88% of all clients, including those who usually reside in an aged care facility). Counting all reported sources of ongoing assistance to community-based clients before the Pilot, 53% were receiving assistance from a primary family carer as well as from government-funded formal services; 38% were receiving assistance from a primary carer without additional assistance from government-funded services; 4% were receiving assistance from government-funded services only (no family carer) and 4% recorded no previous sources of ongoing assistance (Table A3.1). Previous formal support arrangements are unknown for 1% of care recipients in the evaluation.

Carer availability was a prerequisite for entry in a number of projects; even when not specifically required, it was found that most people referred to the projects were receiving assistance at home from a primary carer. Participating carers comprised a mix of co-resident and non-resident carers, with a high representation of sons, daughters and sons- and daughters-in-law (45% of all carers). Men made up 41% of primary carers across the projects. One in four primary carers were not living with the care recipient.

Around 75% of carers who completed the Caregiver Strain Index (CSI) recorded high carer strain, confirming reports from all project coordinators of the very high levels of carer strain evident among family carers. A statistically significant positive correlation was found between levels of carer strain and psychological symptoms in carers including anxiety, insomnia and somatic symptoms. Projects have had to provide high level support to both care recipients and family carers.

Thus, the evaluation found multiple indicators of high risk of entry to residential aged care among the 249 care recipients:

- 240 had ACAT approval for high level residential care
- all 249 care recipients showed significant ADL impairment
- a high proportion of clients experienced moderate to severe behavioural and psychological disturbances and their carers reported experiencing distress as a result of these symptoms
- very high levels of carer strain and associated psychological symptoms.

Only 21% of care recipients were receiving a care package before joining a pilot project.

The Innovative Pool Dementia Pilot and national evaluation occurred prior to the announcement in the 2005 Federal Budget of Extended Aged Care at Home Dementia Program (EACH Dementia), which is part of the initiative *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*.

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

In short, the answer to the first evaluation question is ‘yes, in all cases’, but it is important to appreciate the different approaches that pilot services have taken to offering new care choices for older people with dementia. Reports in Part B detail the operation of each project and the key outcomes achieved (these are also summarised in Chapter 3 of Part A).

Each pilot project has offered a new care choice to referred clients with dementia-related high care needs and their carers. The Pilot is notable for the range of care models that have emerged. Three short-term intervention projects have a strong clinical focus with multidisciplinary input, two of which have addressed some important challenges in delivering services to people in regional, rural and remote areas. These projects have aimed to provide effective and timely specialist intervention at key milestones on the care continuum. Six other projects in the evaluation have offered an EACH-level service with a dementia specific focus.

The unique features of Innovative Pool Dementia Pilot projects are described below.

*Projects with a clinical focus operating at the interface of health and aged care services:*

- DBAMS is a specialist service for people with severe behavioural and psychological symptoms of dementia. There are three arms to the project: outreach, intermediate care, and education. The DBAMS outreach service is like a ‘fly in’ squad. A nurse with psycho-geriatric training (clinical nurse consultant or registered nurse) goes to the client, either in a home in the community or in an aged care facility, to complete a detailed assessment of behaviour and develop a behaviour management plan. If the client cannot be managed in the usual care environment and/or needs specialist medical assessment, for example, full medication review and observation, they are admitted to Yathong Lodge, the DBAMS intermediate care facility, for intensive clinical work-up and observation.

The DBAMS outreach model has addressed significant unmet need for psycho-geriatric specialists in regional and rural communities of southern New South Wales. DBAMS has increased the capacity of aged care services in the region to provide specialist support to people with high and specific dementia-related needs. The establishment of a specialist team of clinicians provides valuable professional support to the few psycho-geriatric nurses who travel thousands of kilometres each week to perform client assessments.

In its first year of operation, the DBAMS education program delivered education to over 1,000 people across 19 locations in southern New South Wales, including care professionals and family carers of people with dementia.

- DRAH is a model of high level case management in an Aged Care Assessment Team (ACAT). A shortage of geriatricians and psycho-geriatric specialists (nurses and medical practitioners) in the Northern Rivers area of NSW means that people with dementia can find it difficult to obtain an accurate diagnosis of dementia and dementia-related or exacerbated conditions. These difficulties often lead to complications in the provision of care at home by family and delays in accessing formal assistance. DRAH enables the North Coast ACAT to provide an intensive case management service, facilitating access to medical specialists via the use of telehealth technology, when required for diagnostic purposes, right through to linking care recipients and their family carers into the system of formal services through a partnership with Clarence Valley Council Community Services. DRAH is one of the first formal collaborations between health and community

services in the region. Through DRAH, ACAT involvement continues beyond the usual period of ACAT assessment to ensure that medical diagnosis is achieved and appropriate services are established.

- NEDID operates within Austin Health, a large provider of health and aged care services in metropolitan Melbourne. Austin Health had previously run a *Trial at Home* project, which demonstrated that a high proportion of dementia patients in Austin Health hospital wards, who would ordinarily be given no option other than residential aged care following hospitalisation, could in fact return home with an appropriate level of support. NEDID accepts clients from Austin Health facilities and from the wider community. The project ensures that people referred from hospital wards receive all necessary physiotherapy and occupational therapy assessments prior to discharge and that in-home services are in place by the time the client arrives home. NEDID is able to help people with dementia avoid hospitalisation through its placement within a health service. NEDID has made a concerted effort to educate acute care staff that residential care is not the only option for high care dementia patients following hospitalisation.

The multidisciplinary team conducts weekly case conferences to monitor client progress. NEDID clients and their family carers receive a high level of support from the team. This project services a region with a high culturally and linguistically diverse population and provides an interpreter/translation service to assist culturally and linguistically diverse clients.

An important finding in relation to specialist behaviour assessment and management for people with dementia is that people who might be precluded from accessing a care package because of severe behavioural and psychological symptoms are more likely to be able to remain at home through package care if they are also 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 these symptoms of dementia 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 homes with limited expertise in specialist dementia care. Priority attention should be given to expanding this type of service provision in locations where specialist services are presently difficult to access.

*Care package projects with a non-clinical, high care focus:*

One short-term intervention project, Flexible Care Service, and four long-term care projects (RSL Care Pilot, Ozcare Packages, South Brisbane and Gold Coast Pilot, and Dementia Care in Alternative Settings) offered a level of package care that was not widely available at the time the Pilot was established. The focus of these services was ongoing intensive case management, high and flexible respite care, high weekly hours of care, high level carer support (education, counselling and referral) and a dementia-specific focus to service delivery. Dementia-specific care requires rostering flexibility with experienced care workers who are able to manage resistant, sometimes unpredictable clients and provide appropriate support to family members. These features plus high hours of care not widely available through mainstream care packages.

Individually, the projects differ in their targeting or in specific aspects of service delivery:

- South Brisbane and Gold Coast Pilot exclusively targets people from culturally and linguistically diverse communities, providing bilingual care workers, two care workers for respite periods (one worker stays with the client while the other provides bilingual support to the carer for times away from home, for example, for shopping and medical appointments). The project matches care workers to the cultural background of the client and offers culturally-specific fresh food services. Twenty-four hour emergency assistance is another important feature of this project that is in limited supply from mainstream services.
- RSL Care Dementia Care Pilot (RSL Care) and Dementia Care in Alternative Settings (DCAS) operate in metropolitan areas. These projects are able to offer more hours of care per week than an average Community Aged Care Packages (CACP) service and a dementia-specific service. RSL Care Pilot offers bilingual support to culturally and linguistically diverse clients but targets people with dementia high care needs of all backgrounds. High level respite care is available. In the reporting period 40% of project expenditure was recorded against respite services. DCAS offers up to 24.5 hours of care per week, which is in excess of a standard EACH package. DCAS offers the most comprehensive range of respite care services seen in the Pilot. DCAS respite offerings are designed to meet the differing needs of different groups of primary carers and this is achieved through a combination of in-home, special-purpose day unit respite and overnight respite.
- Ozcare Packages services a large regional and rural area of southern Queensland. The cost of transport to service high needs clients in these communities would normally preclude the delivery of high hours of direct care from a CACP service. Through flexible funding, Ozcare is able to guarantee higher hours of care while absorbing the high transport costs and other associated costs of staffing a service that operates across a large geographic area. High respite care provision is a main focus of the project: delivery of respite care consumed 47% of project expenditure in the reporting period.
- Flexible Care Service (FCS) is also a dementia-specific comprehensive case management and care package service. This project was originally proposed as a long-term care intervention but was implemented as a short-term intervention at the request of the Department of Health and Ageing. People referred to FCS, like the client groups in long-term package projects, have almost always reached a crisis in care, through death or sudden illness of a primary carer or carer burnout. FCS case managers are social workers who provide high level support to families in difficult circumstances to help stabilise the care environment and introduce required support services. High and flexible respite care is an important tool in this process. *annecto*, the service provider, operates a 24-hour rapid response system (Emergency After Hours Response Service). FCS clients are introduced to this system so that after the period of FCS service they continue to be able to access emergency assistance.

FCS, like other short-term care projects, has faced considerable difficulty in discharging clients to an appropriate level of support. Administration of the project required close to 100% occupancy and this added further pressure, proving difficult to achieve in a flow-through pilot for high needs clients (this level of occupancy monitoring also caused difficulties for the other project in Victoria, NEDID). FCS was not designed with a clinical or transitional care focus. The service model more resembles that of the long-term care package projects in all respects except that the planned duration of care demands that discharge planning starts within a month of client commencement. The need to discharge

clients to other services after establishing a rapport and building confidence is clearly problematic for care recipients, family members and the service provider.

The most compelling evidence that pilot services offer new care choices is found in responses to the Care Experience Survey. The following vignette, one of a number in this report, came from a relative of a client writing of their experiences before and during the Pilot. Before starting with a project the client was receiving formal care from two service providers in addition to care from family but needed 'more hours and therefore more active assistance with bathing, toileting, dressing, medication, meal preparation and at night, changing into sleepwear and getting to bed'.

This was the family's description of previous care:

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

The Dementia Pilot long-term care package offered the client a higher level of service with greater care coordination:

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

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

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

The family particularly liked:

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

*Projects with innovative respite services:*

Two new choices in respite care provision have emerged from the Pilot. One is The Sundowner Club, a project in Adelaide, South Australia, designed to meet the special needs of clients who experience sundowning behaviour. 'Sundowning' is used to describe symptoms experienced by some people with dementia that tend to manifest in the late afternoon and early evening, such as an increased tendency to wander or become agitated. Sundowning behaviours typically occur outside usual business hours and cause distress for carers and others concerned for the safety and wellbeing of the person with dementia.

The Sundowner Club is an evening meal and socialisation program. Clients are collected at their home address and transported to The Sundowner Club by bus where they help prepare a home cooked meal and dine with other members of the club in a small group supported setting (maximum eight clients). An activity program is available during these sessions, from 3.00 pm to 8.00 pm Monday to Friday. This project has proved popular with people who had become socially withdrawn due to dementia and provides a valuable opportunity for family carers to pursue their own interests, uninterrupted, of an evening.

The other innovative respite service is part of the DCAS long-term care project in Perth. Southern Cross Care WA, the approved provider, contributed two retirement village units for the project to operate a day respite service. Small numbers of clients can attend at any one time and benefit from the homelike setting with self-directed activities that cater to

individual interests. Volunteers from the retirement village socialise with the clients and assist respite care workers.

Below is a tabular summary of the main features of the projects. A tick against an aspect of service delivery indicates that this has been a main focus for a project and that the project appeared to be successfully achieving its objectives in this area. 'P' indicates that a project has obvious additional potential, even though the particular aspect of service delivery indicated was not an intended focus or was not relevant to the group targeted during the Pilot.

In time, the new care choices seen in the Innovative Pool Dementia Pilot might come to be viewed as forerunners to EACH Dementia packages. The new EACH Dementia Program is aimed at those at the highest end of the community care continuum. Packages will provide the same full range of services that 'general purpose' EACH packages provide. However, additional specific services and approaches related to the special needs of care recipients with dementia will be considered.

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

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

The evaluation tracked the status of consenting clients who were accepted into short-term care projects from June to October 2004 and consenting clients who were already in or who were accepted into long-term care projects in the same period. Nine DCAS clients had ACAT approval for low level residential care; all other clients had ACAT approval for high level residential care. In addition to the results of ACAT assessments, there is evidence in the evaluation data that people accepted into the projects were at risk of imminent admission to residential care but for the availability of Pilot services.

Responses to the Care Experience Survey articulate the strong desire to continue with care at home. However, the strain on carers from long periods of caring with inadequate support, often combined with full-time employment, is also telling in the responses. This report presents some of those responses and reports on the support needs profiles of clients to demonstrate the tension that exists between desire of, and for, a care recipient to remain at home and the practical issues involved in making that possible.

The evaluation concluded that pilot services do enable clients to live longer in the community and the evidence is summarised below. Two factors have limited the influence of projects on long-term care outcomes:

1. Late referral for formal service intervention in many cases – 41% of care recipients had care needs equivalent to high level residential care but had not received assistance from government community care programs prior to referral to a pilot project.
2. Short-term care projects have been unable to source sufficient numbers of high care packages for post-discharge ongoing support of clients.

Recorded accommodation outcomes need to be viewed in this context.

### **Short-term care projects — 56.5% of clients still living at home**

More than half of the community-based clients of short-term care projects were still living at home when contacted for follow-up in the first half of 2005. Forty-eight of the 85 community-based clients in short-term care projects (56.5% of this group) were still living at home in the community and 26 clients (30.6%) had entered permanent residential care (7.1% deceased). Nine of the admissions to residential care were admissions to low-level residential care, indicating that some clients had reduced care needs at time of entry to a facility compared to their level of assessed need at time of entry to the Pilot. A mean of 231 days had elapsed between date of initial needs assessment for Pilot services and date of follow-up for clients who were at home (range 78 to 336 days), which is the average number of days that each of the 48 clients had so far avoided high-level residential care. Living alone was found to be the only client characteristic to be significantly correlated with discharge outcome, that is, residential status immediately upon discharge from a project (Chapter 4).

Past clients of short-term care projects (community-based during the Pilot) who were found to be still living at home were being supported by a variety of community care programs including EACH packages (eight), CACP (six), Home and Community Care Program (HACC) or Veterans' Home Care (12), and multiple programs (13). The evaluation found indications that clients discharged from pilot short-term care interventions to a HACC or similar service were less likely to be still living at home when contacted for follow-up than



clients discharged to a care package. The program sources of funding (for example, CACP, HACC, EACH or National Respite for Carers Program etc) for ongoing support of community-based clients were commonly found to have changed between discharge from the Pilot and follow-up in 2005. The observed patterns of admission to residential aged care according to discharge community support arrangements and fluidity of formal care sources of funding in the post-discharge period indicates that a straightforward examination of discharge outcomes is unlikely to give a reliable picture of longer term accommodation outcomes and cost savings from short-term care interventions.

DRAH and DBAMS help clients to avoid hospitalisation for dementia, delirium and other mental and behavioural disturbances associated with or complicated by dementia by providing a complete alternative to assessment and treatment in hospital. It is estimated that DBAMS (16 packages) produces an annual saving of 230 hospital patient days through hospital avoidance; DRAH (15 packages) produces an annual saving of around 200 hospital patient days through hospital avoidance and early supported discharge.

NEDID supports clients in the transition from hospital to home; without this service all clients who have been referred to NEDID by acute care facilities would have needed to transfer to residential care.

All short-term care projects reported difficulties in discharging clients to appropriate long-term support programs. The use of multiple support programs may not provide an ideal solution to a shortage of high care packages if it results in multiple service providers and poor care coordination. Data collected for the evaluation show that clients with high levels of ADL and cognitive impairment were discharged to HACC and CACP services, presumably to receive a lower level of service than was available from pilot projects. Measures of client need dispel any notion that lower levels of service upon discharge were associated with reduced need for assistance.

Suboptimal discharge support arrangements may have resulted in more people entering residential care between date of discharge and date of follow-up than if more high care packages had been available for ongoing care.

### **Long-term care projects — 53.2% of clients still living at home**

Likewise, over half (53.2%) of evaluation clients in long-term care projects were still living at home when contacted for follow-up in 2005 and 71 of these 75 clients were continuing with a pilot project. Approximately 30% of the group had entered permanent residential care (27% high level care and 3% low level care), on average 101 days after date of entry to a project.

The long-term care package projects were established over a number of months and this limits the usefulness of between-project comparisons of average duration of service and proportions of clients who entered residential care. Average durations of service calculated from the data (an average of the number of days between service commencement and date of discharge or date of follow-up of individual clients) are minimum estimates because follow-up truncated the service episodes of continuing clients. By completion of follow-up in April to June 2005, average per client days of service ranged from 257 to 349 days, by project. The longest recorded service period was 397 days, for a client who was continuing in a pilot project at time of follow-up.

There is strong evidence in the recorded accommodation outcomes of care recipients who participated in the evaluation that the long-term care package services enable people to live at home in the community for longer than would otherwise be possible. We base this conclusion on an assumption that clients were at imminent risk of entry to permanent

residential care when referred to pilot services – a fair assumption given the levels of impairment and self-reports of carer strain. It is acknowledged that some differences in the needs profiles of the client groups have come about by different targeting strategies.

Further evidence was found in the indicators of carer wellbeing collected and analysed for the evaluation. A key question is how so many clients with severe cognitive and ADL impairment were still at home at the time of referral for pilot services. This of course has to do with the support available from families, and primary carers continued to play a major role in the provision of care during the Pilot. In many cases the crisis that triggered a referral to a pilot project involved carer strain and consequent breakdown in the provision of care at home.

Service activity and expenditure profiles of the projects show a high component of respite care and other forms of carer support. Repeated measures of carer strain and carer psychological wellbeing from the Caregiver Strain Index and General Health Questionnaire respectively showed significant overall reductions in levels of carer strain over time and improved self-reports of well-being (52% of carers reported reduced carer strain; 58% reported improved psychological wellbeing). Although it is not possible to attribute all reported improvements to project interventions, many carers used the Care Experience Survey to directly attribute their sense of improved wellbeing to pilot services and this is likely to have been a key factor in helping many clients to stay at home.

All project coordinators suggested that the ideal form of ongoing community care for members of the target group is a dementia-specific EACH package. Short-term care projects identified an EACH package as the ideal outcome for most discharged clients. EACH packages were either in very limited supply or were not available at all in the projects' service areas at the time of the evaluation.

AIHW discussions with service providers for the Pilot predated the announcement of the Extended Aged Care at Home Dementia (EACH Dementia) program in the 2005 Federal Budget (part of the initiative *Helping Australians with Dementia, and their Carers – Making Dementia a National Health Priority*). The new program consists of 2,000 new flexible care places allocated over three years:

- 667 packages to be released in 2005–06
- 667 packages to be released in 2006–07 (indicative releases)
- 666 packages to be released in 2007–08 (indicative releases).

## **What is the cost of the services per client per day?**

Flexible care subsidy paid to care package projects ranged from \$79.82 to \$106.83 per allocated place day. These prices reflect the cost to the Australian Government for purchase of services on behalf of clients.

Long-term care package projects charged client co-payments of up to \$7.00 per day in line with community care policy guidelines. Many clients received a discount or fee waiver due to financial hardship. DRAH and FCS short-term care projects did not charge client fees. FCS indicated that the overhead of administering client co-payments was unsustainable for short service periods and this led to the decision to forgo income from co-payments.

In comparison, the basic residential care subsidy payable by the Australian Government for care of a person in an aged care facility at Resident Classification Scale (RCS) level 2 was between \$107.10 and \$109.25 per day on 1 July 2004, depending on state/territory location of

a residential service. The range of supplementary subsidies for residential care is not considered here but could apply to members of the target group. People who live in residential care facilities contribute towards the cost of accommodation in amounts negotiated between provider and client.

Projects with a clinical focus such as DBAMS and DRAH short-term care interventions provide a service that brings people with dementia into contact with specialist medical services. Thus, in these projects part of the service episode would otherwise be performed in a hospital or through outpatient visits to clinics and medical specialists, incurring out-of-pocket expenses and costs to Medicare and/or state health budgets. Care in a hospital setting would cost between \$500 and \$750 per day but hospital care is not considered equivalent to the care provided by DBAMS and DRAH since the pilot services allow people to be assessed and assisted in their home environment. This avoids the disruption of transfer to hospital and the negative effects of hospital environments for people with dementia.

Arguably, these short-term clinical interventions are best delivered in a community setting if possible. Assessment and diagnosis in the context of dementia care encompasses social and medical considerations and requires a high level of input from carers, ideally with advocacy. In the hospital setting it is often difficult for family members to be present when treating physicians are available on their rounds and there is no automatic day-to-day advocacy to assist carers in their interactions with specialists. The pilot projects have demonstrated that this interaction can be critical to achieving the best possible outcomes for patient and carer.

Other available service options such as those that many clients were discharged to on leaving a short-term care project, or which clients were accessing before joining a pilot project, include CACP and HACC services. The cost of these services to government is lower than the rates of flexible care subsidy for pilot services, for example, CACP subsidy at 1 July 2004 was \$32.04 per day. However, these types of services would not meet the needs of most people in the Pilot; evidence of this is in the support needs profiles of clients, the fact that a high proportion of clients discharged from pilot projects onto HACC or CACP were discharged onto multiple support programs (hence, the cost is higher than the CACP subsidy rate in many cases), and in reports from family members that multiple service providers, less than 10 hours of formal assistance per week, or poor or no service coordination all contribute to decisions in favour of residential aged care over community care.

A more relevant question would appear to be what price we expect to pay to help people with dementia to live at home when home care is the preference of many families. The subsidy rate for an EACH package may not result in a saving to the public purse compared to residential care subsidy (during the evaluation levels of expenditure in the short-term care projects reached or exceeded EACH-level subsidy). Thus, an important issue highlighted by the Pilot is consumer preference and quality of life through quality dementia care. Less expensive, more readily available forms of community care naturally result in higher short-term savings but are unlikely to produce long-term savings or the best possible outcomes for clients because family members would continue to bear an unsustainably high share of the real cost of care.

## **Pilot strengths and weaknesses**

Through the Innovative Pool Dementia Pilot new and innovative specialist services have been developed to meet the diagnosis and specialist assessment and management needs of people with dementia in regional and rural areas. These services have been trialled in areas

that ordinarily have limited access to geriatric and psycho-geriatric expertise. The three types of short-term intervention – dementia-specific case management capacity in an Aged Care Assessment Team, outreach service for behaviour management in dementia care, and transition care packages – show considerable potential to operate alongside ongoing care packages of in-home ADL and carer support.

It was found that flow-through models of 8–12 weeks duration are well suited to highly specific, targeted interventions such as specialist assessment or transitioning between care settings. These interventions have a well-defined goal that is usually achievable within a time-limited period. The Pilot has not provided strong evidence that the care needs of people in the target groups are relenting to the point that discharge to low level community care would be an expected outcome following a short-term intervention. Flow-through services should ideally operate alongside a supply of ongoing high care packages to maximise the long-term benefits of short-term interventions by ensuring care continuity and consistent levels of service for care recipients and family carers.

Occupancy targets of over 90% that some short-term care projects were subject to are difficult for a provider to achieve in a flow-through service for the target group. Pilot service providers reported having to increase the number of experienced case managers to cope with the unanticipated demand for case management and it is unlikely that they would be able to continue to deliver the high level support over the longer term unless appropriate discharge support arrangements can be more readily sourced. Based on the experiences of short-term care projects, ‘high level case management and coordination’ equates to a one case manager per 8–10 clients (lower staff to client ratios might be manageable for an established and ongoing client group).

A higher than anticipated case management effort in short-term care projects was largely related to discharge planning. The optimal exit strategy for clients discharged to the community from these projects was most often an EACH package but these were hard to source. Changes in formal care arrangements and program sources of funding, typically involving multiple aged care funding programs, in the period between discharge from a Pilot project and follow-up in mid-2005 were commonly observed among people discharged from short-term care packages. Some family carers continued to seek the involvement of project coordinators in the months following discharge of their care recipient. This tended to occur when ongoing community support arrangements were not providing the same high level case management service delivered by the Pilot.

Projects that operate in rural and remote areas face high travel costs for staff. For example, Ozcare estimated that in the service region for Ozcare Dementia Packages, staff travel time runs to 1 hour per 7 hours of delivered client care (Ozcare covers the cost of staff travel time and encourages the use of fleet vehicles). Pilot funding has allowed a number of projects to absorb high travel costs while still delivering high hours of assistance to care recipients. Escalating fuel costs have a significant impact on take-home pay for workers and community care workers need protection of real wages if the workforce is to meet growing demand for services.

Respite care has emerged as a central tenet of service delivery in most projects and two innovative respite care models were demonstrated. The Sundowner Club offers a social outing for clients at a time of day that respite is generally unavailable. A day respite unit operating from a Southern Cross Care WA retirement village in the Dementia Care in Alternative Settings caters to small groups of clients in a home-like setting, an ideal model for clients with primary carers in paid employment and clients who may not adjust well to large groups or residential settings. All projects that delivered comprehensive in-home

support used respite care to introduce formal services to care recipients new to community care and to diffuse difficult home situations at point of referral. Projects demonstrated flexibility in the provision of respite care by offering a range of respite settings to meet individual client and carer needs.

The Pilot has offered service providers greater scope to address the special needs of people from culturally and linguistically diverse backgrounds through the provision of interpreters and translators and bilingual care workers. South Brisbane and Gold Coast Innovative Dementia Care Pilot has been able to double the rostering of carer workers to provide assistance to a primary carer with English as a second language for appointments and shopping in parallel with in-home respite care, culturally specific food services, and a matching of care workers to the language and cultural background of clients.

Project coordinators and care managers have paid close attention to limiting the number of carer workers who attend each client to no more than three and more ideally to one or two people. Judging from responses to the Care Experience Survey, most arrangements were satisfactory for the care recipient and family carer(s). Some relatives said that too many people were involved in service delivery and that this caused anxiety and fear in the person with dementia especially if they were alone during the day when workers called. One family requested that the evaluation highlight the need for care workers to be clearly identified through visual means such as photo identification, uniform, or company logo, so that the person with dementia can feel confident about allowing callers to enter the home.

It is not always possible to keep the number of care workers to the desired minimum because of staff leave and other complications especially in services that operate across large areas and involve high staff travel time. The inevitability of staffing difficulties that arise from time to time and the fact that enough survey respondents mentioned the number of care workers suggests that identification of workers in dementia care, and community care for older people more generally, is an important quality and safety issue.

The Pilot has highlighted workforce issues in servicing the needs of the target group. There is a need for higher levels of training – several projects reported that the basic level of training from a Certificate III qualification may not adequately equip staff to work with clients who have high dementia-related needs, unless staff have previous, extensive experience in the field. Access to dementia-specific training for staff in regional and remote areas is a significant issue and as rising fuel costs increase the cost of travel, professional development opportunities are likely to be limited even further.

The message in responses to the Care Experience Survey is clear. Families have confirmed that by providing more hours of assistance, coordination from one point of contact, and specialist help for diagnosis and behaviour management, the projects have helped to improve the longer term outlook and quality of life for Pilot participants with dementia and their carers.

