

**National evaluation of the
Aged Care Innovative Pool
Disability Aged Care Interface
Pilot**

Final report

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**National evaluation of the
Aged Care Innovative Pool
Disability Aged Care Interface
Pilot**

Final report

**Cathy Hales
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2006

Australian Institute of Health and Welfare
Canberra

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Abbreviations

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
ACAT/ACAS	Aged Care Assessment Team/Service
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
AIP	Ageing In Place (pilot project)
BSCOC	Broad Screen Checklist of Observed Changes
CACP	Community Aged Care Packages
CPDAC	Cumberland Prospect Disability Aged Care Pilot (pilot project)
CSTDA	Commonwealth State/Territory Disability Agreement
CT	Computerised topography
CWPDA	Central West People with a Disability who are Ageing (pilot project)
DACS	Disability Aged Care Service (pilot project)
DADHC	New South Wales Department of Ageing, Disability and Home Care
DALP	Disability and Ageing Lifestyle Project (pilot project)
EACH	Extended Aged Care at Home
FACP	Interlink Flexible Aged Care Packages (pilot project)
FIM	Functional Independence Measure
FNCDAC	Far North Coast Disability and Aged Care Consortium (pilot project)
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
MS	Multiple sclerosis
MSV	Multiple Sclerosis Society of Victoria

NSDACP	Northern Sydney Disability Aged Care Pilot
RCS	Resident Classification Scale
RPDH	Renmark Paringa District Hospital (SA)
SDAC	ABS Survey of Disability, Ageing and Carers

Overview of the evaluation

About this report

This overview chapter provides a summary of the context and findings of this evaluation. It discusses each evaluation question and provides overall comments on the strengths of the supplementation model of aged care for people ageing with a disability and some unresolved issues at the interface of aged care and disability support programs.

The report itself then commences with Chapter 1, which contains a discussion of the origins of the Innovative Pool Disability Aged Care Interface Pilot, followed by a brief survey of the literature on key issues related to ageing in people with disabilities. Pilot participants are profiled in Chapter 2. Chapters 3, 4 and 5 address the three key evaluation questions in turn, using summaries of data and information collected during the evaluation. Summary results from the Care Experience Survey are presented in Chapter 6 to provide feedback from staff in the participating accommodation services on the needs of clients and the Pilot experience.

Brief background

The Disability Aged Care Interface Pilot was established under the Aged Care Innovative Pool, an initiative of the Australian Government Department of Health and Ageing. Through the Innovative Pool, a pool of flexible care places has been made available outside annual Aged Care Approvals Rounds to trial new approaches to aged care for specific population groups. This particular Pilot was aimed at people with aged care needs who live in supported accommodation facilities funded under the Commonwealth State/Territory Disability Agreement (CSTDA) and who are at risk of entering residential aged care.

The CSTDA provides funding for specialist services for people with disabilities of all ages. People who are accepted into the Disability Aged Care Interface Pilot live in CSTDA-funded accommodation services (group homes and smaller residential services for people with disabilities) and may receive other types of CSTDA-funded assistance in addition to living support from an accommodation service provider. Pilot services were to deliver additional services, tailored to individual needs, which are aged care specific, in order to help clients remain in their current disability-funded living situations for as long as possible.

Pilot projects commenced operations in the period between November 2003 and December 2004 and all Pilot providers were required to participate in a national evaluation. This is a report on the evaluation of nine projects in operation across Australia: four in New South Wales, one in Victoria, two in South Australia, and one each in Western Australia and Tasmania (Table 1.1). The evaluation was conducted by the Ageing and Aged Care Unit of the Australian Institute of Health and Welfare (AIHW) under the Memorandum of Understanding between the Institute and the Department of Health and Ageing for the provision of statistical and information services.

An evaluation framework developed by the AIHW was released for consultation in December 2003. The protocol was refined following consultation and approval for the evaluation project to proceed was received from the AIHW Ethics Committee (Register

Number 353).¹ Data collection commenced in June 2004 and evaluation activities continued into 2005 for inclusion of the late-start Cumberland Prospect project and for the submission of two quarters of financial results from all projects. The submission of additional data and information in September 2005 from two projects marked the end of the data collection period.

Evaluation questions

The AIHW was briefed to address three key evaluation questions:

- 1. Do Pilot services offer new care choices that meet the needs of older Australians?**
- 2. Do Pilot services enable clients to either re-join or live longer in the community (defined as long-term accommodation settings other than residential aged care and hospitals)?**
- 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?**

These questions define the scope for an evaluation of aged care pilots; they make no explicit reference to the nature or level of the specialist disability services provided to Pilot clients. The evaluation was further required to report on identified strengths and weaknesses of the Disability Aged Care Interface Pilot.

Aged Care Assessment is a cornerstone of service provision in the Pilot. It forms the basis of eligibility assessment and was designed to define the conditions under which Pilot services would supplement specialist disability services. Specifically, a person living in a participating CSTDA-funded supported accommodation facility could be considered for Pilot services if they were assessed by an Aged Care Assessment Team (ACAT) as requiring a level of care equivalent to at least low level residential aged care. Since people who receive CSTDA-funded accommodation services experience a significant level of disability, quite apart from ageing-related disability, processes to identify aged care specific needs in Pilot clients were a focal point for evaluation. Needs identified through comprehensive assessment, involving ACATs, disability services, and Pilot project teams, have formed the basis of care planning and service delivery. As the Pilot aimed to find ways to address issues at the interface of specialist disability services and mainstream aged care services for people with disabilities who live in supported accommodation, it was relevant to also consider the interaction between clients' assessed aged care needs, primary disability, and living situations. Three additional questions pertaining to aged care specific needs were therefore thought to be of interest:

- (i) What type of aged care specific needs are seen in members of the Pilot target group?
- (ii) Can care needs related to ageing processes be distinguished from disability support needs, and how?

1 A submission was also made to the Department of Health and Ageing Ethics Committee.

- (iii) What types of community-based aged care services are needed to support people with disabilities who are ageing?

Project coordinators, steering committees and participating disability service providers were the main sources of information for the evaluation. Disability support staff with an ongoing client support role assisted project coordinators in the completion of client profiles and functional assessments for the evaluation. A Care Experience Survey, designed to capture the experiences of individual clients, was in most cases completed by disability support workers and thus lends a disability services perspective to the evaluation. It is possible that factors which impact on service delivery at a regional or state level, or within a particular service provider's operations are reflected in responses made on behalf of clients in a systematic way. In designing the evaluation, focus groups were considered as possibly the best means of directly capturing client experiences; however, this approach was precluded by a number of practical considerations including the scale and timeframe of the evaluation and geographic distribution of pilot services. Lack of direct feedback from care recipients is an acknowledged limitation of the evaluation that has meant the evaluation relied on case studies to describe the impact of Pilot services on consumers.

Profile of Pilot clients

One hundred and sixty-five recipients of Pilot services were included in the national evaluation. A range of disability groups is represented in the group – 75% of clients at the time of the evaluation were people with intellectual disability and the remaining 25% included people with neurological disability (including 16 clients with multiple sclerosis in the MS Changing Needs project), acquired brain injury, physical or multiple disabilities. Apart from MS Changing Needs (in which all clients have multiple sclerosis) and the Northern Sydney Disability Aged Care Pilot, the participating accommodation service providers provide services mainly or exclusively to people with intellectual disability.

Pilot projects have generally targeted eligible people aged 50 years or over, although allowance has been made in special circumstances relating to premature ageing. Excluding participants in the MS Changing Needs project, client ages at the time of the evaluation ranged from 32 to 88 years, with a mean of 57.5 years. Eighty-five per cent of participants were aged 50 years or over. MS Changing Needs was found to be servicing a younger group of clients, with ages ranging from 32 to 59 years, reflecting the relatively young ages at which a need for 24-hour intensive nursing care can arise for people with multiple sclerosis. One other project, Disability and Ageing Lifestyle Project (DALP) in South Australia also serviced a relatively younger group of clients: four of the eight DALP clients were aged less than 50 years and 56 years was the highest recorded age in this project. All DALP clients at the time of the evaluation were people with intellectual disability.

Overall, the evaluation group comprised approximately equal numbers of males and females. Slightly more males than females fell into the 60–69 year age group (26 males versus 18 females), whereas females outnumbered males in the 70 years and over age group (12 versus 7).

Government pensions, mainly the Disability Pension and the Age Pension, were the primary source of income of most participants.

At the start of the evaluation 146 participants were living in domestic scale accommodation in the community (group homes), comprising residences owned or leased by disability service providers. Among the 19 participants who were living in larger scale disability

accommodation were all seven clients in Ageing In Place, Tasmania, living in a hostel operated by Oakdale Services Tasmania.

Some relocations occurred during the evaluation. One small institution participating in the Northern Sydney Disability Aged Care Pilot closed and Pilot participants along with other residents were relocated to group homes. In another case, a private landlord refused a minor home modification that was needed to accommodate the needs of an older client so the disability service provider relocated the household to another residence and it was found that all residents benefited from the move to superior accommodation. The critical aspect of ageing in place for members of the target group is not so much remaining at the same physical location but living in a familiar disability-supportive setting with long-term companions for as long as possible.

Overall support needs and aged care specific needs

Approximately 61% of participants experienced severe or profound limitation in at least one area of core activity at the time of joining a Pilot project. For each area of core activity (self-care, communicating with others, and mobility) at least one-third of participants recorded severe or profound activity limitation. The proportion of people who recorded this level of limitation is highest in the area of self-care (45% of participants). A relatively high proportion of Pilot recipients experienced severe or profound communication limitation (31%). This characteristic distinguishes the group from the wider population of community-dwelling older people in receipt of formal assistance for whom rates of severe or profound communication limitation are much lower than rates of severe or profound self-care and mobility limitation (see, for example, AIHW 2004:Table 7). A considerably higher proportion of people in the MS Changing Needs project compared to other projects recorded severe or profound core activity limitation (94%).

All participants required assistance with the instrumental activities of daily living (for example, domestic work, shopping for food and clothes, travelling away from home, management of personal finances, medication use, and using the telephone).

Measures of core activity limitation and need for assistance in the activities of daily living recorded for the evaluation do not distinguish areas of aged care specific need from areas of support need related to a person's primary disability. Nor do they pinpoint areas of increased support need that are strictly related to ageing. Those areas were identified by project coordinators, disability support staff and Aged Care Assessment Teams (ACAT) through joint comprehensive assessment of individual clients.

Following needs assessment, project teams and disability support staff jointly develop a care plan for the delivery of services to each client. In this way the service profiles of clients reflect the agreement reached between project teams and disability staff of clients' aged care specific needs. Indicators of aged care specific needs in data and information collected for the evaluation are found in responses to a Care Experience Survey question (*What are your [the client's] most pressing age-related needs?*) and, for clients with a primary disability of a non-progressive nature, in measures of change over time in need for assistance in activities of daily living.

Systematically documented evidence of support needs increasing or changing over time prior to a client's referral to a project was available from some of the participating accommodation service providers. Much of the evidence for needs assessment was gathered through informant interview. A few accommodation service providers had been tracking client progress for some time using tools like the Broad Screen Checklist of Observed

Changes (Minda Inc.) which, together with informant interview, helped to inform Pilot screening and assessment processes. Project coordinators developed their own tools for the collection of relevant details covering personal histories, health conditions and medication use, and the physical, psychological and social domains of individual functioning. Coordinators performed a substantial amount of up-front screening of referrals including home visits prior to referring people to an ACAT. ACAT assessment was streamlined through this pre-screening and assessment by project coordinators and through the channelling of referrals to specific ACAT members with professional interest and experience in aged care assessment for people with disabilities.

Comprehensive assessment in the Pilot enabled clients to be seen as people who are ageing and not solely as people with disabilities (or in the even narrower context as consumers of government funded disability services), perhaps for the first time. Projects have addressed a range of issues associated with premature entry to residential aged care in the target group. These include increased need for supervision and activity during day-time hours, need for mobility assistance, continence management needs, need for higher levels of personal assistance, intensive nursing care, physical maintenance programs and age-appropriate social activities and community participation. The main drivers for increasing or changing needs in members of the target group that are associated with growing older include an individual's ageing trajectory (which can be disability specific), the existence of early onset chronic progressive disability, and the reciprocal impacts of ageing and living environments, both built and service environments.

Chapter 1 of this report canvasses issues associated with need for and receipt of community-based aged care in the Pilot target group. Available research literature has tended to focus on the ageing experience of people with intellectual disabilities but it is suggested that many of the issues highlighted, particularly those relating to premature ageing and the impact of disability service systems on people as they age, apply to people with various other types of primary disability. For example, biological ageing may start to occur in a person with a disability who is aged in their 30s, 40s or 50s, depending on their primary disability and life expectancy. The long-term experience of being a consumer of disability services can have a profound effect on social ageing pathways, especially for people with a primary disability that inhibits social independence. A person who lives in disability supported accommodation and who spends a large part of adult life in supported employment, for example, will build a social network through their encounters with disability services. The Pilot has served to further highlight the range of issues that impact on a person with a disability as they reach older ages, some regarded as normal ageing issues and others that are more specific to the Pilot target group.

The supported accommodation services of most clients are geared around the lifestyles of residents who work or participate in day programs and activities outside the home between 9.00 am and 3.00 pm. This presents a number of problems for older residents who need or desire to spend more time at home, as many older people tend to do. Withdrawal from disability employment services and day programs due to age-related functional change can lead to social isolation and inactivity unless there is a seamless transition to age-appropriate levels and types of activity and community participation.

It is helpful to think of the target group in the context of individual ageing more generally. One analogy is the older person who is able to remain at home because they have assistance from relatives and friends. Over time it may become necessary for formal services to supplement the assistance provided by carers to enable the person to continue living in the community. This need for additional assistance occurs as the older person's needs increase to

a point where available support resources are exhausted, or where there is a need for specialist input. In the case of a person in disability supported accommodation service, ageing processes that result in physical frailty and/or cognitive decline can increase the need for assistance in activities of daily living to above the levels that are adequately supported by disability support staff who are also attending other residents in a household. It may also be desirable for staff with expertise in ageing to become involved in the provision of support so that, together, disability support staff and aged care staff can better meet the changing needs of the ageing person. A second analogy is the older person in need of assistance who lives alone at home in the community. Older people with disabilities living in supported accommodation may spend long periods at home alone, or at least without staff in attendance, because their daily routines are different from those of younger, more active household members. Thus, the predominant needs of people in the target group reflect some of the characteristics of older people who live alone and characteristics of the typical older person whose existing supports require supplementation and specialisation if they are to successfully remain at home.

Historically, residential aged care has been the only sanctioned point of interface between community-based disability services and aged care services funded by the Australian Government for consumers of CSTDA-funded supported accommodation services. CSTDA supported accommodation consumers are deemed ineligible for services funded under the Home and Community Care Program (HACC) and Community Aged Care Packages Program (CACP) by virtue of the fact that they live in supported accommodation facilities.² Guidelines for these programs, through which the bulk of government-funded community-based aged care is delivered to the older population, are in part composed to prevent people from receiving similar types of assistance from more than one source of government funding. The CACP Program targets people aged 70 years or over in need of assistance, and people from Indigenous backgrounds aged 50 years or over. Members of the Pilot target group with needs related to premature ageing may therefore also be ineligible for CACP-funded services on the basis of chronological age criteria.

People in CSTDA-funded accommodation currently face four critical issues as they age:

1. In any given area of basic living assistance, such as personal assistance, the level of assistance required by an ageing individual may have increased to beyond that which an accommodation provider can sustain for the longer term. While the types of assistance provided by aged care services and supported accommodation services are similar, a person ageing with a disability may require a substantially higher level of service than the ADL support required by younger adults with disabilities living in the community. The difficulties for accommodation service providers increase with increasing numbers of household members reaching ages at which more extensive support is required.
2. Access to community-based aged care services funded by the Australian Government is restricted because the CSTDA funds a similar range of services; however, an individual CSTDA consumer may not be able to access the full range of CSTDA-funded services.

2 CSTDA consumers who live in private residences may be eligible to receive HACC services, although eligibility would be assessed on a case-by-case basis and depend on the range of CSTDA services available to the person and any overlap between these and the type of assistance sought from HACC. For example, a person living in a private residence who receives CSTDA-funded community support could be deemed ineligible for certain types of HACC-funded assistance because community support involves personal care and domestic assistance. Similarly, CSTDA-funded accommodation support comprises accommodation and 'related services'.

Especially in the area of community participation, an older consumer may require a degree of flexibility in service provision that is not available to them. Also in this vein is the issue of whether local service delivery policy and practice is based on official government policy or assumed government policy.

3. Generic residential aged care is widely acknowledged as unsuitable for younger people with disabilities. While it is also the least preferred aged care service model for members of the Pilot target group, it is the only currently available model of government-funded mainstream aged care service outside the Disability Aged Care Interface Pilot.
4. Members of the group have limited opportunity to accumulate wealth over their lifetimes as a result of long-term significant disability and their opportunity to exercise consumer choice at older ages is therefore constrained.

Community-based solutions to the needs of ageing consumers in supported accommodation services existed within the disability services sector long before the inception of the Disability Aged Care Interface Pilot. These local solutions appear to arise through the vision and fortunate practical circumstances of some service providers, rather than as part of a nationally coordinated approach. Some have involved major changes to built environments to accommodate new approaches to service delivery for consumers of all ages, while others have targeted specific areas of service need among older consumers.

The Disability Aged Care Interface Pilot is a nationally coordinated trial of community-based aged care service provision for people with disabilities made possible by cooperation across levels of government and between the disability and aged care services sectors. The three questions set for the Pilot evaluation are addressed below.

Evaluation question 1: Do Pilot services offer new care choices for people with a disability who are ageing? (Chapter 3)

The Disability Aged Care Interface Pilot offers clients the new choice of government-funded community aged care services delivered into existing disability-funded living arrangements. Assessment services and assistance services are the core elements of Pilot service delivery:

Assessment services

- A collaborative approach to the comprehensive assessment of aged care needs of people referred for Pilot services for the purpose of identifying needs that are aged care specific.
- The involvement of Aged Care Assessment Teams for determining eligibility for aged care at home in the community at a level equivalent to at least low level residential aged care.
- Assessment of dementia care needs.

Assistance services

- Higher levels of personal assistance and a focus on the special needs in this area of people with dementia.
- Increased access to allied health assessment and therapy, and intensive home nursing care.

- Improved access to aids and equipment for age-related needs.
- Attention to needs associated with social ageing – increased opportunity for pursuit of personal interests and community participation for people who would otherwise be without supervision and stimulation for long periods during the day.

Pilot assessment processes and the main types of assistance delivered by Pilot services are described below.

Comprehensive, interdisciplinary assessment of aged care specific needs

Arguably, the single most critical service type delivered to disability services clients through the Pilot is the identification of aged care specific needs through interdisciplinary comprehensive assessment involving aged care services, clients' accommodation services and ACATs. While people living in disability supported accommodation do form part of ACAT usual client group, ACATs are generally called on to assess disability services clients for admission to residential aged care when a decision has been taken by family and/or a disability service provider that maintaining the person at home in the community is no longer feasible. ACAT assessment for older people more generally can be initiated with a view to delivery of a range of service offerings, including both residential and community-based options. In the Pilot, ACAT assessment occurs with a view to providing additional care at home; the Pilot has given ACATs a new, often more appropriate, referral option for clients living in CSTDA-funded supported accommodation.

Referrals are screened and aged care specific needs are identified through joint assessment by the respective pilot service and the client's supported accommodation service before a referral is made to ACAT. On average this initial needs assessment takes 7 hours but the complexity and time taken varies considerably from one client to the next and may involve several home visits over a number of weeks. The rigorous assessment processes were said to be taxing for some clients who did not understand the need for multiple assessments involving different people, often asking similar questions. In some cases project coordinators had to stagger the collection of information over multiple visits for this reason. At the time of the evaluation, an average of 49 days elapsed between referral of a client to a Pilot project and the commencement of assistance services; during this time coordinators performed screening and detailed needs assessment.

ACAT assessments were completed on average within 18 days of receipt of a referral by an ACAT. Pre-screening and initial needs assessment by project coordinators in consultation with disability service providers ensures that all necessary documentation is completed prior to referral to an ACAT. ACAT staff then assess eligibility for aged care services having all the documentation at hand. An ACAT may recommend further assessments, for example, occupational therapy, physiotherapy, nutrition assessments, in consultation with the aged care team and disability support staff.

Given the likelihood that multiple assessments to identify aged care specific needs and required interventions are often required, assessment processes need to be conducted with due consideration for the negative impact that this may have on some clients.

Project coordinators and ACAT members confirmed that it is possible, though not in every case, to distinguish aged care specific needs from the progressive nature of some disabilities. The complexity of an assessment depends on the nature of a client's primary disability, the availability and quality of evidence of changing needs, the assessors' relevant knowledge and expertise, and knowledge of the person's use of and access to specialist disability services over time. For example, behavioural symptoms or safety concerns related to a

person's dementia may trigger their gradual withdrawal from an employment service or day program and such withdrawal can signal that dementia-related cognitive decline has reached a critical level where the person is no longer able to function in group settings without increased support.

It was said that the identification of aged care specific needs relies on the ability to describe with a degree of certainty a client's earlier functional 'steady state', for example, what could he or she do before that they can no longer do, and how did he/she used to interact with others, compared to now? This benchmark of normal life for the person with a disability is compared to current functioning in the physical, psychological and social domains of daily life. For some types of primary disability the detection of age-related functional change is made easier by there being a discernible prior steady state. In the case of a person with Down syndrome who has led a productive and active life, for example, the symptoms of dementia in Alzheimer's disease may present a stark contrast to their previous level of domestic and social functioning. Other visible signs of physiological ageing at relatively young chronological ages in people with Down syndrome help to confirm that social and behavioural changes related to premature ageing have occurred. More complex cases have surfaced in the Pilot, principally related to chronic progressive disability, such as multiple sclerosis, or physical and diverse disabilities that lead to complications over time, as a person ages, that is, where increasing functional decline is part of the nature of the primary disability. International research suggests that people with a developmental disability begin to experience functional decline in their mid-40s to mid-50s. There are suggestions that people with severe physical disabilities, such as those resulting from spinal cord injury and acquired brain injury, begin ageing earlier than the general population, and that some health conditions worsen with increased duration of disability (see AIHW 2000).

Assessment of a person in one three-hour session might not reveal the effects of ageing if information on the 'what', 'when' and 'why' of changing routines has not been documented. Project coordinators and participating ACAT staff believe that routine documentation maintained for many clients, for example, Individual Lifestyle Plans, is often unsuitable for an in-depth assessment of needs associated with ageing and recommend against relying on some of the more standard assessment tools used within the disability sector such as the Service Need Assessment Profile for assessing aged care specific needs. A seeming widespread lack of records tracking client functional and behavioural history hampered or prolonged Pilot assessment processes. Projects reported an influx of inappropriate referrals in the early days, which tended to settle as disability support staff became familiar with aged care assessment and the objectives of the Pilot. The Pilot has encouraged documentation practices that will help to record evidence of functional change and inform future service delivery for Pilot clients.

The Pilot has demonstrated that aged care assessment and service capability exists within some accommodation services. However, a number of project teams remarked on a lack of awareness and insight into ageing processes and aged care interventions among personal care workers in supported accommodation services. Pilot projects appear to have made inroads into helping staff to recognise changes in clients that are age related. Joint assessment has played an important role in increasing awareness and understanding among disability support staff of ageing processes and in deepening and broadening awareness of disability-specific ageing issues among participating ACAT staff.

In addition, the Pilot has highlighted the different philosophical approaches in aged care and disability support. Aged care assessment and intervention has given legitimacy to the notion that ageing processes can create *dependency* (in the aged care lexicon), which can be reduced

or compensated through appropriate aged care intervention. This departure from the conventional disability support paradigm offers a different perspective of physical, cognitive and behavioural change and leads to broader insights into what is happening to disability services clients as they age.

Higher levels of personal assistance

Supported accommodation services tend to structure the provision of assistance around the routine of a majority of household members who leave home to work or attend day activities between 9.00 am and 3.00 pm. Typically staff are in attendance for an early morning shift and a dinner/bed time shift and at other times only passive staffing may be available. During the peak periods all members of the household follow much the same pace for showering, dressing and meals. These are periods of time pressure for staff and the slower pace of older residents places additional pressure on staff. A resident who needs more intensive personal assistance due to increasing physical frailty or loss of cognitive function can consume a high proportion of staff time, diverting attention from other residents. This may mean that the older person's need for assistance is not adequately met. Pilot projects have been able to inject additional staff resources to relieve the pressure on disability support staff and allow older clients to move at a more natural pace.

In the reporting period, 79 evaluation participants (53%)³ received additional personal assistance of between 0.4 and 20.9 hours per week (mean 2.8 hours per week). Projects are able to provide personal assistance at times when clients do not ordinarily have access to assistance from disability support staff and at times when disability support staff might not be able to give personalised attention to an older resident with higher needs. Project coordinators reported that the needs of most clients receiving personal assistance were increasing over time. In Central West People with a Disability who are Ageing, for instance, many of the clients who were receiving up to 10 hours in total support from the project during the 2004 evaluation were receiving between 10 and 20 hours by mid-2005 and much of the increase in total additional support hours was reportedly driven by increasing needs for personal assistance in people who were experiencing age-related functional decline.

Case studies recorded for the evaluation highlight the impact of continence management needs on clients' quality of life and most project coordinators referred to this as an area of unmet need for people with a disability who are ageing. Incontinence impacts on the individual, other residents and staff. Without appropriate management, an incontinent person is at risk of premature entry to residential aged care. Aged care assessment for the Pilot has identified continence management needs in clients and projects have provided aids and staff support to resolve or manage continence needs.

3 Excludes MS Changing Needs and Cumberland Prospect Disability Aged Care project clients.

Case study

During initial screening and assessment, a client, known to a project coordinator through her previous position in disability services, was found to be doubly incontinent but not using continence aids. Disability support staff would routinely shower the client multiple times per day. The suggestion that client, staff and other residents in the home would benefit if the client were to use continence aids was initially rejected on the basis that aids would encourage the client to continue to be 'lazy'. The coordinator argued convincingly that the client had been incontinent for three years and was unlikely to remit – that this was not a case of laziness, but an age-related condition that should be managed in an age-appropriate fashion.

Improved access to nursing, allied health care, aids and equipment

Based on anecdotal reports and case studies submitted to the evaluation it is concluded that limited access to allied health intervention contributes to use of residential aged care services by members of the target group. Nursing and/or allied health assessment and physical therapy have therefore been an important focus of service provision in most projects. Allied health assessment has led to ongoing therapeutic intervention and recommendations for the provision of aids and equipment.

People with multiple sclerosis often enter residential aged care at relatively young ages because of an ongoing need for a level of nursing care that is unsustainable in the disability-funded community accommodation setting. The MS Changing Needs project has delivered 24-hour nursing care, seven days a week to people with multiple sclerosis in a disability-specific group home environment. Without the pilot service these people would have entered hospital or residential aged care to access the required level of nursing care.

In other projects needs assessment involving project teams and ACATs has identified clients requiring specialised allied health assessments. These assessments have led to the provision of aids and equipment including, but not limited to, mobility and continence aids and supplies. Project coordinators and disability support staff reported that sourcing items through government-funded aids and equipment programs usually involves lengthy delays – through Pilot funding, once a need is identified it can be addressed. Other outcomes from allied health assessments have taken the form of individual physical therapy plans involving, for example, hydrotherapy, gymnasium programs and a range of alternative therapies that promote mobility and dexterity to address ageing-related physical decline and the effects on clients' functional capacity of dementia-related cognitive decline. Clients with dementia have benefited from improved access to gero-psychological assessment.

Across the projects, excepting MS Changing Needs, the following proportions of clients received allied health interventions:

- 40% (59 clients) and 38% (57 clients) respectively received physiotherapy and occupational therapy assessment and/or active therapy.
- 21% (31 clients) received an average of 3.6 events per week for physical maintenance, usually delivered under the guidance of a physiotherapist.
- 15% (22 clients) received an average of 1.6 hours per week of alternative therapies.
- 3% (4 clients) received an average of 2.1 hours per week of nursing care and 10 clients 7% (10 clients) received an average of 2.4 contacts for other unspecified nursing or medical services, for example, gero-psychology.

Case study

A client who, through ageing had withdrawn from regular activities, had become inactive, uninterested in life and had experienced loss of physical coordination and fine motor skills. Through a pilot project, the client commenced regular physical therapy: hydrotherapy sessions and fine motor skills development through drawing and colouring. Over time, his illustrations of hydrotherapy progressed from an outline of an empty swimming pool to a colourful and detailed portrayal of a happy swimmer in a pool with lap lanes, surrounded by balloons. The client's changed outlook on life was startling and was evidenced in the mural on the wall. The client's fine motor skills and mood improved, he once again became engaged in household activities, and his quality of life increased immeasurably.

A total of \$18,594 (\$13,781 from project funds and \$4,813 from external sources) was spent across all projects on aids and equipment for clients, most commonly mobility aids, small household items that can be more easily managed by residents with age-related frailty and other aids and equipment of unspecified type. These purchases were made as a result of Pilot project assessments.

Case study

A project coordinator found that a client referred for assessment spent inappropriately long periods in a chair because disability support staff had become unable to transfer the client to her walking frame. As a result of immobility, the client developed continence problems that compounded what appeared to be an already strained relationship with disability support staff. The pilot project supplied a tilt chair at a cost of approximately \$1,700. With the use of the chair the client regained her ability to transfer independently and the toileting issue was resolved.

Increased social participation

Projects have paid close attention to the needs of clients to remain engaged in activity as they age. In some projects, social participation has been a main focus of service delivery for all or a high proportion of clients, for example, Disability and Ageing Lifestyle Project, Flexible Aged Care Packages, both in South Australia; Ageing In Place, Tasmania; and Central West People with a Disability who are Ageing, in New South Wales. Retirement from employment and day programs often leaves people in supported accommodation services without supervision for long periods during the day. This poses a safety risk for those with intellectual disability but can also lead to apathy, behavioural problems, and accelerated physical and cognitive decline.

Pilot projects have assisted clients to decide how to spend their leisure time through a range of self-directed individual pursuits, group outings in the community and encouragement and assistance from staff to contribute to household activities. These activities fill day-time hours during which clients might otherwise be without supervised activity. Increased staff resources help to overcome the expediency of staff 'taking over' in cases where a client takes longer to complete tasks because of frailty or poor dexterity. The intervention of aged care teams encourages and allows clients to complete activities as independently as possible.

Some of the areas of assistance which account for higher number of hours of service delivery per week include domestic, social and community participation:

- 24% (36 clients) were receiving an average of 1.6 hours per week of domestic assistance during the evaluation.
- 39% (58 clients) were receiving an average of 8.3 hours per week in recreation and leisure programs.
- 9% (14 clients) were receiving an average of 4.7 hours per week of living skills development services.
- 30% (44 clients) received an average of 3.3 hours per week of social support.
- 20% (29 clients) received an average of four personal transport trips per week and 10% (15 clients) received an average of two community/group transport trips per week.

The outcome of increased opportunity to participate in areas of life is seen in measures of participation recorded for the evaluation. Paired 'before and after' participation ratings were recorded for 124 clients. These ratings reflect the extent of a client's participation in each of several areas of activity on entry to a Pilot project and later, during the evaluation. Though some clients experienced reduced participation in these domains due to deteriorating physical condition (often related to illness), in each domain 23–40% of clients were reported to have experienced increased participation. Participation levels were reported as stable (or not stated) for between 37% and 59% of clients across the surveyed areas of activity.

The highest rates of reported improvement in participation are in the areas of community and social life (40% of clients showed increased participation), interpersonal relationships (35% of clients were reported to be enjoying improved relationships with other members of their households) and domestic life (30% of clients were observed to be taking a more active role in domestic tasks). These results are consistent with reports from project coordinators and disability service providers that Pilot services provide clients with greater opportunity to take part in activities in and outside the home through care plans that incorporate individually tailored lifestyle and skills development programs and increased day-time supervision and accompaniment.

Evaluation question 2: Do Pilot services enable clients to live longer in the community? (Chapter 4)

The issue of whether Pilot services enable clients to live longer in the community is a complex one. Accommodation outcomes recorded over the evaluation period show stability of residence for a large group of clients despite high variation in support needs among clients. Only 13 of the 149 participants in projects other than MS Changing Needs (8.7%) ceased receiving Pilot services during the evaluation: five clients died, five entered high level residential aged care, two were referred to other programs, and one client no longer needed additional assistance. Clients who entered residential aged care were aged between 50 and 58 years. Four of these clients transferred at between 336 and 368 days after referral to a Pilot project⁴ and the fifth client transferred after just 76 days in the Pilot following medical complications and a sudden and severe decline in health status. There is no known way to measure the impact of the additional assistance on these clients' ages at entry to residential care.

4 Elapsed days in receipt of care services was in some cases shorter because specialist assessments were completed over a lengthy period.

Activity of daily living (ADL) scores were recorded on a scale from zero (total impairment) to 20 points (independence in ADL) using the Modified Barthel Index. Low levels or significant decline in ADL function were exhibited by all five clients who entered residential aged care. Four clients recorded a baseline ADL score at or below the threshold associated with a low probability of being able to remain in the community (12 points). The fifth client was accepted into a project with a high ADL score but experienced severe functional decline between the first and second assessments, which reduced the score to just 4 points at time of discharge.

Low but stable ADL scores (scores of 12 or fewer points on the Modified Barthel Index) were recorded for 48% of evaluation participants who were still with their projects at the end of November 2004. For most older people, the levels of ADL functioning observed in this group would precipitate residential aged care placement unless a committed co-resident primary carer was available to provide intensive support. Pilot clients with low ADL functioning are maintained at home with support from specialist disability services, supplemented by Pilot services. It was said that a common trigger for a change in accommodation setting is progressive and significant functional decline rather than a low level of ADL functioning *per se*.

Uncertainty surrounds the impact of Pilot services on the long-term outcomes of continuing clients because it is difficult to gauge entry levels of risk of admission to residential aged care. For a person to be eligible to receive Pilot services they must be receiving accommodation services from a participating disability service provider, be assessed as able to benefit from the type of flexible care offered by a Pilot service, and be approved by an ACAT for residential aged care. ACAT approval for residential aged care in this context is an unreliable indicator of real risk of entry to residential aged care. Some clients were at high risk of entry to residential aged care when they entered the Pilot due to significant age-related decline or other unmet need that could not be managed in the home environment. One disability service provider estimated that in this circumstance the additional assistance from a Pilot service might help delay a transfer to residential aged care by 6 to 12 months. It was also suggested that the amount of additional assistance made available through the Pilot at the time of the evaluation would be unlikely to forestall transfers for significantly longer periods in the case of those people at imminent risk of transfer to residential aged care at time of referral to a project. For many clients, though, it is unlikely that ACAT assessment would have been sought but for the availability of a Pilot service and there is thus a question about actual risk.

Factors outside the scope of Pilot aged care services were found to have a profound effect on long-term accommodation outcomes for members of the target group. Different styles of housing and staffing arrangements in participating accommodation services, in particular, determine the extent to which aged care specific interventions can modify an individual's risk of admission to an aged care facility as they grow older. The differing service profiles of Pilot clients – some mainly or only community access services (leisure and recreation programs and transport) and others mostly personal assistance and physical maintenance therapy – reflect different levels of frailty but may also reveal levels of unmet need for specialist disability services among older people with disabilities.

Project teams identified a set of risk factors for use of residential aged care services by people living in disability-funded supported accommodation facilities:

- severe mobility limitation that would require, for example, the use of a lifter and the presence of two members of staff for transfers

- a need for extended periods of supervision and assistance during daytime hours when disability support staff are not in attendance
- sleep disturbance and wandering, especially if the accommodation service does not operate with active night staff
- altered psychological and behavioural patterns that impact on other residents and staff
- physical home environments that cannot be suitably adapted for the use of aids and equipment – privately leased homes may present difficulties in respect of the type of modifications that assist to maintain people who are ageing at home
- major health events leading to severe and steady decline in health status.

The following section summarises the types of assistance delivered to clients to assist ageing in place. We use the word 'assist' instead of 'enable' because of the uncertainty about risk and long-term accommodation outcomes and in recognition that enablement is a function of the total system of support provided to a person with a disability who is ageing. An additional 10–12 hours of aged care specific assistance per week may be insufficient to maintain a client at home if they require constant supervision and assistance which is not available in the supported accommodation setting.

Services delivered to assist ageing in place

The types of services delivered to clients to assist with ageing in place include additional personal assistance, active physical therapy and lifestyle programs to help maintain levels of activity, mental stimulation, and social interaction. In addition to case management, projects delivered a mean of 6.4 hours of additional assistance per week to each client during the reporting period, plus transport services and a range of specialist assessment and referral services (summary statistics by project are listed below). Personal assistance, domestic assistance, allied health services, nursing care, social support, leisure and recreation programs, and living skills development are included in this average. The extensive range of service types and levels of service reflects the diversity of support needs within the group.

Summary statistics for amount of additional assistance delivered to clients during the evaluation (hours per week), by project excluding MS Changing Needs

Project	Clients	Minimum	Median	Maximum	Mean
Far North Coast Disability and Aged Care Consortium	13	0.1	6.0	15.7	6.9
Central West People with a Disability who are Ageing	30	0.9	11.4	37.3	12.0
Northern Sydney Disability Aged Care Pilot	23	0.1	0.1	7.2	1.9
Flexible Aged Care Packages	30	0.6	4.4	10.2	4.6
Disability and Ageing Lifestyle Project	7	6.0	15.2	19.5	13.9
Disability Aged Care Service	18	0.5	2.5	6.9	3.1
Cumberland Prospect Disability Aged Care Pilot	17	0.4	6.7	9.1	5.7
<i>Subtotal</i>	<i>136</i>	<i>0.1</i>	<i>4.9</i>	<i>37.3</i>	<i>6.4</i>
Ageing In Place	7	19.4	23.7	41.4	25.1
Total	143	0.1	5.4	41.4	7.3

Note: Includes personal assistance, domestic assistance, allied health care, nursing care, social support, leisure and recreation programs, and living skills programs; excludes case management and ancillary services such as transport.

Source: Table 4.2.

MS Changing Needs is a disability-specific nursing care service for people with advanced multiple sclerosis. For clients with multiple sclerosis in need of 24-hour nursing care, there is no doubt that providing this level of community-based nursing care allows clients who would otherwise use residential aged care or spend extended periods in hospital to live in a more appropriate setting. This level of ongoing nursing care at home would exhaust the financial resources of most families.

The capacity of a Pilot service to *enable* a client to remain in their familiar living environment for the long term depends on the extent to which the client's overall level of unmet need is aged care specific need and on the relative contributions of age-related need and disability support need to a person's risk of premature entry to residential aged care. A client who has aged care specific needs that are largely addressed by Pilot services but who has other areas of unmet need assessed as not aged care specific may remain at risk of admission to residential aged care for as long as those other needs are not addressed in the community living situation.

In summary on the question of helping disability services clients to live longer in the community, the answer is a qualified 'yes'. Through the provision of assessment services, assistance services and capacity building within the aged care and disability service sectors, community-based aged care for people with disabilities reduces the risk of early admission to residential aged care. It delivers the important benefit of maintaining continuity of care for those individuals who can continue to be supported primarily by specialist disability services, and their families. Increased awareness of ageing processes among disability support staff will pay longer-term dividends if it means that aged care interventions occur in a timely fashion for other clients in a supported accommodation service. However, the level of risk of early admission to residential aged care is highly individual and because of this the impact of Pilot-type services on the residential aged care system is thought to be heavily influenced by other contextual and individual factors.

Evaluation question 3: What is the cost of services per client per day, both in absolute terms and relative to other service options available to clients? (Chapter 5)

The price of Pilot services to the Australian Government in the form of flexible care subsidy ranged from approximately \$31 to approximately \$69 per client per day. Eight of the nine projects received flexible care subsidy at a rate of over \$54 per package per day. A number of projects accumulated surpluses in 2004 through sustained lower than expected occupancy and/or receipt of flexible care subsidy in excess of the average cost of package delivery and had their payments adjusted.

By comparison with mainstream forms of aged care, the daily rate of Community Aged Care Packages subsidy was \$32.04 in July 2004 and basic residential care subsidy for high care clients in July 2004 (Resident Classification Scale levels 1, 2 and 3) ranged from \$92.27 to \$121.16 depending on state/territory location of a facility (additional subsidies apply for residents with special nursing needs). Pilot clients who have been discharged from a project to enter residential aged care have all entered high level care. Residential aged care is the only mainstream alternative to Pilot services at this time since members of the target group are not eligible for CACP or HACC-funded services.

However, it is not valid to compare levels of flexible care subsidy for Pilot services with residential aged care subsidy except perhaps from the point of view of Aged Care Program funding alone. Flexible care subsidy payments for Pilot clients are in addition to contributions from state governments for accommodation support services and any other specialist disability services that clients may be accessing at the same time as receiving Pilot services. Projects reported contributions for the provision of accommodation services to Pilot clients under the CSTDA, ranging from \$27 to \$391 per client per day. It is known that some of the figures supplied are unreliable.

Only one Disability Aged Care Interface Pilot project collected client co-payments (of up to \$1.14 per day).

Most Pilot clients were receiving the Disability Support Pension and would therefore contribute 85% of the Pension amount in basic daily care fees were they to enter high level residential care. Members of the Pilot target group who enter high level residential care would have their income and assets tested to determine additional means-tested daily care fees and accommodation charge, respectively. Since only four clients in the evaluation had private sources of income – all others were receiving the Disability Support Pension or the Age Pension as their primary income source – additional daily care fees and accommodation charge would apply in very few cases.

During the evaluation, projects reported total expenditure on Pilot services and approximate direct care expenditure covering all care recipients, that is, including clients at the time who did and did not participate in the evaluation. From these data, it is estimated that projects spent an average of between \$22 and \$48 per client service day. The higher figure of \$48 per day was recorded by Ageing In Place, which operates a fully integrated service delivery model in a hostel setting. Excluding Ageing In Place, the average cost of direct care services ranged from \$22 to \$32 per client service day. Total expenditure, including overheads, ranged from \$35 to \$98 per client service day (or from \$35 to \$69 per client service day if Ageing In Place is excluded).

In some cases the posted surpluses prompted a reduction or suspension of flexible care subsidy payments by the Department of Health and Ageing, notably the projects based in New South Wales. Generation of cash surpluses coincided with the evaluation period, during which time most projects were still receiving referrals and completing client assessments. Costs are expected to be higher once places are filled and all clients are actively receiving assistance services.

Strengths of the Pilot model

A statement from an OECD report on community care for older people captures the essence of the Innovative Pool Disability Aged Care Interface Pilot:

Without a decent supply of home- and community-based services, and without opportunities for older people [and younger people with a disability] and their carers to participate in normal social life, ageing in place could well be associated with increasing neglect and isolation for too many people. If this is the case, life in an institution could well be a more attractive option, one which should not be dismissed too readily as long as other solutions have not been put in place (OECD 1996).

The Innovative Pool Disability Aged Care Interface Pilot has given a new care choice to consumers of disability-funded supported accommodation services who have needs associated with ageing. That choice is community-based aged care. The provision of additional services with an aged care focus has significantly improved the quality of life of care recipients. Moreover, collaborative aged care assessment and care planning has promoted the exchange of knowledge and skills between staff in the aged care and disability services sectors.

Leading examples of in-place progression models and innovative services that address needs specific to older disability services consumers have existed with the disability services sector for some time. These appear to be local solutions borne of the vision and determination of individual service providers, rather than part of a nationally coordinated approach in service delivery to meet the changing needs of people with disabilities as they age. This report describes the boundaries between disability services and aged care services, defined by various mainstream program guidelines, which effectively renders residential aged care the only form of mainstream aged care open to members of the Pilot target group.

Most implementations of the Pilot service model are premised on the separate identification of aged care specific needs in people with disabilities. Through a comprehensive and collaborative assessment model and range of assistive services are derived the main strengths of the Pilot:

1. The Pilot is based on a collaborative approach to eligibility and needs assessment. ACAT 'specialling' – the channelling of referrals to ACAT members with experience and professional interest in aged care assessment for people with disabilities – proved to be a main factor in the successful involvement of ACATs. The preparatory work of project coordinators and disability support staff was critical to this achievement.
2. Access to gero-psychology services and close attention to the needs of people with dementia – the Pilot has highlighted the impact of dementia on people with disabilities living in supported accommodation facilities and lends support to expert recommendations in the literature for routine dementia assessments of people aged 45 years or over with Down syndrome and other types of disability known to cause or to be associated with dementia.

3. Pilot care packages provide for higher levels of personal assistance, dementia-specific care, allied health assessment and physical maintenance programs, and access to aids and equipment for members of the target group with high and complex aged care specific needs.
4. A number of projects have enabled clients to participate in community life on a flexible basis in keeping with age-appropriate types and levels of activity, easing transitions from work to home-based and community-based activity and aiming to prevent social isolation, inactive lifestyle and apathy at older ages.
5. The Pilot has promoted the sharing of expertise between staff in the disability services and aged care sectors that builds the capacity of both sectors to support people with disabilities who are ageing.

The evaluation found strong evidence in case studies and the Care Experience Survey that Pilot services have enhanced the quality of life of clients by providing a highly individualised service offering.

Across the projects, evaluation participants received a median of approximately 6 additional hours of assistance during the reporting period in addition to aged care planning and ancillary services such as transport (Table 4.2). Some projects delivered higher median weekly hours per client; evaluation results reflect both maturity and the service focus of a project. At the time of the evaluation very few clients were receiving in excess of 10 additional service hours per week through the Pilot and while projects had capacity to increase service levels to some extent it is clear that with all places filled it would not generally be possible for a project to deliver more than 10 hours to a high proportion of clients. These results emphasise the importance of sharing of expertise between the aged care and disability services sectors so that insight into ageing needs and aged care interventions carry over into the disability support setting.

The Pilot highlighted the difficulties in recruiting and retaining aged care staff with sufficient experience in working with people with disabilities and in recruiting registered nurses for community nursing. Additional demands on disability services associated with comprehensive assessment, higher than usual case management intensity, brokerage arrangements and evaluation activities have been a source of tension in some projects. Brokerage of disability support staff for the delivery of aged care has proved problematic in some outreach service models and it is probably fair to say that dedicated teams of aged care workers operating alongside disability support staff have been viewed more positively by project coordinators. Clients were said to have adapted well to new support staff coming in to deliver aged care services.

One reason the top-up model has worked well for clients in the Disability Aged Care Interface Pilot is because the localised nature of the Pilot produced special arrangements that are conducive to a high level of cooperation and shared vision. Project coordinators were hand-picked for their experience, creativity and personal qualities. In most projects referrals were channelled to or through specific ACAT members with specialist experience. Difficulties were encountered where the relationship with ACAT was built on usual ACAT referral processes, for example, in the Central West People with a Disability who are Ageing project. The 'specialling' of ACAT staff for involvement in the Pilot provides further evidence of the need for attention to workforce issues.

The Pilot has helped to identify those aspects of community living that impact most on risk of premature entry to residential aged care which can be addressed by supplementary, aged care specific funding and other aspects which suggest that other strategic approaches are

needed if growing numbers of older people with disabilities are to enjoy quality of life through community living. These other important issues are discussed below.

Unresolved issues at the interface of disability and aged care programs

The Pilot has achieved successful outcomes for individuals and participating services. It has also highlighted that questions remain concerning the separate identification of aged care needs in people with a disability and the respective roles of aged care and disability services. In this sense the Pilot has also helped to sharpen the focus on these two key issues. The AIHW evaluation team does not purport to have answers to these questions but considers them to be worthy of further consideration and debate and to this end, we outline some of the complexities highlighted by the Pilot.

Different interpretations of ageing-related need

It became evident that different meanings are attached to the catch phrase ageing-, or age-related, need. The two categories of project service profile, one reflecting needs identification and service delivery focused predominantly on personal assistance and therapeutic intervention, and the other showing a stronger focus on social care and lifestyle, are thought to reflect these differences in interpretation. One interpretation is inclusive of the range of needs that can arise for a person with a disability as they grow older and which are considered to increase the risk of the person being admitted to residential aged care in the short to long term. This interpretation of ageing-related need is perhaps less concerned with existing program boundaries and sectoral funding responsibilities than with the task of addressing a person's unmet needs that, from experience, are known to contribute to the risk of future admission to residential aged care. An alternative interpretation, best described as the 'aged care specific' interpretation, seeks to align Pilot service provision within current Aged Care Program guidelines, that is, it gives greater emphasis to distinguishing aged care needs from disability support needs according to existing mainstream service concepts. Simplistically, the 'inclusive' former interpretation tends to consider any unmet need of the individual as potentially within scope of pilot services as long as it is assessed as being related to age or stage in life and associated with risk of future entry to residential aged care; whereas the more exclusive interpretation of ageing related need concentrates on those needs of a client that are assessed to be aged care specific and this is in turn defined by excluding any needs deemed to be the responsibility of specialist disability services. It could be said that the exclusive interpretation seeks to maintain the integrity of Aged Care Program funding by redrawing the program boundaries, while the inclusive interpretation comes closer to removing the program boundaries. There are inherent risks in either approach.

The issue is further compounded by the (designed) pooled funding model of Ageing In Place, Tasmania, and MS Changing Needs, Victoria, which made it virtually impossible for these projects to provide a separate breakdown of service delivery and expenditure for aged care purposes. These two projects have greater scope to address all unmet needs of an individual client because there is not the same emphasis on dissecting needs into disability support needs and aged care specific needs in a day-to-day operational sense. In addition, different program management approaches across the states are reflected in the projects' service activity profiles. For example, projects in New South Wales operated according to a

Schedule of Aged Care Services, whereas those in South Australia took their cue from needs assessments made by Options Coordination, the disability services arm of the state government.

Subtle differences in interpretation reflect the different philosophies of the disability service and aged care sectors. Work to retirement transitioning for people with disabilities who are ageing is a good example. No reports suggested or indicated that lifestyle transitioning for Pilot clients occurred because employment services were withdrawn on the basis of chronological age.⁵ Rather, it was found that clients who were not coping well with continuing full-time employment or group-based programs and others who had already made the transition but had found no suitable specialist disability service offering were given new choices in the form of Pilot services. Some clients were making or had made the work to retirement transition because dementia-related cognitive decline or increasing physical frailty had reduced their capacity to work and interact with others in a workplace or day program environment. For others the service need is borne of a strong desire for a change of pace and more leisure-type activity, just as retirement lifestyle appeals to many older adults more generally. Disability service providers interviewed for the evaluation regard lifestyle transition as age- or ageing-related in either case.

Aged care services for frail older people living in the community are not generally aimed at smoothing retirement transitions and offering lifestyle choice on the highly individualised level as seen in the Pilot. From the aged care perspective an older person experiencing cognitive decline may be assessed and recommended for aged care specific intervention – assistance to manage the symptoms of dementia, assistance with activities of daily living and carer support, if required. Social support services for frail older people target people who live alone and recreation and leisure activities are often connected with the provision of respite care. This report makes the case that members of the Pilot target group share some important need characteristics both with older people receiving assistance from carers and older people living alone.

Quite apart from the issue of substitution is the question of what is and what is not considered an aged care specific service: is it any type of assistance needed by a (chronologically or biologically) older person because they have reached an age or stage in life? Or is it a formally defined type of assistance that reflects what is delivered through mainstream aged care services in Australia? In the light of Pilot experience, a disability service provider operating a complementary aged care service would probably affirm the former notion of aged care intervention, whereas an aged care provider may be more likely to accept the latter meaning.

The role of specialist disability services in helping people who are ageing to live longer in the community

It is difficult to generalise on the impact of additional aged care specific assistance for Pilot clients because the entire package of care involves aged care specific care and assistance from specialist disability services. Pilot services *enable* a person to live longer in their familiar home environment to the extent that specific risk factors for an individual can be addressed by the level and type of assistance being offered by a Pilot project. Risk relates to the match

5 Oakdale Services Tasmania reported that residents at Oakdale Lodge who chose to join the Ageing In Place project were not guaranteed a return to specialist day programs at the conclusion of the pilot. The Ageing In Place coordinator and Advocacy Tasmania counselled eligible residents on the potential future consequences of joining the project.

between all sources and types of assistance (inextricably linked to accommodation setting and living arrangement) and a person's need for disability support and aged care.

One factor is the perception among disability support staff of how a client's need for additional assistance should be managed. In the context of a person's need for aged care, being in need of assistance and demonstrating benefit from the receipt of additional services does not necessarily mean that the person was at imminent risk of entry to residential aged care. Discussions with disability service providers, ACAT members and project coordinators highlighted that residential aged care is widely regarded as unsuitable for people with disabilities.

Criticism of the residential aged care service model is twofold. First, supported accommodation services for people with disabilities are favoured because of higher staff to resident ratios than in most generic aged care facilities. Second, the living environments of aged care facilities are not well suited to the needs of younger people and specialist staff are not generally available to provide the type of support required by people with disabilities, particularly those with intellectual disability. Personal attachment between disability support staff and clients adds another layer of complexity as this has been observed to cloud judgments about the best interests of clients. For instance, a strong conviction that an ageing client is always better off with a higher staffing ratio even if staff are available for only 4 to 6 hours per day ignores the inherent problem of leaving an older person with a disability for many hours without assistance and companionship. Family members also might reject residential aged care for a relative who has formed close bonds with staff and other residents through a lifetime of support from disability services, even if considerable unmet need exists.

Transfer of a disability services client from a group home to residential aged care appears to be a last resort in most instances and there is clearly a fine line between inappropriate or premature admission and inappropriately delayed admission – a line which disability service providers acknowledge they are sometimes reluctantly forced to tread. The implications of prevailing attitudes within the disability services sector towards residential aged care and aged care assessment is that an innovative community-based alternative requiring ACAT approval means that, in many cases, ACAT assessment occurs earlier in the care continuum than would be the case if community aged care were not available. It is reasonable to assume that timelier intervention to arrest or slow age-related functional decline would help reduce or delay admissions to aged care homes but the evaluation has been unable to measure this impact.

Another set of factors relates to a client's disability supports, including the home environment and opportunity for community access and participation through disability services funding. Where a physical home environment is unsuitable for an older person and cannot be adapted or in situations where a person needs 24-hour or night-time supervision that their accommodation service does not ordinarily provide, then Pilot services might not be able to help maintain a client at home over the longer term. A need for constant supervision and/or assistance poses a real and immediate risk of a resident being transferred to another accommodation setting. Pilot projects have in some cases been able to make highly effective and cost-efficient improvements for resident safety and independence at home, for instance, one project installed a hot water urn so that an older resident who had lost dexterity and strength did not have to struggle with a kettle. Night-time supervision, on the other hand, is a more intractable issue. The value of the Pilot in this area has been to provide an aged care perspective that offers insight into an ageing person's world of functioning to determine which risks in the physical environment can be modified through the provision of additional aged care specific services.

Supported accommodation providers in the disability sector associate the languishing lifestyles of many of their older consumers with pathways of physical and mental decline that lead to a need for institutional care. The array of specialist disability services available to a person ageing with a disability influences not only the individual's capacity to age well, but also the response of their accommodation provider in supporting the person's desire to age in place. Where opportunities for clients to engage in meaningful activity cannot be sourced within disability services, for whatever reason, a Pilot service that is able to address this area of need might enable clients to remain living at home for longer, although in the case of an older person with a disability showing no outward signs of age-related physical or mental decline this is more of a preventive intervention with dividends to be realised over the much longer term.

It was not within the scope of this evaluation to explore the impediments to lifestyle choice and participation for older adults with disabilities that exist in mainstream service delivery systems but it is necessary to report on dynamics at the interface of disability and aged care services reflected in the service profiles of Pilot clients. Unmet need in disability services, including community access need, has been well covered elsewhere (see, for example, Bigby 2004 and AIHW 2002). Bigby's is a cogent coverage of service issues for people with disabilities who are ageing, particularly the service silos that most affect people living in disability-funded supported accommodation. Discussion in this report focuses on the arguments and counter arguments made in the course of the evaluation for delivering community access services to help people with disabilities who are ageing to live longer in the community and draws attention to the fact that positions taken on this question have resulted in distinctive differences in the service profiles of the Pilot projects.

Community access services for people with disabilities are funded under the CSTDA and it is an objective of the CSTDA to provide lifelong opportunity for people with disabilities to participate in their communities. It was intended that the provision of aged care services in the Pilot should be an additional element and not substitute for the care already provided: 'In particular, it should not substitute for services, such as employment options, that are being withdrawn simply because the individual has reached a certain chronological age' (project Memorandum of Understanding). Therefore, the provision of mainly community access and social support services by some projects in the Disability Aged Care Interface Pilot may prove to be contentious on the basis that it represents a substitution of Aged Care Program funding for services that are funded under the CSTDA.

An individual CSTDA consumer might not have access to individual funding for community access (rates of individualised funding are lowest in the youngest and oldest age groups of CSTDA consumers) and there may be no places available in local day programs. To a consumer in this situation, it is probably academic that the CSTDA funds community access services. Well-managed lifestyle transitioning at older ages is apparently an area of significant unmet need for people in the Pilot target group. This evaluation did not explore how people gain access to specialist day services administered by state and territory governments following retirement from supported employment services administered by the Australian Government but this is another area within the disability services system that needs to be considered in the context of ageing disability services consumers. We surmise that funding and service systems in the disability sector were designed or have matured to assist adolescents with disabilities to make the transition to adult life but remain underdeveloped for people at later stages of the lifespan and that the resulting unmet need is considered by many within the disability services sector to be ageing-related need.

ACATs and project coordinators approached the assessment of people referred for Pilot services from the point of view of their risk of admission to residential aged care. In assessing a person's risk exposure it is necessary to consider the needs of the individual and what services she or he can access through disability services. Supporting age-appropriate lifestyle is a case in point. That the need for this type of support is perceived to be ageing related is reflected in the service activity profiles of a number of Pilot projects. Ageing In Place expended approximately 31% of total expenditure on leisure and recreation activities for clients, 16% on social support and 8.2% on transport services; Disability and Ageing Lifestyle Project expended approximately 44% of total expenditure on social support, 20% on leisure and recreation activities and almost 10% on transport services for clients; 75% of expenditure in the Flexible Aged Care Packages project was directed to social support services.

The targeting of people with community access needs has arisen because clients reportedly have no other way to access those services, either because they are not funded to receive these types of services or because of constraints other than individual funding. These include, for example, transport and staffing flexibility in the supported accommodation service, the range and flexibility of specialist day programs and local availability of places in those programs, and the capacity of staff operating specialist day programs to manage the needs of ageing clients, such as continence or behaviour management needs. Restricted access to transport assistance can also limit opportunity for people with disabilities who are ageing to participate in generic day programs for older people. Some leisure and recreation directed services delivered by Pilot projects have facilitated individual activities at home or in the community. Individual leisure activities might be offered if places in group programs are unavailable, if the person concerned becomes unsettled in an unfamiliar large group setting, or because the client desires to pursue a hobby or special outing. These service offerings have not been regarded as substituting for disability-funded services because, it was said, this type of community access is not otherwise accessible to the individuals concerned from within disability services funding and service offerings.

Another key area of influence of specialist disability services over long-term living arrangements of people ageing with a disability is home physical environments. The Disability Aged Care Interface Pilot has primarily attended to care environments, although, through the provision of aids and equipment, it has also had an impact on physical environments. Fundamentally, home environments need to meet the needs of older residents who tend to spend longer periods of time at home. In the financial year 2004-05, 13,034 consumers of CSTDA-funded accommodation services were aged 30 years or over, including approximately 4,500 consumers aged 50 years or over. People with intellectual disability accounted for 80% of this consumer group. Almost 8,600 of these consumers were living in group homes and approximately 81% of this number comprised people with intellectual disability.

The above discussion describes how the ageing-related needs of people who live in CSTDA-funded accommodation are intrinsically related to their disability service arrangements. A main driver of need for increased formal service intervention in this group appears to be the structuring of supported accommodation services for residents who are away from home during the day, which may not be a suitable accommodation model for ageing residents. The need for part-time or casual community participation has implications for transport assistance and flexibility in the hours of staff attendance within the accommodation service. So that while the criticism of lower staffing ratios in aged care services compared to disability services may be based on fact, a perhaps more salient issue for people with

disabilities who are ageing is their need for assistance and supervised or supported activity for longer periods and/or more flexibly timetabled periods than is usually possible.

From a system-wide perspective, the top-up model of aged care funding is an incomplete answer to the problem of limited choices in community-based aged care for people with disabilities living in supported accommodation. It helps in individual cases by shielding clients from systemic problems at the interface of disability and aged care programs and at the interfaces between different types of specialist disability services. There is a risk that some groups will fall through gaps in services modelled on separate aged care and disability funding. First, the high degree of overlap between the types of assistance delivered by Pilot projects and those funded under the CSTDA means that criteria are required to establish how aged care funding is to be used. The Pilot has shown that individual care planning will tend to address areas of need that are implicated in an individual's risk of entry to residential aged care and that these areas may be closely related to features of the disability support system as it pertains to the individual. Eligibility criteria based on interpretations of aged care specific need or age-related need, which have been demonstrated to vary, may lead to program management rules such as those which currently prevent access to HACC-funded services for the target group. Using subjective eligibility criteria, the only way to avoid questions of 'double dipping' and 'cost shifting' is for program managers to trust the processes that determine eligibility for aged care.

The range of issues faced by people ageing with a disability possibly needs to be viewed in the context of the levels of flexible care subsidy made available through the Pilot and in the context of what can reasonably be achieved through individual care packages.

Key point summary

The Disability Aged Care Interface Pilot delivered significant benefits to people ageing with a disability and helped increase the capacity of participating disability and aged care services to perform needs assessment and care planning for the target group:

1. Through the Pilot, people ageing with a disability who live in participated supported accommodation settings gained access to community aged care. Assessment and the provision of additional services led to enhanced quality of life for the individuals concerned and is said to have produced flow-on benefits for entire households.
2. Pilot services assist with ageing in place by helping people with disabilities to avoid or delay admission to residential aged care.
3. Knowledge and skills transfer between aged care and disability services is said to have occurred. This increased needs assessment capacity within both sectors and has contributed to improvements in documentation standards with disability services for assessment and review of clients with ageing-related needs.
4. A comprehensive strategy for delivering community-based aged care to the target group needs to factor in workforce considerations. A coordinated, whole-of-government approach is needed to ensure consistency across the country and across the sectors on training requirements and opportunities for staff at all levels who are working with people with a disability who are ageing.

Notwithstanding the clear benefits of Pilot services to clients and the aged care and disability systems, a number of conceptual and practical difficulties are associated with the way in which the Pilot was conceived and implemented, leaving open a number of important questions:

5. Is the term *aged care specific needs* (or *age-related needs*) intended to encompass the range of needs that emerge as a person with a disability gets older (whether in chronological or biological terms) and which contribute to the risk of future use of residential aged care, or is it intended to mean only those needs that are routinely addressed by conventional aged care programs? Alternatively, in the context of people ageing with a disability, should aged care specific need be defined consistent with the aged care needs of the wider population of older people or should there be allowance for different types of need that exist in connection with lifelong or early onset disability and living in disability-funded supported accommodation?
6. How do the subtly different interpretations of aged care specific needs reconcile with a whole-person approach to social services and the primary objective of enabling people with disabilities to live in the community for as long as possible?
7. If aged care funding is directed towards servicing aged care specific needs but significant unmet need remains, then what is the likely marginal impact of community-based aged care on use of residential aged care services by the target group and how is this limited impact to be balanced against improvements in quality of life for individuals?
8. Where do older people with disabilities who live in supported community accommodation (those aged 65 years and over) and who have unmet needs that are assessed as not strictly age related fit within this framework? The needs of this group of older Australians are not addressed by the evaluated model that focuses on aged care specific needs.
9. What should be the role of chronological age in the assessment of needs related to premature ageing, especially in the context of chronic progressive disability?

That these questions do not find easy answers in the Pilot model of aged care provision for people with disabilities does not detract from the obvious benefits of Pilot services to clients. The evaluation was unable to assess the impact of Pilot services on duration of community living in a definitive sense, but there are strong indications in case studies, informant interviews and the Care Experience Survey that additional assistance delivered with an aged care focus has significantly improved the quality of life of individual clients. These improvements are likely to have long-term benefits for individuals and service systems.