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

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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.

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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 competed 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 project[4] 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
Subtotal	*136*	*0.1*	*4.9*	*37.3*	*6.4*
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.

1 Background and context

The Aged Care Innovative Pool Disability Aged Care Interface Pilot was established under the administration of the Australian Government Department of Health and Ageing to trial flexible aged care in the community for people with disabilities who are ageing. The Pilot target group is people with a disability who have a valid ACAT assessment for residential aged care and who are currently receiving disability support services in a supported accommodation setting. Pilot services for younger people in nursing homes come under a another category of Innovative Pool proposal.

Nine projects in the category People with Disabilities Who are Ageing commenced operations between November 2003 and December 2004 across four mainland states and Tasmania (Table 1.1). These projects are designed to help older people with disabilities to remain in their familiar disability-funded living situation through the injection of additional support services to address aged care specific needs. Most people accepted into the Pilot live in group homes, although a handful of small-scale residential institutions for people with disabilities are also represented. Participating accommodation services are funded under the Commonwealth State/Territory Disability Agreement 2002–07 (CSTDA). The projects accept mainly people aged 50 years or over with exceptions made in special circumstances relating to premature ageing. State governments agreed to continue the funding of specialist disability services for clients who join Pilot projects.

This report presents the findings of an evaluation of the nine People with Disabilities Who are Ageing projects. The evaluation was conducted by the Australian Institute of Health and Welfare (AIHW) under a Schedule to the Memorandum of Understanding with the Department of Health and Ageing. An evaluation framework developed by the AIHW was released for consultation in December 2003. Following a refinement of protocols, the AIHW Ethics Committee approved the evaluation project and data collection commenced in June 2004 (AIHW Ethics Committee Register Number 353).[6] Evaluation continued into the first quarter of 2005 for inclusion of the late-start Cumberland Prospect project and for the recording 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.

6 A separate Ethics submission was made to the Department of Health and Ageing Ethics Committee.

Table 1.1: Innovative Pool Disability Aged Care Interface Pilot projects, approved providers, service region, start date and project duration

Project (acronym)	Approved provider	Service locations	Initial place allocation	Start date	Planned duration	Flexible care subsidy daily rate ($)
Far North Coast Disability and Aged Care Consortium, NSW (FNCDAC)	Clarence Valley Council	DADHC-funded group homes, NSW Far North Coast	30	November 2003	3 years	63.47
Central West People with a Disability who are Ageing, NSW (CWPDA)	Uniting*Care* Community Services operating as Wontama Community Services	DADHC-funded group homes, NSW Central West	40	November 2003	3 years	63.00
Northern Sydney Disability Aged Care Interface Pilot, NSW (NSDACP)	New Horizons Enterprises Ltd	DADHC-funded group homes in the Northern Sydney metropolitan area	45	November 2003	3 years	63.70
MS Changing Needs, Vic	Multiple Sclerosis Society of Victoria	MSV-operated group home clusters, Melbourne	16	June 2004	2 years	60.32
Interlink Flexible Aged Care Packages, SA (FACP)	Helping Hand Aged Care Inc.	Adelaide, SA	30	November 2003	2 years	54.73
Disability and Ageing Lifestyle Project, SA (DALP)	Renmark Paringa District Hospital	Renmark, SA	10	June 2004	2 years	30.73
Disability Aged Care Service, WA (DACS)	Senses Foundation	Senses & Activ Foundation group homes, Perth	20	October 2003	3 years	68.50
Ageing In Place, Tas (AIP)	Oakdale Services Tasmania	Oakdale Lodge, Hobart	7	June 2003	3 years	61.94
Cumberland Prospect Disability Aged Care Interface Pilot, NSW (CPDAC)	Uniting*Care* Community Services	DADHC-funded group homes, Western Sydney	30	December 2004	3 years	60.00

Note: DADHC denotes the NSW Department of Ageing, Disability and Home Care.

Source: Policy and Evaluation Branch, Australian Government Department of Health and Ageing.

The AIHW was briefed to address three key questions about pilot services:

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?**

Later chapters in the report address these questions through an examination of the pilot projects—project aims, staffing and service models, case studies, patterns of service delivery and expenditure during the 2004 evaluation. The remainder of this introduction briefly considers the context for a trial of new approaches to caring for people with a disability who are ageing, issues surrounding aged care specific needs in people with an early onset primary disability. It concludes with an overview of the scope and methods of the national evaluation

1.1 Origins of the Innovative Pool Disability Aged Care Interface Pilot

The Aged Care Innovative Pool (the Innovative Pool) was established in 2001–02 as a national pool of flexible care places available for allocations outside the Aged Care Approvals Round with the aim of providing aged care services to existing and emergent client groups for whom more widely available services may not be adequate. Negotiation of the Commonwealth State/Territory Disability Agreement 2002–07 (CSTDA) provided impetus for using the Innovative Pool as a vehicle for testing new models of aged care for disability services clients through partnerships between levels of government and the aged care and disability services sectors.

Access to generic aged care programs and the provision of support more generally for people with disabilities who are ageing has been raised as an important issue that is impacting on increasing numbers of CSTDA consumers. People in the CSTDA target group are increasing in number and are ageing (AIHW 2002). In referring to people with disabilities we adopt the meaning given in the CSTDA:

> 'people with disabilities' means people with disabilities attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (or some combination of these) which is likely to be permanent and results in substantially reduced capacity in at least one of:
>
> - self care/management
> - mobility
> - communication

requiring significant ongoing and/or long-term episodic support and which manifests itself before the age of 65.

This enables a distinction to be made between people with a primary disability before the age of 65 years and the older population in need of assistance from family and/or formal services because of age-onset disability.

National framework for the provision of support services to people with disabilities

The bulk of formal assistance provided to people with disabilities is provided under the auspices of the CSTDA and the Home and Community Care Program.

The CSTDA provides the national framework for the delivery, funding and development of specialist disability services for people with disabilities. This Multilateral Agreement sets out the objectives and respective roles and responsibilities of the Australian and state and territory governments for the planning, funding and delivery of disability services (see Box 1.1 and 1.2).

Under the Agreement all parties are responsible for funding specialist services for people with disabilities:

- The Australian Government has responsibility for the planning, policy setting and management of specialised employment assistance.[7]
- State and territory governments have similar responsibilities for accommodation support, community support, community access and respite.
- Support for advocacy and print disability is a shared responsibility. (CSTDA 2003)

Individual agreements between the Australian Government and each state and territory (the Bilateral Agreements) come under the umbrella of the Multilateral Agreement and commit the parties to work together to address key issues for people with a disability including:

- flexibility between service provision by different levels of government
- the situation of young people living in Australian Government funded residential aged care facilities and
- issues facing people with a disability who are ageing. (FaCS 2005b)

CSTDA places no age-based restrictions on access to services and people who received CSTDA-funded services live in a range of accommodation settings including private homes and supported accommodation. In practice, services are generally directed to people aged under 65 years (AIHW 2002:3).

7 In late 2004 responsibility for administration of open employment services operating under the CSTDA moved from the Australian Government Department of Family and Community Services (now known as the Department of Family, Community Services and Indigenous Affairs (FaCSIA)) to the Department of Employment and Workplace Relations. Supported employment services for people with disability continue to be administered by FaCSIA.

Box 1.1: Objective and policy priorities of the CSTDA 2002–2007

Objective
The Commonwealth and the States/Territories strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community.

Policy priorities
a) strengthen access to generic services for people with disabilities by:

- *– fostering a whole-of-government approach to maximise the opportunity for people with disabilities to participate socially and economically in the community; and*
- *– explicitly recognising access to, and the role of, generic services as a complement to the focus on the funding and delivery of specialist disability services and supports.*

b) strengthen across government linkages by:

- *– positively influencing the service system within and external to the Agreement to ensure that access to appropriate services is supported and strengthened; and*
- *– improving collaboration, co-ordination across programs and governments to ensure that people with disabilities have fair opportunities to access and transition between services at all stages of their lives.*

c) strengthen individuals, families and carers by:

- *– developing supports and services based on individual needs and outcomes, which enhance the well-being, contribution, capacity and inclusion of individuals, families and carers; and*
- *– increasing their opportunities to influence the development and implementation of supports and service at all levels.*

d) improve long-term strategies to respond to and manage demand for specialist disability services through:

- *– a strategic approach to broad national and local/jurisdictional planning to underpin the determination and allocation of equitable funding to respond to unmet demand, growth in demand and cost increases; and*
- *– approaches which enhance prevention and early intervention outcomes, the effective co-ordination across service systems and clear and transparent decision making.*

e) improve accountability, performance reporting and quality by:

- *– improving accountability and transparency for specialist disability services funded under this Agreement; and*
- *– incrementally developing, implementing and reporting progress on the aforementioned national policy priorities.*

Source: CSTDA 2003:Clauses 4(1) and 4(2).

Box 1.2: Types of specialist disability services covered by the CSTDA 2002–2007

Accommodation support	*Services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in their existing accommodation.*
Advocacy	*Services designed to enable people with disabilities to increase the control they have over their lives through the representation of their interests and views in the community.*
Community support	*Services that provide the support needed for a person with a disability to live in a non-institutional setting.*
Community access	*Services and programs designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence.*
Information services	*Services that provide accessible information to people with disabilities, their carers, families and related professionals. This service type provides specific information about disabilities, specific and generic services, equipment and promotes the development of community awareness.*
Print disability services	*Services that produce alternative formats of communication for people who by reason of their disabilities are unable to access information provided in a print medium.*
Respite	*Respite services provide a short-term and time-limited break for families and other voluntary caregivers of people with disabilities, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability.*
Employment	*Services which provide employment assistance to people with disabilities to assist them obtain and/or retain employment.*

Source: CSTDA 2003:Clause 5(2).

Home and Community Care Program (HACC) is the other main vehicle for delivering government-funded services to people with disabilities. HACC-funded services are delivered to eligible people living at home. HACC is a joint Australian Government, state and territory initiative under the *Home and Community Care Act 1985*. The Australian Government contributes approximately 60% of program funding and maintains a broad strategic role for the program whereas the states and territories are responsible for the day to day administration of the Program. Bilateral agreements between the Australian Government and states and territories (the HACC Amending Agreements) are the formal basis for the Australian Government, state and territory arrangements for the HACC Program.

The HACC target population comprises:

(a) persons living in the community who, in the absence of basic maintenance and support services provided or to be provided within the scope of the Program, are at risk of premature or inappropriate long term residential care, including:

  (i) older and frail persons, with moderate, severe or profound disabilities;

  (ii) younger persons with moderate, severe or profound disabilities; and

(iii) such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister; and

(b) the carers of persons specified in (a). (DoHA 2002)

While there is reference to 'older and frail persons', HACC services are delivered on the basis of a person's need for assistance and not on the basis of chronological age.

HACC services aim to provide:

- a comprehensive, coordinated and integrated range of basic maintenance and support services for frail older people, people with disabilities, and their carers
- support that enables people to maximise independence at home and in the community, thereby enhancing their quality of life and/or preventing inappropriate or premature admission to long-term residential care. (DoHA 2002)

The type of services funded through the HACC Program include, but are not limited to, nursing care, allied health care, meals and other food services, domestic assistance, personal care, home modification and maintenance, transport, respite care, counselling, support, information and advocacy, and assessment services.

Around three-quarters of people who received HACC services in 2003–04 were aged 65 years or over (DoHA 2004). Only 0.3% of HACC clients in 2003–04 were living in domestic scale supported accommodation; a further 1.3% of clients were living in larger scale supported accommodation facilities, which would likely include clients living in assisted living units in retirement villages (DoHA 2004:Table A11). By and large, HACC services are delivered to eligible people living in private residences or public or private rental accommodation.

National framework for the provision of support services to people who need aged care

Support services for people who need aged care are delivered under the auspices of a number of government programs that cover both residential and community-based aged care services, for example:

- the HACC Program, as overviewed above
- the Aged Care Assessment Program, Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH), Extended Aged Care at Home Dementia, National Respite for Carers Program, and the Transition Care Program, all administered by the Australian Government Department of Health and Ageing
- Veterans' Home Care and Veterans' Home Nursing administered by the Australian Government Department of Veterans' Affairs
- Residential Care, administered by the Australian Government Department of Health and Ageing, provides residential care subsidy for low and high level care in accredited aged care facilities. This includes permanent and respite residential services.

A number of other programs exist to provide assistance to older people with special needs including various programs for people with dementia and their carers, Day Therapy Centre Program, the Continence Aids Assistance Scheme, and flexible aged care services through Multipurpose Services and services under the National Aboriginal and Torres Strait Islander Aged Care Strategy (AIHW 2005b).

Aged care services are targeted at older people who need assistance with daily living. The older population is traditionally defined in Australia as people aged 65 years or over, which is the entitlement age for males to receive the Age Pension. For planning purposes, the residential aged care and CACP programs have used the number of people aged 70 years or over and Aboriginal and Torres Strait Islander people aged 50 years or over (the aged care provision ratio has been set at 108 places for every 1,000 people aged 70 or over).

Although chronological age is one element of population-based planning of aged care services, access to services is based on the principle of assessed need for aged care. For example, the *Aged Care Act 1997* states under 'Eligibility for approval as a care recipient' (s.21-1):

> A person is eligible to be approved under this Part if the person is eligible to receive:
>
> (a) residential care (see section 21-2); or
>
> (b) community care (see section 21-3); or
>
> (c) flexible care (see section 21-4).

Box 1.4 shows Approval of Care Recipients Principles for residential and community care.

Needs assessment procedures and eligibility criteria are specified in the respective program guidelines. Home and Community Care is the largest program for the delivery of community aged care, in terms of both funding and number of care recipients. People gain access to HACC services through contact with HACC assessment agencies located in the States and Territories. Similarly, the Aged Care Assessment Program provides access to specialist Aged Care Assessment Teams (Aged Care Assessment Services in Victoria) in each State and Territory for the assessment of eligibility for residential aged care and community aged care (CACP and EACH packages) funded by the Australian Government.

The CACP Program delivers care packages to (mainly) older people living in the community. A CACP is a planned and coordinated package of community care services to assist a person who requires management of services because of their complex care needs. CACPs are targeted at frail older people who would otherwise be eligible for at least low level residential care. A typical CACP might deliver assessment and case management in addition to one or more of the following types of assistance: personal assistance, domestic assistance, food services, social support, transport and gardening. As at 30 June 2005, 94% of CACP recipients were aged 65 years or over and the majority of recipients were aged 80 years or over (AIHW 2006a). Around 6% of CACP recipients on 30 June 2005 were aged less than 65 years; 37% of these younger recipients identified as Indigenous Australians. Average age at entry to CACP is 81 years.

Residential aged care comprises accommodation plus care services within the accommodation setting (for example, nursing care, personal care, meals and laundry). A person approved for residential aged care by an Aged Care Assessment Team is approved for either residential respite care or low level or high level permanent residential care. On 30 June 2005 there were 149,091 permanent residents in residential aged care. Fifty-two per cent of permanent residents (77,285) were aged 85 years or over; around 4% (6,483) were aged under 65 years. Seventy per cent of newly admitted residents in financial year 2004–05 were aged 80 years or over (AIHW 2006b).

Disability and aged care program interfaces

It is useful to think of the interface between disability and aged care programs in terms of dictionary definitions of 'interface': (1) a surface regarded as the common boundary to two

bodies or spaces; (2) a point or area at which any two systems act on each other; and for the verb 'to interface', (3) to cause (two systems) to act on each other (Macquarie Dictionary). Drawing on this notion of a boundary that can be described in a physical sense and which is defined by the designed interaction of systems, this section briefly characterises the boundary between mainstream disability and aged care service systems for members of the Pilot target group. We also consider what causes the two systems to act on each other in the way they do as this may help to place the Disability Aged Care Interface Pilot in a policy-relevant context.

For members of the Pilot target group the interface between specialist disability services and aged care services is currently characterised by sectoral exclusivity. Historically, residential aged care has been the main type of service funded by the Aged Care Program to be accessed by people with disabilities who live in CSTDA-funded group homes or larger supported accommodation facilities because this group is not ordinarily entitled to access community aged care programs funded by the Australian Government. Transfer to a residential aged care service usually means cutting ties with specialist disability services.

People with disabilities (including CSTDA consumers) who live in private residences, or another form of accommodation besides disability-funded supported accommodation, form part of the HACC target population and may be eligible to receive HACC services. CSTDA consumers who reside in supported accommodation facilities are normally excluded from HACC services. Access to HACC-funded services is governed by the HACC National Program Guidelines (2002), which state:

> The HACC Program does not generally provide services to residents of aged care homes or to recipients of disability program accommodation support service, when the aged care home/service provider is receiving government funding for that purpose. Nor does it generally serve residents of a retirement village or special accommodation/group home when a resident's contract includes these services.

These guidelines are based on Clause 5(3)(a) of the HACC Amending Agreement which was tabled in 1999 as the revised Schedule to the Act. It states:

> 5.(3) A service of the following kind shall be outside the scope of the Program—
>
> (a) the provision of accommodation (including housing and supported accommodation) or a related service…

In practice, all services provided by supported accommodation services under state and territory disability programs are regarded as 'related services'. The clause was contrived in the spirit that HACC would not provide services where these services were being funded under another government program such as the CSTDA. Since the CSTDA assigns the responsibility to continue the care for CSTDA clients throughout all stages of their lives, HACC services would not be available to substitute for services that are being provided through disability program funding. For instance, domestic assistance, personal assistance, community access and support, respite care, transport and day programs are all service types funded under the CSTDA.

Similarly, CSTDA consumers who reside in supported accommodation would not normally be eligible to receive a CACP. The proviso that allows younger people with disabilities to be considered for a CACP does not apply in the case of those who live in supported accommodation settings and nor would an older person with a disability who resides in supported accommodation be able to access assistance through a CACP since:

> people living in supported accommodation facilities which receive funding through government programs to provide services similar to CACPs or where lease arrangements include the provision of similar services are not eligible to receive CACPs (DHAC 1999).

Outside the Disability Aged Care Interface Pilot, a person who receives CSTDA-funded supported accommodation services and who needs aged care specific assistance at home would need to source that assistance from within available disability services. One underlying cause of the narrowly constructed interface between disability and aged care services is the enactment of legislation which is intended to prevent 'double dipping' (the receipt of substitutable services from multiple program sources of funding). The way that the two systems *act on* each other boils down to interpretations of terms such as 'related services' and 'similar services' that guide eligibility assessment. Community aged care programs act on the disability sector by blocking access to community-based aged care specific services for CSTDA consumers in supported accommodation. Correspondingly, the disability sector acts on the aged care sector by steering disability services clients who are ageing and younger clients with complex needs that cannot be managed at home towards residential aged care. A number of complex issues lie hidden in this simplistic appraisal of the situation.

The issue of 'related services'

There is considerable overlap between the type of basic living support that supported accommodation providers deliver to CSTDA consumers and the types of assistance delivered to older people through community aged care programs. Older people with disabilities and people with disabilities who age prematurely typically experience an increase in support needs that is associated with ageing. Much of the additional need that emerges falls into the areas of personal assistance, domestic assistance and social support—all types of assistance which is presumed to be provided by the person's supported accommodation service. An important question is what level of service a supported accommodation service is funded to deliver and whether the level of funding is designed to meet the lifelong needs of each resident.

Other areas of assistance such as community access services for people with disabilities and allied health care such as occupational therapy, physiotherapy and podiatry, are normally sourced by other providers including other specialist disability service providers and health services, and not by accommodation service providers. Some of these categories of assistance are provided under the HACC Program to eligible HACC recipients, but members of the Pilot target group cannot access these 'unrelated services' through HACC for reasons explained earlier.

The issue of agency funding versus individualised funding and access to CSTDA-funded services

An assumption that an individual consumer is able to access the array of service types funded by the CSTDA may be ill-founded. Access to services implies the availability of funds through agency or individualised funding and acceptance of an individual (and their disability) into a service. Under agency funding, a consumer gains access to a service if the agency has funded places available and accepts the person to fill a vacancy.

As well as funding agencies directly, jurisdictions may provide 'individualised funding' for the purchase of approved services. Individualised funding is allocated to individual service users on the basis of a needs assessment, funding application or similar process. It involves the application of funding to a particular service outlet or outlets which the service user (or

advocate/carer) has chosen as relevant to his or her needs. Individual funding programs allow for greater flexibility and choice of services, and funding is transportable and able to move with the individual if they choose to use another service.

Data on disability support services during 2003–04 reflect the combinations of disability services used by CSTDA consumers. Funding of accommodation support services for 17.7% of CSTDA consumers accounted for over half of expenditure on disability support services during 2003–04 ($1,638 million)[8] (AIHW 2005a). Expenditure on community access services ($390 million), community support services ($350 million) and employment services ($301 million) involved 25.4%, 42.0%, and 34.2% respectively of all CSTDA consumers, including the 82.3% of consumers who did not receive accommodation support (AIHW 2005a). The most common combinations of CSTDA-funded services received by individual consumers in 2003–04 were, in order:

- accommodation and community access (7.5%)
- community support and community access (7.2%)
- accommodation and community support (5.7%)
- community support and respite (4.8%)
- accommodation and employment (3.0%)
- three or more services involving above combinations (6.4%)
- all other combinations (3.8%) (AIHW 2005a).

These patterns demonstrate that CSTDA consumers who receive accommodation support access services from other service providers for types of assistance that are outside the charter of their accommodation support services.

Overall, 31,193 service users (17%) in 2003–04 reported that they received individualised funding (AIHW 2005a). Service users aged 15–24 years were most likely to report such funding arrangements (29%); the oldest and youngest age groups were the least likely (5.6% of those aged 0–4 years, and 5.5% of those aged 60 years or more).

The issue of aged care specific needs

A program's boundary is drawn to ensure that the users of the program are members of the program's target group. In aged care programs this is achieved by the assessment of aged care specific needs. Currently, the boundary between disability and residential aged care programs is drawn by Aged Care Assessment and Approval Guidelines that allow people with disabilities in special circumstances to be considered for residential aged care. For instance, younger people with disabilities may be entitled to be assessed and approved for residential aged care 'if they need the intensity, type and model of care provided in such facilities and no other more appropriate service is available' (DHAC 1999). Additionally, 'ACATs may approve people with psychiatric disorders or intellectual disability where the person requires the type of care services provided through an aged care facility for reasons

8 Supported accommodation services fall into three categories: in-home support, e.g. where a consumer living in a private residence receives personal and domestic assistance at home through CSTDA funding (52% of accommodation support consumers in 2003–04); group homes (34%); and institutional accommodation, which includes hostels for people with disabilities (16%) (AIHW 2005a).

related to functional disability, frailty and age, not solely related to the psychiatric or intellectual disability' (DHAC 1999).

The Disability Aged Care Interface Pilot has removed a barrier to aged care funding by allowing people who live in CSTDA-funded supported accommodation facilities to be assessed for their eligibility for flexible care subsidy. The setting and implementing of eligibility guidelines for the Pilot is a trial in redrawing the boundary between disability and aged care programs. In this sense the model of enhancing service provision through supplementary aged care funding is founded on the idea that people with disabilities who are ageing have additional needs associated with ageing processes that can be differentiated from support needs related to pre-existing disability. Thus, a central theme of the Pilot has been to test this idea in practice and considerable interest is focused on the types of aged care specific needs highlighted in the Pilot, the types of assistance funded by Pilot services and policy implications of the Pilot experience in this area.

Whole-of-government approaches

People with disabilities may require non-specialist services that lie outside the scope of the CSTDA and the Australian and state and territory governments have agreed to encourage and facilitate inter-sectoral action to promote access to other services needed by people with a disability (CSTDA 2003:Clause 5(5)). The CSTDA emphasises the need for whole-of-government approaches, improved cross-program collaboration and coordination, and effective coordination across service systems for achieving the agreed priorities (see Box 1.1). An emphasis on whole-of-government approaches to improving the interface is consistent with the Commonwealth Disability Strategy aimed at 'enabling full participation of people with disabilities' (FaCS 2005c).

Bilateral Agreements between the Australian and state and territory governments identify the key areas for collaborative effort on developing the aged care/disability services interface (Box 1.3).

Box 1.3: Activity areas for developing the disability services/aged care interface

(Extracts from Bilateral Agreements between the Australian and state and territory governments)

Australian Government and New South Wales Bilateral Agreement

Under Clause 3(2) of the Agreement the Parties aim:

i. *To develop effective models of care to support people with a disability who have age-related care needs and require services from both the aged care and disability service systems (government and non-government);*
ii. *To improve the access of younger people with a disability in residential aged care to appropriate disability services and supports, to avoid the admission of younger people with disabilities to residential aged care and, to explore alternative support models for young people in nursing homes including the capacity to transfer younger people who have been inappropriately placed in aged care nursing homes to more appropriate accommodation; and*
iii. *To assist people with disabilities and age-related care needs to access residential aged care in the same way as any other frail, older person.*

Steps identified to progress these objectives include:

1. *Development of mixed program models for people with a disability who have age-related care needs:*
2. *Development of strategies to address the needs of younger people with a disability living in, or at risk of living in, residential aged care.*

Clause 3(3) refers to retirement transition options for people with a disability who have age-related care needs – improving understanding of the needs and characteristics of this group with a view to ensuring that people with a disability who have age-related care needs have access to retirement options consistent with those available to the general population.

Australian Government and Victoria Bilateral Agreement

The Aged Care/Disability services interface is named as an activity area under Policy Priority 2: Strengthen across government linkages.

In Clause 3(a)(ii) both Governments acknowledge the inappropriate placement of some young people with disabilities in aged care facilities and that some older people with disabilities require additional frail aged care services.

For older people with disabilities both Parties agreed to work together to develop:

- *Improved assessment processes informed by an understanding of the needs of people with disabilities as they age.*
- *More flexible funding approaches, including shared funding where appropriate.*
- *To evaluate current models of support for people with a disability who are ageing and explore opportunities to pilot models that consider the needs of people 'ageing in place'.*
- *Appropriate training and skills development for disability and aged care support staff to ensure that both sectors have an improved understanding of the support needs of people with disabilities as they age.*

For young people in nursing homes both Parties agreed to explore together:

- *Alternative support models for young people in nursing homes including the capacity to transfer young people in nursing homes to more age appropriate accommodation.*
- *The capacity to participate in the Innovative Pool Project.*

Australian Government and Queensland Bilateral Agreement

Clause 3(1) refers to strengthening cross-government linkages, particularly at critical life stages and transition points. Development of the aged care/disability services interface is listed as a priority area for activity and the following issues are named as areas of significant importance:

- *younger people (under 50 years) inappropriately placed in aged care facilities (including nursing homes)*
- *older people (over 50 years) in State disability services*
- *ageing carers of people with disabilities.*

Both governments acknowledge the inappropriate placement of some younger people with disabilities (under 50 years) in nursing homes. Some older people with disabilities (over 50 years) require additional and more suitable aged care in appropriate placements. Work on these issues needs to be undertaken in the context of a National Policy Framework and agenda. This has resource implications for both jurisdictions, and will require the involvement of both the Commonwealth Department of Health and Ageing and Queensland Health.

Box 1.3 (continued): Activity areas for developing the disability services/aged care interface

Australian Government and South Australia Bilateral Agreement

In Clause 3(1)the Parties acknowledge the need to ensure people with disabilities using the service system can have fair opportunities to access different services as their needs change during the normal course of the lifecycle and agree to reform programs of both governments to better align pathways, access, and to improve coordination of assessments and reduction of duplication for consumers.

Both Parties agree to work to make the transitions between day services and employment services (in particular) operate for people experiencing routine life transitions.

It was also agreed to establish 'productive communication channels at the local level to work towards improving the management of the Aged Care/Disability Interface in South Australia' with particular reference to coordinating Commonwealth Carer Respite Centres and state government services/planning; adapting the service system to accommodate the frail aged with a lifelong disability; and improving residential options for young people currently residing in nursing homes.

Australian Government and Western Australia Bilateral Agreement

An improved aged care/disability services interface is listed under Policy Priority 1 of the Agreement: Strengthen across government linkages.

Both governments acknowledge the inappropriate placement of some young people with disabilities in aged care facilities and that some older people with disabilities require additional and more appropriate aged care services if they are to age in place or may need to access aged care services. This has resource implications for both jurisdictions, and will require the involvement of the Commonwealth Department of Health and Ageing.

The Parties agreed to work together to develop:

- *improved assessment processes informed by an understanding of the needs of people with disabilities as they age*
- *more flexible funding approaches, including shared funding where appropriate and possible involvement in Commonwealth Innovative Pool Project*
- *models of support which promote 'ageing in place' for people with disabilities*
- *appropriate training and skills development for disability and aged care support staff to ensure that both sectors have an improved understanding of the support needs of people with disabilities as they age.*

Australian Government and Northern Territory Bilateral Agreement

Clause 3(1) refers to strengthening access to generic services for people with disabilities as a complement to the focus on the funding and delivery of specialist disability services and supports.

Clause 3(2) refers to strengthening cross-government linkages, particularly at critical life stages and transition points.

One agreed outcome would be an opening of communication channels with the Department of Health and Ageing to improve the management of the Aged Care/Disability Interface.

The Parties agreed to investigate opportunities to develop trials of models designed to accommodate the needs of people with disabilities who are ageing.

Box 1.3 (continued): Activity areas for developing the disability services/aged care interface

Australian Government and Australian Capital Territory Bilateral Agreement

Strategies to improve aged care/disability services interface

In Clause 3.4 both Parties acknowledge the inappropriate placement of some young people with disabilities in aged care homes and that some older people with disabilities require additional and more appropriate aged care services if they are to age in place or may need to access aged care services. This has resource implications for both jurisdictions, and will require the involvement of the Commonwealth Department of Health and Ageing. The Parties agreed to work together to develop:

- *improved assessment processes informed by an understanding of the needs of people with disabilities as they age*
- *more flexible funding approaches, including shared funding where appropriate and possible involvement in Commonwealth Innovative Pool Project*
- *models of support which promote 'ageing in place' for people with disabilities*
- *appropriate training and skills development for disability and aged care support staff to ensure that both sectors have an improved understanding of the support needs of people with disabilities as they age.*

Several of the Agreements mention Aged Care Innovative Pool pilots as a means to explore shared and flexible funding models and to increase understanding of the needs of people with disabilities as they age, particularly in relation to service needs at key life transition points. This sits within a broader framework for working towards more coordinated access to the range of specialist disability services covered by the CSTDA and generic services outside the CSTDA for people with disabilities of all ages.

Advocates of whole-of-government approaches to social services recognise that service systems need to address the needs of the whole person to be fully effective.

1.2 Service issues for the target group

Inadequate linkage between disability and aged care services has been attributed to the way that disability and aged care programs are constructed in reference to each other and that problems with meeting the needs of people with a disability who are ageing are largely related to program structures and models of service delivery in use (various authors cited in AIHW 2000:191).

This section briefly describes some main service gaps that impact on people ageing with a disability who live in disability-funded supported accommodation. It draws on recent research in the disability services field, most of which deals with the service needs of older people with intellectual disability. Issues that affect older people with other types of disability are less widely reported in a form that can be used to make general observations. While this report refers broadly to 'the target group' and 'people with disabilities', the particular systemic issues surrounding access to services for an older person with a disability depend on the nature of the primary disability and associated ageing trajectory, the services available to the individual through the disability services system, and needs that arise as an individual grows older that may be unrelated to the primary disability. There has been a shift away from using disability group to differentiate people with disabilities but on the

subject of 'dedifferentiation', Bigby (2004:38) advocates for a balanced perspective since although 'the outcomes sought for people with disabilities may not differ between groups, the support necessary to achieve these may well do so'.

Intellectual disability is the most commonly reported primary disability of all CSTDA consumers, of those consumers who receive supported accommodation services, and of consumers in CSTDA-funded employment services (AIHW 2005a; FaCS 2005a). Physical disability is the next most commonly reported primary disability among CSTDA consumers.

The 2004–05 CSTDA Minimum Data Set records 13,034 consumers of CSTDA-funded accommodation services who were aged 30 years or over. Approximately 80% of these consumers had a primary disability of intellectual disability. Approximately 8,600 of accommodation service consumers aged 30 years or over used group home services (8,599 consumers of group home services; 3,430 used larger institutions; 838 used smaller institutions; 295 used hostels). Among the consumers aged 30 years or over who were in group homes 81% had a primary disability of intellectual disability. Across all disability groups, 2,815 consumers were aged 50 years or over (Table 1.2).

The Disability Aged Care Interface Pilot client group comprises mostly people with intellectual disability, a small group of people with a primary disability of physical disability and smaller numbers of people with acquired brain injury, neurological or sensory disability. Pilot participants with a primary disability other than intellectual disability are clustered in two projects, while the other projects have serviced mainly or primarily people with intellectual disability. MS Changing Needs, Victoria, caters exclusively to a group of clients of the MS Society of Victoria who have multiple sclerosis and who need 24-hour intensive nursing care. The Northern Sydney Disability Aged Care Pilot services a diverse client group including people with cerebral palsy, physical disability of other origins, and intellectual disability.

Table 1.2: Consumers of CSTDA-funded group home accommodation services aged 30 years or over, number of consumers by primary disability and age group, 2004–05

	Age group (years)					
Primary disability	**30–39**	**40–49**	**50–59**	**60–69**	**70+**	**Total**
Intellectual	2,415	2,308	1,470	533	231	6,957
Specific learning	2	—	2	1	—	5
Autism	89	26	13	—	1	129
Physical	264	210	145	50	13	682
ABI	96	86	62	29	5	278
Neurological	43	49	44	14	1	151
Deafblind	6	—	1	—	—	7
Vision	10	4	2	2	1	19
Hearing	1	5	1	2	—	9
Speech	—	—	—	—	1	1
Psychiatric	42	50	63	37	9	201
Not stated	36	42	40	17	25	160
Total	**3,004**	**2,780**	**1,843**	**685**	**287**	**8,599**

— Nil.

Source: AIHW analysis of CSTDA Minimum Data Set, courtesy Functioning and Disability Unit.

Many of today's service arrangements for adults with disabilities evolved during the period of deinstitutionalisation of disability services in the 1980s and 1990s when group homes emerged as a dominant accommodation service model. By 1999, 72% of recipients of government-funded disability services who did not live alone or with family were residing in community accommodation, mostly disability-funded accommodation (AIHW 2000:Table 6.3). On the 1999 snapshot day for the Commonwealth State Disability Agreement Minimum Data Set, 8,825 CSDA consumers aged 30 years or over were living in CSDA-funded group homes. That number included 3,555 consumers aged 40 years or over. In the five years to 2004, the number of CSDA/CSTDA consumers aged 40 years or over living in group homes thus increased by approximately 57% (an additional 2,040 persons). The ageing of this group is testing the capacity of specialist disability service systems designed for younger adults.

Accommodation support models premised on a young to middle age group of consumers in full-time employment or day programs, appropriate for a majority of consumers 10 to 15 years ago, are struggling to meet the needs of residents who are ageing. The median age of consumers using accommodation support services has gradually risen over the years (AIHW 2005a) and service providers are faced with the changing needs of increasing numbers of people with disabilities who are attaining older ages. Bigby's (2004) projections of the number of people with intellectual disability alone indicate a 45% increase between 2005 and 2020. Community access services (for example, life skills development, recreation and holiday programs) designed for mostly younger adults as alternatives to employment may not cater well to the needs of older consumers and many business services now operate in highly competitive market spaces making it more difficult for older and less productive workers to cope.

Informants to a study of housing and care for older and younger adults with disabilities indicated support for deinstitutionalisation in theory but questioned whether it had demonstrated the desired outcomes in practice (AHURI 2002). Those anticipated outcomes depend on the provision of a range of accommodation styles and flexible arrangements for the funding and provision of accommodation and other types of assistance. It has been suggested that the predominance of the group home, or community residential unit, model largely came about because it enabled timely closure of institutions by reducing the cost of in-home supervision and waiting lists more effectively than other accommodation options, but that 'there is a lack of clarity about the distinction between a "home" versus an "institution"' (AHURI 2002). The issues faced by many people ageing with a disability who live in disability-funded community accommodation highlight the need for individually tailored services to suit individual ageing trajectories.

Successful models of integrated services to support people with ageing and specialist disability needs have operated for some time. For example, the Yooralla Society of Victoria redeveloped its Flete residential service in the late 1990s to address the needs of distinct groups within the Yooralla client group: one model is a low support needs service for residents with intellectual disabilities; three models offer smaller sites for married couples and single individuals; a high physical support needs service has capacity to meet complex medical needs; and an ageing and disability model supports older residents with diverse and complex needs. The redeveloped service was borne of one service provider's vision for the future. Its physical setting has drawn out 'the best characteristics of both disability and aged care models' for people with many types of primary disability and at different stages of their lives (Sheridan 2000). Another example is the launch in 1998 of *Challenge Plus*, an initiative of one of the Disability Aged Care Interface Pilot partners, Lismore Challenge Limited. This service was developed in response to the identified need for a specialist day service to cater

for ageing clients. It commenced operations as an unfunded transition to retirement service for people with disabilities who were unable to cope with the demands of the workplace due to ageing issues such as declining levels of productivity, poor or deteriorating health and stamina, or an expressed need to slow down and participate in activity-based programs (description taken from an attachment to the Maclean Shire Council Community Services proposal to the Department of Health and Ageing for 'Innovative Care Disability & Aged Care Interface'). *Challenge Plus* received a Community Services Award in 2002.

Case study: CSTDA consumer with severe intellectual disability, aged early 60s

'Client was placed in a local nursing home upon the death of her mother several years [earlier]. The client was ostracised and made to feel unwelcome by fellow residents within the aged care facility. The client responded by displaying inappropriate and violent behaviours.

In early 2002 the client relocated to a group home operated by our organisation and now lives with other residents who also have disabilities. After responding to her needs and implementing appropriate strategies there have been no violent episodes or displays of inappropriate behaviour. The client currently attends our Challenge Plus day program.'

Source: Lismore Challenge Ltd attachment to the Maclean Shire Council—Community Services Proposal: Innovative Care Disability & Aged Care Interface Pilot, 2003.

It is more generally the case that 'as people with intellectual disabilities age their access to specialist disability services is likely to be reduced and restricted' (Bigby 2000 and Thompson & Wright 2001, both cited in Bigby 2004:48). In addition, a range of factors contribute to restricted access to generic community services for people with disabilities who are ageing (adapted from AIHW 2000):

- Individuals with inappropriate or intrusive behaviours are not welcomed in general community-based services and activities.
- Ageing people with a lifelong disability are often perceived as being incompatible with present client groups.
- Day activity programs for older people typically cater to the needs and interests of people in the 75 years and over age group and are unlikely to suit the vastly different life experiences of people with disabilities aged in their 50s to 60s.
- The location of services may make them inaccessible to some people with a lifelong disability.
- People ageing with disability may be excluded from specific services by restrictive program restrictions/requirements.
- Personal financial constraints may limit access to services.
- The resources and staff expertise required to meet the needs of older people with an early onset disability are diverse and complex and may not be available in generic aged care programs.
- There is a lack of trained staff aides to support older adults with intellectual disability.

Older people with a disability are at risk of entering residential aged care accommodation at relatively young chronological ages. Relatively more people with intellectual disability and severe or profound core activity limitations live in cared accommodation compared to people with severe or profound core activity limitations associated with physical disability

(Table 1.3). Over 70% of people with intellectual disability and severe or profound core activity limitations who were aged 75 years or over in 2003 resided in cared accommodation, compared with 18% of people in this age group with physical disability and the same level of core activity limitation.

Generic residential aged care is widely acknowledged as a less than ideal form of accommodation support for people with disabilities who are unable to live in the community. This service model caters to the needs of very old people and rarely offers adequate specialist support or appropriate living environments for people with disabilities aged in their 30s to 60s. Few staff in aged care facilities are trained to care for people with intellectual disability and the integration of mobile, younger residents with intellectual disability can present problems for frail older residents. Residential aged care, characterised by larger facilities with lower costs and inputs, is widely regarded within the disability sector as providing a poor level of service for disability clients. There is a lack of input from or contact with specialist disability services, staff knowledgeable in the disability field, and access to activities and relationships outside the home are restricted (Bigby 2004).

Table 1.3: Persons aged 45 years and over with a severe or profound core activity limitation and intellectual or physical disability, per cent of age group by accommodation setting[(a)], Australia 2003

	Age group (years)			
	45–64	65–74	75+	Number
	Intellectual disability (with or without other types of disability)			
Household	80.0	61.5	27.1	76,200
Cared accommodation	20.0	38.5	72.9	101,800
Total	**100.0**	**100.0**	**100.0**	**178,000**
	Physical disability (without intellectual disability)			
Household	99.0	95.3	72.8	557,800
Cared accommodation	1.0	4.7	18.2	56,000
Total	**100.0**	**100.0**	**100.0**	**613,800**

Note: Figures include all people with intellectual disability as either primary or secondary disability.

(a) Cared accommodation includes hospitals, nursing homes, hostels and other homes. Household includes private and non-private dwellings such as hotels, motels, boarding houses, short-term caravan parks and self-care components of retirement villages. Group homes of seven or fewer residents are included as households.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

Bigby (2004:172) identifies seven areas of living difficulty that commonly precipitate the transfer of a disability services client from supported accommodation in the community to residential aged care:

- accommodation funding models based on a client's full time attendance at a day program preclude long periods of time at home during the day
- lack of resources or flexibility to respond to changed support and care requirements
- concerns about the safety and well being of frail residents in mixed age houses
- poor design and adaptability of houses
- lack of expertise and skilled assessment capacity

- inability to access external specialist resources, including extra services through the aged care system due to rules and guidelines to prevent 'double-dipping'
- misconceptions about ageing.

Bigby highlights the lack of incentive for collaboration and shared use of resources that comes about because of the separation of accommodation services and day services for people with a disability. One issue for people with a disability as they age is that they may become unable or choose to not participate in specialist employment and day programs and begin to spend more time at home; however, supported accommodation services are typically predicated on activity away from home during the day and therefore staff may not be in attendance for long periods. The need for age-appropriate levels and types of participation and attention to ageing needs does not feature in program funding arrangements or objectives of disability services in Australia. Bigby discusses the range of issues that impact on older people with disabilities as a result of structural inflexibility: safety in the home, individual independence and lifestyle choice, sensory deprivation and loss of living skills, to name a few.

A person's retirement from employment or structured day programs can be related to functional decline and/or changing interests and activity levels associated with psychological and social ageing. Generally speaking, the needs of clients making a transition from work to retirement or reducing attendance at day programs are not well addressed within the disability services sector. A 'Transition from Work to Retirement Study' commissioned by the then Department of Families and Community Services examined the range of issues faced by people with a disability on retirement from work (FaCS 2005d). A survey conducted as part of the study indicated that pathways to retirement are not well defined or understood. People with disabilities approaching retirement from specialist employment services have concerns including fear of social isolation, lack of activity, structure and routine, boredom, declining health, low self-esteem, financial loss and problems with access to transport, support services and community activities. The study found that around 1,200 people annually were likely to be affected, including around 700 people with high-level ongoing support needs and a large number of younger retirees, aged from 45 years of age.

Day programs aimed at frail older people may be appropriate for some older people with disabilities but there are gaps including lack of choice, activities targeted to much older age groups, lack of individualised planning (packaging of program) and lack of flexible transport services to support part-time attendance, for example. Funding considerations may also limit access to appropriate day activities.

Dementia care

Dementia affects a significant proportion of older adults with intellectual disability (Janicki et al. 2002). With the rising life expectancy for people with disabilities more generally, it is expected that the incidence of dementia in this population will increase. Udell (1999) and Chaput & Udell (2000) consider issues surrounding dementia care for people with intellectual disability in a group home environment versus nursing home settings.

The progression of dementia is similar for people with intellectual disabilities as for the general population, but Janicki et al. (2002) note that the progression can be compressed (shorter duration and faster decline) for people with intellectual disability, particularly Down syndrome (Janicki et al. 2002). Moreover, the interaction of a greater number of chronic physical health problems and chronic disability that lowers the capacity for self-

directed activity in adults with intellectual disability aged over 50 years who have dementia tends to mask the impact of dementia-related skill loss in this population (Moss & Patel 1997 cited in the [Innovative Pool] Application for Flexible Care Places, Helping Hand Aged Care Inc., 2003).

The neuropathological features of Alzheimer's disease are believed to develop in most people with Down syndrome by the age of 40 years, and initial symptoms tend to be recognised in the mid-50s. By the age of 60 years, at least 56% of people with Down syndrome will have been diagnosed with dementia involving memory loss, cognitive decline, and changes in adaptive behaviour (Bittles & Glasson 2004). A study by Janicki et al. (2002) of individuals with intellectual disability and dementia in 54 group homes in the United States identified individuals with ages ranging from 32 to 79 years and an average age of 55.1 years.

Group home residents with intellectual disability who have dementia place higher demands on staff than residents who do not have dementia. Janicki et al. (2005) reported that dementia was associated with more demands on staff time for hygiene maintenance and behaviour management. The increasing need for intensive, often one-to-one, support reduces the sustainability of community living.

Case study: Three clients with Down syndrome, aged early to mid-50s

'The three male clients share a home together and all have been diagnosed with various stages of dementia. We have been well supported by the local ACAT, GPs and specialists. Our organisation has also developed close links with local aged care facilities and dementia units. At present all of the clients are being supported within the home however unless we are able to gain additional support one client may soon have to seek alternate care options.'

Source: Lismore Challenge Ltd attachment to the Maclean Shire Council—Community Services Proposal: Innovative Care Disability & Aged Care Interface Pilot, 2003.

Community dementia care for people with intellectual disability has been found to be successful providing certain 'programmatic features' exist: specialist health care, terminal care, and individualised dementia-related care (Ahlund 1999, Dodd 2003 and Watchman 2003, all cited in Janicki et al. 2005). Safe, calm and predictable but stimulating home environments offer the best outcomes for people with intellectual disability who have dementia (Kerr 1997 cited in Janicki et al. 2005). Wilkinson et al. (2005) emphasise the 'crucial' issue of training and support for staff working in group homes that needs to be addressed in the policy and practice aimed at supporting people with intellectual disability and dementia to age in place.

The study suggested that disability services need to improve their ability to recognise symptoms, diagnose, and provide services that cater for clients with dementia, defining good dementia care within group homes as comprising the following key elements:

- Early screening and diagnostics—it is necessary to collect data on the client to allow periodic reassessment, initiation of a data set on the person and his/her behaviours before dementia is evident to allow differential diagnosis.
- Clinical supports—use of experienced clinicians and professionals, trained staff, for diagnosis and intervention.

- Environmental modifications—simple changes or major redesign to living spaces can be the difference between being able to age in place or having to move to another unfamiliar setting.
- Program adaptations—re-thinking of how daily activities are planned and managed, for example, sometimes people with dementia need less stimulating and challenging environments than do other residents. Use of behavioural cues, adapted activities, etc. can help people retain the functions they have.
- Specialised care—care has to focus on stage-specific presentations and staff need to adapt to the resulting changes in needs. Later stages of dementia require changes in approaches and increasingly more structured care and supervision.

In another study, Janicki et al. (2002) looked at dementia-related care decision making in group homes for people with intellectual disabilities. They concluded that existing services for people with intellectual disability can be adapted for dementia care capability but that decisions on whether to provide continued community-based care are highly subjective and multifactorial. Factors identified as influencing decisions about long-term care for people with intellectual disability and dementia are likely to apply in most situations that involve a person in shared supported accommodation who has increasing age-related needs. They include dementia (or, more generally, the presentation of age-related needs), staff and home capabilities and the resources that a disability service provider has available to support a client on a continuing or long-term basis (Janicki et al. 2002).

Models for provision of support to people with a disability who are ageing—where does the Pilot model sit?

Various approaches to providing care for people with disabilities who are ageing are surveyed in the literature. Janicki et al. (2000) in relation to dementia care for people with disabilities consider three basic approaches:

(1) continuing provision of ageing in place supports
(2) developing an in-place progression setting, for example, redevelopment of the Flete residential services, mentioned above
(3) referral to a non-specialised long-term care setting, that is, residential aged care.

An evaluation of six types of day programs for people with a disability in Australia found that aspects of implementation rather than program structure are the key determinants of performance in this area (Bigby et al. 2001). Different program models examined in this work were: brokerage; age-integrated day centres; specialist centres for older people with intellectual disability; specialist non-centre based outreach programs for older people in supported accommodation; specialist intellectual disability programs incorporating accommodation and day support; and jointly sponsored centre-based program that integrates older people with intellectual disability into a generic aged day centre (see also Bigby 2004:149–50). An important finding was that client outcomes depend on the capacity of service providers to understand ageing issues and respond appropriately than on the service delivery model itself.

Using these ideas, the Disability Aged Care Interface Pilot can be characterised as an ageing in place model where 'a range of appropriate supports are adapted and provided in the clients' existing care setting, relevant to each stage of need' (Janicki et al. 2000). Projects were developed to meet the needs of people with a disability who are ageing and who require additional aged care specific support services in order to remain in their current disability-

funded supported accommodation, with the aim of preventing inappropriate or premature entry into residential aged care. Pilot services aim to integrate aged care services into supported accommodation settings to maximise independence of the individual, maintain lifestyle and improve quality of life at older ages. Of the program structures listed above, most Pilot projects have trialled a non-centre based outreach model of ageing in place.

Bigby suggests strategies that could provide greater opportunity for ageing in place for members of the target group:

- person-centred planning, coordination and care plan implementation
- design and building modifications
- staff training and education
- changes to staff mix and resourcing
- use of external services to provide specialist assistance
- changed resident selection practices
- strategic location close to aged care facilities
- designation of specific houses with a service for older people.

There have been calls from within the disability sector for improved access to community aged care for older disability services clients to help them avoid or delay entry to residential aged care. The Disability Aged Care Interface Pilot has trialled a 'top-up' model of community-based aged care in which aged care and disability services collaborate on integrated care planning and service delivery. A further important aim of the Pilot is to promote skills transfer at the disability and aged care interface through collaborative processes. This aspect cannot be overemphasised, since the sharing of expertise is the mechanism by which a more holistic approach can be taken to the provision of the full range of supports for people with disabilities who are ageing. Even in the Pilot situation it has been incumbent on disability service providers to initiate referrals for pilot services. Referral relies on a capacity within the disability service to identify people who can benefit from and would be eligible to receive the type of assistance on offer.

1.3 Targeting people who need aged care

The question of what is meant by 'aged' or 'older' person and 'person who is ageing' is an important practical issue in the Disability Aged Care Interface Pilot and targeting outcomes are likely to generate considerable interest. The 'older population' is a term conventionally used to refer to people aged 65 years or over. This usage originates from the age traditionally associated with retirement from the workforce and the age at which men are eligible to apply for the Age Pension. Chronological age is not always a reliable guide to level of support need associated with ageing and most people do not experience losses of functional ability that seriously affect their social, physical or cognitive behaviour, at least until very late in life (McPherson 1990). While the population over a certain chronological age is a parameter in planning for the provision of aged care services, an approval for aged care is made on the basis of evidence of a person's need for a type of aged care (Box 1.4).

A great deal of research effort has documented the early start of individual ageing that occurs in parallel with or because of early onset disability (some of this work is summarised in AIHW 2000: 38–40). Average life expectancy for people with intellectual disability remains lower than that of the wider population and mortality rates are higher though there is

considerable variability according to severity of the disability (Durvasula et al. 2002). Lennox (2004) has described people with intellectual disability who reach the age of 50 years or older as 'healthy survivors'.

Down syndrome is associated with premature mortality; the median life expectancy for people with Down syndrome in Australia is approximately 60 years (Bittles & Glasson 2004). People with Down syndrome or intellectual disability caused by certain other chromosomal abnormalities may begin to age in their 30s, 40s or 50s when signs of ageing recognisable to most people begin to show—premature greying of hair, hair loss, increased autoimmunity, Alzheimer's type dementia and other degenerative diseases common in et older populations (Nakamura & Tanaka 1998; Brown 1987; Das et al. 1995). Nakamura & Tanaka (1998) suggest that the genetic irregularities that cause Down syndrome are responsible for premature biological ageing.

Box 1.4: Approval of Care Recipients Principles relating to residential care and community care

Eligibility for residential care

(1) A person is eligible to receive residential care only if:

(a) the person is assessed as:

(i) having a condition of frailty or disability requiring at least low level continuing personal care; and

(ii) being incapable of living in the community without support; and

(iii) meeting any other eligibility criteria for the level of care assessed for the person that are set out in the classification level applicable under the Classification Principles 1997; and

(b) for a person who is not an aged person – there are no other care facilities or care services more appropriate to meet the person's needs.

(2) In deciding if the criteria mentioned in subsection (1) are met, the Secretary must consider the person's medical, physical, psychological and social circumstances, including (if relevant):

(a) evidence of medical condition, as decided by suitably qualified medical personnel;

(b) evidence of absence or loss of physical functions, as established by assessment of capacity to perform daily living tasks;

(c) evidence of absence or loss of cognitive functioning, as established by:

(i) a medical diagnosis of dementia or other condition; or

(ii) assessment of capacity to perform daily living tasks; or

(iii) evidence of behavioural dysfunction;

(d) evidence of absence or loss of social functioning, as established by:

(i) using information provided by the person, a carer, family, friends and others; or

(ii) assessment of capacity to perform daily living tasks;

(e) evidence that the person's life or health would be at significant risk if the person did not receive residential care.

Eligibility for community care

(1) The person is eligible to receive community care only if the person:

(a) is assessed as having complex care needs; and

(b) would be assessed, if the person applied for residential care, as eligible to receive residential care at least at the low level of care; and

(c) prefers to remain living at home; and

(d) is able to remain living at home with the support of community care.

(2) Complex care needs are care needs that can only be met by a coordinated package of care services.

Source: Approval of Care Recipients Principles 1997 (Part 2 Eligibility to receive care) made under subsection 96-1(1) of the Aged Care Act 1997 (amended 15 November 2005). Viewed at <www.comlaw.gov.au>.

Janicki & Dalton (2000) recommend a baseline assessment for at-risk adults with intellectual disabilities when they reach their 50s and for all adults with Down syndrome when they reach their 40s:

> Routine collection of information on functional status in cognitive, behavioral, and other domains would help provide the necessary comparative data for accurate and trustworthy diagnoses.

Likewise there is evidence that people with severe physical disabilities experience increased support needs associated with premature ageing (Bigby 2004:39 and other authors are cited in AIHW 2000:39). Nakamura & Tanaka (1998) found that biological ageing occurred at twice the rate of chronological ageing in a small sample of people with cerebral palsy aged over 45 years, yet cerebral palsy is not itself a progressive condition. People with physical or intellectual disabilities are susceptible to the range of conditions commonly associated with older age; in the presence of younger onset physical disability, conditions that are commonly associated with ageing can manifest significantly from the age of 40 years onwards. Skin integrity, nutrition management, and reduced mobility can become significant issues for people with disabilities aged in their 40s and 50s.

People with progressive neurological disease such as multiple sclerosis and Parkinson's disease may reach a high level of dependency at relatively early ages and require specialised support as they age (Bigby 2004).

The complexity and diversity of circumstances connected with the passage of time for people with disabilities challenges stereotypical ideas of what it means to be 'aged'. Bigby points to Australian research which suggests that more flexible definitions that accommodate premature ageing tend to be inclusive of much younger people with high support needs. Selzer et al. (1982) cited in Bigby (2004) suggest that chronological age and the following three factors should be considered in determining when a person is old:

1. whether in the absence of illness or physical trauma a person displays greater physical disability and lessened physical resources
2. whether in the absence of illness or physical trauma a person displays diminishing levels of functional skills especially in relation to self-care, personal hygiene and activities of daily living
3. whether the person or familiar other sees him or her as an older person and as preferring to shift to different and age-appropriate activities.

Other similar conceptual frameworks that combine aspects of decreasing physical condition and functional ability and changing social competencies and aspirations can be found in the literature (see, for example, Janicki et al. 1985). A significant clinical issue is the masking of ageing factors in people with disability due to deteriorations as a result of ageing being attributed to disability (Maclean Shire Council—Community Services Proposal: Innovative Care Disability & Aged Care Interface Pilot, 2003).

Thus, targeting for the Disability Aged Care Interface Pilot demands a more flexible perspective on what constitutes an 'aged person' than conventional notions allow. Key questions for ACATs and project coordinators surrounding referral and assessment have included:

- Does the person show signs of ageing processes, that is, is the person an 'aged person'?
- Based on available evidence of the person's medical, physical, psychological and social circumstances, would the person be eligible for at least low level residential care?
- Is the person likely to be able to remain at home with the support of Pilot services?

Biological ageing is 'the process or group of processes that result in the progressive decrement of viability of the organism with the passage of time' (Comfort 1969 cited in Nakamura & Tanaka 1998). By definition, biological ageing manifests as disability. Ageing is a highly individual experience, defined by a myriad of genetic and environmental variables. It may be difficult or impossible to disentangle the effects of early onset disability and ageing and according to the research literature, the presence of early onset disability can have a profound effect on the when and how of ageing. For some types of non-progressive disability it is easier to pinpoint the onset of ageing processes and track their impact on an individual over time. People with early onset disability of a progressive nature also experience changing needs as they age but age itself marks the progression of the primary disability.

Most projects in the Disability Aged Care Interface Pilots are required to target people in participating supported accommodation facilities who are aged 50 years or over (60 years or over in one project) although there is flexibility to accept younger people in special circumstances relating to premature ageing. Eligibility for Pilot services is established by applying the principles of aged care assessment and any additional criteria stipulated in the Memorandum of Understanding between the approved provider and the Department of Health and Ageing and, consistent with those criteria, any guidelines developed by the project steering committee. Eligibility assessment in most projects is confronted with questions of chronological age, biological ageing, and the interrelation between disability and ageing and in this way the Pilot has been a vehicle for testing assessment practices at the boundary of disability support and aged care.

Aged care specific needs

Given the diversity of the Pilot target group in terms of disability groups and support needs, and the inbuilt flexibility to consider people with needs related to premature ageing, key issues for eligibility assessment in the Disability Aged Care Interface Pilot have to do with the need for aged care and what is considered to be aged care specific need. There are needs common to all older people, whether or not ageing occurs with a lifelong or early onset disability, that relate to biological, psychological and social ageing. Thus, aged care encompasses the care needs of the whole person, not just those related to physical frailty.

In general older people tend to have a greater requirement for health, social, psychological and various other support services, including accommodation, recreation and leisure, mobility, finance, advocacy and family support (AIHW 2000). Some of the typical needs that result from biological, psychological and social ageing are listed in Table 1.4.

Consideration of a person's need for a type of care provides a useful alternative to chronological age as a basis for assessing eligibility for Pilot services. However, even following this concept, it can be seen that grey areas exist in relation to the respective responsibilities of aged care services and specialist disability support services in meeting the needs of Pilot clients. For instance, in assessing the risk that an older person will be admitted to residential aged care, Aged Care Assessment Teams pay close attention to the impact of social ageing. As a person grows older their social network may contract through loss or inaccessibility of relatives and friends. The psychological effects of reduced social participation can have a significant impact on overall wellbeing and psychosocial aspects of ageing have been found to be a key factor in admissions for low-level residential care (LGC 2002).

AIHW (2000) summarises the literature on the special needs of older people with an early onset disability as follows:

- They have a high need for formal support services, particularly accommodation support services, since they often do not have good informal support networks and may lack independent living skills.
- They have a high need for age-appropriate day activity and leisure programs. Separate specialist activity programs may be required in addition to, or instead of, community-based services designed for older people generally.
- Appropriate activity services may be required for people with an early onset disability who have previously worked in either supported or open employment.
- They have a high need for assistance in choosing, locating, negotiating access and travelling to community-based programs, and may also require short-term or ongoing assistance in order to participate in chosen activities.
- They have a high need for assistance in personal financial planning. The extra costs incurred by people with lifelong disability can mean that they face old age with few financial resources.
- The impact of disability changes throughout the life span and needs for support tend to increase with ageing. Therefore, reassessment of needs should be available to ageing people with a lifelong disability and they should be involved in initiating reassessments as required.

It is clear that a person who is ageing with an early onset disability typically requires high level support across the full range of life activity areas. It is also apparent that retirement from full-time employment or day programs has far reaching implications for the level and mix of support services that an older person with a disability is likely to need.

Disability services are responsible for ensuring that their consumers are able to live as valued and participating members of the community and this responsibility is not limited by a service recipient's age. Thus, a complicating issue is that the social dimension of life for many people who live in supported accommodation, especially those with intellectual disability, is largely defined by their service experience. Friendships and roles build within and are impacted by the service sphere in a way that does not often occur for people who are able to live independently of formal services until they reach 'old age'. Boundary areas like

this will inevitably give rise to questions about what is aged care specific unless service provision is able to focus on the needs of the whole person.

Table 1.4: Needs common to the general ageing population

Result of ageing	Assistance potentially required
Biological ageing	
Signs of ageing	Assistance with grooming and personal care such as podiatry, hairdressing and skin care.
Sensory deficits (for example, vision, hearing)	Access to regular assessments, medical services, augmentative devices (for example, glasses, hearing aids), adapted environments (for example, placement of furnishings) and large-print materials.
Reduced fitness, muscle tone and strength	Need for continued opportunities for exercise and recreation, and rehabilitation services.
Reduced mobility	Ambulatory aids (for example, sticks, wheelchairs), assistance with learning to use aids, adapted environments (for example, handrails, ramps and bathroom grip rails), safety monitors, transportation and rehabilitation services.
Dietary risk	Adequate diet and nutrition assistance, assistance with food shopping and meal preparation, delivered meal services.
Increased risk of physical illness and chronic disease	Access to health care and monitoring services, medical assistance including dental services, education about the signs of impending illness and disease.
Increased risk of dementia	Medical services, increasing levels of supervision and support to carers.
Increased risk of some other mental disorders (for example, depression)	Access to health care and monitoring services, awareness of causes of stress and stress-reduction strategies.
Psychological ageing	
Personality change	Opportunities for reminiscence and life review.
Motivational change	Stimulation in personally valued experiences, a variety of activity options and opportunities for new experiences.
Changes in cognition and intelligence	Need for continued practice to maintain/learn skills and interest areas.
Change or perceived change in personal control and choice	Opportunities to have input into decisions affecting the individual and a range of options.
Social ageing	
Transition from work to retirement (changes in financial status, social roles, social network)	Pre-retirement planning/advice, opportunities for part-time or voluntary work, assistance in leisure time preparation.
Social network and role change	Opportunities for social contacts and inter-generation contacts, continuing links with the community and valued role at home and in the community.
Social effects of biological ageing (for example, increased loss of social contacts due to reduced mobility, health problems and sensory loss)	Transportation and mobility assistance to maintain community contact and support in facilitating contacts.

Source: Adapted from AIHW 2000:44–5.

1.4 Overview of Pilot projects

This section overviews the key operational features of each project in the national evaluation and the roles of Aged Care Assessment Teams and project partners in assessment and approval procedures.

Chapter 2 examines key characteristics of Pilot participants. Chapter 3 contains a more detailed description of the projects to highlight the way that each has offered new aged care choices to people with disabilities.

The nine projects covered by the national evaluation include six services in capital cities and three servicing clients in regional and rural communities (Table 1.5). There is considerable variation in the size of the projects, ranging from seven allocated places in Ageing In Place, Hobart, to 40 allocated places in the Central West People with a Disability who are Ageing in central western New South Wales. Projects are further differentiated according to whether they operate within or outside a participating disability service and staffing model as indicated in Table 1.5. Three projects (MS Changing Needs, Disability Aged Care Service, and Ageing In Place) operate from within a participating disability service. The Northern Sydney project operates from within the disability services arm of New Horizons Enterprises Ltd, which is a provider of both residential aged care and disability services. In this project all client referrals are sourced from other disability service providers. Three projects are operated by non-government organisations that are approved community aged care providers (Central West, Cumberland Prospect, and Flexible Aged Care Packages). Two projects (Far North Coast and Disability Aged Care Consortium) are operated by government authorities that also deliver mainstream community aged care and disability services.

A number of different staffing models for the delivery of aged care services to Pilot clients are represented across the projects and two projects operate mixed staffing models (Table 1.5). Recruitment and retention of staff has provided some challenges and these are covered where relevant in Chapter 3. Overall, case management remains with a client's disability service provider. Assessment and care planning for the purpose of delivering Pilot services is a joint collaborative activity. Project coordinators have developed recording systems for aged care planning and delivery to be integrated with individual lifestyle plans and other documents maintained by the accommodation services.

Pilot projects have operated either by pooling disability and aged care budget or by operating a separate aged care budget (Table 1.6). In Ageing In Place and MS Changing Needs, income from Flexible Care Subsidy is pooled with disability funds to provide ageing in place supports. Both of these Pilot services are operated within and by the client's existing supported accommodation service, drawing on existing staff resources (aged care funding also enables MS Changing Needs to provide additional nursing staff). Other projects are structured to provide or purchase services on behalf of clients from a separate aged care budget.

Client selection

The general eligibility criteria for entry into the Disability Aged Care Interface Pilot are that clients should:

- have a valid Aged Care Assessment Team (ACAT) approval for residential care
- be currently residing in supported accommodation within a disability service
- have an assessed need for specific aged care services over and above the services they are receiving from the disability service
- provide their agreement and fully informed consent to participate in the pilot program.

State and territory government partners agreed to guarantee continued funding for accommodation and other disability support services for clients who elect to participate in the Pilot.

Some projects have applied age eligibility criteria, most often developed by project steering committees but in some cases also specified in the Memorandum of Understanding. For example:

- Interlink Flexible Aged Care Packages (South Australia) was designed to target people aged 60 years or older, allowing some flexibility for special circumstances relating to premature ageing.
- Disability Aged Care Service (Western Australia) was designed for people who are prematurely ageing; in practice the project has accepted people with ageing needs who are aged 50 years or over.

All projects were intended to select people who demonstrate increasing support needs due to conditions relating to ageing and who are therefore likely to enter into residential aged care in the near future if they do not receive additional support.

Table 1.5: Innovative Pool Disability Aged Care Interface Pilot projects, key operational features

Project	Place allocation	Location description	Approved provider	Number of accommodation provider partners	Siting of project team	Staffing model
Far North Coast (FNCDAC)	30	Regional NSW	Local government provider of aged care and disability services (CACP provider & HACC service agency)	6	Aged care service	Brokered accommodation support staff
Central West (CWPDA)	40	Rural/remote NSW	Aged care service (CACP provider)	6	Aged care service	Dedicated aged care team with brokering of accommodation support staff for three clients.
Northern Sydney (NSDACP)	35	Metropolitan NSW	Disability/aged care service (Residential aged care provider)	4[(a)]	Disability service	Dedicated aged care team (agency staff)
MS Changing Needs	16	Metropolitan Vic	Disability service	Approved provider only	Disability service	Salaried registered nursing staff; existing personal care attendants employed by MSV
Flexible Aged Care Packages (FACP)	30	Metropolitan SA	Aged care service (CACP provider & HACC service agency)	4	Aged care service	Subcontracted accommodation support staff
Disability and Ageing Lifestyle Project (DALP)	10	Regional SA	State government health service (CACP provider) in partnership with State-funded disability service network	3	Aged care service (Community Care Division of Renmark Paringa District Hospital)	Brokered accommodation support staff
Disability Aged Care Service (DACS)	20	Metropolitan WA	Disability service	2, including approved provider	Disability service	Salaried dedicated aged care team
Ageing In Place (AIP)	7	Metropolitan Tas	Disability service	Approved provider only	Disability service	In-place accommodation support staff
Cumberland Prospect (CPDAC)	30	Metropolitan NSW	Aged care service (CACP provider)	6	Aged care service	Mixed model: brokerage of accommodation support staff where possible, agency aged care workers in other homes

(a) The initial proposal was for NSDACP to work with five accommodation services; however, one service withdrew from the consortium in the establishment phase.

Table 1.6: Innovative Pool Disability Aged Care Interface Pilot projects, funding models, service aims and scope of service provision

Funding model	Projects	Service aims and scope of service provision
	Fully integrated models of disability and aged care service provision	
Pooled aged care and disability funds	MS Changing Needs, Multiple Sclerosis Society of Victoria	The service model will test the effectiveness and efficiency of pooling disability and aged care funding to provide a seamless approach to meeting individual care needs by providing the opportunity and resources for MS sufferers at risk of being admitted to residential aged care, because their increasing aged care needs cannot be met through disability support alone, to remain in their current disability-funded living situation for as long as possible. The intention of the project is to supply additional aged care services to meet the emerging aged care needs of the eligible participants.
	Ageing In Place, Oakdale Services, Tasmania	The service model will test the effectiveness and efficiency of pooling aged care funding and disability funding to provide ageing in place. Oakdale is responsible for developing, coordinating and implementing individual care plans for all clients. The program will address individual needs and assist people to maximise mobility, cognitive ability and daily living skills.
	Collaborative models of disability and aged care service delivery	
Separate aged care and disability funds	Far North Coast Disability Aged Care Consortium, Clarence Valley Council, New South Wales	These service models will test the effectiveness and efficiency of providing separate aged care and disability funds to allow ageing in place for people with disabilities living in supported accommodation services. Assist people with disabilities whose support needs are increasing due to conditions relating to their ageing, to maximise their independence and continue their lifestyle. Examples of service scope: Aged care specific individual personal care planning is to be integrated with the client's existing disability care plan and care delivered in collaboration with the client's disability service provider. Provide a range of additional services that are aged care specific to meet the changing needs of people with disabilities that cannot be met through disability support services. Services are to be planned and provided through collaborative case management and brokerage to a wide range of generic and specialist aged care services in accordance with a Schedule of Aged Care Services. Enable ageing in place for individuals with a disability who are prematurely ageing through the provision of additional care and support services that are aged care-specific.
	Central West people with a Disability who are Ageing, Uniting*Care*, New South Wales	
	Northern Sydney Disability Aged Care Pilot, New Horizons Limited, New South Wales	
	Interlink Flexible Aged Care Packages, Helping Hand Inc., South Australia	
	Disability and Ageing Lifestyle Project, Renmark Paringa District Hospital, South Australia	
	Disability Aged Care Service, Senses Foundation, Western Australia	
	Cumberland Prospect Disability Aged Care Pilot, Uniting*Care*, New South Wales	

Source: Memoranda of Understanding between the Australian Government Department of Health and Ageing and Disability Aged Care Interface Pilot approved providers. Courtesy of the Department of Health and Ageing.

Role of Aged Care Assessment Teams

Prior to the launch of the Disability Aged Care Interface Pilot, people living in the participating accommodation services would normally encounter an Aged Care Assessment Team if and when aged care placement was being sought. In the past many disability services clients referred for ACAT assessment have reached the point of very high need for aged care intervention by the time a referral is made to an ACAT and clients are often not known to the ACAT through earlier assessments.

In contrast, the role of ACAT in the Disability Aged Care Interface Pilot has been to assess a person's eligibility for flexible care. Following confirmation of aged care specific needs and potential to benefit from flexible care in a Pilot service, ACAT assessors are required to approve the person for residential aged care in order for them to be accepted into a project. Some participating ACAT members considered this to be an artificial approval process that goes against the principles of ACAT assessment, that is, to recommend the most appropriate care in terms of mode, type and intensity. Other ACAT assessors conceded the artificiality but preferred to view the process as the means to an end.

In the early days of the Pilot disability support staff at some locations were fearful that referral to ACAT for community-based care which involved approval for residential care could lead to clients being transferred to an aged care facility at some future date, despite that not being the intention of the initial referral. The level of suspicion and mistrust caused difficulties for some projects in establishing an early flow of referrals. Over time confidence in the process increased and it helped that disability staff came to realise that the ACAT approvals for Pilot eligibility would not be used to admit clients to residential aged care (a client who eventually needs to enter residential aged care is reassessed at that time). It was said that the early difficulties could have been avoided had ACATs been directed to approve for the type of care being offered rather than residential care and/or through better briefing of ACAT and disability service providers before the Pilot became operational.

Overall, the experience of ACAT staff working with the target group for the Pilot has been very positive. Service providers and project coordinators commented on the significant benefits to clients of increased access to specialist ACAT knowledge. Participating ACAT staff expressed their satisfaction at assessing people with disabilities with a view to being able to offer community care. It was remarked that ACAT assessors need a 'perceptual flexibility' to be able to work successfully with the target group and that staff with this outlook have developed professionally as a result of the cross-sectoral exposure.

Most projects have had the benefit of working with selected ACAT members who have had previous experience in working with clients with intellectual disability. It was noted that not all ACAT staff would be well equipped to work with this client group. It also needs to be said that not all projects have enjoyed the full support of the ACATs they have been working with for the Pilot. ACAT staff have had to work closely with disability support staff in the assessment of clients for the Pilot. Familiarity with clients and changes in their routines has proved vital in the identification of needs related to ageing, as distinct from needs associated with pre-existing disability. In the early stages most projects received a number of inappropriate referrals, which were screened before on-referral to an ACAT. These reduced over time as disability support staff became educated in the identification of age-related needs through working with project coordinators and the implementation of screening tools.

Participating ACATs have generally applied a lower age limit of 50 years, although a small number of younger clients have been approved where it has been possible to establish evidence of premature ageing.

Referral and assessment processes

Clients in the Ageing In Place and MS Changing Needs projects mostly completed their ACAT assessments 6 to 9 months ahead of their official launches, at the time that the service providers were developing proposals for Innovative Pool funding. In these two projects, clients were able to commence services on or soon after the official start date.

Other providers developed funding proposals by estimating demand for places in a pilot service in consultation with an intended group of partner accommodation services and ACAT assessments were completed at a later stage when people were referred to an operational service. Different patterns of referral and assessment emerged, seemingly reflecting the level of involvement of approved providers in the initial targeting of clients during the project planning phase. Some providers worked closely with accommodation service partners to identify clients with aged care needs and completed much of the groundwork for an initial intake of clients before the official start date, thereby reducing the time between the official launch of a project and referral of clients for ACAT assessment. In other cases the participating accommodation service providers surveyed group homes to estimate the number of residents who appeared likely to be eligible for pilot services. Then, when project coordinators received referrals for an initial intake, they often had to spend considerable amounts of time in seeking additional information to form an accurate picture of a client's changing needs. A number of project coordinators reported rejecting significant numbers of initial referrals in the initial intake phase, either because it was determined on closer examination that a person referred for pilot services did not have aged care specific needs or because additional information was required in order to make the assessment. Referrals to an ACAT tend to be made only when all the necessary documentation has been completed. Following the completion of an ACAT assessment a client may be required to undergo further specialist assessments. Projects that, in the early days, relied on the public health system to complete allied health or other types of assessment encountered lengthy delays for some clients and eventually turned to private health services out of necessity to streamline assessment processes. All of these factors have contributed to the different patterns of referral and assessment among Pilot clients.

The evaluation collected date of first referral to Pilot service, date of referral to an ACAT, completion date of ACAT assessment and date of service commencement. Across all projects, ACAT assessments took a median of 18 days to complete (165 clients; mean: 26 days, range: zero to 158 days). Considering just those clients who were first referred to a project after the project's official start date (excluding clients who might have been assessed during the planning phase of a project), the elapsed time between date of referral to a project and the date on which the client started receiving services was a median of 49 days, although this figure varies across the projects (Table 1.7).

Table 1.7: Innovative Pool Disability Aged Care Interface Pilot projects, summary statistics for days between referral to pilot service and referral to ACAT, days to complete ACAT assessment and days from first referral to commencement of pilot services[(a)]

Project	Number of records	Median days from referral of client to project until referral received by ACAT	Median days to complete ACAT assessment (min–max)	Median days from first referral to service commencement (min–max)
FNCDAC	8	0	77 (12–158)	98 (22–236)
CWPDA	25	61	22 (4–133)	196 (40–222)
NSDACP	22	16	7 (2–45)	16 (0–126)
FACP	24	0	36 (0–91)	77 (34–181)
DALP	8	0	9 (5–23)	34 (2–50)
DACS	18	9	18 (7–69)	52 (10–124)
CPDAC	10	0	20 (6–39)	20 (6–39)

(a) Includes clients referred after official project start date; excludes all Ageing In Place and MS Changing Needs clients.

1.5 Evaluation methods, limitations and coverage

Disability Aged Care Interface Pilot projects were required to participate in a national evaluation. The evaluation aims to answer the three key evaluation questions and to highlight strengths and any weaknesses of the service models observed at the time of the evaluation.

The AIHW developed an evaluation framework in the latter half of 2003 to define a set of data items that could be collected for reporting on the age-related care needs and service activity of Pilot clients. A proposed framework was released for consultation in December 2003 and subsequently finalised in March 2004. Approval for the project to proceed was given by the AIHW Ethics Committee (Register Number EC 353).

Participation in the evaluation was subject to informed consent provisions and was in nearly all cases given by proxy.

Methods

Client participation in the evaluation was subject to written consent from either the client or his/her appointed advocate.

The evaluation used quantitative and qualitative methods in an observational study. Project coordinators recorded client-level data between 14 June and 30 November 2004 (January–June 2005 for the late-start Cumberland Prospect project) covering basic socio-demographic and functional profiles of clients, including activities of daily living, extent of participation in major activity areas, and if relevant, behavioural and psychological symptoms.

The quantum of services delivered to each client, by service type, during the reporting period was recorded in standard service units according to a pre-specified set of service type codes. Projects were able to record services funded by a pilot project plus any services initiated by project assessment processes but funded through other channels.

To complement the quantitative data, the AIHW evaluation team met with project coordinators, disability service providers and project steering committees throughout June and July 2004 to gain insight into the operation of each project. Projects were encouraged to submit case studies that describe assessment and service delivery in practice and to give real examples of the types of age-related needs that have been identified and addressed. This information together with service activity profiles was used to define the new care choices offered by the Pilot described in Chapter 3.

Projects closed off the client-level data collection on 29 November 2004 and recorded the accommodation status of all clients who had participated in the evaluation at that point. Results are reported in Chapter 4.

Financial and occupancy reports covering the period 1 July to 31 December 2004 were submitted to provide a basis for assessing the cost of services (Chapter 5).

A Care Experience Survey (anonymous postal survey) was issued to gather information from consumers and their advocates about prior unmet need for aged care services and their Pilot experience. Few clients were able to respond independently and few had involved family members to provide proxy responses. In most cases the questionnaire was completed by disability support staff, commenting on the needs of an individual client and their perspective of the client's Pilot experience. Survey results are summarised in Chapter 6.

Strengths and limitations

The evaluation was designed to assess the effectiveness and efficiency of pilot aged care services and has thus focused on the additional services received by Pilot clients through Aged Care Program funding and not on the entire package of services delivered by disability and aged care services in parallel. Successful ageing in place depends on individual need factors and the extent to which all sources of support combined are able to reduce the impact of disability. Clearly, both specialist disability services and Pilot aged care services have an important role to play in enabling ageing in the community where this is possible to achieve, but the evaluation gives insight only into the aged care side of service provision. Data collected for the evaluation do not facilitate a comparison of service levels during the evaluation period to earlier patterns of service utilisation.

It was thought that the level of disability funding for a client might give an indication of pre-Pilot service delivery; however, the data received proved unreliable indicators of levels of support need. In most cases the disability service providers estimated the level of disability funding to an individual by pro-rating the block grant to the accommodation service. Some of the supplied figures are known to be unreliable. Privacy provisions in the evaluation protocol did not allow for confirmation of the supplied figures with the relevant state authorities.

The usual caveats of descriptive studies apply. A main focus of the evaluation has been to describe the range and mix of services that are offered to support ageing in the community and to identify barriers to successful ageing in place for people with disabilities who live in supported accommodation. While data and information collected for the evaluation provide a rich picture of client experiences of aged care services, and for helping to explain discharge

outcomes, it is not possible to directly attribute outcomes to project interventions or to particular types or levels of service delivered through the Pilot.

Certain data collection and measurement difficulties were foreseen at the outset and three in particular deserve mention. The projects are working with vulnerable client groups and the evaluation was unable to access many family members or other advocates not directly involved in service delivery. Independent assessment teams were not established so that functional assessments for the evaluation were completed by disability support staff and/or aged care teams. This is thought to be a minor limitation since the main thrust of functional assessments has been to characterise the support needs of clients, to help validate service records and to highlight significant change in ADL functioning in clients that might indicate changing support needs over time in the Pilot target group. In other words, the evaluation was designed in recognition of ADL change as a common outcome for people who are ageing but the thrust of the evaluation has not been to assess Pilot services on the basis of recorded ADL levels.

Second, an important objective of the evaluation—the identification of age-related needs in the target group—presents a measurement challenge. The evaluation documented the functional needs of Pilot clients and change in ADL functioning and participation over the timeframe of the evaluation but the functional measures do not allow a client's aged care specific needs to be identified separately from disability support needs. Measures of activities of daily living, cognitive and social functions that can be interpreted relative to population norms for community-dwelling health adults do not facilitate a meaningful interpretation of aged care specific needs in people with disabilities. For this application functional measures would need to be recorded at regular intervals over a relatively long period of time, ideally beginning at the time of a person's peak level of functioning. The evaluation employed a number of these types of measures for the sole purpose of describing the target group and for measuring change over time in functional domains pertinent to the risk of older people requiring residential aged care or substitute. It is assumed that the service profiles of Pilot clients, as direct outcomes of care planning processes, accurately reflect the needs of clients that were identified to be age related through Pilot assessment procedures.

Some of these measures have proven informative. For example, increasing mobility limitation in a person with intellectual disability is highly likely to be age related. An important point to emerge from the Pilot is that identification of age-related needs in people with pre-existing high levels of disability relies on consistent and sound record keeping practice. Four projects in the Pilot demonstrated the use of the Broad Screen Checklist of Observed Changes (Minda Inc.) for the purpose of documenting functional change. ACAT assessment of clients has drawn heavily on the long-term knowledge of clients' lifestyle patterns, preferences and social functioning among staff caring for clients in their homes, often over periods of many years. The identification of an individual's aged care specific needs is highly contextual and relative. Given the levels of pre-existing disability support need in the target group, the evaluation has had to rely on subjective forms of evidence such as informant interview, case study and responses to the Care Experience Survey on the issue of age-related needs.

Third, the Care Experience Survey which would ideally have been completed by clients and/or family members was in most cases completed by disability support staff on behalf of a client. The large-scale nature of the evaluation and geographic spread of clients in each project presented a number of logistical difficulties that precluded a more satisfactory approach to obtaining consumer feedback. Survey results need to be interpreted as a

disability sector perspective of client needs and project effectiveness in meeting those needs, and of the 'top-up' model as a structural response to the disability aged care interface for this target group.

Coverage

A total of 165 clients participated in the evaluation, representing approximately 85% of the planned allocation of places (Table 1.8). Coverage of the client group at the time of the evaluation is in fact higher than this percentage suggests because not all allocated places were taken up during the reporting period.

Central West People with a Disability who are Ageing (CWPDA), with a planned allocation of 40 places, received funding for 30 places in November 2003 and an additional 10 places became operational in April 2004. The planned allocation is therefore valid for the evaluation period and the project reported full occupancy during that period although not all CWPDA clients participated in the evaluation.

Far North Coast Disability and Aged Care Consortium (FNCDAC) had a planned allocation of 30 places, which was carried throughout the evaluation period and revised downwards by 10 places in October 2004 due to sustained low occupancy, said to be the result of one disability service provider's gross overestimation of age-related need among its clients. Consent to participate in the evaluation was obtained for all clients who were active at the time.

The Northern Sydney Disability Aged Care Pilot (NSDACP) received an initial allocation of 45 places, which was reduced by 10 places prior to the start of the evaluation due to low occupancy. Occupancy subsequently increased and an additional 10 places became operational after the evaluation. Seventeen clients who joined the project close to the end of the evaluation did not participate. Written consent could not be obtained for six NSDACP clients, thus coverage for this project reflects both occupancy and lack of informed consent.

Disability Aged Care Service (DACS) in Western Australia filled all allocated places by December 2004. Two late-start clients are not included in the evaluation but participation covered all clients who were active during the reporting period.

Cumberland Prospect Disability Aged Care Interface Pilot (CPDAC) was established in December 2004 and filled 25 of the allocated 30 places between January and May 2005. An additional five clients were in the process of ACAT assessment by late May 2005. The AIHW received data for 18 clients whose care plans were sufficiently established by April 2005 to contribute to the evaluation.

All active clients in MS Changing Needs, Ageing In Place, Flexible Aged Care Packages and Disability and Ageing Lifestyle Project during the reporting period participated in the evaluation.

Table 1.8: Innovative Pool Disability Aged Care Interface Pilot, evaluation coverage by project

Project	Operational places	Active clients[a]	Evaluation clients		Evaluation clients as per cent of active clients
			Profile records	Discharge records	
FNCDAC, NSW[b]	30	13	13	4	100.0
CWPDA, NSW[b]	40	33	33	2	100.0
NSDACP, NSW[b]	35	38	22	2	57.9
MS Changing Needs, Vic	16	16	16	—	100.0
FACP, SA	30	31	30	4	96.8
DALP, SA	10	8	8	—	100.0
DACS, WA[c]	20	20	18	1	90.0
AIP, Tas	7	7	7	—	100.0
Subtotal as at 30 November 2004	*188*	*166*	*147*	*13*	*88.6*
CPDAC, NSW	30	28	18	—	64.3
Total	**228**	**194**	**165**	**13**	**85.1**

(a) Number of clients active between 1 July and 31 December 2004. *Source*: Occupancy reports provided by projects.

(b) Operational places reflect funding arrangements during the greater part of the evaluation period. In the case of the three established NSW pilots, funding was varied in response to occupancy fluctuations.

(c) DACS, WA reached full occupancy in December 2004. Two late admissions to the project are not included in the evaluation.

— Nil.

2 A profile of Pilot clients

This chapter summarises selected socio-demographic and functional characteristics of Pilot clients who participated in the national evaluation. Subject to written consent, project coordinators recorded data on clients who were already receiving services when the evaluation started; clients accepted into projects between 14 June and mid-October 2004 were also invited to participate. Baseline functional measures for established clients reflect levels of functioning at date of entry to a pilot service. The data presented here describe the group during the evaluation in the latter half of 2004.

2.1 Socio-demographic snapshot

The evaluation captured information on 165 clients. As at 30 November 2004, these clients had been in pilot projects for an average of 210 days, ranging from 15 days to 516 days.[9]

Ages of clients at the time ranged from 32 to 88 years (mean 57.5 years). The group comprised roughly equal numbers of males and females (Tables 2.1 and 2.2).

Figure 2.1 contains a box plot of the age distribution of clients in each project. The shaded box area depicts the range of ages for the middle 50% of clients (that is, from the 25th percentile to the 75th percentile age). The heavy black line that bisects most boxes is the 50th percentile (median) age. Lines extend from the ends of the boxes to the minimum and maximum inlier age respectively. 'Outliers' or extreme age values relative to the project's age distribution are marked as small circles.

The median age, by project, was 60 years or lower, except for the Cumberland Prospect Disability Aged Care Project (CPDAC) and Flexible Aged Care Packages (FACP) (Figure 2.1). Far North Coast Disability and Aged Care Consortium (FNCDAC) and Ageing In Place (AIP) projects recorded more age homogeneous groups. Northern Sydney Disability Aged Care Pilot (NSDACP), Cumberland Prospect Disability Aged Care Project and Flexible Aged Care Packages recorded higher median ages and greater variation in ages than the other projects. Disability and Ageing Lifestyle Project (DALP) and MS Changing Needs recorded lower median ages of around 50 years, with age distributions skewed towards younger ages. FACP and Disability Aged Care Service (DACS), on the other hand, had client groups with age distributions skewed towards older ages.

9 Excluding clients from the Cumberland Prospect Disability Aged Care Project, none of whom commenced before January 2005.

Table 2.1: Innovative Pool Disability Aged Care Interface Pilot, number of clients by age group and sex (excluding MS Changing Needs)

Age (years)	Males	Females	Persons
		(number)	
30–39	3	1	4
40–49	9	9	18
50–59	30	34	64
60–69	26	18	44
70–79	3	8	11
80–89	4	4	8
Total	**75**	**74**	**149**
		(per cent)	
30–39	2.0	0.7	2.7
40–49	6.0	6.0	12.1
50–59	20.1	22.8	43.0
60–69	17.4	12.1	29.5
70–79	2.0	5.4	7.4
80–89	2.7	2.7	5.4
Total	**50.3**	**49.7**	**100.0**

Table 2.2: MS Changing Needs, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	2	1	3
40–49	1	3	4
50–59	4	5	6
Total	**7**	**9**	**16**
		(per cent)	
30–39	13.0	6.0	19.0
40–49	6.0	19.0	25.0
50–59	25.0	31.0	56.0
Total	**44.0**	**56.0**	**100.0**

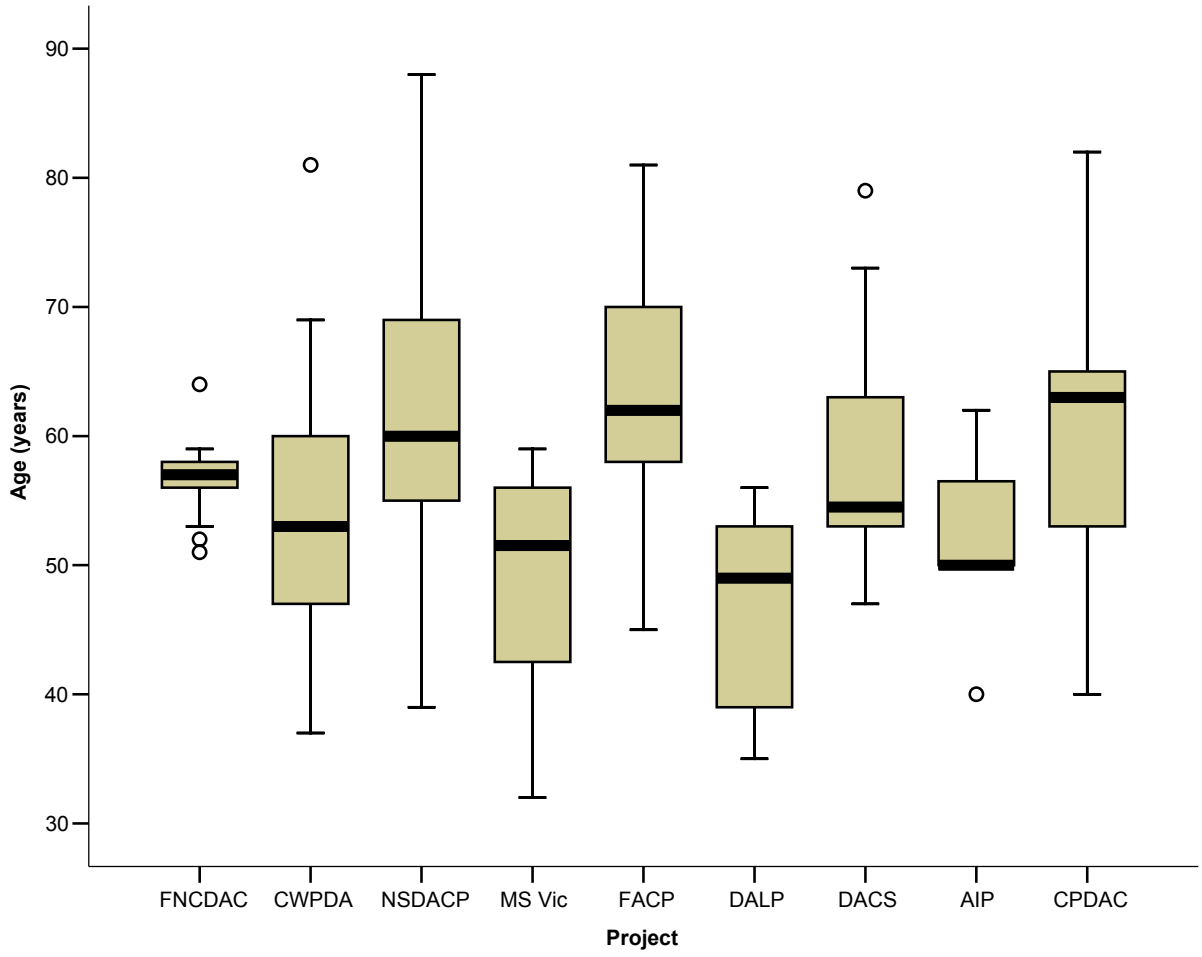


Figure 2.1: Innovative Pool Disability Aged Care Interface Pilot, client age distribution by project

Disability groups

Most referrals for pilot services were for people with intellectual disability (Table 2.3). Sixteen clients with multiple sclerosis in the MS Changing Needs project are recorded in the neurological disability group. Excluding this project, over 80% of evaluation participants were people with intellectual disability.

Table 2.3: Innovative Pool Disability Aged Care Interface Pilot, number and per cent of evaluation participants by disability group

Disability group	Number of clients	Per cent
Intellectual	124	75.2
Neurological	18	10.9
Physical	8	4.8
Acquired brain injury	6	3.6
Multiple/diverse disabilities	7	4.2
Sensory (vision)	1	0.6
Psychiatric	1	0.6
Total	**165**	**100.0**

The majority of participants were living in small group homes in the community, a mixture of residences operated by state government agencies and private residences owned or leased by disability service providers (Table 2.4). The Ageing In Place project is based at Oakdale Lodge, a hostel for people with intellectual disability and acquired brain injury. Six clients in other projects were recorded as living in private residences.

Table 2.4: Innovative Pool Disability Aged Care Interface Pilot, client living arrangements and accommodation settings

	Accommodation setting			
Usual living arrangement	Private residence	Supported community accommodation	Residential disability accommodation	Total
	All projects excluding MS Changing Needs			
Lives with family	4	—	—	4
Lives with others	2	124	19	145
Total	**6**	**124**	**19**	**149**
	MS Changing Needs			
Lives with family	—	—	—	—
Lives with others	—	16	—	16
Total	**—**	**16**	**—**	**16**

— Nil.

Government pensions were the primary source of income for most clients—the Disability Support Pension (135 clients) or the Age Pension (26 clients). Four clients had private sources of income.

2.2 Core activity limitations

Activities involving self-care, mobility and communication comprise the core activities of daily living. A person's capacity for carrying out core activities is associated with their ability to live independently in the community. Severe or profound core activity limitation is used to describe a degree of activity limitation that means a person needs supervision or assistance at times (severe limitation) or always (profound limitation). A person with a moderate level of core activity limitation does not need assistance but experiences difficulty in performing the activity; mild limitation is defined as not having difficulty performing a core activity but using aids or equipment because of disability. By definition, core activities involve tasks that are expected to be performed on a daily basis and thus severe or profound limitation in core activities usually means that a person cannot function in these areas of daily living without daily assistance.

It is to be expected that Pilot clients have at least one core activity limitation regardless of chronological age because of pre-existing, in many cases lifelong, disability. One of the assessment challenges for the projects and participating ACATs has been to identify age-related needs in people with pre-existing high disability related needs. This section makes no attempt to separate the two types of support need and the evaluation is unable to present data that clearly delineate age-related need. The identification of age-related needs of Pilot clients is achieved through comprehensive interdisciplinary assessment conducted by ACAT staff, project coordinators, disability support staff and other specialists, as required. On this basis, the most cogent indicators of the type of age-related need that exist among Pilot clients are the clients' service activity profiles.

Results presented here are intended to describe the client group in terms of levels of core activity limitation at time of entry to projects. These data form part of the basic client profiles recorded for the evaluation. Overall, slightly more than 60% of clients had a severe or profound core activity limitation on entry (Table 2.5). The rate of severe or profound limitation was much higher among clients in the MS Changing Needs project (94%) than across other projects (57%).

Table 2.5: Innovative Pool Disability Aged Care Interface Pilot, number of clients by presence of severe or profound core activity limitation at entry (self-care, mobility or communication)

Does client experience a severe or profound level of core activity limitation?	All projects excluding MS Changing Needs		MS Changing Needs		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
Yes	85	57.0	15	94.0	100	60.6
No	64	43.0	1	6.0	65	39.4
Total	**149**	**100.0**	**16**	**100.0**	**165**	**100.0**

Across projects other than MS Changing Needs, the proportion of clients with a severe or profound activity limitation was highest in the area of self-care (45%). Mobility and communication activity areas each registered 33% of clients with severe or profound

limitation. A high rate of communication limitation distinguishes this group from the wider population of older people, where communication limitation is less common. A sizeable proportion of clients fell into the mild to moderate activity limitation range. The majority of MS Changing Needs clients (94%) had a severe or profound core activity limitation in the areas of self-care and mobility (Table 2.6).

Table 2.6: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of core activity limitation and area of core activity at entry

	Level of activity limitation					
Core activity	No limitation	Mild	Moderate	Severe or profound	Not stated	Total
			(number)			
All projects excluding MS Changing Needs						
Self-care	3	25	53	67	1	**149**
Mobility	20	39	41	49	—	**149**
Communication	20	35	44	50	—	**149**
MS Changing Needs						
Self-care	—	—	1	15	—	**16**
Mobility	—	—	1	15	—	**16**
Communication	10	3	2	1	—	**16**
			(per cent)			
All projects excluding MS Changing Needs						
Self-care	2.0	16.8	35.6	45.0	0.7	**100.0**
Mobility	13.4	26.2	27.5	32.9	—	**100.0**
Communication	13.4	23.5	29.5	33.6	—	**100.0**
MS Changing Needs						
Self-care	—	—	6.3	93.8	—	**100.0**
Mobility	—	—	6.3	93.8	—	**100.0**
Communication	62.5	18.8	12.5	6.3	—	**100.0**

— Nil.

2.3 Activities of daily living measures

Activities of daily living (ADL and instrumental ADL, or IADL) are a key element in the field of aged care assessment and care planning because they define the most basic competencies of old age (Lawton 1983). Gill et al. (1996) and Miller et al. (1999) showed that functional abilities are central to older people's adaptation and stability of residence (cited in Lichtenberg et al. 2000) and it has long been recognised that declining functional competencies also affect environmental press—the demands of a person's home, social and neighbourhood environments and how these demands match with a person's competency in activities of daily living (Lichtenberg et al. 2000; Lawton 1983). ADL scales give a detailed breakdown of support needs in each of the core activity areas. For example, an ADL scale

describes self-care limitation in terms of a range of self-care tasks such as bathing and showering, dressing, grooming, continence management and so on. In the aged care lexicon the composite scores derived from ADL and IADL scales are measures of 'dependency'.

This section summarises baseline activity of daily living (ADL and IADL) scores and change in these scores over time. Client functioning in ADL was measured using the Modified Barthel Index (MBI). The MBI is an index that measures performance in self-care and mobility tasks and generates scores from zero (complete impairment) to 20 (independent function). Functioning in instrumental ADL (IADL) was measured using the Older American Resources and Services IADL scale. Scores on this scale can range from zero to 14 representing complete IADL impairment to full independence in IADL.

Tables 2.7 to 2.10 present summaries of baseline ADL and IADL levels and changes in levels over the course of the evaluation. Tables 2.7 and 2.8 summarise all recorded baseline results. Tables 2.9 and 2.10 summarise baseline and change scores for clients who completed baseline and final assessments.

Approximately 50% of clients recorded baseline scores indicative of severe or complete dependency in ADL and a further 44% recorded moderate dependency (Table 2.7). A wide range of functioning in ADL was observed with baseline scores ranging between the possible minimum (zero) and maximum scores (20 points) (Table 2.8). The maximum observed IADL score of 10 points indicates that no client was fully functional in IADL on entry to the Pilot.

Table 2.7: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of dependency in ADL (all clients with baseline assessments)

Level of ADL dependency	All projects excluding MS Changing Needs	MS Changing Needs	Total
		(number)	
Independent	4	—	4
Slight dependency	4	—	4
Moderate dependency	66	—	66
Severe dependency	52	2	54
Total dependency	23	14	37
Total	**149**	**16**	**165**
		(per cent)	
Independent	2.7	—	2.7
Slight dependency	2.7	—	2.7
Moderate dependency	44.3	—	42.2
Severe dependency	34.9	12.5	28.6
Total dependency	15.4	87.5	23.8
Total	**100.0**	**100.0**	**100.0**

— Nil.

Table 2.8: Innovative Pool Disability Aged Care Interface clients, summary statistics for baseline ADL and IADL scores

ADL measure	Clients	Minimum	Median	Maximum	Mean	Std dev
All projects excluding MS Changing Needs						
Baseline ADL	147	0	13	20	11.6	5.0
Baseline IADL	135	0	3	10	3.7	2.3
MS Changing Needs						
Baseline ADL	16	0	2	10	2.1	2.6
Baseline IADL	16	2	3	7	3.8	1.6

Summary statistics for baseline scores of clients who completed baseline and final ADL assessments do not differ significantly from those for all 147 baseline ADL scores (compare baseline data in Tables 2.8 and 2.9). Considering only those clients with completed baseline and final ADL assessments (Table 2.9), there was a mean change score (score at final assessment minus score at baseline assessment) of –0.3 points with a standard deviation of 2.9 points. Change scores ranged from –16 (16-point decline in ADL function) to 6 points (6-point improvement), reflecting wide variation in functional change and zero average change scores across projects excluding MS Changing Needs. In MS Changing Needs, there was also an average of no change in ADL (mean –0.5; median 0), however the range was –0.2 points to zero, indicating no MS Changing Needs client experienced improved ADL functioning.

Table 2.9: Innovative Pool Disability Aged Care Interface Pilot, summary statistics for paired baseline and final ADL scores

ADL measure	Clients	Minimum	Median	Maximum	Mean	Std dev.
All projects excluding MS Changing Needs						
Baseline ADL	128	0	13	20	11.8	5.1
Change in ADL	126	–16	0	6	–0.3	2.9
MS Changing Needs						
Baseline ADL	14	0	1.5	6	1.5	1.6
Change in ADL	14	–2	0	0	–0.5	0.7

Likewise for the IADL measure, summary statistics for baseline scores of clients with completed baseline and final assessments (n = 120 across projects; n = 14 for MS Changing Needs; Table 2.10) did not differ significantly from those for all recorded baseline scores (n = 135 across projects; n = 16 for MS Changing Needs; Table 2.8). It is therefore reasonable to examine scores for the subset of clients with baseline and final assessment data as a guide to patterns of functional change in the larger group (Table 2.10).

This subgroup recorded a mean change in IADL score (score at final assessment minus score at baseline assessment) of –0.3 points with a standard deviation of 1.9 points. IADL change scores ranged from –7 (7-point deterioration in IADL functioning) to 4 points (4-point improvement in IADL functioning), also reflecting a range of functional change from marked deterioration to moderate improvement, with little change on average across projects excluding MS Changing Needs. MS Changing Needs clients recorded stable IADL scores as

might be expected for clients in a 24-hour nursing care living situation (change minimum –1, median 0, maximum 0).

Table 2.10: Innovative Pool Disability Aged Care Interface Pilot, summary statistics for paired baseline and final IADL scores

ADL measure	Clients	Minimum	Median	Maximum	Mean	Std dev.
All projects excluding MS Changing Needs						
Baseline IADL	122	0	3.5	10	3.8	2.4
Change in IADL	120	–7	0	4	–0.3	1.9
MS Changing Needs						
Baseline IADL	14	2	3	7	3.6	1.4
Change in IADL	14	–1	0	0	–0.1	0.3

It is important to note that the ADL and IADL scores are at best indirect measures of cognitive function. Additionally, they do not fully capture aspects of quality of life and participation, which are an important focus of most projects.

2.4 Participation measures

The evaluation captured measures of clients' participation restriction in areas of activity relevant to the objectives of pilot projects: self-care, mobility, communication, domestic life, social and community life, and interpersonal relations. In contrast to ADL measures that focus on level of need for assistance, participation measures attempt to capture the extent to which an individual is able to participate in an area of activity within the resources of their current living environment. Participation takes into account the person's level of interest and the mediating effect of physical assistance and guidance on the impacts of disability and ageing. Participation measures provide important information about social outcomes and quality of life improvements that can occur even in the absence of measurable improvements in physical function.

A World Health Organization trial participation module facilitates the measurement of participation on two levels—extent of participation restriction and satisfaction with participation. Both levels were included in the evaluation protocol but self-reports of satisfaction proved infeasible and the final data include only measures of participation restriction over time, as reported by project coordinators in consultation with disability support staff. Baseline measures reflect levels of participation restriction at time of entry to the projects. A second measure was taken at each client's final assessment, which occurred as close as practicable to four months following the baseline assessment.

Paired before and after participation restriction ratings were recorded for 124 clients (Tables 2.11–2.16). Reduced participation (increased restriction, represented in cells shaded in dark grey) was recorded for a proportion of clients over the reporting period, ranging from 11% of clients in the area of domestic life to 25% of clients in the area of communication. In all areas, however, higher proportions of clients (23% to 40%) are reported to have experienced increased participation (represented in cells shaded in light grey). The highest rates of reported improvement in participation were in the areas of community and social life (improved participation for 40% of clients), interpersonal relationships (improved participation for 35% of clients) and general domestic life (30%).

Participation levels remained stable (or were unknown) for between 37% and 59% of clients across all areas of activity.

These results are consistent with anecdotal reports from project coordinators that many clients demonstrably benefited from greater opportunity to take part in activities in and outside the home through care plans with individually tailored lifestyle and skills development and increased daytime supervision and accompaniment.

Table 2.11: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in performing self-care activities at baseline and final assessments

Self-care, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	14	6	1	2	—	**23**
Severe	3	26	9	2	—	**40**
Moderate	5	4	16	10	—	**35**
Mild	2	2	4	14	2	**24**
None	1	—	—	—	1	**2**
Total	**25**	**38**	**30**	**28**	**3**	**124**

— Nil.

Table 2.12: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in activities involving mobility at baseline and final assessments

Mobility, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	9	3	2	2	—	**16**
Severe	3	13	4	2	—	**22**
Moderate	3	1	26	10	1	**41**
Mild	1	2	9	14	5	**31**
None	—	2	3	3	6	**14**
Total	**16**	**21**	**44**	**31**	**12**	**124**

— Nil.

Table 2.13: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in activities involving communication skills at baseline and final assessments

Communication, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	2	—	1	1	—	**4**
Severe	1	20	9	4	—	**34**
Moderate	—	8	23	10	2	**43**
Mild	—	2	11	9	6	**28**
None	—	2	1	6	5	**14**
Not stated	—	1	—	—	—	**1**
Total	**3**	**33**	**45**	**30**	**13**	**124**

— Nil.

Table 2.14: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in domestic life at baseline and final assessments

Domestic life, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	18	4	7	1	—	**30**
Severe	3	24	10	4	—	**41**
Moderate	2	3	19	10	—	**34**
Mild	2	—	4	6	1	**13**
Not stated	4	2	—	—	—	**6**
Total	**29**	**33**	**40**	**21**	**1**	**124**

— Nil.

Table 2.15: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in community and social life at baseline and final assessments

Community and social life, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	13	4	5	2	—	**24**
Severe	1	17	13	10	—	**41**
Moderate	3	7	13	13	2	**38**
Mild	2	2	5	10	—	**19**
None	—	—	—	1	1	**2**
Total	**19**	**30**	**36**	**36**	**3**	**124**

— Nil.

Table 2.16: Innovative Pool Disability Aged Care Interface Pilot, number of clients by level of participation restriction in interpersonal relationships at baseline and final assessments

Relationships and interactions, level of participation restriction						
	At final assessment					
At baseline assessment	Complete	Severe	Moderate	Mild	None	Total
Complete	10	5	1	1	1	**18**
Severe	1	16	20	4	—	**41**
Moderate	—	5	21	9	2	**37**
Mild	1	3	8	10	1	**23**
None	—	3	2	—	—	**5**
Total	**12**	**32**	**52**	**24**	**4**	**124**

— Nil.

2.5 Corollary: clients with intellectual disability

In this section we consider separately the 124 clients with intellectual disability, the largest single disability group in the Pilot.

The mean age of clients with intellectual disability across the projects was 57.9 years (range 35–82 years). Nineteen members of this group were younger than 50 years and 15 were aged 70 years or over (Table 2.17).

Table 2.17: Clients with intellectual disability, number and per cent of clients by age group and sex

Age group (years)	Males	Females	Persons
		(number)	
Under 50	12	7	19
50–59	26	27	53
60–69	24	13	37
70+	6	9	15
Total	**68**	**56**	**124**
		(per cent)	
Under 50	9.7	5.6	15.3
50–59	21.0	21.8	42.7
60–69	19.4	10.5	29.8
70+	4.8	7.3	12.1
Total	**54.8**	**45.2**	**100.0**

Sixty-six per cent of clients with intellectual disability could communicate effectively in spoken language (Table 2.18). Just under one-third of the group had little or no communication. This is a mainly English-speaking group of clients.

Table 2.18: Clients with intellectual disability, number of clients by method of communication with others, by age group

	How does the client usually communicate with others?					
Age group (years)	Little or none	Sign language	Effective spoken	Other method	Not stated	Total
Under 50	5	1	13	—	—	19
50–59	15	1	35	1	1	53
60–69	11	1	23	1	1	37
70+	2	—	11	2	—	15
Total	**33**	**3**	**82**	**4**	**2**	**124**

— Nil.

Accommodation and living arrangement

Five clients with intellectual disability were living in private residences. Nineteen clients were living in larger residential care for people with disabilities at the start of the evaluation (some of these clients subsequently moved to group home accommodation).

Less than 5% of clients with intellectual disability were on a waiting list for residential aged care placement when they entered the Pilot (Table 2.19).

Table 2.19: Clients with intellectual disability, number of clients on a waiting list for residential aged care placement by age group

	On a waiting list for residential aged care?			
Age group (years)	**Yes**	**No**	**Unknown**	**Total**
		(number)		
Under 50	1	17	1	19
50–59	2	51	—	53
60–69	2	35	—	37
70+	1	14	—	15
Total	**6**	**117**	**1**	**124**
		(per cent)		
Under 50	0.8	13.7	0.8	15.3
50–59	1.6	41.1	—	42.7
60–69	1.6	28.2	—	29.8
70+	0.8	11.3	—	12.1
Total	**4.8**	**94.4**	**0.8**	**100.0**

— Nil.

Health conditions and health status on entry

The number of health conditions recorded for clients at entry to a pilot project ranged from two to 11. Overall, approximately 46% of clients had five or more health conditions; however 63% of clients in the 50–59 year age group had five or more health conditions (Table 2.20).

Table 2.20: Clients with intellectual disability, number of health conditions at entry to Pilot by age group

	Age group (years)				
Number of health conditions	**Less than 50**	**50–59**	**60–69**	**70+**	**Total**
Two	5	2	8	2	17
Three	6	7	10	6	29
Four	3	9	8	1	21
Five	3	11	6	—	20
Six	2	7	3	1	13
Seven	1	5	—	3	9
Eight	—	5	1	—	6
Nine	3	—	1	1	5
Ten	—	1	—	—	1
Eleven	1	1	—	1	3
Total	**24**	**48**	**37**	**15**	**124**

— Nil.

Table 2.21 lists primary health conditions recorded at ACAT assessment for this client group.

Table 2.21: Clients with intellectual disability, number of clients by primary health condition, by age group at entry to project

Age group (years)	Primary health condition	Number of clients
Under 50	Congenital malformations, deformations and chromosomal abnormalities	8
	Intellectual and developmental disorders	8
	Diseases of the nervous system	2
	Dementia	1
50–59	Intellectual and developmental disorders	28
	Congenial malformations, deformations and chromosomal abnormalities	14
	Diseases of the nervous system	3
	Dementia	1
	Endocrine, nutritional and metabolic disorders	2
	Diseases of the musculoskeletal system and connective tissue	1
	Hypertension	1
	Disorientation/confusion	1
	Other diseases of the eyes and adnexa	1
	Symptoms and signs concerning food and fluid intake[(a)]	1
60–69	Intellectual and developmental disorders	25
	Congenial malformations, deformations and chromosomal abnormalities	7
	Diseases of the musculoskeletal system and connective tissue	1
	Endocrine, nutritional and metabolic disorders	1
	Diseases of the digestive system	1
	Dementia	1
	Heart disease	1
70+	Intellectual and developmental disorders	8
	Diseases of the musculoskeletal system and connective tissue	2
	Heart disease	2
	Endocrine, nutritional and metabolic disorders	1
	Diseases of the nervous system	1
	Other mental and behavioural disorder	1

(a) Includes loss of appetite, excessive eating & thirst, abnormal weight loss and gain.

Across the age groups, a majority of clients (73%) were assessed of being at risk of falls due to impaired gait or balance (Table 2.22). Vision impairment also features, with over half of all clients recording this condition. A higher proportion of the younger than 50 years age group recorded total or partial paralysis, missing or non-functional limbs and/or

disorientation/confusion than in the other age groups. Proportionally more clients in the 50–59 and 70 years and older age groups had a diagnosis of depression than did clients in the other age groups (17% and 20% respectively).

Table 2.22: Clients with intellectual disability, number of clients by selected sensory, mental and physical conditions, by age group

Age group (years)	Total or partial paralysis	Missing or non-functional limbs	Vision impairment	Hearing impairment	Gait and/or balance impairment	Diagnosis of depression	Disorientation/ confusion
				(number)			
Under 50	3	2	11	2	12	2	2
50–59	5	4	27	10	40	9	4
60–69	3	1	21	13	28	4	—
70+	—	—	5	2	10	3	—
Total	**11**	**7**	**64**	**27**	**90**	**18**	**6**
				(per cent)			
Under 50	15.8	10.5	57.9	10.5	63.2	10.5	10.5
50–59	9.4	7.5	50.9	18.9	75.5	17.0	7.5
60–69	8.1	2.7	56.8	35.1	75.7	10.8	—
70+	—	—	33.3	13.3	66.7	20.0	—
Total	**8.9**	**5.6**	**51.6**	**21.8**	**72.6**	**14.5**	**4.8**

— Nil.

Tables 2.21 and 2.22 indicate that Pilot clients with intellectual disability experienced a range of additional health conditions, many of which are commonly associated with ageing. A high proportion of clients experienced multiple health conditions in addition to intellectual disability, highlighting the likelihood of a person in this group having complex health care needs.

Clients with intellectual disability were taking between zero and 13 different types of medication at time of entry (Table 2.23). Overall, 63% of clients were taking four or more medications.

Table 2.23: Clients with intellectual disability, medication use by age group

Age group (years)	Range of number of medications	Median number of medications	Number taking 4 or more medications	Total clients in age group
Under 50	0–9	4	12	19
50–59	0–12	4	34	53
60–69	1–9	5	22	37
70+	0–13	6	10	15
All clients	**0–13**	**4**	**78**	**124**

Disability support staff or a family member or other advocate was asked to rate client health status and change in health status over the past 12 months using a 5-point Likert scale (Short-Form 36). Health status was reported for 74 clients in total across the age groups (Table 2.24). The majority of clients were said to be in fair or good health. Of the 19 clients

with a report on change in health status, most were said to be in about the same health or somewhat worse health than one year earlier.

Table 2.24: Clients with intellectual disability, number of clients by health status ratings, by age group

Age group (years)	Very good	Good	Fair	Poor	Total
Under 50	—	3	8	5	16
50–59	6	16	12	2	36
60–69	2	7	6	2	17
70+	1	2	2	—	5
Total	**9**	**28**	**28**	**9**	**74**

— Nil.

Level of core activity limitation

Most clients with intellectual disability (77%) experienced moderate to profound activity limitation in the area of self-care across the age groups (Table 2.25). Those aged under 50 years were less likely to show severe or profound self-care limitation. The proportion of clients with moderate to profound mobility limitation increases with increasing age.

Table 2.25: Clients with intellectual disability, number of clients by level of core activity limitation, by age group

	Level of activity limitation					
Core activity	No limitation	Mild	Moderate	Severe or profound	Not stated	Total
			Under 50 years			
Self-care	1	6	6	6	—	19
Mobility	5	5	6	3	—	19
Communication	3	6	2	8	—	19
			50–59 years			
Self-care	2	5	19	26	1	53
Mobility	8	15	13	17	—	53
Communication	8	6	19	20	—	53
			60–69 years			
Self-care	—	9	16	12	—	37
Mobility	4	13	11	9	—	37
Communication	5	13	9	10	—	37
			70+ years			
Self-care	—	3	5	7	—	15
Mobility	1	2	7	5	—	15
Communication	2	4	4	5	—	15

— Nil.

Support needs

The majority of clients with intellectual disability needed help or supervision in all activity domains (Figure 2.2). In general, clients required less assistance with mobility than with self- care, domestic life, and community and social life.

There are no discernible age-related trends in support needs, nor in the overall levels of ADL and IADL function (see Figures 2.3 and 2.4 below), suggesting that screening and approval processes determined support needs rather than chronological age.

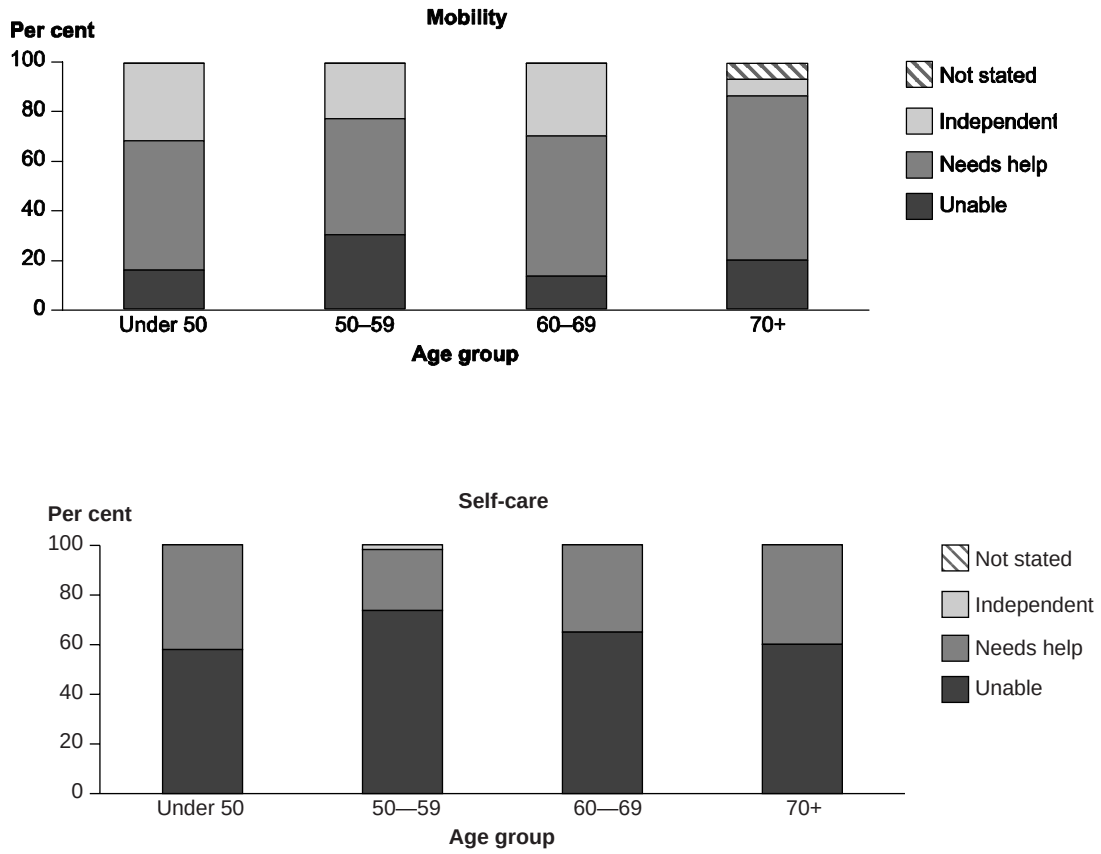
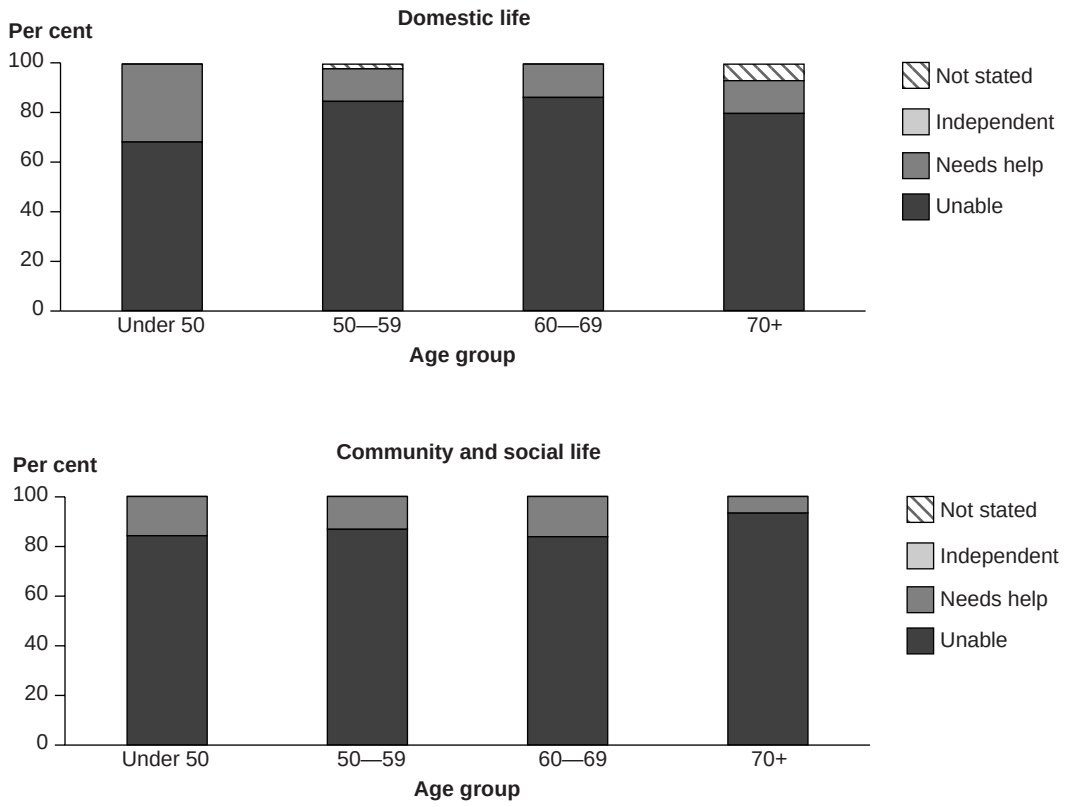


Figure 2.2: Clients with intellectual disability, level of support needed in selected activity areas, by age group (per cent)

(continued)



Source: Appendix Tables A1–A4.

Figure 2.2: Clients with intellectual disability, level of support needed in selected activity areas, by age group (per cent)

Activities of daily living

ADL scores at entry to the Pilot for clients with intellectual disability ranged from zero to 20 out of 20 points. The mean baseline score across all clients with intellectual disability was 12.8 points with a standard deviation of 4.5 (median 13). Table 2.26 presents summary statistics for ADL score by age group, showing little variation in the distribution of scores across the age groups. Baseline ADL scores are missing or incomplete for two clients.

Table 2.26: Clients with intellectual disability, summary ADL statistics by age group

Age group (years)	Number	Minimum	Median	Maximum	Mean	Standard deviation
Under 50	18	0	14	18	12.8	4.5
50–59	53	0	13	20	12.1	4.7
60–69	36	1	13	20	12.8	4.2
70+	15	4	13	18	12.4	3.6
All clients	**122**	**0**	**13**	**20**	**12.4**	**4.4**

According to a scoring system for the Modified Barthel Index proposed by Shah et al. (1989), the ADL scores indicate that approximately 49% of clients with intellectual disability were moderately dependent in activities of daily living and a further 37% showed severe dependency. Table 2.27 gives the number of clients by level of dependency for each age group and reveals no clear age-related trends, other than clients aged less than 50 years were more likely than older age groups to show moderate than severe dependency in ADL.

Table 2.27: Clients with intellectual disability, number of clients by level of dependency in activities of daily living, by age group

Age group (years)	Independent	Slight dependency	Moderate dependency	Severe dependency	Total dependency	Total
			(number)			
Under 50	0	0	13	4	2	19
50–59	2	1	24	21	5	53
60–69	1	3	16	15	2	37
70+	0	0	8	6	1	15
All clients	**3**	**4**	**61**	**46**	**10**	**124**
			(per cent)			
Under 50	0.0	0.0	68.4	21.1	10.5	100.0
50–59	3.8	1.9	45.3	39.6	9.4	100.0
60–69	2.7	8.1	43.2	40.5	5.4	100.0
70+	0.0	0.0	53.3	40.0	6.7	100.0
All clients	**2.4**	**3.2**	**49.2**	**37.1**	**8.1**	**100.0**

Figure 2.3 shows the proportion of clients who are dependent, partially dependent and independent in specific ADL. The proportion of clients at each level of dependency within each age group is similar across the ADLs.

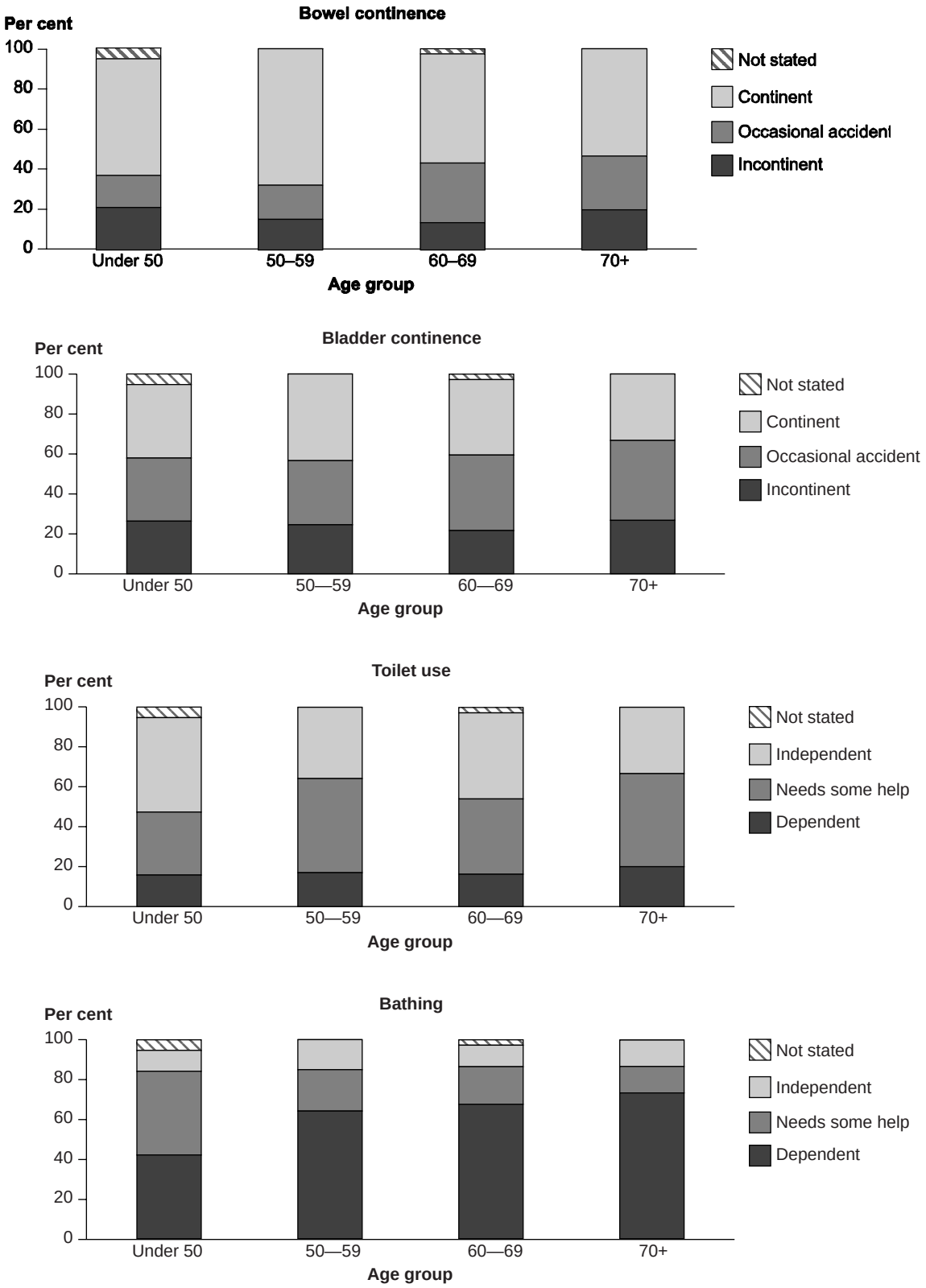


Figure 2.3: Clients with intellectual disability, per cent of clients by level of dependency in self-care and mobility tasks, by age group

(continued)

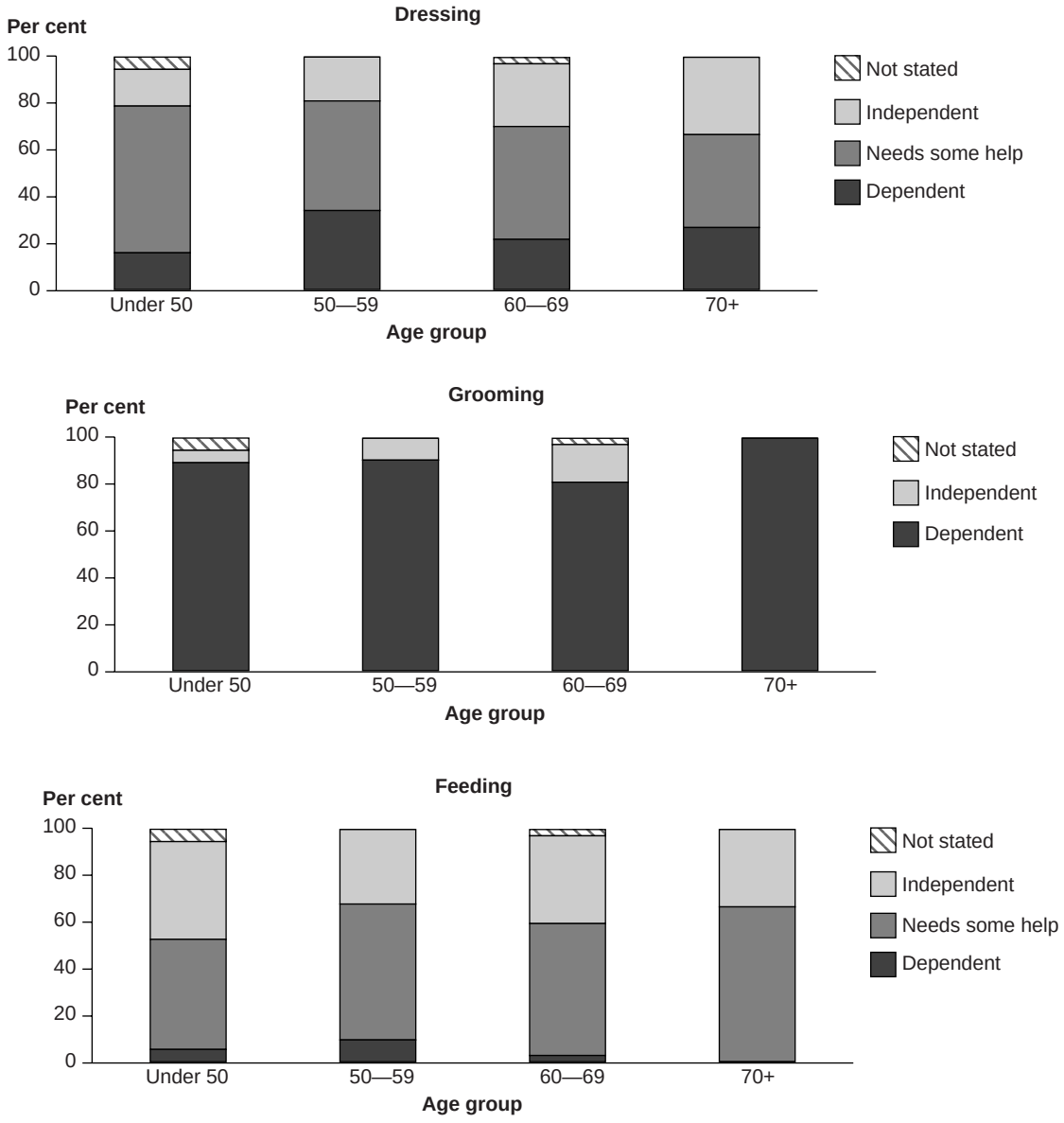
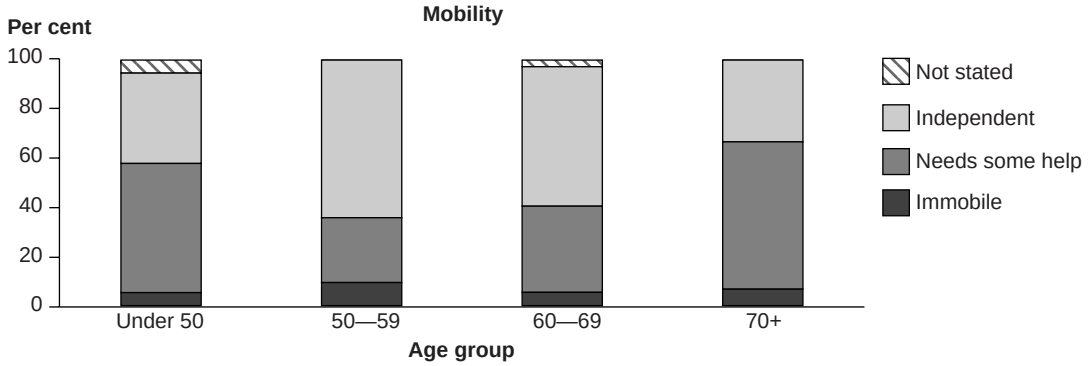
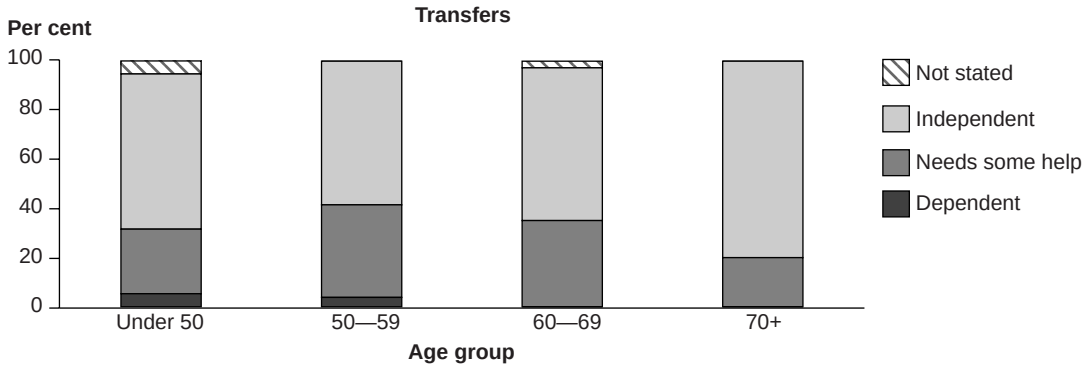
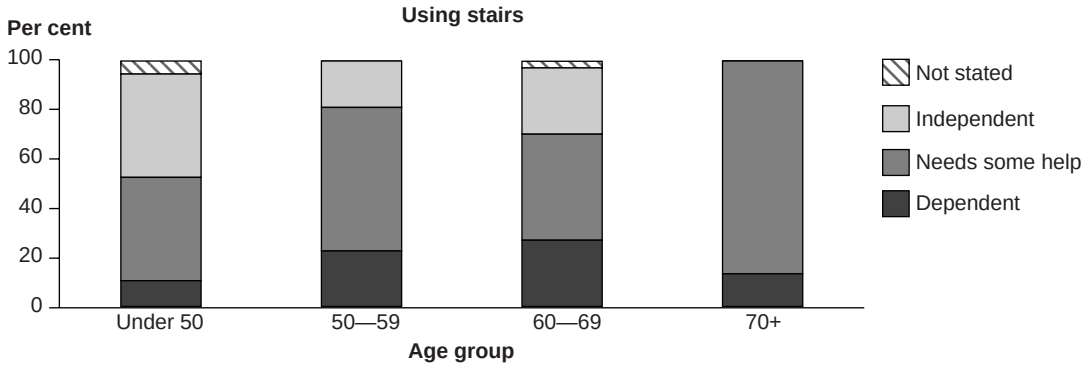


Figure 2.3 (continued): Clients with intellectual disability, per cent of clients by level of dependency in self-care and mobility tasks, by age group

(continued)







Source: Appendix Tables A5–A14.

Figure 2.3 (continued): Clients with intellectual disability, per cent of clients by level of dependency in self-care and mobility tasks, by age group

Final assessments were conducted between 63 days and 432 days after baseline assessments (mean 169 days). One hundred and five clients had ADL scores recorded at both baseline and final assessments. Table 2.28 presents summary statistics for changes in ADL score between baseline and final assessments. Overall, change scores ranged from –16 points (a 16-point reduction in ADL function as measured by the Modified Barthel Index) to 6 points (a 6-point improvement in ADL functioning). The median change in ADL score was zero points for all age groups, and the distribution of change scores was similar across age groups except in the 50–59 year age group where greater variation in change scores was apparent (range –16 to 5 points, standard deviation 4.1 points).

Table 2.28: Clients with intellectual disability, summary statistics for change in ADL scores between baseline and final assessments by age group

Age group (years)	Number of clients	Minimum	Median	Maximum	Mean	Standard deviation
Under 50	17	–4	0	5	0.2	2.8
50–59	46	–16	0	5	–0.6	4.1
60–69	29	–7	0	2	–0.1	1.8
70+	13	–5	0	6	0.2	2.4
All clients	**105**	**–16**	**0**	**6**	**–0.3**	**3.2**

Clients with intellectual disability exhibited dependency in between zero and seven out of seven IADL at the time of entry to the Pilot (median number of items for which a client records total dependency is four). Overall, the 110 clients for whom baseline IADL data were provided scored between zero and 10 out of a possible 14 points on the IADL scale (mean 3.7 points, standard deviation 2.3 points; Table 2.29). The distributions of IADL scores within each age group are similar.

Table 2.29: Clients with intellectual disability, summary statistics for IADL baseline assessment results by age group

Age group (years)	Number of clients	Minimum	Median	Maximum	Mean	Standard deviation
Under 50	18	0	4	8	4.1	2.1
50–59	49	0	3	10	3.3	2.4
60–69	30	1	4.5	8	4.2	2.4
70+	13	1	3	7	3.0	1.6
All clients	**110**	**0**	**3**	**10**	**3.7**	**2.3**

Figure 2.4 shows the proportion of clients who were dependent, partially dependent or independent on specific IADL. Almost all clients for whom data were provided required assistance in each IADL. As for ADL, the distribution of levels of functioning within each age group is similar across the items.

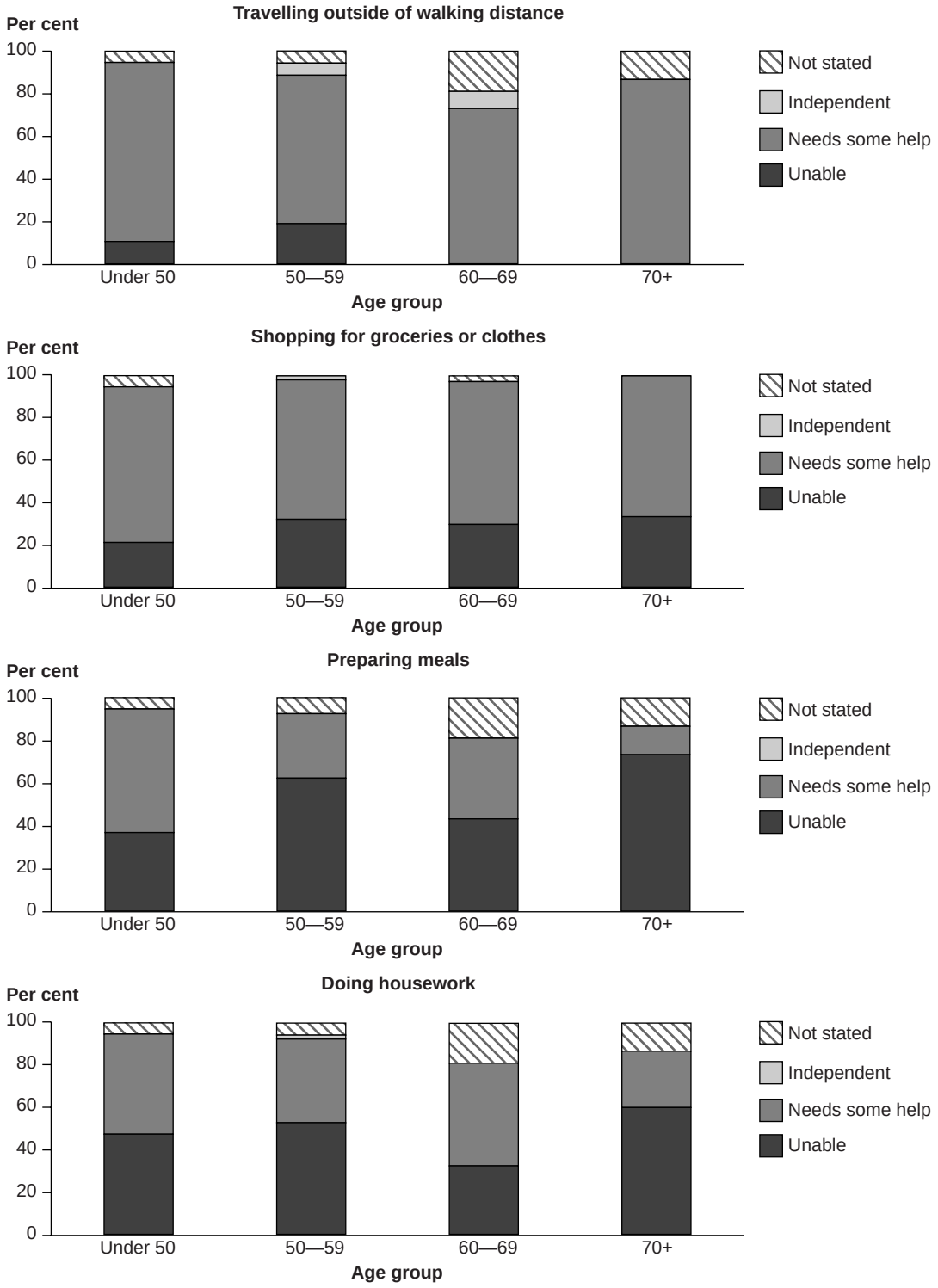
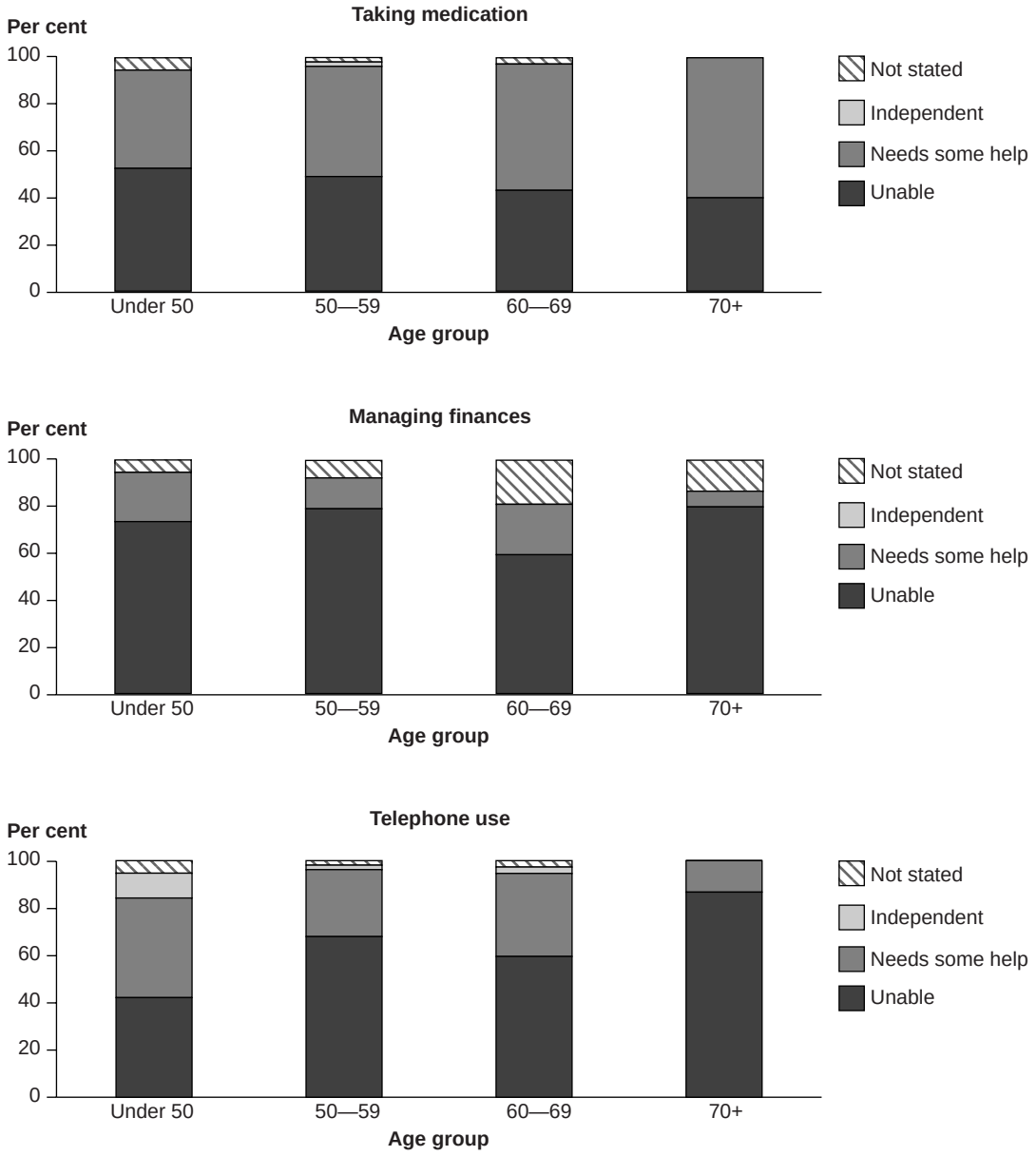


Figure 2.4: Clients with intellectual disability, per cent of clients by level of dependency in IADL, by age group

(continued)



Source: Appendix Tables A15–A21.

Figure 2.4 (continued): Clients with intellectual disability, per cent of clients by level of dependency in IADL, by age group

IADL assessment was completed at baseline and final assessments for 99 clients (Table 2.30). Change scores ranged from –7 points (a 7-point reduction in IADL function) and 4 points (a 4-point improvement in IADL function). On average, IADL scores changed by –0.3 points (zero median, standard deviation 2.0 points). The distribution of change in IADL score was similar in each age group.

Table 2.30: Clients with intellectual disability, summary statistics for change in IADL scores between baseline and final assessments by age group

Age group (years)	Number of clients	Minimum	Median	Maximum	Mean	Standard deviation
Under 50	17	–7	0	3	–0.9	2.4
50–59	45	–4	0	4	0.0	1.7
60–69	26	–6	0	3	–0.5	2.3
70+	11	–1	0	2	0.2	0.8
All clients	**99**	**–7**	**0**	**4**	**–0.3**	**2.0**

The main points to emerge from ADL scores recorded for the evaluation are:

- Low levels of functioning in self-care activities and IADL among clients with intellectual disability; hence high levels of support need in self-care among a group of clients who show no obvious age-related patterns most likely because client selection was based on an identification of aged care specific needs rather than chronological age criteria.
- Up to 60% of clients, by age group, had continence management needs.
- Up to 60% of clients in each age group had a need for mobility assistance.
- Variation in patterns of change in need for ADL assistance over time: approximately 38% of clients with intellectual disability experienced loss of mobility between entry to the Pilot and final assessment; 33% experienced loss of self-care function over this period; 29% of clients experienced loss of both self-care and mobility function between entry to the Pilot and the final assessment (58% of clients recorded no change in level of support need for self-care and mobility). These results are consistent with reports from the projects of increasing age-related support needs in a substantial number of clients.

3 New care choices

This chapter overviews each pilot project, covering project aims, target group, staffing model and service profile. Project coordinators and steering committees shared their experiences of running pilot projects during discussions with the evaluation team. Their remarks about local achievements and challenges are included here so that the evaluation might reflect the learning from the Pilot.

Projects have focused on delivering higher levels of personal assistance to most or all clients and beyond that have tended to concentrate on either a therapeutic care model of allied health or nursing intervention (physical maintenance programs or intensive nursing care, provision of aids and equipment) or a social care model (recreation and leisure programs and increased participation in domestic and community life). Based on the service profiles during and after the 2004 data collection period, the projects can be broadly grouped according to the main service delivery focus for the majority of clients at the time:

Mainly therapeutic intervention:

- Far North Coast Disability and Aged Care Consortium, New South Wales
- Northern Sydney Disability Aged Care Project, New South Wales
- Cumberland Prospect Disability Aged Care Pilot, New South Wales
- Disability Aged Care Service, Perth, Western Australia
- MS Society Changing Needs, Melbourne, Victoria

Mainly social intervention:

- Central West People with a Disability who are Ageing, New South Wales
- Flexible Aged Care Packages, Adelaide, South Australia
- Disability and Ageing Lifestyle Project, Renmark-Paringa, South Australia
- Ageing In Place, Hobart, Tasmania.

Most projects were observed to offer an extensive range of services such that, although most clients received mainly therapeutic intervention or mainly social intervention in the reporting period, a smaller number received services in both categories or mainly but not exclusively services in one or the other category. This is partly due to the timing of the evaluation—in some cases the projects were gradually introducing social support and community participation or still completing allied health assessments and over time therapeutic interventions were starting to become evident in the service profile—but it also indicates that a project's service focus is driven by the prevailing needs of a client group and the flexibility to deliver other types of assistance usually exists.

Descriptions of the projects cover the staffing models seen in the pilot, which comprise the full integration model (the project operates entirely within the supported accommodation service as a continuation of usual care with enhanced service levels); the brokerage model (the project brokers existing disability support staff to deliver pilot services under direction of the project coordinator); and the direct engagement/employment model (project employs salaried aged staff or engages aged care workers from an agency to deliver pilot services).

Ageing In Place, Hobart, is the only example of the full integration model. Since project service delivery is fully integrated into usual care, service activity data for Ageing in Place clients represent the combined assistance from the disability and aged care budgets. A number of projects had anticipated operating a brokerage staffing model but implementation difficulties resulted in direct engagement or employment of aged care workers. Far North Coast Disability and Aged Care Consortium operates a brokerage staffing model. The three other projects in New South Wales had intended to also operate with brokered disability staff but encountered difficulties that resulted in either a mainly direct aged care staffing model (Northern Sydney Disability Aged Care Pilot and Central West People with a Disability who are Ageing) or a combination of direct and brokered staff (Cumberland Prospect Disability Aged Care Pilot). The two projects in South Australia also operate with mixed staffing models, using brokered disability support staff and agency aged care workers according to availability. Disability Aged Care Service in Perth was always intended to operate with a distinct aged care team and has been successful in this implementation. DACS contracts to an allied health service and maintains continuity of care by having the same allied health professionals for monitoring of clients' progress against physical therapy programs. MS Changing Needs employs registered nurses for the project. Personal care is provided by clients' usual care assistants employed by the Multiple Sclerosis Society of Victoria.

Staffing aspects are discussed under each project, below.

3.1 Far North Coast Disability and Aged Care Consortium

The Far North Coast Disability and Aged Care Consortium (FNCDAC) provides flexible care services to people with disabilities whose support needs are increasing due to age-related conditions. This project commenced on 26 November 2003 with the objectives of:

- applying the principles of ageing in place to enable people with a disability who require additional services because they are ageing to be maintained in their group home setting
- providing appropriate short-term intensive services to meet the aged care needs of people with a disability to maintain or increase a level of functional independence so that the target group can continue to receive appropriate support from the disability sector
- providing training on aged care issues to disability staff to enhance their ability to manage the aged care related needs of the target group who are ageing
- establishing whether joint assessment processes can up-skill aged care and disability staff in each other's field of work and to avoid inappropriate or duplicated assessments.

Clients remain in the project until its completion unless their age-related support needs can be addressed under their existing disability support funding arrangements or they no longer benefit from remaining in disability-funded supported accommodation.

An initial allocation of 30 places was made, covering the Far North Coast Aged Care Planning Region/DADHC Local Planning Area, which encompasses 10 local government areas including Ballina, Byron, Kyogle, Lismore, Richmond, Tweed and Maclean. In October 2004, the allocation was reduced to 20 places due to sustained low occupancy.

Stakeholders

The approved provider is Clarence Valley Council, a local government body with expertise in disability and aged care service provision on the Far North Coast of New South Wales. The Council is a provider of supported accommodation for people with disabilities (the approved provider named in the Pilot Memorandum of Understanding, Maclean Shire Council, amalgamated with three other local councils to form Clarence Valley Council and began operating as such from 1 July 2004).

The project consortium includes Lismore Challenge Ltd, Caringa Enterprises Inc., Accommodation Network Pty Ltd, ON-FOCUS Inc., Ballina and District Community Services Association Inc., and the New South Wales Department of Ageing, Disability and Home Care (DADHC) Accommodation and Respite Services—all providers of supported accommodation services for people with disabilities—plus the North Coast Area Health Service (formerly Northern Rivers Area Health Service).

DADHC funds supported accommodation for clients participating in the project. Accommodation includes group homes run by consortium members in the catchment area. The Australian Government Department of Health and Ageing funds the project up to $694,996.50 a year or $63.47 per allocated place per day.

Referral and assessment

Clients are referred to the project by their existing disability service provider, who is required to provide detailed information about the client. Disability services reported that 8 to 10 hours are required to complete the referral documentation and liaise with the project coordinator, time which was not factored into the budget. The project coordinator screens referrals and liaises with the disability service provider as required before referring the client to ACAT for assessment.

Stakeholders report that the project screening processes are working well, and referrals to ACAT have been appropriate. A major benefit of the Pilot has been timely referral to ACAT. It is likely that all project clients have been referred for comprehensive assessment earlier through FNCDAC. Consent to participate in the project has been obtained from the client or responsible adult, in most cases a family member. There is an understanding that, though clients must be approved by ACAT for residential aged care in order to be eligible for the project, clients will not be transferred to residential aged care without another ACAT assessment being completed.

The initial assessment for the project is conducted by the following parties:

- project coordinator
- disability service provider case manager
- ACAT (usually two ACAT staff)
- key disability support worker in most cases
- client
- person responsible or family member, if available.

The project completes the Broad Screen Checklist of Observed Changes (BSCOC) every 6 months for most clients and results are used to inform other assessment and care planning processes. Clients can be referred to a geriatrician or a gero-psychologist through the ACAT, services which were not accessible prior to clients having contact with the ACAT. These

services are invaluable in assessing and diagnosing cognitive decline and differentiating other conditions such as anxiety disorders which can present as cognitive decline.

Care planning

ACAT requested further assessments for all clients who have been referred to the project, such as assessment by a geriatrician or gero-psychologist, occupational therapist, physiotherapist, etc. Arranging these assessments (usually the responsibility of the client's disability service provider) generally forms the first phase of care planning and can be time-consuming as there are waiting times to see medical/health professionals. Delays between the date a client is accepted into the project and the date that a formal care plan is in place are usually a result of this initial assessment phase. A care plan is developed and reviewed within the first 3 months of implementation. The bulk of the project coordinator's time is taken up with care planning, case coordination, organising services and care plan reviews, in conjunction with clients' group home managers.

Client group

Clients participating in the project include those in the target group who:

- can be supported in their current residence with additional aged care specific services (joining the project should not involve a change of residence)
- have their current disability service support guaranteed
- agree to participate in the project
- have a valid Aged Care Assessment Team (ACAT) assessment that they are suitable for residential aged care services.

Project stakeholders believe that 65 years of age is too high a threshold for access to aged care services for clients who have disabilities. They feel that 50 years of age is a more appropriate age threshold for the target group, but they would prefer to see the threshold dispensed with altogether as there is no specific age at which age-related needs manifest.

FNCDAC client group profiles are given in Appendix B (see Appendix Tables B1.1–B1.9).

Service model

In addition to ACAT, medical and allied health care assessments, FNCDAC offers a range of services to clients including domestic assistance, personal assistance, social support, and access to a variety of allied health services. The project has purchased mobility and other aids for a number of clients.

The project has increased client access to assessment tools and geriatric services through ACAT which were previously not accessible to people under the age of 65 years. For example, gero-psychology services can identify behavioural issues related to ageing processes and provide effective interventions to assist disability support staff to manage behavioural symptoms. The project has assisted clients to access age-appropriate activities, for example, mainstream aged care day centres.

In-home services funded by the pilot have been delivered by existing disability support staff. The project provides training including manual handling techniques appropriate for

individual clients. General training in aged care is provided, such as the use of aged care assessment tools and the identification and management of early cognitive decline.

The project also functions as a starting point for families to consider transition planning. Many families have not considered their relative's changing needs as they age.

FNCDAC submitted evaluation data for 13 clients, 12 with a main disabling condition of intellectual disability and one client with acquired brain injury. The service activity of these clients during the evaluation is summarised in Tables 3.1 and 3.2.

Assessment and referral and higher levels of personal care are the main benefits of the Pilot for a majority of FNCDAC clients. Initial needs assessment averaged 9.8 hours per client. Around half the clients have received relatively high levels of personal and domestic assistance from the project (Table 3.1). The project provided aids and equipment for a small number of clients, including shower chairs and other bathroom aids, exercise equipment, and mattress hire.

Most disability clients participating in the project would ordinarily access allied health care, if and when needed, through the public health system. Just one client participating in FNCDAC had the means to access allied health services privately. The FNCDAC coordinator remarked that allied health care appears to have been an area of significant unmet need prior to the Pilot. FNCDAC has provided allied health assessment and therapy services mostly through private purchasing arrangements. Disability support staff played an important role in the delivery of allied health interventions for a number of clients through accompaniment of clients to appointments and active involvement in therapeutic activities under the direction of an allied health professional. The project reported a range of allied health care including physiotherapy, occupational therapy, gero-psychology, speech pathology and swallowing assessment, hydrotherapy and dietetics.

In a number of cases, the joint assessment process of FNCDAC initiated further specialist nursing and medical assessments and interventions, including wound management, diabetic foot clinic, radiology, bone density assessment, referral to continence clinical nurse consultant, audiology and optometry.

Disability service provider staff and vehicles were used for all transport assistance associated with delivery of out-of-home services such as allied health assessment and therapy and community integration. FNCDAC recorded staff accompaniment time separately and additional costs associated with client transportation have been recorded as external costs. Table 3.2 summarises 'external services' most of which were funded by the public health system. Participating disability service providers did not report any additional costs they absorbed as a result of clients participating in the project, for example, transportation assistance for activity associated with aged care plans.

Joint case management, involving the FNCDAC coordinator and disability support staff, is a key strength of the project and contributed to the professional development of disability workers, helping to raise their awareness of age-related needs and appropriate interventions. The project recorded ongoing case management in number of contacts (standard) and hours (voluntary), for each client according to source—project or disability services, as high intensity case management is a key feature of the project. During the reporting period. per client case management time, excluding time for initial needs assessment, ranged from 4.5 to 26.0 hours from the FNCDAC coordinator and between 1.5 and 16.0 hours from disability services. On average during this period, a client received 12 hours in case management from the FNCDAC coordinator and 7 hours from their disability service provider (median across all clients), relating specifically to the Innovative Pool project. At the time of the AIHW site

visit, it was clear that the additional case management load was problematic for at least one disability service provider and FNCDAC was approached to increase funding to cover additional costs to disability services incurred through joint case management for the project.

Table 3.1: Far North Coast Disability Aged Care Consortium, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Personal assistance	6	Hours	1.4	9.7	13.0	8.7	4.1
Domestic assistance	5	Hours	2.4	3.6	4.2	3.3	0.8
Social support	5	Hours	0.1	1.0	1.5	0.9	0.6
Psychologist	4	Hours	0.1	0.1	0.2	0.1	0.0
Physiotherapy	3	Hours	0.0	0.2	0.3	0.2	0.1
Aids other	5	Dollars	3.9	11.1	39.3	18.2	14.7
Mobility aids	2	Dollars	3.0	15.4	27.9	15.4	17.6
Home modifications	1	Dollars	31.7	31.7	31.7	31.7	. .
Follow-up needs assessment	13	No. contacts	0.5	0.7	2.3	0.9	0.5
Geriatrician	1	No. contacts	0.0	0.0	0.0	0.0	. .
Living skills development	2	No. days/nights	0.8	0.9	0.9	0.9	0.1
Referral to other provider	11	No. events	0.1	0.2	0.6	0.3	0.1
Personal other	5	No. events	0.2	1.0	3.9	1.4	1.4
Needs assessment other	3	No. events	0.0	0.0	0.0	0.0	. .
Allied health other	2	No. events	0.1	0.1	0.1	0.1	0.0
Dietetics	1	No. referrals	0.1	0.1	0.1	0.1	. .

. . Not applicable.

Table 3.2: Far North Coast Disability Aged Care Consortium, minimum, median, maximum and mean service units per client per week of services initiated by the project and funded externally, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Social support	2	Hours	8.0	17.0	26.0	17.0	12.7
Nursing care	2	Hours	7.5	9.3	11.0	9.3	2.5
Physiotherapy	6	Hours	0.5	1.0	14.0	3.7	5.3
Occupational therapy	5	Hours	0.5	0.5	2.0	0.9	0.7
Community service other	1	Number	5.4	5.4	5.4	5.4	. .
Personal transport	4	Number	0.8	2.1	2.8	1.9	0.9
Referral to other provider	1	Number	0.5	0.5	0.5	0.5	. .
Nursing/medical other	4	Number	0.1	0.2	1.3	0.5	0.6
Allied health other	6	Number	0.0	0.3	1.1	0.4	0.5
Follow-up needs assessment	13	Hours	0.2	0.3	0.7	0.4	0.2

. . Not applicable.

Achievements and challenges

The project coordinator remarked on changed practices in participating group homes that reflect a greater awareness of age-related issues for target group:

> 'FNCDAC has facilitated the introduction of new and good practices which will benefit people with disabilities who are ageing on the Far North Coast:
>
> - The Minda BSCOC has been implemented as standard practice for clients over a certain age, to be completed six-monthly. This is expected to gather baseline data, note the time of onset of change, and assist disability support staff to identify changes. In practice, the tool has proved to be quite subjective, and it was found that high reliance cannot always be placed on the raw scores. For example, one agency consistently recorded very high BSCOC scores, whilst others consistently recorded much lower scores. In another case, the BSCOC was administered twice, at a short interval, with the same interviewer interviewing different support workers for each BSCOC (same client). Scores varied markedly, which suggested low inter-rater reliability. However, the project did find that clients with very low scores (little evidence of functional change) were those who were rejected by ACAT at assessment. It was concluded that BSCOC is a useful tool for (a) Disability Service Providers to track changes in clients; and (b) providing a basis for discussion at ACAT assessment; BSCOC scores were found to be not informative in the absence of other detailed knowledge of a client.
> - As part of the work-up for either ACAT assessment, or the assessments that follow, CT scans are occurring earlier in the lives of (relevant) clients than prior to the project.
> - The project is currently investigating other screens and tests validated for this client group, with a view to using them to assist in the assessment process. The difficulty in determining what is age related has led to this search for better assessment tools. Tools need to be internationally validated, specific to this target group, and able to be administered by care staff or ACAT assessors.
>
> A working party on screening tools identified further tools and the following were adopted as recommended standard practice:
>
> - Minda BSCOC to chart change and for valuable information, particularly around ADL functioning.
> - The DMR (Dementia questionnaire for person with intellectual disabilities, Holland) an internationally validated screening tool for dementia in people with intellectual disabilities. FNCDAC bought the tool and the project coordinator facilitated a short introductory training session with client service managers from participating disability service providers in April 2005 (some disability service providers started using it).
> - PAS-ADD checklist—a screening tool for mental health disorders in people with disabilities. FNCDAC chose the Checklist, rather than the Mini-PAS-ADD, because (a) the Checklist can be used by support workers and (b) the Mini PAS-ADD required training that is not currently available in Australia as there is only one accredited trainer, who was occupied with research activity. Dr Steven Moss of England has developed all the PAS-ADD tools, which are internationally validated.
>
> Additionally, FNCDAC continued with the Cornell Depression Scale and the Montgomery and Asberg Depression Rating Scale (MADRS). The project funded training in MADRS for staff from the relevant disability service providers as depression in the elderly is common and can parade as dementia. These two tools have been developed for people with impaired cognition.
>
> The whole area of screening has been raised through the ACAT assessments; ACAT assessors are careful to not reach a hasty conclusion that a client has dementia. Many referrals through the project have presented a complex and confusing picture, highlighting the important and

challenging issue of distinguishing dementia from other mental health and medication issues faced by members of the client group.

By promoting such tools and assisting disability service provider client managers in their use, FNCDAC aims to enhance the early and accurate identification of disorders (dementia, mental health and otherwise) and provide useful and relevant information for ACAT assessment. The ACAT gero-psychologist and an ACAT assessor were members of the working party that explored the various screening tools and made the selection outlined above.

The referral to FNCDAC and ACAT has provided clients with full medical and health reviews; this has assisted medical practitioners and disability service providers to view clients from the perspective of ageing, rather than just disability. All ACAT assessments have led to further health/medical assessments by a variety of specialists. The disability sector does not operate from a medical model; it employs non-medical staff to provide accommodation and living support. The aged care sector assesses age-related conditions that often require a medical or health diagnosis; ACAT assessors are health/medical practitioners. The interface of the two sectors has led to learning in both, and outcomes for clients that could not have occurred if the client had not had access to the expertise of both sectors.

Initiatives in the area of practice for transitioning older people with a disability into residential aged care have emerged through FNCDAC. One disability service provider developed a new policy and procedure for clients transitioning to aged care facilities and a working party was established to draft a joint response to transitioning issues (policy, procedure, information shared, etc.) for submission to the regional meeting of directors of nursing. It was expected that over a number of months a clear and accepted transition process would become established. This is a positive but unexpected outcome of the Pilot.

FNCDAC has also highlighted the need for direction on whether providing care to people with a disability who are ageing is a state government or Australian Government responsibility. Consortium members raised this as a question for further debate, suggesting that tensions between levels of government with responsibilities at the disability/aged care interface are a major impediment to client care and are not going to disappear. The project and outcomes being achieved for individual clients are highly valued; however, it is believed that the Disability Aged Care Interface Pilot leaves a fundamental question unanswered.

The interface between aged care services and disability services necessitates a cultural shift on both sides. The project has helped to identify gaps and interface issues between the sectors, and to develop ways to overcome them. For example, clinical tensions have traditionally existed between the disability sector and the aged care and health sectors in the Far North Coast area but the capacity of this project to accept people under the age of
65 years has fostered cooperation and increased understanding. The project is building capacity within the disability service sector to manage clients with age-related needs through the sharing of expertise, staff training and greater cross-sectoral awareness. This has also been an educational experience for ACAT members in how to assess people with disabilities, the philosophy of the disability sector, and disability-specific issues in aged care.'

Occupational health and safety issues in group home environments are a major risk factor for client entry into residential aged care. The need for home modifications can present significant challenges in this area. Modifications can be expensive but funding from the New South Wales Department of Ageing, Disability and Home Care may not be available if the need is considered to be 'age related'. Even if funding is available, making a modification may not be possible as many of the participating group homes are private rental houses.

Difficulties at the interface between aged care and health systems are another factor that impacts on the care of people with a disability who are ageing. Specifically, lack of identification of allied health care needs, primarily, but not only, those associated with poor

mobility, compounded by limited access to publicly funded allied health care may constitute a risk for premature or avoidable entry to residential aged care. Declining ADL function that often occurs as a client becomes less socially active and more confined to the home environment for long periods without stimulation can lead to a downward spiral that ends in aged care placement. The project coordinator consulted widely in an attempt to gain the required level of access to allied health care through the public health system for FNCDAC clients. While it was generally possible to arrange a limited number of allied health assessments through public health, the system is not resourced to react responsively to a referral for multiple assessments for a client with complex needs or to provide the level of ongoing allied health care management and review that can be required (usually involving repeat home visits). Months elapsed between different types of allied health assessments for FNCDAC clients with complex needs, prolonging the entire assessment process and delaying the establishment of care plans.

It was speculated that resources for public allied health care services have not kept pace with population growth in the region. In response to the difficulties experienced, FNCDAC chose to turn to the private system for allied health care assessment and intervention. There is thus a question over the financial sustainability of this approach if responsibility for age-related allied health care needs come to rest within the disability services sector. A second innovation has been the hiring of pieces of equipment on a trial basis drawing on project funds. Clients are able to use the hired equipment on a trial basis under close supervision for up to a month; this has prevented the unnecessary purchase of equipment that a client could not or would not use.

It is further speculated that the Pilot has increased the awareness among disability support staff of the relationship between mobility, falls and the risk of premature nursing home admission as well as the need for exercise and movement programs under guidance of a physiotherapist for maintaining mobility and reducing falls risk.

Family of a person with a disability and disability support staff typically expect that the client will be able to be cared for in their group home for the term of their natural life so that transition to residential aged care is not considered a natural progression. In addition, disability service providers are mostly reluctant to place people from group homes into residential aged care because it is believed that aged care facilities are not expert in dealing with people with disabilities and staffing ratios in residential aged care facilities are said to be considerably lower than in group homes. This results in a strong motivation to maintain people 'in place' as they age. Often this expectation becomes unrealistic as the client's support needs increase beyond the level of service the group home is able to provide as would occur if, for example, a client needs a high level of nursing care or more continuous supervision during daytime hours than is generally available in that setting.

3.2 Central West People with a Disability who are Ageing

The Central West People with a Disability who are Ageing project (CWPDA) provides services to clients in supported accommodation in rural and remote locations in the Central West of New South Wales. The catchment area covers the townships and surrounding districts of Orange, Bathurst, Lithgow, Parkes, West Wyalong and Blayney. CWPDA accepted its first clients in November 2003.

Project objectives are to:

- provide a flexible service, within financial capacity, to meet the needs of people with a disability who are ageing and who require additional support services that are aged care specific in order to remain in their disability services funded accommodation
- provide a quality of life with dignity for recipients, to reduce social isolation, promote independence and maintain and improve health, safety and confidence
- build on current disability services by providing a flexible comprehensive and specific aged care service to realise the expectations of ageing in place
- provide care that is sensitive to clients' cultural and special needs
- address skill transfer and training needs of partners and staff.

The project was initially allocated 40 places for a maximum of 3 years but only 30 were made operational on the official start date of 1 November 2003. The remaining 10 places were made operational on 1 April 2004 when the pilot's capacity to utilise these places had been demonstrated. Occupancy has been full since that date but the Department and Uniting*Care* reached an agreement to withhold the April 2005 quarterly payment due to accumulated surplus.

Clients remain in the project until its completion unless they can no longer benefit from remaining in disability-funded supported accommodation or their age-related support needs can be addressed through mainstream disability services.

Stakeholders

The approved provider is the Uniting Church in Australia Property Trust (New South Wales), which provides community services throughout the Central West, including Wontama homes. The pilot consortium comprises eight supported accommodation services funded by the Disability Services Directorate of the New South Wales Department of Ageing, Disability and Home Care (DADHC): Orange City Council; Breona Residential Services; Currajong Enterprises, Parkes; Orange Community Resource Organisation; Lithgow Information and Neighbourhood Centre; Marashel Inc., Bland; Orana Lifestyles at Gilgandra and Westhaven at Dubbo.

DADHC funds the supported accommodation services for clients participating in the project. The accommodation is in group homes and smaller facilities run by consortium members in the catchment area.

The Australian Government Department of Health and Ageing funds the pilot up to $919,800 a year or $63 per allocated place per day.

Target group, referral and assessment

Clients participating in the project include those in the target group who:

- can be supported in their current residence with additional aged care specific services (joining the project should not involve a change of residence)
- have their current disability service support guaranteed
- agree to participate
- have valid ACAT approval for residential aged care.

The main areas of age-related need that the project was designed to address are mobility, continence, sleep pattern, dementia, physiotherapy and occupational therapy needs, and socialisation.

Referrals from participating disability service providers are made using the Service Needs Assessment Profile (SNAP) instrument, which is used within DADHC and disability services, for needs assessment. On receipt of a referral, CWPDA performs an initial needs assessment, applying nursing and social care needs criteria, to screen clients before referring on to an ACAT. Among 68 clients referred by disability services providers up to the time of the evaluation team site visit, 38 clients had been accepted for referral to an ACAT.

Identifying aged care needs versus disability support needs is a key issue for the project and joint input from aged care and disability services is critical to this process. There were some initial difficulties in identifying age-related needs through ACAT assessment, partly due to perceived changes in criteria for the Innovative Pool Pilot, but also due to an apparent feeling among some ACAT members that they were under pressure to find clients for the project. The ACAT process involves identifying all of a client's needs, then 'teasing out' age-related needs, taking account of services already available in the group home.

Uniting*Care* operates physiotherapy and occupational therapy services and these have been used to assess CWPDA clients and establish physical maintenance programs as required. Only in West Wyalong has it been necessary for the project to broker physiotherapy. A Uniting*Car*e physiotherapist conducts regular reviews of client progress. The Uniting*Care* occupational therapist conducts assessment and measurement for aids and equipment for CWPDA clients. Recommendations for provision of aids and equipment are made to group home managers for implementation by the disability service. In one case, the landlord of a private rental home would not approve required modifications and the whole household moved to another home. It was observed that all members of the household benefited from moving to an improved physical environment.

Once a client is accepted and assessments are completed, a holistic care plan is developed to describe client aged care needs, care goals and interventions. Needs identified that are considered to be unrelated to the ageing process are communicated to the client's disability service provider.

The project coordinator conducts monthly assessments of each client (more frequently if necessary) and reviews the care plan. More frequent monitoring is done by telephone.

CWPDA client group profiles are given in Appendix B (see Appendix Tables B2.1–B2.9).

Staffing and service model

CWPDA operates with direct staffing except in Lithgow and West Wyalong (three clients at these locations). This means that most clients receive aged care services from members of an aged care team who work alongside and in liaison with staff in the supported accommodation service.

Uniting*Care* had initially planned to implement a combination of direct service delivery in the supported accommodation facilities in Orange and an outreach program of flexible brokered services to homes in the smaller communities of the Central West. Difficulties arose in brokering existing staff in supported accommodation services and attracting qualified aged care workers to the project. Almost all staff working with project clients are salaried employees of Uniting*Care*.

CWPDA provides aged care training for staff.

CWPDA services are additional to existing disability services. The agreement between Uniting*Care* and the Department of Health and Ageing lists a range of service types to be made available to clients on the basis of individual need, including specialised nursing care and medical management, pain management, nutrition management, management of sleep and behavioural disorders, transport and case coordination.

CWPDA supplied evaluation data for 33 clients—19 men and 14 women. Thirty-one participants were people with intellectual disability and two clients with psychiatric or multiple disabilities. The service activity of CWPDA clients who participated in the evaluation is summarised in Table 3.3. Most clients received additional personal assistance from the project and opportunity to participate in leisure activity programs. CWPDA reported that the types of services provided for each client change over time. When a client first starts in the project, social support is introduced to help familiarise a client with the new support team. Gradually, additional services are introduced to meet the client's identified needs. During the evaluation, CWPDA clients were receiving up to 10 hours per week of support from the project in addition to support provided by their accommodation service. CWPDA observed significant increases in the age-related care needs of individual clients in the ensuing months. By September 2005, most clients were receiving between 10 and 20 hours of additional support from CWPDA. Increases were mainly associated with higher need for personal assistance and physical maintenance.

Table 3.3: Central West People with a Disability who are Ageing, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Personal assistance	23	Hours	0.1	0.5	2.5	0.9	0.8
Occupational therapy assessment	13	Hours	0.0	0.0	0.1	0.0	0.0
Domestic assistance	12	Hours	0.2	0.7	2.5	1.0	0.9
Podiatry	5	Hours	0.0	0.0	0.1	0.0	0.0
Nursing care	4	Hours	0.1	1.6	5.0	2.1	2.3
Alternative therapies	4	Hours	1.1	1.6	1.7	1.5	0.2
Food service other	2	Hours	0.2	0.4	0.5	0.4	0.2
Physiotherapy assessment	1	Hours	0.0	0.0	0.0	0.0	. .
Social support	1	Hours	0.1	0.1	0.1	0.1	. .
Follow-up needs assessment	30	No. contacts	0.1	0.2	0.4	0.3	0.1
GP consultation	8	No. contacts	0.1	0.2	1.1	0.3	0.3
Nursing/medical other	7	No. contacts	0.0	0.1	8.3	3.3	4.1
Dementia management	2	No. contacts	0.0	0.0	0.1	0.0	0.0
Psychiatrist	1	No. contacts	0.3	0.3	0.3	0.3	. .
Recreation/leisure programs	27	No. days/nights	0.2	2.1	11.2	2.5	2.3
Living skills development	5	No. days/nights	0.2	0.8	1.1	0.8	0.3
Needs assessment other	3	No. events	0.1	0.2	0.2	0.2	0.1
Personal other	3	No. events	0.1	0.2	0.4	0.2	0.2
Allied health other	1	No. events	0.2	0.2	0.2	0.2	. .
Community service other	1	No. events	7.3	7.3	7.3	7.3	. .
Referral to other provider	1	No. events	0.0	0.0	0.0	0.0	. .
Personal transport	16	No. one-way trips	0.4	2.2	15.1	3.8	3.5
Community transport	9	No. one-way trips	0.1	2.2	4.3	2.0	1.1

. . Not applicable.

Achievements and challenges

Consortium members observed that, with additional support from CWPDA, clients have been able to stay in their homes for longer. Some clients entered residential aged care after a period with the project and often this had to do with a need for 24-hour supervision. CWPDA reported that in homes without a 24-hour staff roster (hence a lengthy block of unsupervised time during the day), a client needing a high level of aged specific care might be maintained at home for between 3 and 6 months with additional support from the project. The project is able to help maintain clients at home for much longer periods where there is 24-hour supervision from the accommodation service.

With CWPDA staff coming in, clients with age-related needs have received higher levels of personal assistance, which, due to funding and time constraints, staff in a group home would not ordinarily be able to provide. This in turn has led to improved quality of life for CWPDA clients and other members of their households. With the injection of additional support for clients who have increased support needs due to ageing, disability support staff do not have

to spend the extra hours with a particular client but are able to share their time more evenly between members of the household.

Assessments by the project team in consultation with disability support staff, Uniting*Care* allied health professionals and ACATs have been able to differentiate between disability support needs and needs associated with the onset of ageing processes. This has also meant that other clients in a home are benefiting from the Pilot because staff members are better equipped to identify age-related needs as they emerge.

A major benefit of the CWPDA project is increased access to allied health care for disability clients. Allied health care input greatly improves client quality of life and assists disability service providers in supporting clients with age-related needs. Physical therapy helps to maintain client function and arrest or slow age-related physical decline; aids and equipment help to compensate for age-related functional loss. It was said that access to allied health care through normal channels is severely limited due to funding constraints and other barriers that include active discrimination within health services against disability clients (it was noted that people with dementia often face similar difficulties in interacting with health services).

Coordination and negotiation with existing services was time-consuming at first and is likely to continue throughout the life of the project. CWPDA faced resistance from staff within the accommodation services, which is thought to have been related to a perceived threat of aged care services 'taking over' from disability staff. Also, at the time of project establishment, DADHC was undergoing a major restructuring and this was said to have raised job security concerns in the disability services sector. More attention to education of staff in the group homes in the establishment phase would have ensured a greater understanding of project goals in the set-up phase.

Staff education has been a major ongoing focus for the project. Disability workers have a strong disability support focus and commitment to the principles of encouraging independence. Through the Pilot experience, disability workers have learnt that it is often the case that a client is no longer capable of performing at the level that he or she used to. A good example is continence management. Through CWPDA, disability workers have learnt to accept continence management need as an ageing process that requires appropriate intervention rather than considering incontinence as a behavioural problem. Likewise, aged care workers in the pilot have gained increased understanding of disability support by working alongside the disability support staff. Through the pilot they are able to more effectively meet the aged care needs of people with a disability.

The project has had to work hard to maintain a clear understanding that CWPDA aged care workers are not there to fill gaps in group home staff rosters. There have been some instances of disability services treating the project as an additional staff resource for their own purpose instead of treating the team as dedicated aged care providers. Clients, too, need to become familiar with project providers and come to trust them as care plans are implemented. Considerable effort is required to manage the expectations of disability service providers, clients and families.

Staff turnover has been low in some locations, while in others the project has managed to maintain staffing with some difficulty. Clients in Bathurst and Orange have benefited from very low turnover of CWPDA aged care staff. Staff retention in Dubbo and Gilgandra posed a greater challenge. There is also high turnover in disability support staff at these locations. Uniting*Care* operates care packages in the wider community with a stable staff. In locations where difficulties exist, the challenge is in finding and retaining aged care staff with

expertise in the disability field. A disability client may fail to understand and accept staff changes and a change can exacerbate client behaviour and cause setback in the care plan.

The project has highlighted a number of lessons in assessment practice for the target group. Only around 40% of referrals received by CWPDA were accepted and referred on for ACAT assessment. CWPDA strongly recommends against SNAP as a basis for identifying a client's age-related needs. The CWPDA initial needs assessment processes proved a more appropriate basis for selecting disability clients to participate in the Pilot. CWPDA stresses the importance of joint disability and aged care assessment; however, multiple assessments by different parties have been a burden for some clients. Clients have been assessed first by their disability service for referral to CWPDA, then by CWPDA for screening and finally by ACAT. Too many referrals have been required to reach the point of being able to refer to ACAT and clients find multiple assessments tiring and confusing.

CWPDA suggests that for ACAT staff to work successfully in the disability support and aged care partnership, the ACAT assessor needs not only education in disability support but demonstrated experience of working in the disability field. CWPDA encountered difficulties working with one ACAT where it is perceived that ACAT judged that disability service clients were receiving adequate care in the group home. CWPDA recommends that a service such as theirs would benefit from one ACAT contact with experience in disability sector acting as the primary ACAT contact for the region. It is thought that this arrangement would lead to a more uniform and equitable approach.

Among other issues identified, travel time and costs across the large catchment area have proved to be an ongoing challenge. There is some difficulty with 'remote' management from DADHC in Sydney and the level of understanding of the respective roles of state and Australian Governments in program delivery among staff at the coalface of service delivery.

Some consortium members believe that the evaluation should have been carried out towards the end of the project to gain more insight into its effectiveness and suggest that a longitudinal perspective would have provided a more detailed picture of the increase in ageing issues/needs and the increased hours over time to support a particular client.

With clients receiving between 10 and 20 hours of additional support each week through CWPDA, concern was raised that the Pilot has created high dependency on the service and a withdrawal of that support would place a great deal of pressure on disability service providers.

3.3 Northern Sydney Disability Aged Care Pilot

The Northern Sydney Disability Aged Care Pilot (NSDACP) provides flexible care to people with disabilities whose support needs are increasing due to conditions relating to their ageing. NSDACP was established in November 2003 as a consortium led by New Horizons Enterprises Limited in partnership with supported accommodation services in the Northern Sydney region, all funded by the New South Wales Department of Ageing, Disability and Home Care. The project received its first clients in April 2004.

NSDACP objectives are to:

- assist clients to maximise their independence and continue their lifestyle within their existing group home or institution
- demonstrate that flexible service delivery will meet individual client needs and prevent premature or inappropriate admission to residential aged care

- integrate aged-specific care with the client's existing disability care plan.

The project was initially intended to operate for 3 years. Clients remain in the project until its completion, or until they no longer benefit from remaining in disability-funded supported accommodation or their age-related support needs can be addressed under their existing disability support funding arrangements.

Forty-five places were made operational from the start date of 1 November 2003, covering the northern Sydney local government areas of Warringah, Manly, Mosman, North Sydney, Willoughby, Lane Cove, Hunters Hill, Ryde, Ku-ring-gai and south of Hornsby in the Hornsby Local Government Area. On 28 May 2004, 10 places were taken offline and the April 2004 quarterly payment withheld due to consistent low occupancy, on agreement with New Horizons Enterprises to adjust the accumulated surplus. Occupancy grew to over 100% against those places and the 10 withdrawn places were made operational again on 1 April 2005, bringing the project back to 45 operational places. The April 2005 quarterly payment was withheld on agreement with New Horizons Enterprises to adjust the accumulated surplus.

Stakeholders

NSDACP was established under a Memorandum of Understanding between New Horizons Enterprises Limited, the New South Wales Department of Ageing, Disability and Home Care (DADHC) and The Australian Government Department of Health and Ageing. DADHC continues to fund disability support services for clients accepted into NSDACP. The Australian Government funds the project up to $1,046,272.50 a year or $63.70 per allocated place per day.

New Horizon Enterprises Limited is a non-government, not-for-profit provider of aged care and disability services in Sydney, the Central Coast and the Hunter Region. New Horizons operates residential facilities and community-based programs, with a focus on supporting people with intellectual or psychiatric disability. New Horizon's core activity is case management.

NSDACP sources clients from group homes and small institutions operated by consortium partners in the catchment area (referrals are not sourced from New Horizons residential facilities). Initially the consortium comprised, in addition to New Horizons Enterprises, Metro North Accommodation and Respite Services (a DADHC funded and operated service), The Spastic Centre, the Sunnyfield Association, Sunshine Home and House With No Steps. House With No Steps withdrew from the consortium prior to service commencement and three organisations joined the consortium in 2005: Seton Villa, Crowle Foundation and Inala. Consortium partners are mostly large, long-established disability service providers.

The Spastic Centre was established in 1945 to support people with cerebral palsy and their families. Today, The Spastic Centre of New South Wales delivers a range of services to over 3,000 children and adults each year, including therapy services, community living and employment services, respite services, education and support. The Centre operates 60 sites across metropolitan Sydney and Newcastle and centre-based and outreach services for people in rural and remote areas.

Established in 1952, the Sunnyfield Association offers support to people with a disability and their families living in Sydney and the Central Coast. Sunnyfield provides accommodation

services in over 30 group homes in the community, therapy services and day programs for people with a disability, respite and day programs, and training and employment services.

Sunshine Home has been providing accommodation, day programs and employment opportunities for adults and adolescents with an intellectual disability for over 80 years. The organisation operates day options (including specific programs for seniors and younger people with intellectual disability), employment services and accommodation services. Until recently, Sunshine Home accommodation services comprised group homes and a larger hostel facility that accommodated approximately 100 residents at Gore Hill, the original Sunshine Home site. The hostel closed and several clients participating in the evaluation who were some of the earliest residents at Gore Hill moved into group home accommodation during the course of the evaluation.

Seton Villa is a residential service for women with intellectual disability. It began operating in 1966 from premises in Eastwood under the auspice of the Daughters of Charity of St Vincent de Paul, a worldwide religious community. Seton Villa receives funding from DADHC to operate seven houses and two units in the Eastwood, Marsfield and North Ryde areas of Sydney. Staff members assist residents with daily living skills acquisition, personal development, integration into the community, health and medical needs, money management, personal care, leisure and recreational opportunities and social outings.

The Crowle Foundation is a charitable organisation established in 1952 to support people with intellectual disabilities and their families. The Foundation is based in Ryde and operates a range of accommodation models, day activities, workplace training and employment services.

Inala, a Rudolf Steiner community, cares for children and adults with disabilities. Accommodation is located in The Hills District, north-west of Sydney.

Target group

Clients eligible to join the project include people residing in DADHC-funded accommodation services operated by consortium members who:

- can be supported in their current residence with additional aged care specific services (joining the project should not involve a change of residence)
- have their current disability service support guaranteed
- agree to participate in the project
- have a valid Aged Care Assessment Team (ACAT) assessment that they are suitable for residential aged care services.

This is a more diverse client group than other Disability Aged Care Interface Pilot projects. Clients from The Spastic Centre have cerebral palsy, a permanent physical condition that affects movement; a range of disability groups is represented in Sunnyfield Association clients; and clients from accommodation services operated by other members of the consortium have intellectual disability. Comprehensive assessment for NSDACP clients therefore involves the identification of age-related needs superimposed on a diverse range of pre-existing disability.

NSDACP client group profiles are given in Appendix B (see Appendix Tables B3.1–B3.11).

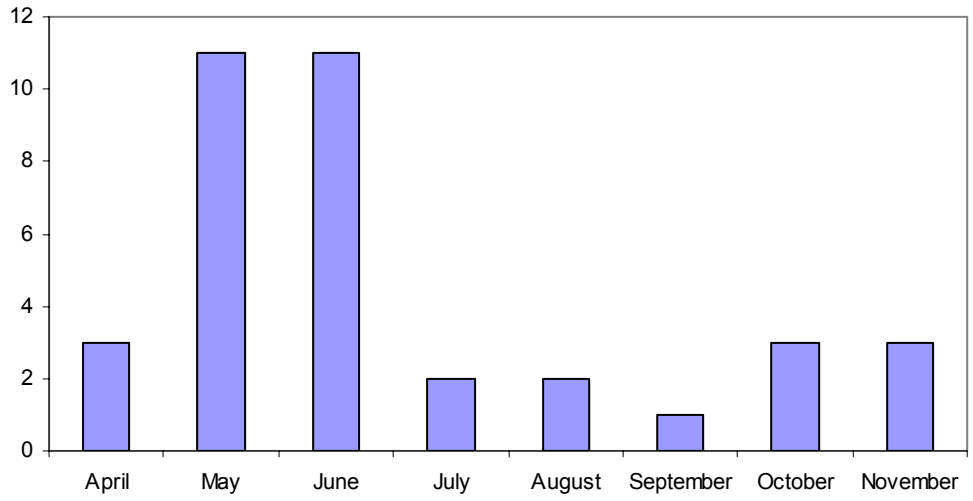
Referral and assessment

The referral and assessment process for NSDACP is targeted at appropriateness: selection of clients with potential to remain in the community but who need additional support in order to do so. Clients are referred to the project by their disability service provider, who is required to complete a comprehensive referral form and provide background information on the client's existing care plan and any previous ACAT assessments. The referral form includes information about client level of functioning in activities of daily living, sensory and physical impairments, medical conditions, continence and behaviour.

Referrals are screened and the project coordinator may need to liaise with the originating service provider before forwarding the referral to the project's ACAT contact. The catchment area is serviced by five ACATs; however, the project deals with one ACAT representative who channels a referral to the relevant team. This streamlined process has proved highly efficient for both the ACATs and NSDACP. Project staff noted that limiting close involvement to just one ACAT member may not, however, be the best way to build capacity within the system.

By early September 2005, NSDACP had received 88 referrals from consortium members and approved 62 for on-referral to an ACAT. Fifty-four of these referrals progressed to ACAT assessment, of which 53 were approved by ACAT (Table 3.4). Completion of assessment processes for five more referrals was expected to take the total number of commencements between May 2004 and September 2005 to 48 people, covering 28 different group homes operated by NSDACP consortium partners.

The national evaluation coincided with a period of slow referral and assessment processes which, together with consent provisions, limited the number of evaluation participants to 22 of the 30 clients who had commenced by September 2004 (Figure 3.1). The number of group homes with one or more residents receiving NSDACP services rose from three in April 2004 to 11 by June and to 19 by November 2004. A proportion of early referrals from disability service providers was rejected by the NSDACP coordinator as inappropriate or incomplete. It has taken time to educate disability service staff on how to identify and document age-related needs, particularly in the area of dementia superimposed on Down syndrome. Initially the project relied on information disseminated at consortium meetings filtering down to staff in facilities but this proved to be an ineffective means of communicating NSDACP requirements to staff directly responsible for their implementation. Over time and with education, the referral and assessment process became streamlined and efficient. Major delays have not occurred at the ACAT end of the process.



Source: NSDACP (New Horizons Enterprises), 7 September 2005.

Figure 3.1: Northern Sydney Disability Aged Care Pilot, number of service commencements (new clients) by month, 2004

Table 3.4: Northern Sydney Disability Aged Care Pilot, number of referrals by project and ACAT assessment outcome, May 2004–September 2005

	NSDACP assessment status				ACAT status		
Consortium partner	**Referrals received**	**Number resubmitted**	**NSDACP approved**	**NSDACP not approved**	**Assessed**	**Approved**	**Awaiting completion**
DADHC	25	3	10	15	10	10	—
Sunshine Home	13	—	12	1	11	11	—
Sunnyfield	16	—	9	7	9	9	—
Spastic Centre	22	7	19	3	19	18	—
Crowle Foundation	4	—	4	—	3	3	—
Seton Villa	6	2	6	—	2	2	3
Inala	2	—	2	—	—	—	2
Total	**88**	**12**	**62**	**26**	**54**	**53**	**5**

— Nil.

Source: NSDACP (New Horizons Enterprises), 26 September 2005.

A broad spectrum of aged care needs is seen in the referrals, requiring a range of assessment tools for screening and needs identification. NSDACP deals with clients who experience many of the common maladies of older age plus disability-specific health conditions that are age-related. NSDACP clients with cerebral palsy are at the high end of the spectrum of need for physical support. The Broad Screen Checklist of Observed Changes (Minda Inc.), used extensively across the Innovative Pool projects to inform assessments of clients with intellectual disability, cannot be used for this group. The Spastic Centre has made use of the Functional Independence Measure (FIM) for assessment of people identified for referral to the project and had routinely used the FIM over a period in the late 1990s. A comparison of the two sets of FIM scores revealed marked physical decline over the intervening period. The

FIM is recommended for use with this group of NSDACP clients and is found to facilitate communication with health care professionals due to its widespread application in the health sector. Spinal cord compression typically occurs in people with cerebral palsy who are aged over 30 years. This condition requires specialist diagnosis by a physiotherapist (a GP may not be equipped to diagnose spinal chord compression in a patient with cerebral palsy) and neurosurgical intervention.

Clients with Down syndrome are at increased risk of developing Alzheimer's disease in their 30s and 40s and may require additional support for behaviour and daily living due to dementia and associated behavioural and psychological symptoms.

People with physical or intellectual disabilities are also susceptible to the range of conditions commonly associated with older age; in the presence of younger onset physical disability, common age-related conditions are more likely to manifest significantly from the age of 40 years and onwards. Skin integrity, nutrition management and reduced mobility can become issues for people with physical or intellectual disability aged in their 40s and 50s.

Service model

The disability service provider remains responsible for the client's overall care plan (Individual Plan). Joint assessment to identify a client's age-related needs in developing the NSDACP care plan is a collaborative effort between the NSDACP coordinator, disability support staff and in cases requiring specialist input, allied health professionals. It is essential that the process is informed by the knowledge from within the disability sector of the care needs and trajectories of pre-existing disabling conditions. ACAT may become involved at the needs assessment stage but, more typically, NSDACP compiles all relevant information for ACAT in advance of the ACAT assessment.

A care plan specifically for the project is written by project staff in collaboration with the disability service provider for incorporation into the client's Individual Plan.

Following initial assessment the NSDACP coordinator maintains close, usually daily, contact with disability staff until the care plan becomes established. This ensures that the client accepts the staff responsible for implementing the care plan and that service runs smoothly. Occasionally it is necessary to reassign staff to ensure a good rapport with the client. This process is vital for delivering services effectively to people with disabilities, particularly people with intellectual disabilities in a group home setting.

The project also provides some assistance in care planning for clients who are referred but not accepted into the project. This sharing of expertise is an added benefit of the project for disability service providers and their other clients.

New Horizons initially envisaged that the project would broker to participating disability service providers for staff to deliver NSDACP services. Such an arrangement proved unfeasible, due mainly to a lack of capacity within the disability services, and NSDACP engaged agency aged care workers to work in all but one of the participating facilities. Agency workers have been able to work successfully alongside disability support staff and the coordinator reported that clients have responded positively to new people offering additional support and activities. Aged care workers are invited to participate in the NSDACP in-service training program.

NSDACP services are additional to existing disability services. The range of services provided by the project includes:

- initial assessment and care planning

- personal assistance to address specific aged care needs but not to duplicate existing personal care delivered by disability services
- incontinence, dementia, skin and nutrition care
- provision of aids and equipment
- aged care specific recreation activities and diversional therapy
- programs for mobility support, chronic conditions, sight, hearing and speech
- allied health services, including podiatry and physiotherapy
- transport assistance and access to community services
- facilitated access to relatives, aged-care advocacy services and complaints systems.

NSDACP supplied evaluation data for 22 clients. Consent to participate could not be obtained from another six clients who were active in the 2004 reporting period. Among the evaluation participants, seven were people with intellectual disability, seven were people with physical disability, and eight were people with other types of disability including acquired brain injury and multiple diverse disabilities.

Table 3.5 shows the service activity profile of evaluation participants during the 2004 reporting period. This profile reflects the completion of allied health assessments of clients at that time.

Table 3.5: Northern Sydney Disability Aged Care Pilot, minimum, median, maximum and mean service units per evaluation client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std Dev
Physiotherapy	22	Hours	—	—	1.0	0.1	0.3
Occupational therapy	22	Hours	—	—	—	—	—
Personal assistance	9	Hours	1.6	3.2	6.5	4.1	2.3
Podiatry	1	Hours	—	—	—	—	—
Dietetics	4	No. referrals	—	—	—	—	—
Follow-up needs assessment	22	No. contacts	1.0	1.7	2.2	1.7	0.3
Aids other	5	Dollars	2.0	26.5	35.2	21.1	14.9
Mobility aids	1	Dollars	43.1	43.1	43.1	43.1	. .

— Nil or rounded to zero.

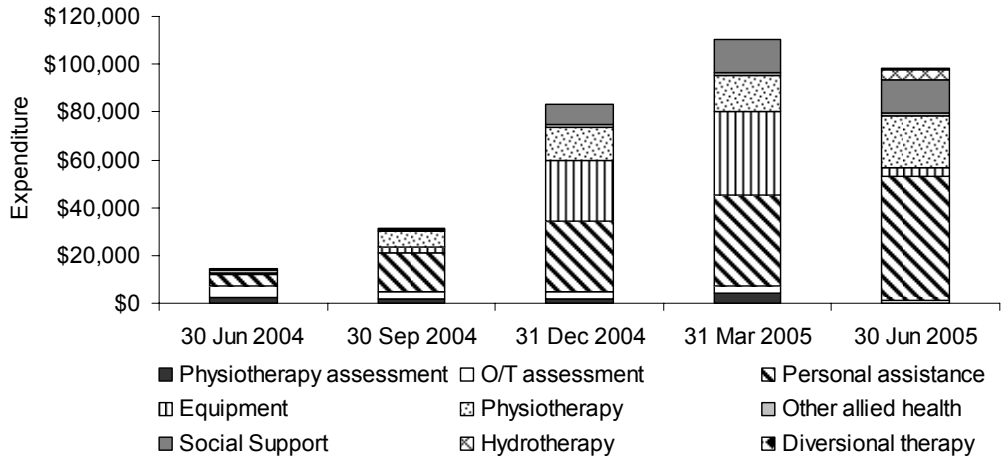
. . Not applicable.

A picture of service activity in the maturing NSDACP is reflected in the project's September 2005 report of service expenditure (Table 3.6 and Figure 3.2), which shows increases in expenditure on personal assistance, physical therapy and the provision of aids and equipment as assessments were completed and care plans became established.

Table 3.6: Northern Sydney Disability Aged Care Pilot, quarterly expenditure on selected service types, 1 April 2004 – 30 June 2005

	Quarter ending					Total to
Service type	**30.6.2004**	**30.9.2004**	**31.12.2004**	**31.3.2005**	**30.6.2005**	**30.6.2005**
AH assessment—physiotherapy	2,691.00	1,944.00	1,971.00	4,059.00	264.00	10,929.00
AH assessment—occupational therapy	4,686.00	2,688.00	2,875.80	3,102.00	693.00	14,044.80
Personal assistance	4,688.76	16,676.11	29,349.77	37,870.45	52,348.53	140,933.62
Social support	649.44	884.28	8,200.07	13,594.26	13,608.58	36,936.63
Physiotherapy	0.00	6,714.00	13,630.84	14,926.60	21,802.08	57,073.52
Provision of aids and equipment	765.00	2,236.36	25,542.68	35,434.00	3,521.04	67,499.08
Other allied health	1,095.00	415.00	1,391.01	1,152.00	1,110.00	5,163.01
Hydrotherapy	0.00	0.00	0.00	174.24	4,193.52	4,367.76
Diversional therapy	0.00	0.00	0.00	0.00	748.00	748.00
Total	**14,575.20**	**31,557.75**	**82,961.17**	**110,312.55**	**98,288.75**	**337,695.42**

Source: Northern Sydney Disability Aged Care Pilot (New Horizons Enterprises Ltd).



Source: Table 3.6.

Figure 3.2: Northern Sydney Disability Aged Care Pilot, quarterly expenditure on client services by service type, 1 April 2004 – 30 June 2005

Achievements and challenges

NSDACP has been described as a 'pressure reliever'. By taking responsibility for the management of age-related needs of clients, the project has freed up capacity within the participating disability services, allowing resources to be more evenly shared between all residents of a household. This reduces the burden on disability support staff and helps to improve the quality of life for project clients and other residents alike.

Disability service providers highlighted provision of aids and equipment, access to skilled dementia care and advice, and access to allied health care as three aspects of the NSDACP service model that are of major benefit to clients. The project demonstrates the need for aged care models of allied health support to be integrated into disability service settings. In this and a number of other respects NSDACP has helped a small number of people to overcome systemic barriers to service provision for people with disabilities. The NSCACP team and consortium pointed to issues that impact on the capacity of mainstream services to provide appropriate care for older people with disabilities:

1. *People in the target group are unable to access HACC-funded dementia advisory services.*

Group homes and other residential facilities for people with a disability funded under the Commonwealth State/Territory Disability Agreement are not funded to employ a dementia clinical nurse consultant and most disability clients do not have the means to access private specialist dementia services. In January 2005, the Community Care Northern Beaches Dementia Care Advisory Service was launched with funding from DADHC. Disability clients who live in Sydney's Northern Beaches area are able to access a dementia care advisor through this state-funded service, while clients in other areas remain without dementia-specific support.

2. *People with disabilities can face active discrimination when attempting to access health services.*

The AIHW was told that disability clients are often denied access to rehabilitation therapy and allied health care more generally. This is thought to stem from two misconceptions among some staff in the health care sector: first, that a person with a disability—particularly intellectual disability—is unable to benefit from rehabilitation by virtue of having a disability and second, that allied health care for people with a disability is the responsibility of disability services and not health services. Further, acute care staff may insist on the disability service provider providing 24-hour supervision for a person with a disability to be admitted to hospital, or to remain in a ward for an appropriate period following treatment. Anecdotal reports were given of public hospitals refusing to admit a person requiring treatment because of their intellectual disability. The AIHW is unable to confirm these reports but notes a consistency between accounts of the interface between disability and health services from Innovative Pool projects across Australia.

3. *Older people with a disability face barriers in accessing dementia-specific aged care day programs.*

It was said that services which offer day programs for people with dementia discriminate against people with a disability, referring to them with inappropriate language and actively discouraging participation. There is unmet need among older people with a disability who have dementia for appropriate day options.

4. *People with a physical disability face barriers in accessing day programs operated by disability services.*

Many disability day programs cater primarily to the needs of people with intellectual disability and are reluctant to accept new clients who have a physical disability. Sometimes this reluctance is due to physical access barriers, for example, the lack of a ramp for wheelchair access. In other cases staff have been unwilling to accommodate a person with somewhat different needs to the rest of a group.

The project has highlighted the difficulties associated with placing a person with a disability into residential aged care to receive what disability service providers view as less appropriate care with a lower staff to client ratio than a client is accustomed to receiving. However, once age-related needs increase to the extent that a client needs high level nursing care or significant manual handling, group home accommodation becomes inappropriate. The project coordinator posited that potential solutions are to provide adequate training opportunities for staff in the aged care sector and training on ageing and aged care for staff in the disability sector to enable staff to deliver appropriate community care to people with disabilities who are ageing, and to provide specialist nursing homes for people with a disability.

NSDACP experience suggests that key unmet age-related needs in the target population relate to nutrition, challenging behaviours, one-on-one personal care, mobility management, access to allied health care and staff training. The project has revealed a general feeling among staff in the disability sector that aged care placement is inappropriate for people with a disability because of lower staff ratios, inappropriate activities, a generation gap between people with a disability who are ageing and the majority of other residents, and lack of training for aged sector staff in disability support.

Anecdotally, some existing DADHC-funded group homes and institutions in the project's catchment area are functioning like de facto nursing homes, because they have the resources to provide higher levels of care. It is believed that some organisations operating in the Northern Sydney area may be unique in this respect, as they tend to be older, well established organisations with access to private sources of finance in addition to government funding. The practice of maintaining people in disability-funded community accommodation when they have high age-related needs leads to questions around what is 'appropriate' ageing in place.

Other issues highlighted by the project include access to aids and equipment (NSDACP has funded these items because usual supply channels are too slow); staff continuity; occupational health and safety and restrictions on lifting (even though the availability of a lifter would keep some clients out of a nursing home); and funding of age-appropriate leisure programs for retirees in their sixties who have intellectual or psychiatric disability.

3.4 MS Changing Needs

The Multiple Sclerosis Society of Victoria (MSV) is the approved provider for a 16-place Innovative Pool project, MS Changing Needs, which aims to address the high nursing care needs of people with multiple sclerosis.

The Society has 100 members and around 4,500 clients, this latter number estimated to be half the number of people in Victoria with MS. Approximately 60% of the Society's funding comes from government, including around $7 million in state government funding under the Commonwealth State/Territory Disability Agreement that is specifically channelled into service delivery. Services operated by the Society include:

- two residential facilities (group homes with four to five beds each in two clusters, totalling 28 beds)
- residential and in-home respite services
- information and library services
- peer support program and support groups

- volunteering program
- client advocacy.

MSV applied for Innovative Pool funding because MS clients have been found to require significantly higher levels of nursing care than can be accessed through mainstream disability services. Although there is a nursing presence in mainstream MSV services, 24-hour nursing care to deal with the many risks and procedures involved in high level care of people with MS is not widely available. Numerous stories were quoted of people aged in their 30s and 40s being placed into nursing homes because of a lack of other care options. This is attributed to a disability support system designed more for people with intellectual disability and a lesser focus on the needs of people with acquired conditions. Specifically, it is thought that a disability service model predominantly based on a philosophy of social integration tends to overlook the needs of people with physical disability and high nursing care needs. People with MS are generally well integrated into their communities, they often have partners and children, and they nearly always reach a point of requiring high level nursing care, for example, administration of drugs of addiction, swallowing issues and peg feeds. Services that cater for people with partners and families and who have work experience are needed for this target group. MSV indicated that the Victorian Spinal Cord Injury group home care model includes 24-hour nursing care.

MSV suggested that a moratorium on new group homes in Victoria accounted for more than half of the increase in demand for nursing home beds. The Society estimates that there are more people with MS in residential aged care facilities (for MS-related care) than there are people with MS in disability services supported accommodation.

There is high demand but very low turnover in existing MS-specific residential facilities—in 2003 only one out of the 28 beds operated by MSV became vacant.

The maximum funding from the Australian Government for 16 places will total $829,160 over 2 years. This is equivalent to $60.32 per allocated place per day.

Target group

Clients in the target group have multiple sclerosis and around 90% require high level nursing care. Most clients are aged in their late 30s to late 50s. Average life expectancy for people with MS is similar to that of the general population. Many clients stay in a group home for more than 10 years before transferring to residential aged care.

MS is a progressive neurological disorder affecting both physical and cognitive functions in varying degrees from mild to very severe. Each resident has a neuropsychological assessment which informs care planning, and these assessments are updated as required (for example, where a client's capacity to make informed decisions about financial or medical matters needs to be established).

Most clients are immobile—hoists are already in place.

Disease progression means that the needs of residents in disability-funded accommodation increase over time, resulting in a need for age-related supports to be provided at a younger age. Some of the age-related conditions seen in people with MS include:

- swallowing problems that necessitate dietary changes, assistance with feeding or enteral feeding
- bowel and bladder incontinence
- high blood pressure

- skin integrity problems requiring wound dressing.

Differentiating age-related needs from disability-related needs is thought to be nonsense in the context of this client group and in this respect MS Changing Needs is unique among the Disability Aged Care Interface Pilot projects. In practice, an ongoing need for high level nursing care of the type that is available in high care residential aged care facilities is used to identify the target group.

MS Changing Needs client group profiles are given in Appendix B (see Appendix tables B4.1–B4.8).

Service environment

Clients in MSV group homes receive around 8 hours of nursing care per day. Allied health services are generally accessed through the public hospital system. People with MS can access Home First, a state-funded personal care service for people with physical disabilities that provides 34 hours of care per week. Home First does not deliver nursing care. Thirty-four hours of care, excluding nursing care, is insufficient to maintain a person with MS in the community over the long term.

There were 30 EACH packages in the catchment area when the project was established in mid-2004. People with MS also have access to aged care via the CACP program. However, if a disability services client accepts an aged care package they may forfeit access to some disability services (for example, aids and equipment through state disability programs). HACC also has policies designed to prevent 'double-dipping' and in so doing may present a barrier to people with MS who need aged care services. Ironically, a person with MS who accepts a CACP may be at higher risk of entry into residential aged care if there is consequential loss of specialist disability support.

Some MSV clients list themselves for residential aged care; however, in many cases placement is unlikely because a person with MS-related high nursing care needs is an unattractive prospective client. They are generally younger and have high likelihood of a prolonged duration of stay. One MSV client, for instance, has been waiting for aged care placement for 6 years.

Referral and assessment

Clients are identified from within MSV group homes. Most clients have Aged Care Assessment Service (ACAS) approval for high level residential aged care. Once identified, a client's needs over the next few months are anticipated and on the basis of these forecasts candidates are invited to join the project.

The project reported that some ACAS members have been positive and have provided invaluable input, while others have been more difficult to deal with. Some are thought to resent the perceived use of ACAS as a 'rubber stamp' for residential aged care simply to get a person into the project. It was said that other ACAS members give the impression that they believe people in the target group to be already receiving high levels of service in comparison with others in the community. It appears that aged care services of any kind are seen by ACAS as a last resort for people with MS and clients are encouraged to first exhaust all avenues of state-funded support. This client group can experience long delays for ACAS assessment, which is said to be due to assigned low priority.

Service model

The MS Society is using Innovative Pool funding to inject additional services into existing MSV group homes. The focus is on offering 24-hour nursing care, which is an area of high unmet need for people with MS. The project is funded quarterly, based on occupancy (the project received 100% funding for the initial quarter to allow for set-up costs). Clients are not required to pay additional fees for the project. The first clients started in June 2004.

All staff members working on the project, including the nursing staff, are employed by the MSV. Registered nurses are employed specifically for the project, and existing MSV care workers deliver personal assistance. MSV does not have trouble recruiting care workers as the Society offers a 20% higher rate of pay than is normally offered to workers for in-home service. There has been considerable difficulty in recruiting nurses despite the fact that MSV also offers above the award rate for nursing staff.

MS Changing Needs supplied evaluation data for 16 clients, including seven men and nine women with MS. The project's service activity profile describes the distinct nursing tasks involved in caring for people with MS (Table 3.7). A major feature that is not well captured in the service profile is 24-hour monitoring and supervision of clients in a disability-specific care setting.

Table 3.7: MS Changing Needs, minimum, median, maximum and mean service units per client per week, by nursing care activity

Service type	Clients	Minimum	Median	Maximum	Mean	Std dev.
Medications	16	0.3	2.3	7.4	2.6	1.8
Incontinence management	16	0.3	0.6	2.0	1.0	0.6
Counselling	16	0.5	1.0	2.0	1.1	0.4
Training and education	16	0.2	0.3	1.7	0.4	0.4
Individual care plan assessment	16	0.1	0.2	1.5	0.3	0.3
Advocacy	16	0.2	0.5	0.7	0.5	0.1
Liaise with allied health professional	16	0.1	0.1	0.5	0.2	0.1
Nutritional monitoring	16	—	0.1	0.6	0.2	0.1
Other	16	0.3	0.5	0.5	0.5	0.1
Referrals	16	0.1	0.1	0.3	0.1	0.1
Updating care plan	16	0.5	0.8	0.8	0.7	0.1
Equipment purchase/ordering	16	0.1	0.1	0.1	0.1	—
Handover	16	0.9	1.0	1.1	1.0	—
Medical consultations	16	0.1	0.1	0.3	0.1	—
Updating histories/reports	16	0.5	0.5	0.5	0.5	—
Wound care	15	0.1	0.5	2.6	0.7	0.7

— Nil or rounded to zero.

Achievements and challenges

MS Changing Needs is helping to show that both levels of government can cooperate to achieve a good outcome for clients. Most people with MS enter residential aged care via hospital. When a person needs to be hospitalised, often the group home cannot accept them

back because it is unable to provide 24-hour nursing care. The wait in hospital for a residential aged care bed can be long—delays of up to 18 months or more have occurred in the past.

Twenty-four-hour nursing care in MSV residential facilities benefits all residents, not just those in receipt of an Innovative Pool package. Thus, the project has had flow-on benefits. MSV is hoping to obtain state funding to allow the project to continue beyond the Pilot. The project has stimulated an examination of the issues faced by people with advanced MS. Disability programs can be accessed by clients who leave the project, that is, places in community programs will be held until the end of the Pilot.

It is expected that most of the clients will be looking to enter residential aged care should project services be discontinued.

Ideological differences and communication difficulties between the aged care and disability sectors have presented some challenges.

3.5 Interlink Flexible Aged Care Packages

Interlink Flexible Aged Care Packages (FACP) were developed to enhance the provision of services for ageing people with disabilities who are at risk of premature entry into residential aged care. FACP accepted its first clients in November 2003. Key objectives are to:

- provide an holistic and proactive service to facilitate individualised and flexible support
- work with each individual to achieve the best possible outcomes while encouraging independence within their home environment
- illustrate how aged care and disability sector partnerships can achieve positive client outcomes based on health, aged and social care needs.

The project was designed to test the effectiveness and efficiency of providing additional aged care services to people with disabilities who are currently living in supported disability accommodation and receiving disability services. The project was initially intended to operate for 2 years. Clients remain in the program until the completion of the project, or until they no longer benefit from remaining in disability-funded supported accommodation or their age-related support needs can be addressed under their existing disability support funding arrangements.

The project has 20 low and 10 high care packages, covering metropolitan Adelaide and the Adelaide Hills.

Services for people with disabilities who are living in the community are limited and while their need for services is not in dispute, who should be responsible for providing those services is debated. There is a general feeling that group home residents cannot access mainstream aged care packages. Interlink sees this project as helping to address the gap.

Stakeholders

The approved provider is Helping Hand Aged Care Incorporated, an organisation established in 1953 which provides residential care to older people along with rehabilitation, therapy and other support services for the aged. The project coordinator is employed by Helping Hand. The project consortium includes, apart from Helping Hand, the following partners: Adults with Physical and Neurological Disability Options Coordination; Barkuma

Inc.; Brain Injury Options Coordination; Hills Community Options Inc.; Minda Inc.; Orana Inc.; and the Intellectual Disability Services Council (supporting role).

The consortium members provide supported accommodation in group homes and smaller facilities. The Australian Government Department of Health and Ageing funds the project for up to $599,330 a year or $54.73 per allocated place per day.

Client group

All clients in the target group have intellectual disability. They are generally aged 60 years or older, are currently receiving disability support services in an accommodation setting, have increasing high and low level care needs related to ageing and are likely to enter residential care in the near future if they do not receive additional support.

Specifically, eligibility is restricted to those people in the target group who:

- can be supported in their current residence with additional aged care specific services (joining the project should not involve a change of residence)
- have their current disability service support guaranteed
- agree to participate in the pilot
- have a valid Aged Care Assessment Team (ACAT) approval for residential aged care services.

Priority of access is based on the capacity of the project to meet the individual client's needs and the concept of 'ageing in place'—linking care and support services to the place where the individual wishes to live.

Distinctions between age-related and existing disability-related needs are made on a case-by-case basis, similar to the way ageing issues are considered in the Indigenous community. The project has been welcomed by providers as a referral alternative to residential aged care. Needs that are not generally well addressed within the disability sector include limited opportunity for socialisation due to mobility and frailty; accompaniment to leave the house for appointments and shopping; personal and nursing care; continence management; dementia care; day care for people with a disability who have left their place of employment.

FACP client group profiles are given in Appendix B (see Appendix Tables B5.1–B5.12).

Service model

Disability support staff identify potential clients and refer them to the project coordinator who screens and refers to ACAT. Prior to the project, ACAT would assess disability clients in group homes but generally only for residential care as there was no opportunity to refer for community care. ACAT indicated that sometimes it is obvious that a person with intellectual disability has age-related needs but that assessment can be complex in other cases.

Once a person gains ACAT approval they, together with the project coordinator, carers and service providers, meet to plan services that will best meet the client's needs. Disability support staff help to identify suitable activities and estimate the number of hours required. The cordinator develops a care plan, arranges for services to be delivered and checks regularly that services continue to meet client needs. The coordinator does not undertake case management; this continues to be the responsibility of the client's disability service provider.

Project services are additional to disability services and include:

- personal assistance, such as bathing, showering and toileting assistance
- dressing and undressing
- mobility assistance, including shopping, appointments and social occasions
- meal preparation, including special meals, and eating
- house cleaning, laundry and gardening
- help during short-term illness and help with medications.

Packages are individually tailored because care needs are highly individual. Thus, different clients need a different number of hours of care (generally varying from around 2 to 12 hours per week). Often clients start on a low number of hours, which are then increased in line with changing needs. Helping Hand believes that the one-to-one model of care is valuable in assisting some clients to be maintained on a fewer number of additional hours of care. The project focuses on promoting client independence and achieving continuity in care.

Services are provided by additional staff directly employed for the project or by brokering staff already working in the supported accommodation service. Training in aged care is provided by the project.

FACP recorded evaluation data for 30 clients whose service activity during the evaluation is summarised in Table 3.8. Twenty-seven clients were people with intellectual disability, two with neurological disability, and one with acquired brain injury.

FACP is primarily a social support model that also delivers additional hours of personal assistance to around one-quarter of clients. The project has delivered a limited range of service types. Allied health care and transport services were not the main focus of this project in the reporting period.

Initial needs assessment time has averaged around 7 hours per client accepted into the project.

Table 3.8: Flexible Aged Care Packages, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Social support	30	Hours	0.6	3.9	6.3	3.7	1.4
Personal assistance	8	Hours	0.7	1.8	7.4	2.8	2.3
Physiotherapy	3	Hours	—	—	—	—	—
Domestic assistance	2	Hours	1.9	2.6	3.3	2.6	1.0
Food service other	1	Hours	1.5	1.5	1.5	1.5	—
Follow-up needs assessment	18	No. contacts	—	0.1	0.1	0.1	—
Personal other	1	No. events	1.0	1.0	1.0	1.0	—

— Nil or rounded to zero.

Achievements and challenges

Working with agencies with staff already attending clients has been the project's major challenge. A large part of the project involves building relationships between the consortium members. The model is described as supporting disability services to help clients. As

outlined above, the project itself does not provide case management but develops a care plan which enables an existing disability services case manager to ensure that appropriate care is delivered to the client. It has been important for each sector to value the work of the other. Consortium members believe the model could be used anywhere once links are established and competition gives way to collaboration. Project staff identified initial challenges in working with consortium members but relationships have developed with the establishment of communication lines and training. Some group home staff seemed to find the arrival of new staff threatening.

Distinguishing age-related needs from disability-related needs has been a main focus. In the past, group home residents seeking access to mainstream aged care in the community have encountered difficulties, for example, through restrictions on access to Home and Community Care services. Anecdotal evidence suggests FACP has given clients greater independence and security. This reflects the strengths of the concept of being able to 'add value' to existing disability services, being flexible enough to provide additional hours depending on need, and drawing on shared information and expertise of staff from the two sectors.

Disability service providers were initially cautious in estimating hours required for services but this is expected to change with experience. There was some difficulty in communicating the distinction between age-related and disability-related needs to consortium members and this affected take-up of packages in the early stages. The referral rate slowed again during 2004 to below anticipated levels.

Staff continuity is a priority for the project but there have been some recruitment difficulties, particularly for male workers and staff to work in the Adelaide Hills. There is good access to allied health care through Helping Hand's other units and community sources. The project has had positive spin-offs for other staff and clients in the group homes where staff time has been freed for other residents. There have been some monitoring issues where services are brokered.

Consortium members are concerned that the project was to run for 2 years, given the impact on clients with an intellectual disability who may lack the capacity to understand the implications.

3.6 Disability and Ageing Lifestyle Project

The Disability and Ageing Lifestyle Project (DALP) is an initiative of the Community Care Division at Renmark Paringa District Hospital (RPDH) in partnership with Options Coordination, South Australia.

RPHD manages a residential aged care facility, an acute care facility, domiciliary and outreach service, Community Aged Care Packages service, National Respite for Carers Program service, Veterans' Home Care service and administers extensive brokerage contracts.

RPDH has significant experience in the delivery of a broad range of home-based services to a variety of clients with special needs. Current target groups of RPDH include frail older people, younger people with disabilities, people with challenging behaviours, people with mental health illness, people from culturally and linguistically diverse backgrounds, and carers of people in these groups. RPDH is involved in community aged care through the provision of CACPs in addition to operating an 89-bed residential aged care facility (high and low care).

RPDH employs local staff in the towns where services are delivered. Approximately 90% of RPDH staff work in some aspect of aged care or disability service provision.

Options Coordination is an umbrella organisation for disability services in South Australia. The organisation comprises five agencies across the state. Options coordinators perform needs assessments for people (adults and children) with disabilities and assists clients to find places in specialist services. The case management of many disability services clients in the region is undertaken by Options Coordination and the Options coordinator involved with DALP is a respected source of knowledge of the needs of individuals in group homes in the DALP catchment area.

The proposal for an innovative service received support from three disability services in the region: Lifestyle Assistance and Accommodation Service Inc., Dakota House—Riverland Group Housing Association, and Orana Inc.

DALP was initially funded to operate 10 places and commenced operations in June 2004. The evaluation coincided with the project's establishment phase; data on eight clients were supplied. The project achieved full occupancy in December 2004. As of mid-August 2005, no clients had been discharged from the service.

Service environment

The RPDH and Options Coordination submission for Innovative Pool funding to establish DALP outlined features of the local service environment that impact on the services available to people with disabilities who are ageing:

- A significant shift in people preferring a community-based care delivery similar to a CACP rather than residential care was evident. At the time, 75% of persons assessed as requiring the equivalent of low level residential aged care specifically request a CACP.
- Clients with a disability often find residential care unsuitable to their needs and the age group they are required to reside with (in a residential setting) is incompatible with their sense of wellbeing.
- A considerable increase in the dependency levels of people living at home was identified.

Clients in group homes are not usually able to access CACPs or other types of community aged care. The project coordinators suggested that older disability clients in group homes would benefit from a community care package if accessible (three project clients from group homes were accessing a day activity program for older people at the time of the evaluation).

There are no accommodation services in the area specifically designed for people with brain injury, neurological disorders or physical disabilities. People with these conditions are usually cared for in hostels or residential aged care facilities when they can no longer cope at home. This is a major service gap in the district. However, several aged care and disability service initiatives operate in the area and RPDH has established strong relationships with them.

Project coordinators believe the major gaps in service provision in the area for the target group are personal assistance, social support and appropriate recreation activities. In July 2004, the project was planning services in each of these areas. Aids and equipment and assistance to access allied health care are well sourced within the disability services so that the project is not concerned with these types of service, with the exception of physiotherapy. Staff in group homes are used to managing challenging behaviours and the project is

confident of being able to work together with disability support staff for clients with behaviour management needs.

Client group

The DALP target group is people with intellectual disability living in group homes. Project staff suggested that about 12 out of 36 clients in group homes in the area are at risk of entry to residential aged care because they need more support to stay at home than is available through disability services. If a client wanders extensively or another safety risk is posed, or if a client suffers from severe health problems, the project might not be able to provide adequate support over the longer term.

Within a group home there is usually one staff member per five residents. One staff member is on the overnight shift and two may be on shift during peak times of the day such as morning and evening meal times. The majority of residents in group homes access up to 30 hours of day activities per week—disability services could find it difficult to maintain them at home otherwise. As residents become older they experience a lack of appropriate day activities for ageing people with intellectual disability. The physical, emotional and psychological consequences of inability to attend day activity programs can jeopardise a resident's ability to live in the community.

DALP client group profiles are given in Appendix B (see Appendix Tables B6.1–B6.6).

Referral and assessment

Following ACAT assessment of clients, Options Coordination assumes responsibility for the case management component of DALP and liaises with RPDH regarding the types of assistance required to enable clients to remain at home. RPDH is notified of the negotiated care plans and is responsible for implementation.

DALP developed a referral pack for disability support staff working in the catchment area. It includes the Broad Screen Checklist of Observed Changes (Minda Inc.), a consent form and assessment of support needs.

Referral packs were distributed to the three participating supported accommodation providers who were responsible for identifying potential clients for the project. Guidance given to supported accommodation agencies regarding eligibility for DALP was 'Persons with a disability who have ageing issues impacting their care who live in supported accommodation setting' (DALP Flow Chart for Project Procedures). Supported accommodation staff complete the documentation contained in the referral pack and forward all documents to Options Coordination. Options Coordination is responsible for collating the information and, if satisfied that a referral is appropriate, an ACAT assessment is organised. On receipt of ACAT approval for residential care, Options Coordination and the DALP team develops a care plan and forwards a letter to the client's medical practitioner requesting any necessary medical information.

All supported accommodation agencies with clients accepted into the project are required to complete an inter-agency brokerage service agreement with Renmark Paringa District Hospital. Clients (and their representatives) are also required to complete a client service

agreement with Renmark Paringa District Hospital prior to services commencing. A client service contract is agreed for each client once his/her care plan is finalised.

A participating ACAT member stated that assessment of clients in group homes is routine as is assessment for people with a disability who are ageing in the community. ACAT indicated that there is a great need to support people with disabilities across a range of accommodation settings, including private residences and group homes.

Service model

All services to be delivered are documented in advance. It was expected that clients would receive an average of 10 hours of additional assistance per week through the project.

DALP was proposed to operate with a variety of different service delivery options. The program is open to a range of staffing options:

- program staff
- brokerage of staff in other programs
- brokerage of peer support
- maintenance of existing disability support workers.

At the time of the site visit, RPDH was planning to broker existing disability support staff to deliver project services and use existing Community Care Division staff as well. In 2005 the project was continuing to operate with mixed staffing arrangements, using some disability support staff in addition to RPDH Community Care Division staff.

RPDH aged care workers for DALP may work across other RPDH community programs. The exact arrangement varies according to the availability of disability support staff to give extra hours and the agreed arrangement between the project team and supported accommodation service.

RPDH does not generally experience difficulty in recruiting and retaining staff. Staff training is provided on an as-needs basis with plans underway for a more formal training schedule. Disability support staff working on the project will be trained in RPDH service type codes and reporting procedures. All RPDH community care staff are provided with extensive training in dementia care.

Bi-monthly steering committee meetings are held. Case management and project coordination is shared between the Options Coordination staff member and the project coordinator/care manager at RPDH.

Evaluation data for eight clients were submitted. All were people with intellectual disability. The service activity during the evaluation of these clients is summarised in Table 3.9.

DALP delivered an extensive range of service types. Recreation/leisure programs and living skills development, together with transport, were the main focus of this project in the reporting period. Three clients received additional personal assistance through the project, at a somewhat lower intensity than observed in other projects. The team reported that the participating group homes generally have little difficulty in sourcing aids and equipment required by residents and this is therefore not expected to be a main area of service provision for DALP.

It was anticipated that over time DALP would work up to delivering an average of 10 hours of additional support per client each week.

Table 3.9: Disability and Ageing Lifestyle Project, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Personal assistance	3	Hours	0.4	0.7	2.0	1.0	0.8
Domestic assistance	3	Hours	0.1	0.1	0.7	0.3	0.3
Social support	1	Hours	—	—	—	—	—
Follow-up needs assessment	6	No. contacts	0.1	0.1	0.2	0.1	—
GP consultation	3	No. contacts	0.1	0.1	0.2	0.2	—
Behaviour management	2	No. contacts	0.2	0.6	0.9	0.6	0.5
Nursing/medical other	1	No. contacts	0.1	0.1	0.1	0.1	—
Recreation/leisure programs	7	No. days/nights	0.9	1.7	2.2	1.6	0.4
Living skills development	7	No. days/nights	0.3	0.9	2.2	1.1	0.6
Information other	7	No. events	0.1	0.1	0.2	0.1	—
Dementia other	1	No. events	0.9	0.9	0.9	0.9	—
Community transport	6	No. one-way trips	1.2	2.9	4.0	2.6	1.0
Personal transport	6	No. one-way trips	0.4	1.7	4.7	1.9	1.5

— Nil or rounded to zero.

Achievements and challenges

Initially the coordinators found that disability support staff tended to overestimate clients' capabilities and some Broad Screen Checklist of Observed Changes scores needed to be revised before referral to ACAT.

It was noted that disability support staff sometimes inappropriately maintain people in the group home environment when there is clearly a need for another mode of care. The project is attempting to educate disability staff about appropriate care for people with age-related needs.

RPDH was confident of being able to maintain high needs clients on the pilot packages over the longer term.

By mid-August 2005 no clients had been discharged from the service.

3.7 Disability Aged Care Service

Senses Foundation Incorporated, Western Australia, is the approved provider for the Disability Aged Care Service (DACS). DACS services clients in group homes funded by the Western Australia Disability Services Commission and operated by Senses Foundation or Activ Foundation. All homes are located in Perth.

Senses Foundation, formerly the Royal Institute for the Blind, is a long-established disability service provider. The work of the Foundation falls into three main areas:

- accommodation services—seven group homes for people with a disability funded by the Western Australia Disability Services Commission
- services for the deaf-blind

- aged care, including recreation programs.

Senses Foundation supports people with intellectual and/or sensory disabilities. Senses Foundation has undergone a major restructuring of services in recent years, which involved closure of the aged care hostel. This resulted in a natural co-location of clients with age-related needs.

Activ Foundation delivers services to people with intellectual disability.

The project aims to offer more care options to clients with age-related needs who live in group homes in order to avoid or delay transfer to residential aged care. Senses Foundation emphasised that the onset of cognitive decline is often a reason for clients transitioning to an aged care service. Managing clients with dementia presents a challenge to disability services, which generally do not offer secure built environments. Senses Foundation indicated that the community does not currently provide appropriate interventions for the target group. Disability services provide about 4 hours of supervised care per day—breakfast and morning personal assistance plus evening meal preparation. DACS offers clients a minimum of 6.7 additional hours of assistance per week.

The Department of Health and Ageing funds the project up to $500,050 per year which is equivalent to $68.50 per allocated place. The project began in October 2003 and was intended to operate for 3 years with 20 places.

Client group

Eligibility for the DACS program is restricted to persons with a disability, aged 50 years or over, living in a Western Australia Disability Services Commission-funded group home operated by Senses Foundation or Activ Foundation, who is eligible for an ACAT assessment.

Most clients in the project have intellectual disability; Senses Foundation clients with sensory impairment only tend not to satisfy the age eligibility criteria.

The main age-related issues identified in project clients relate to decline in cognitive function and mobility. DACS staff noted that age-related needs are observed in clients younger than 45 years. Early onset of age-related needs is particularly evident in clients with Down syndrome.

DACS client group profiles are given in Appendix B (see Appendix Tables B7.1–B7.8).

Referral and assessment

Potential clients are identified by Senses and Activ staff. The project coordinator completes a screening assessment before referring the client for an ACAT assessment. Identification of age-related needs follows a holistic approach, covering all areas of client functioning. Senses Foundation has experienced little difficulty in identifying age-related needs using tools such as the Broad Screen Checklist of Observed Changes in conjunction with an examination of client histories and discussions with care workers. Specific tools are used by the project coordinators because historical information about clients is not always available. Initially, DACS developed a comprehensive Resident Needs Assessment (RNA) tool, which covers nutrition, self-care, mobility, communication, social functioning, medications and behaviours. The RNA was later replaced by the Broad Screen Checklist of Observed Changes for the purposes of client assessment.

The project works with two ACATs—Bentley (South ACAT) and Sir Charles Gairdner. One member of each ACAT performs assessments for clients.

Service model

DACS coordinators use information collected at the initial needs assessment to write a daily care plan covering assistance in activities of daily living; management of sleep disorders, if present; social and communication needs. The daily care plan maps out the times of day that staff will attend to the client, the interventions designed to address identified client needs, and the desired outcomes of each intervention. From the daily care plan an activity plan is developed to be implemented by those working with the client.

Care and activity plans are developed by DACS coordinators and implemented by aged care workers employed by DACS. Senses Foundation has entered into contracts with allied health professionals for the delivery of allied health assessment and therapy to DACS clients to ensure timely response to referrals for allied health care.

An activity plan defines the activities, goals and a daily timetable to address a specific functional domain. The care plan for an individual client thus comprises any number of activity plans, according to the number of identified areas of age-related need. Each activity plan highlights the client's current area of need in the activity domain, issues to be addressed each day and goals to be achieved. Care workers are required to document in detail against items on the activity plan and their comments are used to monitor the client's progress towards goals. The activity plan is revised as necessary, in response to client progress and expressed preferences. The project coordinators visit each client weekly to monitor care plan implementation and a formal review of client progress takes place every 8 weeks.

Sample exercise and continence management plans are shown below to demonstrate the incorporation of needs and goal identification, targeted intervention, and client progress review. The DACS coordinator develops one such activity plan for each area of client functioning that is identified through comprehensive assessment as requiring intervention due to age-related need, for example, continence management, behaviour management, self-care, physical activity and therapies. Plans are reviewed every 2 months and in response to client progress. The documentation that evolves from this system builds a detailed functional history for each client, tracks the onset of change in each functional domain and provides a basis for referral to other services for specialist assessment.

The project focuses on client performance in activities of daily living, hygiene and food and fluid intake, and aims to both assist clients and raise awareness of ageing processes among disability support staff. A primary aim is to encourage clients to maintain their independence for as long as possible. DACS coordinators acknowledge that it is sometimes difficult for disability support staff to encourage a client's full potential for independence in the domestic setting because of time pressures. DACS also aims to manage client sleep and behaviour patterns and to build confidence and enjoyment of life.

The project has found that Innovative Pool funding allows for one-to-one interaction between a client and staff, which has proven very beneficial. Activities with a client might focus on mobility, ADL performance, cognitive function or behaviour management. One client, for example, has concentrated on drawing and colouring activities to help restore fine motor skills.

Simple devices have been installed to promote independence in the home environment. In one case the project installed an urn to allow clients to independently prepare hot drinks as the kettle was too heavy to handle safely.

Prior to the evaluation, Senses Foundation reported that low care clients received an average of 6.7 hours of care per week (hours for low-care clients vary depending on individual needs) through the project. Generally clients receive more intensive support in the period immediately following entry to the project to allow DACS staff and the client to become familiar and comfortable. After a burst of intense support, it is usually possible to scale back the service hours.

It has proven more difficult to estimate average weekly hours for high care clients. Senses Foundation has relocated some clients so that aged care clients can share the same group home. Co-location makes it easier to manage several high needs clients in the project. There is a 24-hour-care home where there is normally one care worker on duty. The project operates on a one staff member per client basis in this environment (no less than one staff member per two clients). It is not normally possible to work with more than two or three high care clients at the same time for skills-based activities.

Senses Foundation (Inc) **Individual Specific Care Plan**

Name: MISS S Issue Date: _____ Facility: SENSES STREET

Topic: EXERCISES Review: Every 2 months.

Problems	Intervention
• Impaired mobility • Potential for deterioration in current range of movement • Poor balance **Goals** (expected outcome) Miss S will maintain/ improve • current level of mobility • current level of balance • maintain ROM & strengthen lower limbs	1. Refer to the client by preferred name Miss S, introduce yourself to her. 2. Invite Miss S to participate in activity program, and respect her choice not to participate. 3. Encourage Miss S to participate in music selection. 4. Provide 1:1 intervention during exercise program. Staff to physically demonstrate actions/activity. Allow Miss S to work within her range of movements. Ensure appropriate clothing and footwear is worn. 5. Examples of seated exercises: Pull shoulders to ear. Head side to side. Hand/s in the air/left to right. Touch knees/reach for ceiling/floor. Lift feet off the floor. Stretch alternate leg out. Rotate wrists/ankles. Throw/catch ball. Repeat each exercise several times. Concentrate on knee extension of right side. Paying particular attention to right lower limb. 6. Standing exercises, examples: Marching on the spot, arm swings, hands on hips/reach to the ceiling. Wiggling hips, dancing. Take hold of client's hands, facing staff, and alternate lifting feet off the floor, and working within limits of client's capabilities. 7. Ensure adequate time, and room, is provided for Miss S to do activity. 8. Document changes in progress notes, including difficulties with activities, and Miss S's level of participation. Staff signature_____ Client signature _____ **Review/evaluate care plan every 2 months in progress notes. Sign and date over page.**

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Senses Foundation (Inc) **Individual Specific Care Plan**

Name: MISS S Issue Date: _____ Facility: SENSES STREET

Topic: CONTINENCE MANAGEMENT Review: Every 2 months

Problem / s	Intervention
• Incontinence (urinary) • Potential for increase in incontinence episodes • History of urinary tract infections • Episodes of poor fluid intake **Goals** (expected outcome) • Miss S incontinence will be managed effectively and episodes will be reduced. • Miss S will remain comfortable and dignity will be maintained. • Miss S's skin integrity will be maintained.	1 Refer to resident by preferred name Miss S and introduce yourself to her. 2 Encourage Miss S to go to the toilet 2–3 hours while she is awake, such as when she gets up in the morning, before/after meals, before going out, after she comes home, and prior to going to bed in the evening. (Do you think you need to go to the toilet? When was the last time you went to the toilet? How about you try to go to the toilet?) 3 Prompt her to remain seated until she has finished completely. Prompt her to wipe her peri-anal properly, front to back. (Maintaining her privacy and dignity) observe peri-anal area for redness and excoriation. Refer changes in skin conditions to coordinator as required. 4 Ensure that adequate incontinence aids are available for Miss S and that she takes some with her when she leaves the house for lengthy periods. • Miss S uses pull-up pants during the day. • Miss S uses a large Tena pad with an insert at night. 5 Ensure that all staff are aware of the need to prompt Miss S to go to the toilet every 2–3 hours. 6 Encourage fluid intake 1.5 L per day; record on an input chart. 7 Observe client's behaviour, possible changes could indicate a urinary tract infection. Refer to coordinator. 8 Document changes in Miss S's continence in the progress notes. Staff signature _____ Client signature_____ **Review/evaluate care plan 2 months in progress notes. Sign and date over page.**

Date	Evaluation in progress notes	Signature	Date	Evaluation in progress notes	Signature

The project can deliver intensive nursing care if required and employs a registered nurse and an enrolled nurse. Senses Foundation noted that hospitals find it difficult to manage patients with disabilities particularly where there is behavioural and/or speech impairment. On occasions, a patient has been sent home from hospital, requiring 24-hour care, to a supported accommodation setting that can provide only 4 hours of care per day. Senses Foundation anticipates an increase in the need for high level post-acute care within the disability sector as people with a disability live to ages that have not been reached in the past and experience levels of health service utilisation that are commonly observed in older populations.

DACS submitted evaluation data for 18 clients whose service activity during the evaluation is summarised in Table 3.10. Seventeen evaluation participants were people with intellectual disability; blindness was the main disabling condition in one client.

The DACS service activity profile reflects a strong therapeutic focus for all clients together with additional hours of personal assistance for 10 clients. All clients received physiotherapy, occupational and alternative therapies on a regular basis during the reporting period and 17 of the 18 clients received other forms of allied health care. Daily activity plans drawn up from the care plan for each client specify activities to help maintain and develop clients' fine and gross motor skills and cognitive function. These could entail, for example, hydrotherapy sessions, puzzles, drawing and colouring, sweeping, which have been recorded under 'Allied health other' because of therapeutic intent. Many clients (15) also received additional food service averaging between 0.1 and 3.6 hours per week.

Table 3.10: Disability Aged Care Service, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service Unit	Minimum	Median	Maximum	Mean	Std dev.
Personal assistance	10	Hours	0.1	2.4	3.6	1.9	1.4
Alternative therapies	18	Hours	0.3	1.5	3.1	1.6	0.9
Physiotherapy	18	Hours	0.1	0.1	0.6	0.1	0.1
Occupational therapy	18	Hours	0.1	0.1	0.1	0.1	—
Food service other	15	Hours	0.1	0.9	3.6	1.3	0.9
Domestic assistance	7	Hours	0.2	0.5	1.1	0.5	0.3
Follow-up needs assessment	18	No. contacts	0.6	3.6	4.2	3.2	1.0
Needs assessment other	18	No. events	0.7	0.8	1.0	0.8	—
Allied health other	17	No. events	0.5	6.4	10.9	6.5	2.8

— Nil or rounded to zero.

Achievements and challenges

Initially, the project was slow to fill places. Many potential clients didn't fit the eligibility criteria because they were aged in their 40s, despite the said presence of age-related needs. All places were filled by December 2004.

A major positive aspect has been increased access to ACAT assessment for Senses and Activ clients. In the past, a client receiving disability services would not have had contact with an ACAT unless they experienced an acute episode or an urgent need for aged care placement. ACAT assessment is now viewed as a positive encounter. ACAT staff involved with the

DACS project have also reported that they are pleased to have a more positive option to offer disability services clients. One senior ACAT member remarked that assessment of clients for DACS demands a 'flexibility of perspective' that not all ACAT staff would have. DACS values highly the particular ACAT staff working with project staff and clients. In turn, ACAT members involved in the project remarked that it has been a professionally rewarding experience. The pre-screening procedure of DACS has meant that most referrals received by ACAT have been appropriate, with the clients showing obvious signs of age-related functional decline. The ACATs have been pleased to see that therapy needs of the clients are being met in a more timely fashion through the project and that clients' medication regimes are well managed, which, in the past, could not always be said.

DACS is leading to improved socialisation of clients and more appropriate levels of personal assistance and medical care, all of which are promoting greater client independence. One of the success factors from an ACAT perspective is the centralised case management model of DACS. Similar observations were made by other members of the project steering committee. Highly effective case management and communication between the stakeholders are seen to be factors that differentiate DACS from mainstream aged care services such as CACPs. The skills and experience of the DACS manager in both disability and aged care and her personal dedication to client welfare is viewed as central to the achievement of successful outcomes for clients and the smooth running of the project.

DACS coordinators have experienced problems in accessing detailed client histories because disability services do not always maintain adequate documentation. In addition, it has been difficult to get disability support staff to maintain quality documentation for the project and to follow the care plans. The project coordinator is seeing progress in this area and believes that the project has successfully introduced best practice in care planning and documentation into the disability services.

The project has had difficulty recruiting trained staff. Disability support staff sometimes lack training in manual handling processes and in managing clients with psychological and behavioural symptoms. DACS staff reported that the use of the Broad Screen Checklist of Observed Changes tool has proved invaluable in helping to educate disability support staff to recognise age-related cognitive decline. Senses Foundation reports that staff who work in homes have become more aware of clients' ageing needs as the project has unfolded.

Contracting of allied health professionals for the project has been an important enabler for DACS service delivery. DACS noted that the project would be unable to deliver the required level of allied health service to clients were it to rely on the public system. Most disability clients do not have the financial means to access private allied health services.

The project has identified a number of issues which arise for clients who begin to spend longer periods of time at home during the day without supervision. First, there may be no-one to prompt the client to go to the toilet so continence management becomes an issue. Second, it is not always safe for a client to be at home without supervision (access to medications, use of kitchen equipment, etc.). Third, an unsupervised client may not remain active and interested when left to their own devices for hours at a time, so there is the question of the impact of lack of structure to the day for people who have formerly lived highly regimented active lives.

Senses Foundation reported that it would be difficult to maintain a highly immobile client in the project because group home physical environments are rarely suitable. Also, if a client became incontinent and required intervention on a 24-hour basis, an appropriate level of support from the project could prove unsustainable.

3.8 Ageing In Place

Oakdale Services Tasmania established the Ageing In Place pilot project at Oakdale Lodge, a residential facility for people with intellectual disability in Warrane, a suburb of Hobart. The project was established in June 2003 to cater to the ageing needs of seven residents. Service delivery commenced in July 2003 and was intended to operate for 3 years.

Maximum funding from the Department of Health and Ageing will total $158,275 per year which is equivalent to $61.94 per allocated place per day.

Stakeholders

Oakdale Services Tasmania is the approved provider for Ageing In Place. Oakdale Services is a not-for-profit organisation established in 1970 that now delivers supported accommodation and other services to over 50 people with intellectual disability or acquired brain injury.

The Tasmanian Department of Health and Human Services maintains the block grant payable to Oakdale Services Tasmania under the Commonwealth State/Territory Disability Agreement.

Client group, referral and assessment

The proposal for Ageing In Place was developed following a number of submissions to the Australian Government Department of Health and Ageing for additional funding to support the needs of ageing residents at Oakdale Lodge. Staff had, over several years, been noticing subtle changes in the behaviour and psychological state of older residents that would often manifest as a rapid decline in a resident's capacity to perform once-familiar tasks. For other clients, peaks and troughs in functioning were evident over a period of time. In addition, medical conditions associated with ageing such as arthritis, chest complaints and dementia were becoming more prevalent among residents at Oakdale Lodge. The signs of age-related decline often first become evident in the workplace—a resident might exhibit uncharacteristic behaviours that cause disruption or place him or herself or other workers at risk. Oakdale Services staff noted that deterioration in a resident's functioning was often traceable to the period when withdrawal from the workplace became necessary.

Observation of these changes led to ACAT assessment of 18 Oakdale residents in 2000–01. Three residents were assessed as not exhibiting age-related needs. The remaining residents all exhibited health conditions that are common among people at older ages and 10 residents received ACAT approval for aged care, reflecting a mix of low and high care needs. A second round of ACAT assessments was completed in January 2003 as part of the development of an Innovative Pool project proposal. Most of the residents still at Oakdale who had been assessed two years earlier showed marked deterioration in condition.

Package recipients need to have been assessed by the ACAT as eligible to receive high level residential aged care and endorsed by Oakdale Services as suitable for participation in the project. Client selection involves the consent of the resident or a relative of the resident, the project coordinator and an advocate. Advocacy Tasmania Inc. plays an important role in client selection and care provision. The first clients commenced services in July 2003, comprehensive assessment having been completed as part of the development of the project proposal.

The project enjoys strong links with the South Tasmania ACAT, which were well established by the time the project began. The ACAT has staff experienced in assessment and care of both older people and people with a disability, lending valuable input to Ageing In Place. There is strong support for ACAT services playing an ongoing role in the assessment of people with a disability who are ageing. It is thought that ACAT services have a crucial role in educating the disability sector about aged care but also have a responsibility to learn about the assessment and care of people with disabilities. Standard ACAT assessment would find it difficult to set a benchmark of the 'normal' support needs for a client with intellectual disability. Comprehensive assessment involving both the ACAT and disability support staff who are familiar with a client's history is considered essential.

AIP client group profiles are given in Appendix B (see Appendix Tables B8.1–B8.7).

Service model

The project aims to assist residents to remain at Oakdale Lodge while pursuing quality of life in their retirement years. This is achieved by allowing clients greater flexibility during the day. For example, project clients can sleep beyond the usual wake-up time of 6.15 am and still receive assistance with breakfast and morning routines. They are not bound to the highly programmed lifestyle of younger Oakdale residents whose routines centre on work and day programs. A primary objective of the project is to empower each package recipient to make decisions on how to use their time in retirement and to allow adequate time for clients to adjust their self-expectations.

The care for the majority of clients has not changed dramatically as a result of Ageing In Place. The project has allowed for the support of clients with increasing care needs, due to advancing dementia or other medical condition, to be adjusted accordingly. The project is more about subtle lifestyle changes for older residents, most of who are in a period of transition from work to retirement. There is a focus on building capacity to transport clients for community participation and individual recreational pursuits. Programs are both diverse and flexible allowing clients to plan ahead yet to also change their mind as circumstances vary. Further, it also enables clients to combine a mixture of favourite activities with new experiences. Clients can choose not to participate in a particular activity and instead opt to relax at home.

Gerontologist and psychologist services are consulted on an as-needs basis, usually through the one general practitioner who attends most of the residents at Oakdale Lodge.

Services to Ageing In Place clients are delivered by familiar staff at Oakdale—there is no second shift of aged care workers. The project pools disability services and Innovative Pool funding for Ageing In Place clients to deliver more flexible care using existing staff resources. Staff in both the Aged and Disability Divisions of Oakdale Services are involved in the project. For the purposes of reporting on financial operations (for the evaluation), management calculated staff resources allocated to the project based on estimates of the time shared across project clients and other residents.

A representative of Advocacy Tasmania attends quarterly project meetings to represent clients' views of services and facilitates informal sessions between clients and Oakdale Services to discuss the project. Services to an individual client are constantly reviewed and refined if necessary through the input of Advocacy Tasmania which liaises with the project coordinator on the expressed needs and desires of individual clients.

AIP supplied evaluation data for seven clients, all people with intellectual disability. Ageing In Place is perhaps best described as a model of social care for people with a disability who are ageing. A main focus of the project is supporting lifestyle transition for clients in or approaching retirement. This is reflected in the project's service activity profile, which featured high rates of service delivery for social support, domestic assistance, transport and recreation programs during the 2004 evaluation (Table 3.11).

The project provides additional hours of personal assistance to all clients, ranging from moderate to high intensity. Enhanced personal assistance involves an increase in the weekly hours of personal assistance available to each client but also greater flexibility in when that type of assistance is available. Clients who are reducing or who have ceased employment or day programs are able to alter their daily routine to allow for more rest in the mornings. This requires a double 'breakfast shift'.

Domestic assistance is additional to what clients would normally receive because with increasing amounts of time at home clients receive extra supervision, interaction and encouragement to participate in domestic activities during daytime hours.

AIP also initiates services that are funded from other sources: all clients received an average of 1.7 hours per week of alternative therapies; three and one client respectively received podiatry and other allied health care; aids were purchased for several clients (for example, continence and hearing aids) and a home modification was required by one client.

Initial needs assessment was for most clients conducted well in advance of project establishment and is reported to have taken around 4 hours for each client.

Table 3.11: Ageing In Place, minimum, median, maximum and mean service units per client per week, by service type

Service type	Clients	Service unit	Minimum	Median	Maximum	Mean	Std dev.
Social support	7	Hours	3.0	4.4	5.9	4.2	1.0
Domestic assistance	7	Hours	2.4	3.0	3.0	2.9	0.2
Personal assistance	7	Hours	1.5	2.2	20.9	5.6	7.0
Food service other	7	Hours	1.5	1.6	1.9	1.7	0.2
Recreation/leisure programs	7	No. days/nights	1.8	2.4	3.3	2.5	0.5
Personal transport	7	No. one-way trips	4.1	5.8	6.8	5.7	0.9
Follow-up needs assessment	7	No. contacts	0.1	0.1	0.2	0.1	—
GP consultation	6	No. contacts	0.1	0.1	0.4	0.2	0.2
Nursing/medical other	2	No. contacts	0.1	0.2	0.2	0.2	0.1
Medication review	4	No. events	0.0	0.1	0.4	0.2	0.2

— Nil or rounded to zero.

Service environment

The evaluation team discussed service provision for people with intellectual disability with management and staff at Oakdale Lodge, the referring ACAT team leader and the client advocate at Advocacy Tasmania. There is agreement that aged care needs cannot always be adequately addressed in conventional group home and hostel environments but that nor does residential aged care cater to the needs of this group. Transfer to residential aged care is often the only option for a disability services client who has high nursing care needs or who

needs 24-hour supervision because of high-risk behaviour. However, experience has shown that most aged care facilities have difficulty coping with residents who have intellectual disability.

A number of reasons were posited for why generic residential aged care is unsuitable for this client group. One is that people with intellectual disability have limited social skills and this prevents them from readily adapting to new environments. A second reason is the marked generation gap between many people with disabilities who are ageing and the majority of older residents in an aged care home. Services—meal times, food types and general level of activity—are geared around a resident population with an average age typically in excess of 80 years. Disability clients are usually younger, more mobile and more physically capable than other residents who are more likely to have age-related frailty. In addition, the mindset among older residents may not be conducive to living in harmony with people with intellectual disability. Generic aged care services are not equipped with the specialised skills to manage severe behavioural disturbances associated with dementia. When these disturbances are superimposed on an intellectual disability, aged care staff usually cannot cope.

Arguably, some of these difficulties in the provision of residential aged care extend to other groups in the population. For example, older people with dementia living in generic aged care facilities, younger people with dementia-related behavioural symptoms without physical frailty living among mostly frail older people, and frail aged but cognitively intact persons living with or attending day programs that cater to a largely cognitively impaired clientele could equally be seen as less than ideal arrangements. The issue raised of particular relevance to people who are ageing and living in disability-funded group homes is an apparent lack of access to nursing care at home and community services for older people in general, both of which are vital to avoiding premature entry to residential aged care for people with intellectual disability. Oakdale Services Tasmania has embarked on a new capital works program to construct a secure aged care facility at the Oakdale Lodge site.

On the question of access to home nursing care, Oakdale Services indicated a preparedness to provide nursing care if that is what a resident needs to be able to remain at Oakdale Lodge. More typically, the inability to maintain a resident in the community is attributed to behavioural symptoms associated with dementia. There is a fine line between the most appropriate living arrangement for a client with high care needs and the most appropriate situation for other residents in the communal living environment. Night-time wandering and physical aggression make it difficult to maintain a resident in the supported accommodation setting; so that while high nursing care needs is a factor in transfers to residential aged care, it is not always the only or main consideration.

Achievements and challenges

Staff members at Oakdale Lodge are learning to accept that their role is not limited to providing support for people with a disability. They have become aware of different patterns of need emerging as a result of residents getting older—needs that are not adequately met in the highly programmed routine of the conventional disability services model. The process of introducing a new perspective on caring for people with a disability has been gradual but is reaping rewards in establishing a new, more resident-centred culture among staff.

A major challenge for the project has been a lack of appreciation at state government level of the significance of the Disability Aged Care Interface Pilot. Oakdale Services management indicated it had received advice from the Tasmanian Government that specialist day places

for Ageing In Place clients would not be secured for the duration of the project. Thus, if the project is discontinued at the end of the 3-year funding period, clients will need to join the Disability Services waiting list and be assessed on the basis of need and priority at that time in order to resume daytime disability services. Oakdale Services and Advocacy Tasmania counselled potential clients on the long-term implications of joining the project. In some cases, clients needed to be given a trial period in Ageing In Place before fully committing.

For the referring ACAT, the main difficulty in assessing clients with intellectual disability (not just for Ageing In Place) is in determining whether all options for service provision have been exhausted. Confusion sometimes exists between appropriateness and availability such that the term 'inappropriate' is conveniently used to describe what is more accurately an availability issue. Thus, and quite apart from the Ageing In Place project, the ACAT rejects a proportion of referrals for assessment of people with a disability in younger age groups because they would be more appropriately supported by services within the disability sector than the aged care sector, were the required services available. On this point, the Southern Tasmania ACAT recommends firm guidelines for the assessment of aged care needs, as distinct from disability support needs, for any potential future roll-out of disability/aged care interface programs.

3.9 Cumberland Prospect Disability Aged Care Pilot

Uniting*Care* NSW.ACT is the approved provider for the 30-place Cumberland Prospect Disability Aged Care Pilot (CPDAC) in western Sydney. Clients live in group homes and larger residential facilities funded by the New South Wales Department of Ageing, Disability and Home Care (DADHC). As of mid-2005, seven supported accommodation services had referred clients to the project.

The project was established in November 2004 with an allocation of 30 places and initially funded for 3 years. ACAT assessments were underway for the first intake of clients in December 2004. By the end of May 2005, 25 places were filled. An additional five clients were awaiting completion of ACAT assessment to fill all available places. Eighteen clients with care plans established by late-April 2005 are included in the evaluation.

CPDAC aims to:

- provide early identification of needs related to the ageing process
- deliver age-appropriate services based on individual need
- develop skills of disability service staff to provide aged care specific services
- promote greater understanding of the needs of people with disability who are ageing among aged care service providers and ACAT.

Project management and service coordination is cited adjacent to a Uniting*Care* residential aged care facility at Westmead. The project team comprises one full-time coordinator and one part-time administrative assistant. The coordinator has extensive experience in the disability services sector and undertook several months' work experience in an aged care facility to prepare for the coordination role.

Stakeholders and partners

Uniting*Care* NSW.ACT is an agency of The Uniting Church in Australia and is an approved aged care provider. While working with people with disabilities who are ageing through the

CPDAC project marks a new direction for the organisation, Uniting*Care* has a long history of providing mainstream aged care services, including residential care and Community Aged Care Packages.

Uniting*Care* collaborated with McCall Gardens Community Ltd over a 12-month period to develop models of innovative care and support for people with disabilities who are ageing leading to the final project proposal (Uniting*Care* submission to the Department of Health and Ageing, February 2004). Uniting*Care* manages all aspects of the project delivery.

The Australian Government Department of Health and Ageing funds the project for up to $657,000 per annum over 3 years, or $60 per allocated place per day.

DADHC participates in the project both as a provider of accommodation services and as guarantor for continued funding of clients' existing disability services.

As of May 2005, seven providers of supported accommodation services were involved in the project: McCall Gardens Community Ltd, New South Wales Department of Ageing, Disability and Home Care, The Spastic Centre, Lifestyle Options, Interactions Disability Service, Ability Options and Jennings House. Several other originally identified accommodation service partners when further lobbied actually had no clients to put forward for assessment to receive an aged care package.

Client group

CPDAC targets people with disabilities who are living in DADHC-funded group homes and who are at risk of premature admission to residential aged care. The evaluation has coincided with the early stages of project establishment and initial client intake, during which time the predominant areas of age-related need in the target group were identified as:

- continence management advice, including catheterisation and catheter care
- mobility and transfer
- dementia care
- access to psycho-geriatric assessment
- nutrition management and swallowing
- skin integrity and wound management.

Criteria in addition to the standard Innovative Pool eligibility requirements have not been necessary for screening purposes. Clients referred to the project have presented with the types of age-related needs that were anticipated for the target group. There was some initial concern about the eligibility requirement of ACAT approval for residential aged care, however services, clients and family members have been made aware that participation in the project does not automatically render a client eligible for placement.

It was found that ageing issues are easily overlooked in this client group, often because of a higher consciousness of disability issues. Working with clients on a daily basis over long periods of time, often extending to years, can lead to a lack of awareness of change in client cognitive and physical functioning. Change in behaviour and functioning is sometimes attributed to disability rather than to decline that, under closer consideration, is in fact associated with ageing processes.

CPDAC client group profiles are given in Appendix B (see Appendix Tables B9.1–B9.9).

Assessment and service model

Following referral, an initial screening assessment is completed by the project coordinator (approximately 2 hours) prior to referral to ACAT. ACATs at Westmead, Blacktown and Auburn hospitals accept referrals from the project coordinator and within each team the project has a primary contact. Assessments may, however, be conducted by any member of the ACAT staff. ACAT assessment of clients has proceeded smoothly and is said to have been a valuable learning experience for all involved.

Project coordinators visit clients weekly or fortnightly as appropriate.

Care services are as per personalised care plans and may include any or all of a range of aged care services specified in the Memorandum of Understanding between Uniting*Care*, the Department of Health and Ageing and DADHC—comprehensive assessment and care planning; continence management advice; behaviour management and dementia care advice and referral; wound care; pain management advice; sleep management; mobility programs; supporting access to allied health care services and assistance to clients with sensory loss; supporting access to community services, therapy and rehabilitation services; assistance to access aged care advocacy and complaints systems.

It was originally intended for the project to broker personal care assistants from the participating disability service providers to maintain continuity of care for clients. The actual outcome has been a mixed staffing model with brokerage of some disability support staff and the engagement of agency staff for some clients.

Physiotherapy, occupational therapy, speech pathology, dietetics and continence management services are brokered on an as needs basis. Nursing care is available from a registered nurse attached to the project team.

CPDAC supplied evaluation data for 18 people, comprising the initial client intake. Seventeen CPDAC evaluation participants were people with intellectual disability and one client had multiple/diverse disabilities. The service activity profile of evaluation participants (per week averages between January and April 2005) reflects the completion of initial needs assessment of the 18 clients and gradual introduction of services. At this early stage the project was observed to be focusing on additional personal assistance (on average 2 hours per client per week), provision of aids and equipment and recreational programs (Table 3.12).

Table 3.12: Cumberland Prospect Disability Aged Care Pilot, minimum, median, maximum and mean service units per client per week, by service type (January–April 2005)

Service type	Service unit	Number of clients	Minimum	Median	Maximum	Mean	Std dev.
Initial needs assessment	Hours	18	0.1	0.5	0.6	0.4	0.2
Physiotherapy	Hours	12	—	0.1	0.7	0.2	0.3
Occupational therapy	Hours	4	—	—	—	—	—
Recreation/leisure programs	Hours	17	0.2	5.2	6.6	4.1	2.5
Personal assistance	Hours	13	—	1.9	3.1	1.8	1.4
Follow-up needs assessment	No. contacts	8	0.2	0.2	0.2	0.2	0.0
Dietetics	No. referrals	14	—	—	—	—	—
Allied health other	No. events	11	—	—	—	—	—
Recreation/leisure programs	No. days/nights	17	—	1.0	1.3	0.8	0.5
Mobility aids	Dollars	4	9.5	9.9	10.3	9.9	0.6
Continence aids	Dollars	2	16.5	16.5	16.5	16.5	. .
Aids other	Dollars	5	14.1	33.1	75.6	39.0	27.0

— Nil or rounded to zero.

. . Not applicable.

Achievements and challenges

The evaluation coincided with the establishment phase of CPDAC and this is reflected in the service profiles of evaluation clients, where assessment and case management feature prominently. Even in the early stages some important effects were reported. Aids and equipment provided by CPDAC, for instance, had a profound effect on the mobility, comfort, and quality of life of recipient clients.

Some early difficulties were experienced as a result of management changes in partner organisations. New management staff in some supported accommodation services were not familiar with the project proposal and time was needed to establish sound communication pathways.

Brokerage arrangements proved unmanageable for DADHC case managers and the project has engaged agency staff to attend clients in DADHC-operated homes. This will reduce the cost efficiency of services to those clients and care workers in the homes view agency staffing as a less ideal arrangement from a client care perspective.

Cultural differences between disability support staff and the aged care team were noted. For instance, it has been found that disability support staff tend to underreport clients' support needs on the basis that symptoms or behaviours are 'normal' or 'to be expected'. It appears that this is compounded by poor record keeping practice such that heavy reliance is placed on anecdotal report. There is a tendency for symptoms and conditions to be noted but for adequate follow-through to not necessarily occur.

3.10 Case studies

Some of the projects supplied case study reports that describe individual care planning and outline the range of presenting needs for additional support. These are given below in the original words of the project coordinators. Projects are not identified for confidentiality reasons.

The reports show how comprehensive assessment involving ACATs, specialist disability and aged care services triggered further specialised assessment and medical management, active and passive physical therapy and increased social participation. Case studies 1 to 12 highlight care plans with a mainly assessment and therapeutic focus. Case studies 13 to 15 describe care with a mainly social support/lifestyle transition focus.

Case study 1

'The client is a lady in her early 50s who entered the project following an ACAT assessment in December 2003.

The client had up until 1999 been employed. She was able to care for herself and communicate effectively; she had also been able to go on a cruise, indicating her higher level of both physical and cognitive ability at this stage.

Primary diagnosis is Down syndrome, and additional diagnoses include vision impairment, gout, hypothyroidism and peptic ulcer.

The initial age-related problems included:

- impaired short- and long-term memory recall
- confusion
- disorientation to time and place
- impaired mobility, both fine and gross motor skills
- self-care deficit
- impaired swallowing
- incontinence of urine and occasionally faeces with a history of urinary tract infection.

Additional areas of concern were:

- sleep disturbances
- intrusive and resistive behaviour.

Care staff reported prior to the ACAT assessment, an increase in supervision of the client with verbal prompting and physical assistance needed throughout the day.

Staff expressed a concern that the client was at times unable to locate her bedroom or the bathroom and she would often enter other clients' rooms, picking up their personal belongings and relocating them to other parts of the house, usually a cupboard or drawer.

The client was confused and at times unable to recognise familiar staff members. She would become distressed for no apparent reason resulting in high frustration levels with sporadic episodes of verbal disruption, and physically hitting out at staff and other clients.

The client had several falls prior to the ACAT assessment and she was now ambulating with a Zimmer frame, would often forget her frame and would be found furniture walking, holding on to unstable objects such as oscillating pedestal fans.

The client also experienced problems getting up from a seated position and she also had problems getting out of bed, requiring an increase in staff intervention and manual handling.

The client required full assistance with all activities of daily living. Staff needed to attend to her hygiene needs, in terms of showering, grooming and oral care. Full assistance was also required to dress and undress. The client required continence management, continence aids and full staff assistance with toileting. The client was on a soft diet; staff were required to cut up meals and closely observe the client for choking as part of mealtime management.

The client experienced difficulties settling to sleep at night, and wakeful restless periods.

Following the ACAT assessment a period of further in-house assessments commenced.

A continence assessment was completed alongside a pain assessment and a sleep assessment, and later a behaviour assessment. The aim of the assessments was to gain further knowledge of the existing problems, identify triggers and useful interventions.

Following review of assessment results, and with staff consultation, care plans were formulated for staff to follow (see exercise and continence plans below).

Pain in the knee was identified, a GP visit organised, and medical intervention was reviewed. A care plan outlining staff intervention for pain management was formulated, and physiotherapy and occupational assessments were planned.

Following the physiotherapy assessments, recommendations were implemented into the existing program, including chair exercises to upper and lower limbs and hydrotherapy with the aim of maintaining current range of movement and improve balance. The occupational therapy assessment revealed a need for the client's current seating height to be adjusted, allowing for greater ease during relocation, an adjustable shower chair with arm rests was also introduced as was a bed with both height and headrest adjustments; a small self-help rail was secured to the bed allowing the client an increase in independence while getting in and out of bed.

A lip plate was purchased to assist with meal time management.

The care plan implemented by the project was based on the client's identified aged care needs and hours of service were dictated by the individual needs of the client, with an emphasis on the appropriate timing.

Aspects of the client's program included:

- assisting the client with hygiene needs—showering/dressing/grooming/toileting
- assisting the client to prepare meals and drinks as well as mealtime management
- assisting the client with physical exercise
- assisting the client to attend hydrotherapy
- assisting the client to participate in discussion/what did you do today/current events and reminiscence groups
- assisting the client to participate in drawing/board games and clay modelling activities
- assisting the client to participate in touch therapy/hand and foot massage
- assisting the client to participate in her washing program.

Each activity has its own individual specific care plan outlining the problem, the staff interventions and the goals for the interventions. Goals include:

- maintain/improve client's level of effective communication skill
- maintain/improve mobility, such as current range on movement, fine motor and dexterity skills, balance, and gait
- maintain/improve activity of daily living skills, such as hygiene needs and continence, also maintaining dignity, comfort and skin integrity
- maintain/improve current level of cognitive functioning
- maintain client safety (client lacks awareness of personal safety)

- maintain/improve client's social skills and prevent social isolation.

The client responded well to the one-on-one interventions provided through the program. Gradually staff reported changes in the client's level of participation such as the client initiating choice of a dress to wear. The client over time was able to wash and dry reachable body parts; staff continued to adjust the water temperature and provide verbal prompting and step-by-step instructions. She was able to attend to brushing her hair and complete oral care as well as dressing and undressing within her ability, with minimal staff physical intervention. The client participated well in her meal preparations; she would collect items from the cupboards and fridge with staff providing one-to-one verbal prompting and single-step instructions. The client was observed to initiate washing up and drying dishes, an activity that she previously used to engage in but hadn't for a long time. Increasing client confidence both in the kitchen and bathroom was noted by staff on a regular basis.

The client commenced touch therapy and participated with enthusiasm in hydrotherapy. She would smile and laugh while getting into her bathers, while in the pool she would hold her staff members' hands and jump up and down on one leg, she would do walking forwards, backwards and sideways in the pool as well as do various gymnastic-like exercises with pool noodles and kicking boards, some self initiated.

The board games and drawing activities and games of quoits were approached by the client on a more superficial level; the client verbally indicated her preference for dancing to ABBA music in the lounge room.

The client initiated conversation with staff and participated in discussions with staff about her day. Poor short-term memory recall remained evident when she required verbal prompting to recall the morning's events.

The client's overall mobility improved, especially fine motor and dexterity skills. She began to initiate activities more often, became more animated and started to communicate effectively with staff and other clients in the home. The client demonstrated increased confidence in her approach to tasks and participated within her physical and cognitive ability.

Care staff and others dealing with the care of this client have been pleasantly surprised in the client's level of participation and enthusiasm. The project team also acknowledges the professional medical management of the client's GP, particularly the sensitive approach to investigations and treatment of presenting medical problems.

By August 2004, the program for this client was meeting its objectives in terms of maintaining and, where possible, improving skills. The client was being maintained in her current preferred accommodation.

In October 2004 the client became medically unwell with gastrointestinal problems. Her recovery rate was poor and decline in condition noted. The client tired easily and a fear of water emerged, necessitating hydrotherapy to be removed from the care plan. The client's ability fluctuated on a daily basis and staff reports varied greatly as the client presented so differently on any given day.

By early January 2005 the client had had two episodes of urinary tract infection and once more recovery was slow. The project had by this time provided just over 12 months of service to this client. The rapid decline in all areas of ability was upsetting for all involved in care of the client.

In March 2005 the client was assessed by a rehabilitation physician from the Department. Recommendations which included a medication review were forwarded to the client's GP and were subsequently implemented. The client was diagnosed with Alzheimer's type dementia.

At this stage assessments and staff observation indicated that the client required and was receiving one-on-one assistance with all daily living activities on most occasions.

A sleep assessment was conducted due to documentation of a poor sleep pattern with wakeful episodes, incontinence and confusion. Aromatherapy was implemented to assist with relaxation and promotion of sleep (this is still being used and has proven helpful).

The client experienced more incontinent episodes despite the toileting program.

The client had a fluid intake chart in place and staff completed this on a daily basis to monitor fluid intake in order to reduce and prevent the incidence of urinary tract infection. Staff monitored behaviour and recorded observations on a behaviour assessment as needed, to identify triggers and monitor changes as indication of a possible urinary tract infection.

Full one-on-one assistance with ADL was continuing in July 2005.

The client continued to participate in drawing and colouring activities—her activity of choice—on most days. Soft toys and dolls were introduced in response to increasing episodes of confusion, frustration and verbally disruptive behaviour. The client responded well to this approach which has proved to be a valuable tool in the behaviour management plan.

The project purchased an electric recliner chair for the group home after the client started to experience difficulty with transfers.

On joining the project this client was at risk of being admitted to a residential aged care facility due to her increased aged care needs. However, through the project the client had been maintained safely in her preferred accommodation for 19 months as of the time of this case study report.'

Case study 2

'The client is a 60-year-old man with acquired brain injury. Two strokes had affected functioning down his right side, which is very weak. The client has epilepsy. He does not have early onset intellectual disability, but has memory, speech and mobility impairments as a result of illness and injury. He can walk with a three-pronged aid over very short distances and use a wheelchair with minimal physical assistance. The combination of short-term memory impairment, impulsiveness and reduced balance and mobility places the client at a high risk of falls.

The client was living in a group home for 2 years with people with intellectual disabilities. He had largely withdrawn from social activity, both in and outside the household. He did not attend the day program for people with intellectual disability as this was unsuitable for him. His BSCOC results showed significant functional decline (score of 47), the greatest decline in the areas of physical competencies, sensory integration and activities of daily living.

The client was referred to the project and was assessed by ACAT in August 2004. ACAT assessors noted that the client had a reduced range of movement in his right shoulder and muscle weakness in the right arm, though he was able to transfer well. He required a minced diet with thickened fluids because of swallowing difficulties, and needed prompting to wear appropriate clothing due to lack of sensory perception. The client has poor word-finding and slurred speech and poor immediate recall which impacts on new learning. He is easily distracted and can follow only one-step instructions. He had become unmotivated and socially isolated and was displaying increased irritability and frustration. He also suffered from insomnia and smoked two packets of cigarettes a day.

The ACAT recommended screening for depression and referral to the GP for possible anti-depression medication and to address peripheral circulation problems. It was also suggested that the client see a psychologist for cognitive behavioural therapy, a physiotherapist to develop a rehabilitation program. An investigation of opportunities for increased community participation to assist with mood, mobility and social isolation was recommended.

The client was the first and only client in the project who was able to consent to his own involvement in the Pilot and who had direct input into a care plan. He was very keen to commence a rehabilitation program in a gym but was not at all amenable to seeing a psychologist.

The client was diagnosed with depression and his GP prescribed an antidepressant, which quickly helped to improve mood and sociability and reduce irritability. The risk of falls was also reduced because the client became more agreeable to receiving assistance and supervision. A physiotherapist was engaged to work with the client and a rehabilitation program was developed. This was implemented at a local gym with transport and physical assistance provided by his two key workers. The client is motivated to do the exercises and often does them at home as well as at the gym. On a trial basis, gym visits were increased to two per week as they were seen to be having a strong positive impact on mobility, balance, strength, mood and sociability. Gym visits are often combined with community integration, for example, lunch or coffee in town. A shower chair was purchased to reduce the client's risk of falling in the bathroom.

The incidence of falls has been halved since the client began taking an antidepressant and commenced physiotherapy. He is due for review by the physiotherapist in March, with the expectation that he will demonstrate marked improvement. The exercise program will be adapted as necessary.

Outcomes

The client enjoyed tangible benefits from the project. His physical, mental and cognitive problems had been increasing; physical deterioration could have led to a situation where care could no longer be managed by the disability service provider. The antidepressant produced quick and lasting results, and the exercise program has given solid benefits on the physical level. It is envisaged that the client will continue to improve through the exercise program and perhaps plateau. At that point, his mobility, strength and balance should be able to be maintained at a level that makes his care manageable in the group home environment, thus keeping him out of the residential aged care system.

This client has been serviced by three different systems in recent years: the state health system, the state disability system and, through this project, the Australian Government aged care system. The state health department provided rehabilitation services to the client up to a point, then he was discharged. State-funded disability services have provided accommodation and support services. However, there has been a mismatch between the client's needs and what his state-funded disability service can deliver. This project is providing extra services targeted to increasing needs as he ages. If the project were not available to meet some of this gap, there is every indication that the client would have been prematurely admitted to residential aged care.'

Case study 3

'The client is a lady with intellectual disability, aged in her late 50s. She spent many years in a large institution and now lives in supported accommodation. She has been living in the same group home with the same housemates for more than a decade. Ms V was referred to the project in December 2003 with intellectual disability, osteoporosis, Bowen's disease and epilepsy. Her challenging behaviours included non-compliant aggression, physical aggression and foul language. She was taking six different medications. The client scored 13 points on the BSCOC, indicating functional change had taken place before the client joined the project.

The client was assessed by ACAT in early 2004. Early cognitive change, weight loss, old fractures in the lumbar and thoracic spine, some episodes of urinary incontinence, and deteriorating skin integrity were noted. The ACAT recommended a series of allied health assessments including an occupational therapy assessment of the client's home environment, a review of dietary and fluid intake, and the development of a physiotherapy program to maintain her strength, balance and bone density. It was also recommended that staff caring for the client be educated about the monitoring and management of early cognitive changes.

The necessary assessments were arranged. The client joined a community art class, and plans to expand her community participation. She is also taking part in an individual exercise program designed to strengthen her upper body, increase bone density and improve posture. Walking to art class has provided a further opportunity for exercise to improve balance and maintain bone density. The project funds a support worker to accompany the client and some exercise equipment has been purchased.

Outcomes

Though progress has been slow, the client showed early benefits from a regular exercise program, and enjoyed the contact with the women in her art class. She gradually extended her time at these activities. Disability support staff join the project coordinator for regular reviews with her health and allied health care professionals to ensure that the care plan remains appropriate to her changing needs.'

Case study 4

'The client is a man with Down syndrome aged in his mid-50s. He used to enjoy watching TV, reading magazines, playing cricket, swimming and music. He once had a wonderful memory and was a passionate fan of Elvis Presley. He has lived in his supported accommodation for only 2 years. Prior to this, the client lived independently in his own flat and attended work each day. He has been involved with the local disability service provider since he was a young child. His parents are both deceased—his sister takes responsibility for his welfare.

The client was referred to the project in October 2003 because of a dramatic increase in his personal care needs due to dementia and incontinence. His personal safety was compromised by his absconding and he could no longer be left unsupervised. He sometimes became aggressive when he was confused or disoriented. This decline to requiring 24-hour care was quite rapid. His BSCOC score was 118 with the highest scores being in the perceptual/cognitive, social/emotional and activities of daily living domains.

ACAT assessment identified Down syndrome, dementia, hypertension, cataracts, sleep apnoea and gout. It was noted that the client had ceased initiating tasks, and was becoming frustrated and resistant at times. He was unsteady on his feet and unable to judge changes in floor level, leading to a risk of falls even though he is able to walk unaided. He needs prompting to eat and requires a diet of soft foods. The client's interaction with others had reduced to almost nil, whereas he used to be very social.

The client's care plan in the project includes two hours of personal care per day, including time in the morning to enable him to do things at his own pace and go to his day program a little later, which has been successful in reducing resistance. He was assessed by a geriatrician and a gero-psychologist, which included a medication review. The project implemented daily walks to maintain mobility and the provision of aids and equipment. A manual handling expert was engaged to assess staff manual handling practices for this client and another client and to provide necessary training to staff. The client is also visited by a community nurse who treats his ulcerated ankle.

The client's care plan evolved as his needs increased. For example, changes were initially made to his walking route to keep him away from crowds and public places that made him anxious. Then, as seizure activity increased, staff began taking him for walks in his wheelchair and ensuring that the route is within his 'cognitive comfort zone'.

Outcomes

While the client's health continued to deteriorate, the project made significant contributions to his quality of life and the decline is likely to have been far more rapid without the interventions of the project. As a consequence of the project, he is less resistant to staff performing personal care tasks, and is overall less grumpy and aggressive. The provision of equipment improved his physical safety and dignity and decreased the risk of pressure sores from increased hours in bed and chair. The client enjoys one-on-one walks with staff in the local neighbourhood to watch children playing sport or go to shops for a milkshake. The behaviour management plan and environmental interventions have decreased his anxiety. A minor reduction in his medications has resulted in a marked improvement in mood, and the client is an obviously happier person, with benefits for both him and the people he lives with.'

Case study 5

'The client is a man with Down syndrome aged in his mid-50s. He commenced employment with his disability service provider in 1960 and worked for 37 years until his retirement in 1997. The client was also active outside work, riding his bicycle to and from work, being an active member of a local bowling club with his brother, and becoming a well-known identity in the local dancing fraternity through his love of ballroom dancing.

The client's mother developed dementia and was placed in residential aged care in 1998. The client lived in respite care accommodation for 3 months before moving into supported accommodation with his disability service provider in 1999. After he retired from work, the client transferred to a day program for retired people with disabilities. He withdrew from this in 2002 due to deteriorating health. He developed myoclonic seizures in conjunction with progressive dementia. He deteriorated rapidly in the following 18 months and required high support for several months. His GP visited the home regularly, and the client was reviewed annually by the ACAT geriatrician.

The client was referred to the project in October 2003. Information at referral noted Down syndrome, progressive dementia, limited verbal communication, seizures, declining functional abilities, mobility problems, and low blood pressure. He had several consultations with the geriatrician prior to referral. In addition to the support and care offered by the disability service provider, the client was having weekly visits from community nurses for management of a wound resulting from the removal of a skin cancer, visits from a podiatrist and weekly leg and arm massage through a local university clinic. The client's GP does home visits as required.

The client's BSCOC score was 128, showing significant functional change, which was spread across each of the six sub-scales.

ACAT assessed the client and recommended several allied health assessments, including a physiotherapist to develop a mobility program, a speech therapist for swallowing, a dietician, and an occupational therapist to develop an ADL program and to advise on physical access in the home. Assistance from aged care specialists to manage continence, medication, skin integrity, manual handling and nutrition and to review practices for high level care provision was also recommended. The assessment highlighted a need for dementia education of staff and regular in-home respite to supplement staff resources because of the client's high care needs.

A detailed care plan was developed and incorporated into the client's daily schedule. The client continues to receive regular home visits from the GP. The frequency of GP visits increased due to increased seizure activity and dental infection which required surgery in 2004.

Outcomes

In June 2004, the disability service manager met with the client's family to discuss his increasing care needs and the constraints on the disability service provider in meeting those needs. The main constraints were said to be inadequate funding from the state disability department to support his high and increasing need for assistance, and the increasing risks for both the client and staff posed by occupational health and safety issues. The family agreed to a further ACAT assessment with the view to residential aged care. This assessment took place in August 2004 and the client was approved for residential care.

In September 2004, the family placed their brother in the aged care facility in which the client's mother resides. Positive aspects of the move are that the client was closer to his mother (though contact with her is dependent on facility staff as she lives in a different wing), he has regular access to specialist diversional therapy, and there are nursing staff on site to provide wound care and other services. Other consequences of the move into residential aged care are that he is now living in an unfamiliar environment and is sharing a room with another resident, which he has never had to do. There is a lower staff-to-client ratio at the facility than in the previous group home and the staff are not familiar with his history. The move has impacted on the client's social support system, as he has virtually no contact with friends and housemates.

This client had high needs at point of referral to the project. While the project was in a position to initiate a thorough health assessment (as recommended by ACAT) and provide additional personal care, the fact that the project only became available more than a year after the client's health had begun to deteriorate meant that there was limited capacity to provide preventative or restorative care. The focus became one of supporting the disability service provider to support the client's high care needs for as long as possible. Comprehensive and intensive assessments and a trial at supplementary care in the community ensured that all options to maintain the client at home in the community were exhausted before he entered an aged care facility.'

Case study 6

'The client was aged early 50s when the package commenced. The client fell over and as a result suffered a fractured neck of femur and was hospitalised. Post surgery, the Acute Health Service Team decided that the client was not a suitable candidate for rehabilitation due to intellectual disability. The client was transferred to an aged care facility for respite.

During this time the project provided physiotherapy and occupational therapy assessments. The client then received a rehabilitation program at the aged care facility with an ongoing physiotherapy support program.

The physiotherapist provided education to the staff working in the client's supported accommodation service on how to perform correct passive movements. Further assessments were conducted by the occupational therapist at different stages of the client's progress. Equipment was purchased to enable the client to return home.

Through a team approach the client was discharged after a period of 61 days respite and returned home. The familiar environment and the support of friends assist the client with their rehabilitation. The project provided two hours per day to assist with personal care, and the client continued with the physiotherapy program arranged by the project.'

Case study 7

'The client was aged late 30s when the package commenced. The client's mobility was deteriorating and this was impacting on all areas of the client's life. It prevented the client from attending outings and participating in activities with friends. The use of a walking frame had proved to be inadequate on longer outings and, with decreased energy levels, the client was evidently frustrated and showed little motivation.

Once referred and accepted to the project, a series of assessments were completed. Following recommendations from the occupational therapist, a wheelchair was purchased for the client to use on longer outings. This enabled the client to maintain an active social life and be part of the community. Physiotherapy sessions commenced with strengthening exercises and a walking program was implemented. Staff were actively involved in all stages of the program and encouraged the client to continue with the strengthening exercise regime.

As the physiotherapy program progressed and the client's motivation increased, hydrotherapy was introduced. The client had previously been reluctant to participate in hydrotherapy. Positive reinforcement and encouragement through the project has given the client a one-on-one focus and has increased the client's motivation and confidence. Due to this increase in confidence and motivation the client continues to strive to reach their goal.'

Case study 8

'The client is a lady in her 60s. She has congenital hypothyroidism and intellectual disability. She has been living in supported accommodation for 2 years, prior to which she was in the care of family. The client was referred to the project in January 2004, with congenital hypothyroidism, intellectual disability, anaemia, arthritis, Bakers cyst, hyperlipidaemia, hypertension and nocturnal insomnia. The referral noted that the client's cognitive ability had declined rapidly and she was becoming emotionally dependent on individual members of staff. The decline in her physical abilities and health were of concern and required ongoing reassessment and monitoring. The client had numerous falls in the prior 6 months, leading to a fractured pelvis.

Her BSCOC score was high at 250, with the highest scores being in health, perceptual/cognitive and social/emotional sub-scales.

The client was assessed by ACAT in March 2004. The ACAT assessor sought further advice before making recommendations. Around this time, the client also had an annual medical check-up with her GP. Recommendations arising from the ACAT assessment and GP consultation were for the GP to review bloods for thyroid function, check sugars, check cough, and vision/hearing; referral to an occupational therapist for assessment of hand function, transfers, and requirement for aids, home visit to assess safety and provide education to staff about interventions for increasing her activities of daily living functioning; referral to a physiotherapist to assess balance and mobility; assessment for depression or other mood disturbances. A geriatrician was asked to review four separate problems—cognition, falls, medication and insomnia, in addition to existing medical conditions.

The geriatrician provided a further list of recommendations. Geriatrician recommendations for measures to improve mobility, anti-gravity muscle strength and balance and to reduce falls risk have not been acted on for various reasons. His recommendation for a walker was vetoed by the client's brother, who was concerned that this would result in dependency (he had recently bought a pair of orthopaedic shoes to improve her gait). The client's skin condition, a result of a fatty liver condition, has prevented her from taking up hydrotherapy. Her medication was adjusted to deal with the skin condition, insomnia, challenging behaviours, mood disturbance and incontinence. The client presents as a complex case because of so many medical conditions with possible medication side-effects and interactions.

The client's social withdrawal and increasing dependency on staff was addressed by including her in a weekly small group of seniors who join various mainstream activities for older people. The project is funding additional support staff for her to join this group. It is envisaged that when she can attend hydrotherapy, staff will be brokered from another service to accompany her to the sessions in order to discourage further reliance on a few select staff.

Outcomes

The seniors group experience has been positive for the client, who now joins her friends to attend activities in the community each week. The group visits four different mainstream seniors groups in each week of the month and this has allowed the client to establish connections with four new groups of people.

A key outcome for the client has been access to the holistic assessment by ACAT and the various medical and allied health assessments flowing from that. For this client, the medication review, trialling of new medications and opportunity for ongoing review by the geriatrician has been an important part of her care plan.'

Case study 9

'The client is a lady with Down syndrome aged in her late-50s. Since her parents' deaths, a cousin has been responsible for her and maintains regular telephone contact. The client has been living in supported accommodation since 1979 and is currently residing with other older clients in a suitable house in the suburbs. The client worked for more than 20 years in the business service operated by her supported accommodation provider. She is now retired and attends a day program for people who are ageing with a disability on four mornings a week.

The client was referred to the project in October 2003 due to observed behavioural changes, including hiding or throwing out personal belongings of her own and her housemates. It was noted at the time that the client had Down syndrome, hypothyroidism, a pacemaker, asthma, scoliosis, a zinc deficiency and osteoporosis. She had a BSCOC score of 58. The BSCOC assessor noted that some of the client's skills had deteriorated over a period of more than 6 months prior to the tool being administered on this occasion.

An ACAT assessed the client in January 2004 and the client was accepted into the project. The ACAT noted that the client presented with age-related problems in the area of vision, hearing, mobility, cognitive change, emotion/mood, activities of daily living and upper limb function. It was also noted that she had withdrawn from usual activities, and often refused to go to her day program, preferring to spend more time at home. This presented a problem because her supported accommodation service is not resourced to cater for this choice. ACAT recommendations included an assessment for depression, referral to a gero-psychologist for assessment and the development of a cognitive deficit plan and dementia education for staff; occupational therapy assessment for upper limb function; physiotherapy for mobility; the development of a behaviour management plan; and the continued involvement of the visiting podiatrist.

A care plan was implemented incorporating a behaviour management plan and physical therapies. The client commenced hydrotherapy sessions with the support of a care worker, and her socialisation improved as she was spending half-days at her day program. In late June 2004 the client was diagnosed with significant osteoporosis in her lumbar spine and proximal femur following a bone density scan. She fractured both elbows in separate falls soon afterwards. Toilet rails were installed as a preventative measure. The client's osteoporosis and risk of falls will necessitate the involvement of rehabilitation services in the longer term.

The client has been a low needs client for the project. Financial assistance from the project involved mainly gero-psychology services and the additional support worker to attend hydrotherapy. Rehabilitation services are accessed through the local health service. The disability service provider continued with vision and hearing tests, regular podiatry appointments and assisting the client with her medications and nebuliser in addition to services provided through the project.

Outcomes

Thorough assessment by the gero-pyschologist led to a provisional diagnosis of generalised anxiety disorder with agoraphobic and hoarding features. Early 'sundowning' behaviours were also noted, and the evening routine was adjusted to better manage these. The behaviour management strategy developed by the gero-psychologist and implemented by staff led to a 90% reduction in problematic behavioural symptoms.

Effective behaviour management has led to an increased engagement by the client in her day program and greater satisfaction with life for many months. However, the client is again withdrawing, becoming less compliant, and has had extremely high anxiety when going to the doctor.

The gero-psychologist will continue to monitor the client and adjust the management plan to meet changing needs. Staff have been alerted to the potential for further behaviours to emerge and these will be managed as they arise.

The rehabilitation centre was reluctant to see the client at the centre and preferred to devise an in-home program. However, as it is not the support worker's role to act as physical therapist, nor is this their area of expertise, compliance with the exercise program was compromised. The client's rehabilitation plan was adapted to focus on exercises that could be incorporated into her regular routine and take advantage of some her ritualised behaviours, for example, pegging the clothes on the line, and the disability service managers will be working with disability support staff to integrate exercise into her daily program.

Although the client is a low-care client in terms of project level of funding for additional supports, she continues to challenge staff. She has very clear likes and dislikes and refuses to participate in many activities which have come to include swimming, exercise, wearing glasses and wearing shoes. Non–compliance has complicated the implementation of an exercise program. The client also loves to wear socks, not shoes or slippers, which increases her risk of falls. Hydrotherapy has been discontinued because she began to refuse to go to the pool or once there, to get into the water. A private physiotherapist was engaged to work with the staff in identifying ways of incorporating weight-bearing exercise into the client's daily routine, to replace the formal exercise program.

The need to assess the client and other clients for depression led to a two-hour training session for disability support staff, run by the ACAT gero-psychologist, on use of the Cornell Scale for Depression in Dementia and the Montgomery and Åsberg Depression Rating Scale.'

Case study 10

'The client was aged late 50s when the package commenced. The client lived in supported accommodation with an ageing partner and received care assistance during the day. The client has diabetes and administers the injections independently.

The client's overall health status had decreased and there was a concern about peripheral vascular disease in the leg. The insulin injections needed to be closely monitored due to the client's memory loss. The client also regularly suffered from diabetic episodes. While staff members were present during the day, the client was most at risk during the evenings when staff members weren't present.

On joining the project, the client underwent physiotherapy and occupational therapy assessments, followed by a dietician assessment. On the recommendation of the physiotherapist, a recliner chair was provided to increase comfort levels and provide a foot rest to elevate the legs, which helped with the peripheral vascular condition.

Due to the high risk of diabetic episodes during the evenings, the project provided two hours every evening to assist the client with evening meal preparation and insulin injections. The dietician supplied a sample daily menu and other suggested low glycaemic index foods to reduce the risk of diabetic episodes. With the ongoing support hours and the new menu options, the client experienced a reduction in diabetic episodes.'

Case study 11

'The client was aged early 60s when the package commenced. Prior to being accepted into the project, the client lived in supported accommodation with a low support level. A fall resulted in a fracture. The client, unable to care for themself, was transferred to a residential aged care facility for 4 months and lost physical strength, mobility, some skills of daily living and gained a considerable amount of weight.

On return to disability supported accommodation, the client expected all activities of daily living to be performed by staff, as experienced in the aged care facility. Prior to the fracture the client was able to cook and manage aspects of their daily living under supervision. The client had become accustomed to living in an aged care facility; however, if the client could no longer be supported in the home, the client would have to be readmitted to an aged care facility, losing their independence. The client's employment was also threatened.

On joining the project the client received physiotherapy and occupational therapy assessments. Through a dietician assessment, several menus were introduced so that the client, with staff support, could cook for themself with the aim of reducing weight.

The client had another admission to hospital resulting in a four-day stay. The client returned home for three days and was then readmitted to hospital for 25 days.

Increased support levels encouraged the client to remember independent living skills to maintain independence. The staff support has also given the client one-on-one social interaction and increased confidence. Staff now report the client is more positive and happier. The client was able to return to work.'

Case study 12

'The client was aged early 70s when the package commenced. The client previously enjoyed an active social life and going to work. Due to an unsafe incident, the client was no longer able to go out independently and retired from work. This caused the client distress and frustration—the client often expressed the wish to die.

Shortly after joining the project, the client was admitted to hospital with pneumonia where they aspirated and a PEG was inserted. The client had physiotherapy and occupational therapy assessments both prior to and after the hospital admission. A dietician assessment also occurred to address weight loss during the hospital stay.

Due to the 14-hour PEG feeds, the project provided a recliner chair to aid comfort and reduce the risk of skin breakdown. The chair enables the client time to rest and recover. An alternating air flow mattress and an electric hi-lo bed was also provided to minimise the risk of pressure areas. The knee-break in the bed also allowed the client to receive the enteral feeds at night in bed. The provision of the mattress has improved the quality of sleep. This has enabled the client to regain strength and energy.

Ongoing physiotherapy was provided to help increase mobility and muscle tone and to provide chest exercises to reduce the risk of pneumonia.

The project provided two hours to assist the client with personal care. An additional optional four hours per week assists the client in social outings and for one-on-one socialisation. Physiotherapy sessions are another outlet for socialisation, as the client attends with a group and enjoys the interaction with the physiotherapist and others.

The client now has a more positive outlook on life.'

Case study 13

'The client is aged early-40s and has intellectual disability, hypothyroidism, and atrial fibrillation.

Client lives in a group home with two other males, visits family every other weekend and attends day options on five days per week.

Pre-project entry levels as per BSCOC (Minda Inc.): staff reported a moderate degree of functional change in the 6 months preceding involvement in the project, particularly in the areas of daily living skills, sensory integration, and perceptual cognitive functioning.

The original care plan was developed in August 2004 and provided for blocks of 1.5 hours every day which focused on recreational and social activities that appropriately support the client's health and ageing issues. The plan included activities to encourage him to go slower, but provided opportunity for exercise.

On review in December 2004, the care plan was changed to one six-hour and one two-hour block weekly. Activities included low impact exercise in a heated pool, improving personal presentation skills and purchasing new clothes, learning to prepare nutritional foods and making healthy choices when eating out.

The client's service review in April 2005 supported continuation of these activities and a further focus on helping him develop the garden at home. This will provide some low impact physical exercise under supervision, choice making and negotiation with other residents.

The only challenges that have presented in the delivery of this service have been to ensure that the times are suitable for the client's concentration and stamina, supporting rather than replacing his current activities.

Outcomes

At last review on 14 April 2005 the client stated that he was very happy. He especially enjoyed morning tea at the bakery, going to the pool and spa, and shopping for new clothes. He is looking forward to starting a new garden at his group home.'

Case study 14

'The client is aged mid 30s and has Down syndrome, mild heart failure, scarred oesophagus, hypotension, vision loss, dermatitis and disruptive behaviour.

The client lives in a group home with one other male and three females and visits family occasionally. The client works at a supported employment centre five days a week.

Pre-project entry levels are as per BSCOC (Minda Inc.). Staff reported a significant degree of functional change in the 6 months before the client joined the project, particularly in the areas of sensory integration, perceptual cognitive functioning and social and emotional function.

The original care plan, developed in September 2004, was for one hour on each of Monday, Wednesday and Friday mornings to develop a personal care regime, one hour of one-to-one behaviour management therapy and 7.5 hours fortnightly of social support to access gender appropriate activities. This project also negotiated for the client to be able to participate in a special day program one day a week, thereby reducing his work days to four.

On review in December 2004, personal care support was increased to five mornings a week, provided by a support worker. Social support was reduced to 6.5 hours a fortnight. Day program attendance one day per week continued. Behaviour management was reduced to half an hour per week.

On review in March 2005, the project negotiated for the client to reduce work days to attend a day activity program for older people. At the same time the behaviour management component was able to be dropped. Implementation of routines that supported choice and decision making had significantly reduced the incidence of behavioural issues.

This client had further reviews of health status that led to some interventions. At times this disruption has escalated the demanding and challenging behaviour. The client responded well to strategies that increase choice and visual cues to assist in routine management.

Outcomes

The services are primarily provided by a worker who enhances the client's access to a positive gender role model. The incidence of challenging behaviours has significantly reduced particularly when the client has access to choice and routines. The transition from supported employment to a day activity centre and special purpose program reduced fatigue and aggression associated with the work environment and exposed the client to social interaction with a range of people.

This client reported being very happy with the care plan and eagerly looks forward to every session—even the morning personal care routine!'

Case study 15

'The client has intellectual disability, microcephaly, ectrodactyly, heart murmur, incontinence, severe foot abnormality, chronic back pain, and evidence of short-term memory loss and depression. The client is aged early 50s.

He lives in his own unit in a supported care hostel and works five days per week at a supported employment centre. He visits his sibling irregularly.

Pre-project entry levels are as per BSCOC (Minda Inc.). Staff reported significant functional change in the 6 months before the client joined the project, particularly in the areas of sensory integration, and perceptual cognitive functioning.

This client replaced three days per fortnight of work with 5.5 hour blocks of support that focus on community access, visits to farms and saleyards (a primary area of interest), taking photos for a chat book and going out for lunch. The program also focused on implementation of strategies to reduce aggressive and intolerant behaviour toward others.

A review in April 2005 revealed that the care plan was meeting the client's needs and he expressed satisfaction. Support staff identified that he was tiring quickly and that they needed to closely monitor the pace and number of activities.

The care plan and its implementation has been without challenge—both client and support staff express very positive feedback.

Outcomes

The client is very happy with being able to sleep in on three days per fortnight while his peers go to work. He has also thrived on the one-to-one attention and ability to pursue personal interests. His photography is assisting him to record important people, events and objects in his life that assist him with both communication and memory.'

3.11 Main findings

Different staffing models have been used to provide clients with increased hours of personal assistance, physical maintenance therapies, and support for improved domestic and community participation. These models include the fully integrated staffing and service delivery model of Ageing In Place; the (mainly) dedicated aged care teams of NSDACP, DACS, CWPDA; the full brokerage model of FNCDAC; and mixed brokerage and agency staffing seen in FACP, DALP and CPDAC. Workforce has been a significant challenge for most projects.

Additional hours of personal assistance allow older clients to move at a different pace to younger members of a household whose routines are structured around full-time participation in disability services programs. At the time of the evaluation, clients were receiving a mean of 2.8 hours of additional personal assistance per week; additional personal assistance of up to 20.9 hours per week was recorded for one client (Table 3.13). Increasing hours of personal assistance could be expected as client groups mature. The injection of new personal care workers or the funding of additional personal assistance from disability support staff relieves pressure from household staff.

Therapeutic interventions have been developed following ACAT and allied health assessments to address loss of fine and gross motor skills that affect mobility and capacity to

participate in activities. Projects have delivered a range of other activities including 'news groups', story telling, individual pursuits and small group activities to promote mental activity, use of language and social interaction. This range of service types is thought to be important for people ageing with a disability who need to withdraw from long-term employment and day programs and who may face physical and psychological decline due to limited flexible daytime options.

Provision of aids and equipment has emerged as an important area of service delivery for small numbers of clients. Although vast sums have not been spent on aids and equipment it is clear from case studies provided to the evaluation that attention to the physical home environment of older clients can have a marked impact on quality of life, improve the relationship between client and disability support staff, and help to maintain ageing clients in their familiar home environment for longer. Often the pieces of equipment purchased have been small and inexpensive but have enabled clients to safely spend short periods at home without supervision. More expensive items such as a tilt chair or special purpose mattress have also been acquired and these are seen to benefit not only one client but potentially other members of a household (or accommodation service) who in future could experience similar needs.

Projects have also been conduits for the delivery of medical and other services because various types of referral have flowed from needs assessment processes.

By offering the new choice of community aged care, the projects assist clients to live longer in the community by helping to arrest or slow the physical and cognitive decline that occurs at older ages and by mitigating a range of factors that can prevent the longer term maintenance of a person with age-related needs at home such as need for a higher level of personal assistance, mobility assistance and continence management. Comprehensive, specialised assessment underpins these interventions and the Pilot has exposed high variation in the skills and experience within supported accommodation services for the identification of age-related needs in people with disabilities.

Table 3.13: Service units delivered to clients during the evaluation, by service type, all projects excluding MS Changing Needs

Service type	Number of clients	Service unit	Minimum	Median	Maximum	Mean
Initial needs assessment	147	Hours/service episode	1.0	5.0	27.0	7.2
Follow-up needs assessment	123	Contacts/service episode	—	7	102	22.6
Needs assessment other	24	Events/service episode	1	20	20	15.6
Nursing and medical care						
Nursing care	4	Hours/week	0.1	1.6	5.0	2.1
GP consultation	17	Contacts/service episode	2	3	18	4.6
Geriatrician	1	Contacts/service episode	1	1	1	1.0
Psychiatrist	1	Contacts/service episode	5	5	5	5.0
Nursing/medical other	10	Contacts/service episode	1	2.5	168	51.9
Medication review	4	Reviews/service episode	1	2.5	9	3.8
Allied health care						
Physiotherapy	59	Hours/week	—	0.1	1.0	0.2
Occupational therapy	57	Hours/week	—	—	0.1	0.1
Psychologist	4	Hours/week	0.1	0.1	0.2	0.1
Podiatry	6	Hours/week	—	—	0.1	—
Alternative therapies	22	Hours/week	0.3	1.6	3.1	1.6
Dietetics	19	Referrals/service episode	1	1	2	1.1
Allied health other	31	Events/service episode	1	66	264	85.7
Dementia care and behaviour management						
Dementia management	2	Contacts/service episode	1	1	1	1.0
Behaviour management	2	Contacts/service episode	2	8	14	8.0
Dementia other	1	Contacts/service episode	14	14	14	14.0
Community mental health service	1	Contacts/service episode	2	2	2	2.0
Social support, leisure and community access						
Social support	44	Hours/week	—	3.6	6.3	3.3
Recreation/leisure programs	58	Hours/week	0.2	7.7	32.3	8.7
Living skills development	14	Hours/week	1.0	4.3	10.8	4.7
Community transport	15	One-way trips	0.1	2.2	4.3	2.3
Community service other	1	Events/week	7.3	7.3	7.3	7.3
Personal and domestic assistance						
Personal assistance	79	Hours/week	—	1.8	20.9	2.8
Domestic assistance	36	Hours/week	0.1	1.1	4.2	1.6
Food service other	25	Hours/week	0.1	1.4	3.6	1.3
Personal transport	29	One-way trips/week	0.4	3.2	15.1	3.9
Personal other	9	Events/week	0.1	0.9	3.9	1.0
Referral and information services						
Referral to other provider	12	Referrals/service episode	1	5	8	4.7
Information other	7	Events/service episode	2	2	2	2.0
Aids and equipment						
Mobility aids	7	Dollars/service episode	72	249	1,041	397.40
Continence aids & supplies	2	Dollars/service episode	399	537	675	537.00
Other aids & equipment	15	Dollars/service episode	44	640	1,825	610.70
Home modifications	1	Dollars/service episode	765	765	765	765.00

— Nil or rounded to zero.

4 Living longer in the community

This chapter considers the impact of the additional services available to clients through the Pilot on accommodation outcomes recorded during the evaluation.

4.1 Short-term accommodation outcomes

Accommodation status recorded at the end of the evaluation shows stability of residence for the majority of participants, despite reports of increasing age-related support needs. Between 14 June and 30 November 2004, only 13 of the 147 evaluation participants in 2004 (8.8%) ceased receiving services from projects, five of whom entered high level residential aged care (Table 4.1).

Table 4.1: Innovative Pool Disability Aged Care Interface Pilot, discharge outcomes current 30 November 2004

Status 30 Nov 2004	Number of clients	Per cent	Service episode median (days)	Range of ADL scores at entry (min–max)
Continuing client	134	91.2	190	0–20
Deceased	5	3.4	210	1–13
Residential aged care	5	3.4	266	3–20
Other[(a)]	3	2.0	186	10–12
Total[(b)]	**147**	**100.0**	**190**	**0–20**

(a) Includes one client who no longer needed assistance and two clients referred to other programs.

(b) Excluding 18 evaluation participants in the Cumberland Prospect project who commenced services after 30/11/04.

Those clients who entered residential aged care either registered very low ADL scores when they joined a project or experienced severe deterioration in ADL functioning after joining. Four of these clients recorded a baseline ADL score at or below the level at which an individual is likely to be able to remain in the community for the longer term (12 points). The fifth client entered a project with a high ADL score but experienced functional decline between the first and second assessments and at the time of the second assessment scored just 7 points on the Modified Barthel Index, reducing to 4 points at time of discharge.

Approximately 48% of evaluation participants who were still with their projects at the end of November 2004 had recorded an entry ADL score of 12 points or lower. For most older people, such a low level of self-care and mobility functioning is likely to result in residential aged care placement (failing the 24-hour presence of a committed primary carer), yet this high proportion of disability clients were able to be maintained at home. Thus, though low or rapidly declining ADL function was a common factor among clients who were transferred to residential aged care, other clients with similar ADL profiles were able to be maintained in place through the combination of usual care and additional support from Pilot services.

Individual client experiences appear to reflect risk factors in addition to functional decline, some of which may be situational. Four of the five discharges to residential aged care took place in projects in New South Wales, of which three clients were in the Far North Coast project. One of the larger disability service providers participating in this project provides

supported accommodation in privately leased homes. The physical environment of a home may not be conducive to ageing in place but it is not always possible to make minor modifications under leasing arrangements. Another factor found to impact on longer term community living is availability of a 24-hour staff roster. Pilot projects have helped to address gaps in daytime rosters but even this could be insufficient for a client who requires 24-hour supervision.

Staff in participating accommodation services expressed concern about their ability to maintain Pilot clients at home should the additional support be withdrawn because there is no other community-based alternative. Pilot services are addressing age-related needs in the target group which are not expected to resolve, indeed which are generally observed to increase over time.

4.2 Levels of additional support for ageing in place

In addition to case management, projects delivered between 0.1 and 37.3 additional hours of additional support per client per week, counting additional hours of personal assistance, domestic assistance, allied health care, nursing care, social support, leisure and recreation programs and living skills development (Table 4.2). These additional services were directly related to care plans developed jointly to address clients' identified age-related needs. A range of other types of assistance not recorded in hours are not included in these figures, for example, transport services, medication review, and referrals to health services such as geriatricians, general practitioners and dieticians. The extensive range of service types and levels of service delivered to clients reflects the variation in individual age-related needs within the target group.

Table 4.2: Innovative Pool Disability Aged Care Interface Pilot projects, summary statistics for additional support services per client per week during the evaluation, by project (hours)[(a)]

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

(a) Includes services measured in time units: personal assistance, domestic assistance, allied health services, nursing care, social support, and leisure and recreation programs and living skills development. Excludes case management time, transport, food services, medication review and time involved in referring clients to other services.

(b) Ageing In Place is a fully integrated case management and service delivery model. These figures include disability support and ageing needs support.

Time spent on initial needs assessment varied between 1 and 27 hours per client, with a mean across the projects of 7.2 hours per client (Table 4.3). A number of factors influenced the time spent on initial needs assessment. Most clients had completed initial needs assessment before the start of the evaluation and some coordinators relied on recall to estimate the time spent on initial assessments, which meant that the same number of hours was recorded for every client. For example, initial needs assessment for all Ageing In Place clients was completed well in advance of project establishment at the time when Oakdale Services was surveying clients for ageing needs to develop a funding proposal. Other projects were able to report initial needs assessment time from file records. Actual time taken depends on the complexity of client needs, number of referrals made for further assessment and whether these other assessments involve lengthy follow-up by the project coordinator, and the quality of documentation flowing from disability service providers to project coordinators.

Case management from project coordinators is in addition to case management performed by disability services. Project coordinators kept records of the number of contacts with a client or with a client's disability service provider beyond the initial needs assessment for the purpose of care plan review and service adjustment. Table 4.4 gives an indicative number of contacts per client service episode, highlighting that ongoing case management is a feature of the additional support given to clients.

Table 4.3: Innovative Pool Disability Aged Care Interface Pilot, summary statistics for time spent on initial needs assessment per client, by project

		Initial needs assessment time per client (hours)				
Project	**Number of records**	**Minimum**	**Median**	**Maximum**	**Mean**	**Standard deviation**
Far North Coast Disability and Aged Care Consortium, NSW	13	5.5	9.5	15.5	9.8	2.7
Central West People with a Disability, NSW	30	1.5	1.5	1.5	1.5	n.a.
Northern Sydney Disability Aged Care Pilot, NSW	22	12.0	17.5	27.0	20.2	5.2
Flexible Aged Care Packages, SA	31	1.0	1.0	1.0	1.0	n.a.
Disability and Ageing Lifestyle Project, SA	7	7.0	7.0	7.0	7.0	n.a.
Disability Aged Care Service, WA	18	6.0	9.0	9.0	8.8	0.7
Ageing In Place, Tas	7	4.0	4.0	4.0	4.0	n.a.
Cumberland Prospect Disability Aged Care Pilot, NSW	18	1.5	11.0	16.5	8.9	4.9
Total	**146**	**1.0**	**5.0**	**27.0**	**7.2**	**7.1**

n.a. Not applicable.

Table 4.4: Innovative Pool Disability Aged Care Interface Pilot, summary statistics for number of ongoing case management events (contacts) per client service episode, by project

		Case management contacts per client service episode				
Project	Number of records	Minimum	Median	Maximum	Mean	Standard deviation
Far North Coast Disability and Aged Care Consortium, NSW	13	11	17	26	17.6	4.9
Central West People with a Disability, NSW	30	2	5	9	5.8	1.7
Northern Sydney Disability Aged Care Pilot, NSW	22	17	42	48	38.6	8.1
Flexible Aged Care Packages, SA	18	0	1.5	3	1.6	0.8
Disability and Ageing Lifestyle Project, SA	6	2	2	2	2.0	. .
Disability Aged Care Service, WA	18	14	88	102	76.9	24.9
Ageing In Place, Tas	7	3	3	4	3.1	0.4
Cumberland Prospect Disability Aged Care Pilot, NSW	8	5	5	5	5.0	. .
Total	**123**	**0**	**7**	**102**	**22.6**	**28.0**

. . Not applicable.

4.3 Main findings

The evaluation coincided with a period of stability of residence for most Pilot participants. A link between receipt of pilot services and stability of residence is difficult to establish because of the observational nature of the evaluation and the diverse circumstances and support needs of clients. ACAT approval for high level residential care is not considered a reliable guide because for many clients ACAT assessment was initiated only because of the Disability Aged Care Interface Pilot.

Approximately 48% of evaluation participants who were still with their projects at the end of November 2004 had recorded an entry ADL score of 12 points or lower. For most older people, such a low level of self-care and mobility functioning is likely to result in residential aged care placement (failing the 24-hour presence of a committed primary carer), yet this high proportion of disability clients were able to be maintained at home. Thus, though low or rapidly declining ADL function was a common factor among clients who were transferred to residential aged care, other clients with similar ADL profiles were able to be maintained in place through the combination of usual care and additional support from Pilot services.

It is reasonable to conclude from the available evidence that around 7 hours of additional support per week, on average, has reduced pressure on disability support staff and improved the quality of life of Pilot participants and their household companions. Maximum levels of additional support during the reporting period ranged up to 37 hours per client per week. On this basis it could be concluded that a proportion of clients with high age-related

need were at risk of transfer to residential aged care but were able to be maintained at home with Pilot services.

Partners in the Pilot identified the following factors as presenting risks to remaining at home in the community for members of the target group:

- severe mobility limitation which would require, for example, the use of a lifter and the presence of two members of staff for transfers
- physical, cognitive and/or behavioural decline to the extent that extended periods of daytime supervision and assistance are required
- sleep disturbances, especially in group homes that do not have an overnight staff roster
- 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.

Whether a level of additional support helps a client to remain at home for longer than would otherwise be possible therefore depends on the extent to which the specific risks for the individual can be reduced or compensated. These can encompass any or all of individual need characteristics, home physical environment, household routines and culture, for example, the ages and activity patterns of other residents, culture and philosophy of the disability service and the beliefs and practices of staff in the home, and family involvement. The process of comprehensive assessment involving project coordinators, disability support staff and ACAT has identified the risks that apply in a given situation and projects have clearly tailored interventions to individual needs. Some interventions are designed to mitigate immediate risk of transfer to residential aged care, for example, disability-specific 24-hour nursing care for multiple sclerosis clients, additional personal assistance, provision of mobility and continence aids, and physical maintenance programs. Other interventions produce immediate benefits to clients but their impact on rates of transfer to residential aged care can only be measured over the longer term if indeed 'measurement' is possible (increased social participation and self-directed leisure, for instance).

The Pilot has brought an awareness of ageing processes and age-appropriate interventions. According to project coordinators, staff in some supported accommodation services showed little prior knowledge in this area but the Pilot has provided on-the-job training and support tailored to the needs of individual clients. Skills transfer will potentially benefit not just Pilot participants but all clients in a household. We caution against any generalisation on capability for aged care assessment and intervention within disability services because it was also observed that in other cases resources rather than knowledge appears to have been the major impediment prior to the Pilot. In these circumstances, the Pilot has created a mechanism by which disability services are able to respond to observed changes that would otherwise be impossible due to boundaries between aged care and disability services, structural inflexibilities within the disability services sector, and funding constraints that seem to rule out local initiative.

We conclude that the Pilot has helped people with disabilities to live longer at home as they age in two ways: first, by fostering an awareness of age-related change through comprehensive assessment and second, by enabling aged care intervention. In all cases the source of referral has been the client's supported accommodation service, so that in a hypothetical mainstream service scenario the capability of staff working in supported accommodation services to identify clients with age-related needs would be critical. Staff selection, training and support, and documentation practices are fundamental in this regard. The Pilot top-up model is effective in helping clients stay at home as long as it delivers both

additional hours of support to clients and support for disability workers to acquire knowledge and apply workplace practices which support ageing clients.

5 Cost of Pilot services

This chapter contains an analysis of project income and expenditure in consideration of the third evaluation question on the cost of Pilot services. Project financial and occupancy reports for the quarters ending 30 September and 31 December 2004 are the source of material presented here.

5.1 Comparative cost of Pilot services

In the financial reporting period for the evaluation, flexible care subsidy payments totalling $2.13 million were reported by all projects with the exception of MS Changing Needs and Cumberland Prospect Disability Aged Care Pilot (Table 5.1; figures are subject to verification by the Department of Health and Ageing). MS Changing Needs did not report income. Cumberland Prospect reported financial results for the quarters ending 31 March and 30 June 2005 (Table 5.2). Projects derived most of their income from flexible care subsidy payments.

Flexible care subsidy payments ranged from $30.73 to $68.50 per place day (Table 5.3), being the prices paid by the Australian Government to deliver additional support to disability clients with age-related needs. There is currently no mainstream community care alternative to the Pilot 'top-up' model of aged care for these clients. Residential care basic subsidy for high level care as at 1 July 2004 was between $92.27 (RCS 3) and $121.16 (RCS 1) with minor variation for different state and territory locations. Additional Australian Government subsidy amounts are payable for residents with certain special nursing care needs.

People who enter high level residential aged care also contribute to the cost of their care in the form of basic daily care fees and, possibly, additional (means tested) daily care fees and accommodation charges (based on an assets test). Most people in the Disability Aged Care Interface Pilot receive the Disability Support Pension or Age Pension as their primary source of income. People in this situation would not normally pay additional daily care fees and accommodation charges for residential aged care (the basic daily care fee is set at 85% of the full pension). People living in disability-funded community accommodation also generally contribute to the cost of board and lodgings. Arrangements vary across and within the states and territories and depend on individual circumstances. Information provided to the AIHW indicates that a client in receipt of the Disability Support Pension would typically contribute up to 75% of the Pension towards the cost of board and lodging in a disability-funded accommodation service.

It is not strictly valid to compare levels of flexible care subsidy for Pilot services to residential aged care subsidy except 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 made under the CSTDA for the provision of accommodation services to Pilot clients in the range $27 to $391 per client per day. Some of the figures supplied are known to be unreliable and it became clear that the evaluation would not be able to report average per client total funding levels.

Table 5.1: Innovative Pool Disability Aged Care Interface Pilot, income and expenditure, quarters ending 30 September and 31 December 2004, by project

	Income					Expenditure			
Project	Flexible care subsidy[(a)]	Other income[(b)]	Total new income	Funds carried forward	Total available funds	Services expenditure	Non-services expenditure	Total expenditure	Expenditure as a per cent of new income
FNCDAC, NSW									
September quarter	175,177	735	175,912	228,135	404,047	50,021	39,409	89,430	50.8
December quarter	116,785	742	117,527	330,461	447,988	36,703	53,191	89,894	76.5
Total	*291,962*	*1,477*	*293,439*	*558,596*	*852,035*	*86,724*	*92,600*	*179,324*	61.1
CWPDA, NSW									
September quarter	463,680	—	463,680	370,505	834,185	73,491	27,247	100,738	21.7
December quarter	226,800	—	226,800	733,447	960,247	91,555	41,769	133,324	58.8
Total	*690,480*	—	*690,480*	*1,103,952*	*1,794,432*	*165,046*	*69,016*	*234,062*	33.9
NSDACP, NSW									
September quarter	205,114	—	205,114	291,262	496,376	36,069	28,302	64,371	31.4
December quarter	405,769	—	405,769	291,262	697,031	92,419	45,563	137,982	34.0
Total	*610,883*	—	*610,883*	*582,524*	*1,193,407*	*128,488*	*73,865*	*202,353*	33.1
FACP, SA									
September quarter	149,833	3,961	153,794	295,667	449,461	62,251	49,575	111,826	72.7
December quarter	—	3,911	3,911	337,635	341,546	55,938	55,504	111,442	(b)
Total	*149,833*	*7,872*	*157,705*	*633,302*	*791,007*	*118,189*	*105,079*	*223,268*	141.6[(b)]
DALP, SA									
September quarter	—	—	—	29,985	29,985	10,212	–514	9,698	—
December quarter	55,314	—	55,314	—	55,314	18,277	–5,168	13,109	23.7
Total	*55,314*	—	*55,314*	*29,985*	*85,299*	*28,489*	*–5,682*	*22,807*	41.2

(continued)

Table 5.1 (continued): Innovative Pool Disability Aged Care Interface Pilot, income and expenditure, quarters ending 30 September and 31 December 2004, by project

	Income					Expenditure			
Project	Flexible care subsidy[(a)]	Other income[(b)]	Total new income	Funds carried forward	Total available funds	Services expenditure	Non-services expenditure	Total expenditure	Expenditure as a per cent of new income
DACS, WA									
September quarter	125,012	—	125,012	112,510	237,522	50,035	64,848	114,883	91.9
December quarter	125,013	—	125,013	122,639	247,652	56,169	57,586	113,755	91.0
Total	*250,025*	—	*250,025*	*235,149*	*485,174*	*106,204*	*122,434*	*228,638*	91.4
AIP, Tas									
September quarter	39,569	34,291	73,860	–8,674	65,186	31,310	21,783	53,093	71.9
December quarter	39,569	33,329	72,898	12,093	84,991	30,808	43,088	73,896	101.4
Total	*79,138*	*67,620*	*146,758*	*3,419*	*150,177*	*62,118*	*64,871*	*126,989*	86.5
Total excluding MS Changing Needs									
September quarter	1,158,385	38,987	1,197,372	1,319,390	2,516,762	313,389	230,650	544,039	57.6
December quarter	969,250	37,982	1,007,232	1,827,537	2,834,769	381,869	291,533	673,402	56.7
Total	*2,127,635*	*76,969*	*2,204,604*	*3,146,927*	*5,351,531*	*695,258*	*522,183*	*1,217,441*	*57.1*
MS Changing Needs, Vic									
September quarter	n.r.	n.r.	n.r.	—	—	109,171	—	109,171	n.a.
December quarter	n.r.	n.r.	n.r.	65,870	n.r.	109,171	—	109,171	n.a.
Total	*n.a.*	*n.a.*	*n.a.*	*65,870*	*n.a.*	*218,343*	—	*218,343*	*n.a.*

(a) Subject to verification by Department of Health and Ageing.

(b) Other income includes state government and auspice body grants (AIP only), client co-payments, and interest earned on project funds.

— Nil; n.r. Not reported; n.a. Not available.

Source: Project financial reports to AIHW.

Table 5.2: Cumberland Prospect Disability Aged Care Pilot, income and expenditure in quarters ending 31 March and 30 June 2005

	Income					Expenditure			
Project	Flexible care subsidy[(a)]	Other income	Total new income	Funds carried forward	Total available funds	Services expenditure	Non-services expenditure	Total expenditure	Expenditure as a per cent of new income
March quarter	44,859	—	44,859	—	44,859	34,057	10,802	44,859	100.0
June quarter	120,236	—	120,236	—	120,236	77,396	42,840	120,236	100.0
Total	**165,095**	**—**	**165,095**	**—**	**165,095**	**111,453**	**53,642**	**165,095**	**100.0**

(a) Subject to verification by Department of Health and Ageing.

Note: Project established in December 2004 with initial intake of clients continuing through to May 2005.

Source: Project financial reports for March and June 2005.

Table 5.3: Innovative Pool Disability Aged Care Interface Pilot, flexible care subsidy payments and client co-payments to projects per client service day

	Daily payments ($)	
	Flexible care subsidy	Client co-payment
Far North Coast Disability and Aged Care Consortium	63.47	—
Central West People with a Disability who are Ageing	63.00	—[(a)]
Northern Sydney Disability Aged Care Pilot	63.70	—
MS Changing Needs	60.32	—
Flexible Aged Care Packages	54.73	0.73[(b)]
Disability and Ageing Lifestyle Project	30.73	—
Disability Aged Care Service	68.50	—
Ageing In Place	61.94	—
Cumberland Prospect Disability Aged Care Pilot	60.00	—

(a) One CWPDA client is recorded as paying $29.63 per day for the project, whereas all other CWPDA clients did not pay a co-payment.

(b) From nil to $1.43 per day.

— Nil.

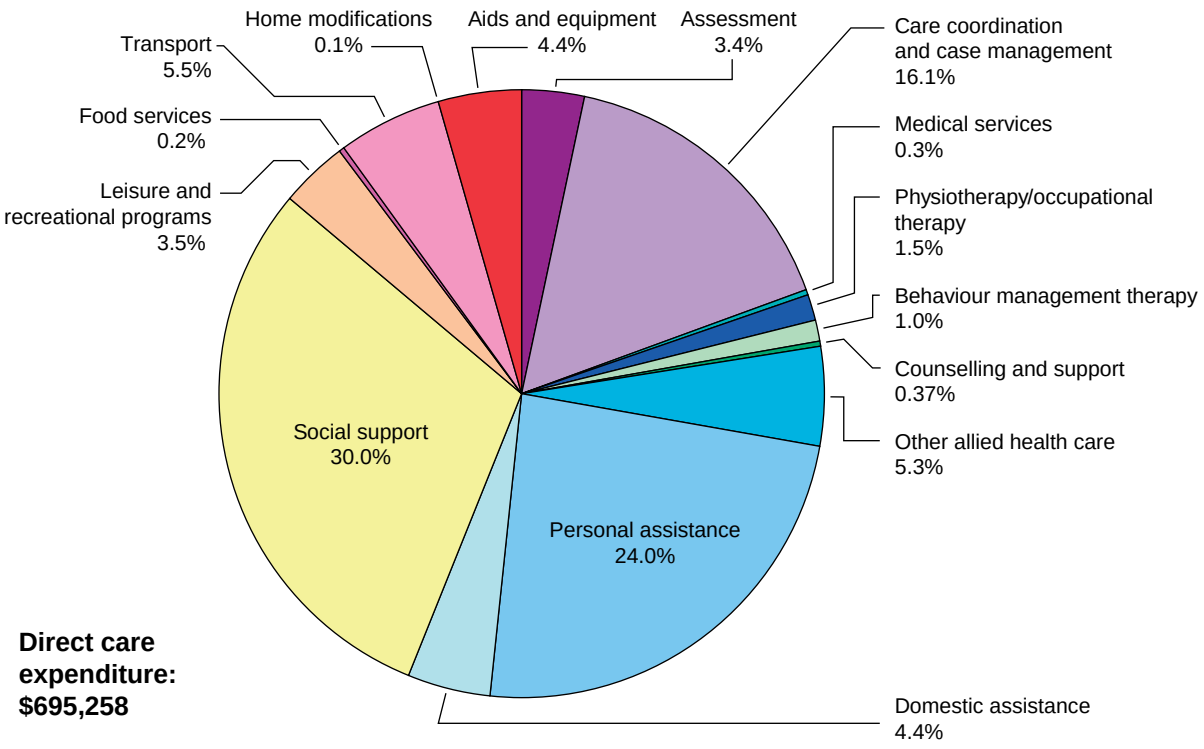
Source: Department of Health and Ageing (flexible care subsidy rates); evaluation database (client co-payment rates).

5.2 Expenditure patterns

Project expenditure reports detail expenditure on all activity covering evaluation participants and non-participating clients.

Projects reported spending between 33% and 100% of new income (new income excludes funds carried over from previous quarters) in the reporting period covered by evaluation (see expenditure as a per cent of new income, Tables 5.1 and 5.2). Department of Health and Ageing state offices monitored project occupancy and adjusted flexible care subsidy payments accordingly; some adjustments occurred within the reporting period and others occurred in earlier and later quarters. Projects that had filled all or almost all allocated places reported levels of total expenditure close to income received through flexible care subsidy. Expenditure lower than income was mostly associated with low occupancy and delays in establishing ongoing services while waiting for assessment processes to complete. Flexible care subsidy rates appear to align with total expenditure per client service day when occupancy is high.

Projects also reported a breakdown of expenditure by different categories of assistance to clients. MS Changing Needs and Cumberland Prospect Disability Aged Care Pilot are excluded from the overall breakdown of direct care expenditure shown in Figure 5.1. Across the remaining seven projects, over 75% of direct care expenditure was spent on a combination of social support (30.0%), personal assistance (24.0%), assessment and case management (19.5%), and allied health assessment and therapy (6.8%). The service expenditure profile changes over time as projects complete the bulk of assessments and establish care plans. Thus, the proportion of direct care expenditure on assessment and case management was influenced by the fact that some projects were still completing initial client intake.



Source: Appendix Table C1.

Figure 5.1: Innovative Pool Disability Aged Care Interface Pilot: total services expenditure by service type, all projects except MS Changing Needs and Cumberland Prospect Disability Aged Care Pilot, 1 July – 31 December 2004

A similar breakdown of services expenditure in each project can be seen in Figure 5.2. Three projects in New South Wales—Far North Coast Disability and Aged Care Consortium, Northern Sydney Disability Aged Care Pilot and Cumberland Prospect Disability Aged Care Pilot—show expenditure on client services focused mainly on providing additional personal assistance and allied health interventions. The expenditure profiles of the latter two are similar, reflecting the completion of initial needs and allied health assessments during the evaluation. Northern Sydney Disability Aged Care Pilot provided an update on project expenditure to June 2005, reflecting a stabilised expenditure profile for an established client group (see section 3.3 in Chapter 3).

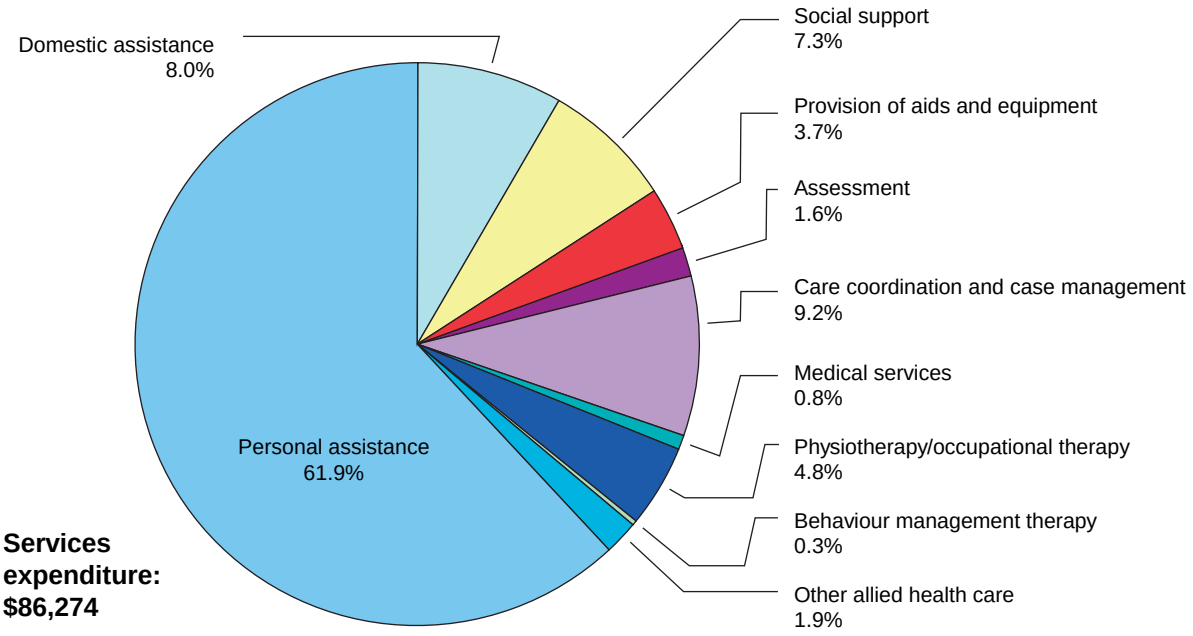
Central West People with a Disability who are Ageing (New South Wales), and the two projects in South Australia, Flexible Aged Care Packages and Disability and Ageing Lifestyle Project, recorded service expenditure profiles that more closely resemble each other than those of other projects. During the evaluation these projects directed a relatively high proportion of service expenditure to social support, recreation and leisure and associated transport costs. Subsequently, Central West People with a Disability who are Ageing reported delivering higher amounts of personal assistance to clients during 2005, which is likely to have altered that project's service expenditure profile.

Disability Aged Care Service (DACS) in Perth is a primarily therapeutic service, channelling most service expenditure into personal assistance, allied health and physical maintenance

and life skills development programs. Following allied health assessments, DACS develops individual care plans that aim to maintain fine and gross motor skills, and stimulate conversation and cognitive and sensory function. These programs are developed with and monitored by allied health professionals contracted to Senses Foundation for DACS.

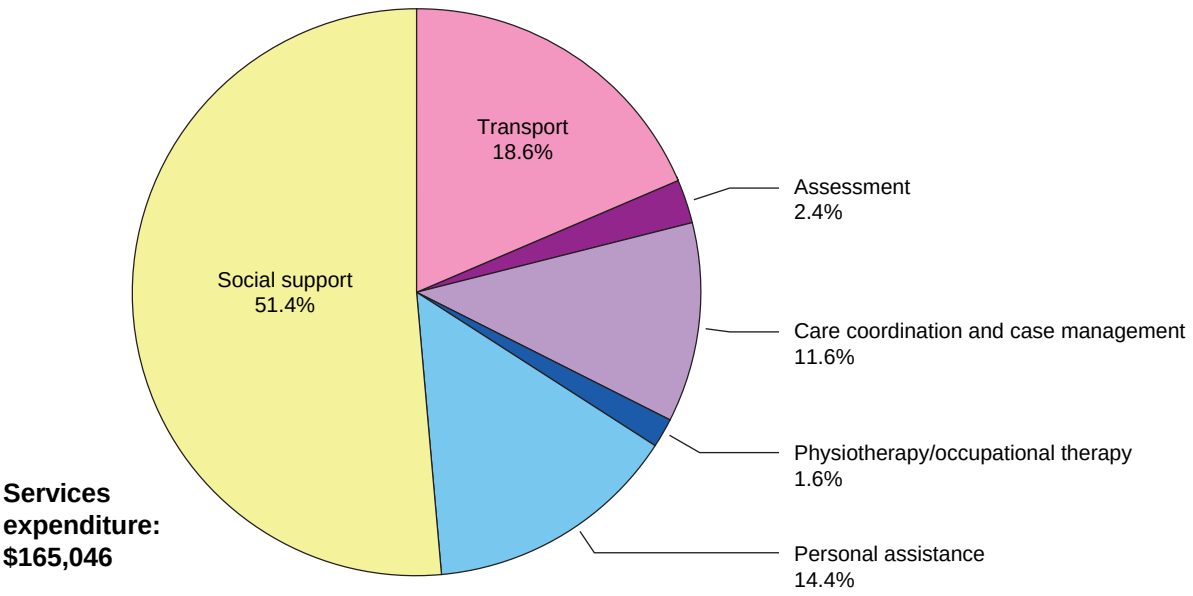
Ageing In Place, Tasmania, shows a mixed service expenditure profile covering personal assistance, behaviour management and social interventions. The project was designed to extend daytime supervision and care for clients from the 66 hours per week available through disability funding to 96 hours per week. This extension of hours to cover the period 9.00 am to 3.00 pm has provided scope to engage clients in day programs in the local community and activities tailored to individual hobbies and interests. Additional capacity for personal assistance through the Pilot and seen in the AIP services expenditure profile allows clients who have made or are in the retirement transition to depart from the usual household morning routine.

Far North Coast Disability and Aged Care Consortium



Services expenditure: $86,274

Central West People with a Disability who are Ageing

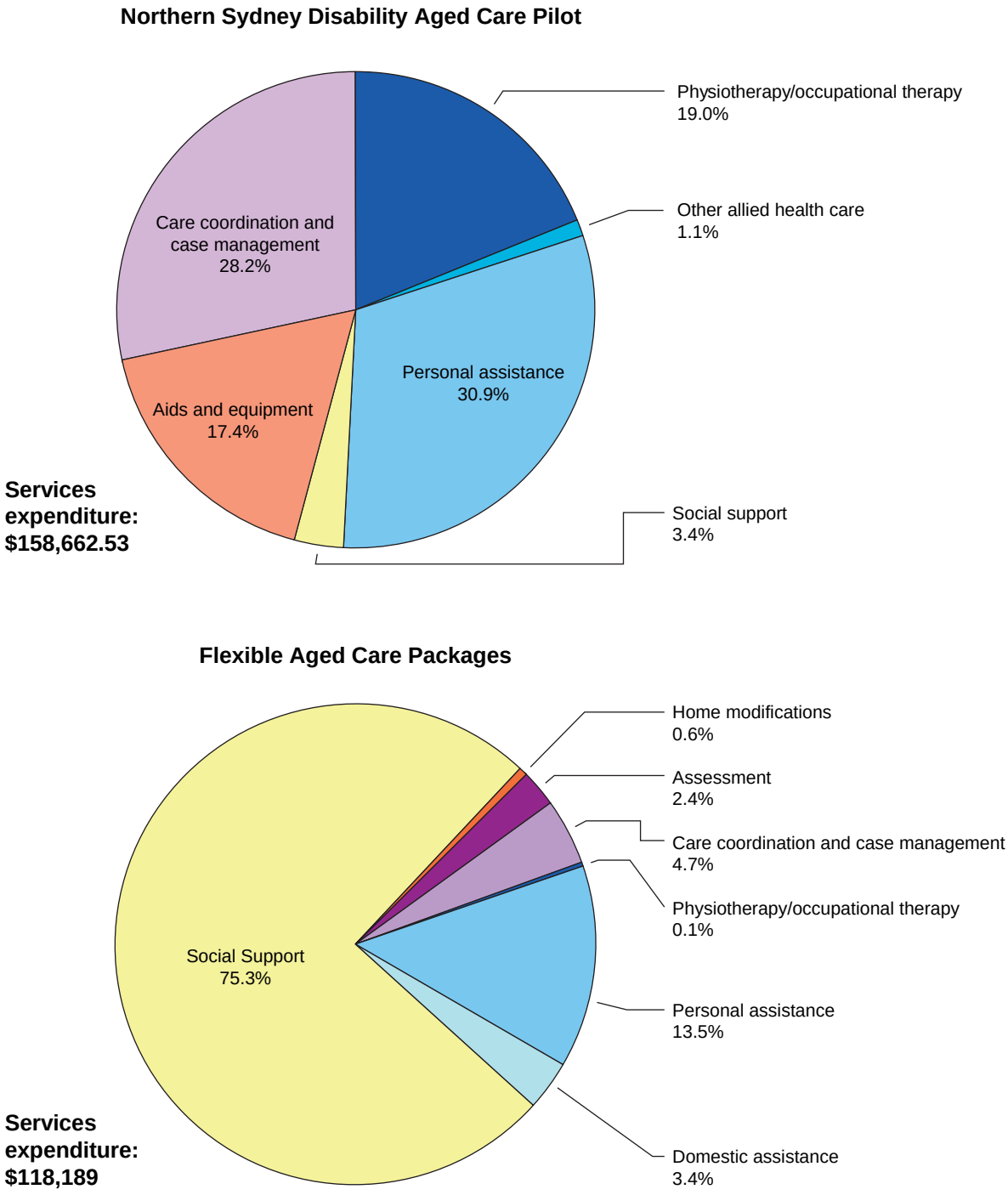


Services expenditure: $165,046

Source: Appendix Tables C2 and C3.

Figure 5.2: Innovative Pool Disability Aged Care Interface Pilot, services expenditure by service type, by project, 1 July – 31 December 2004

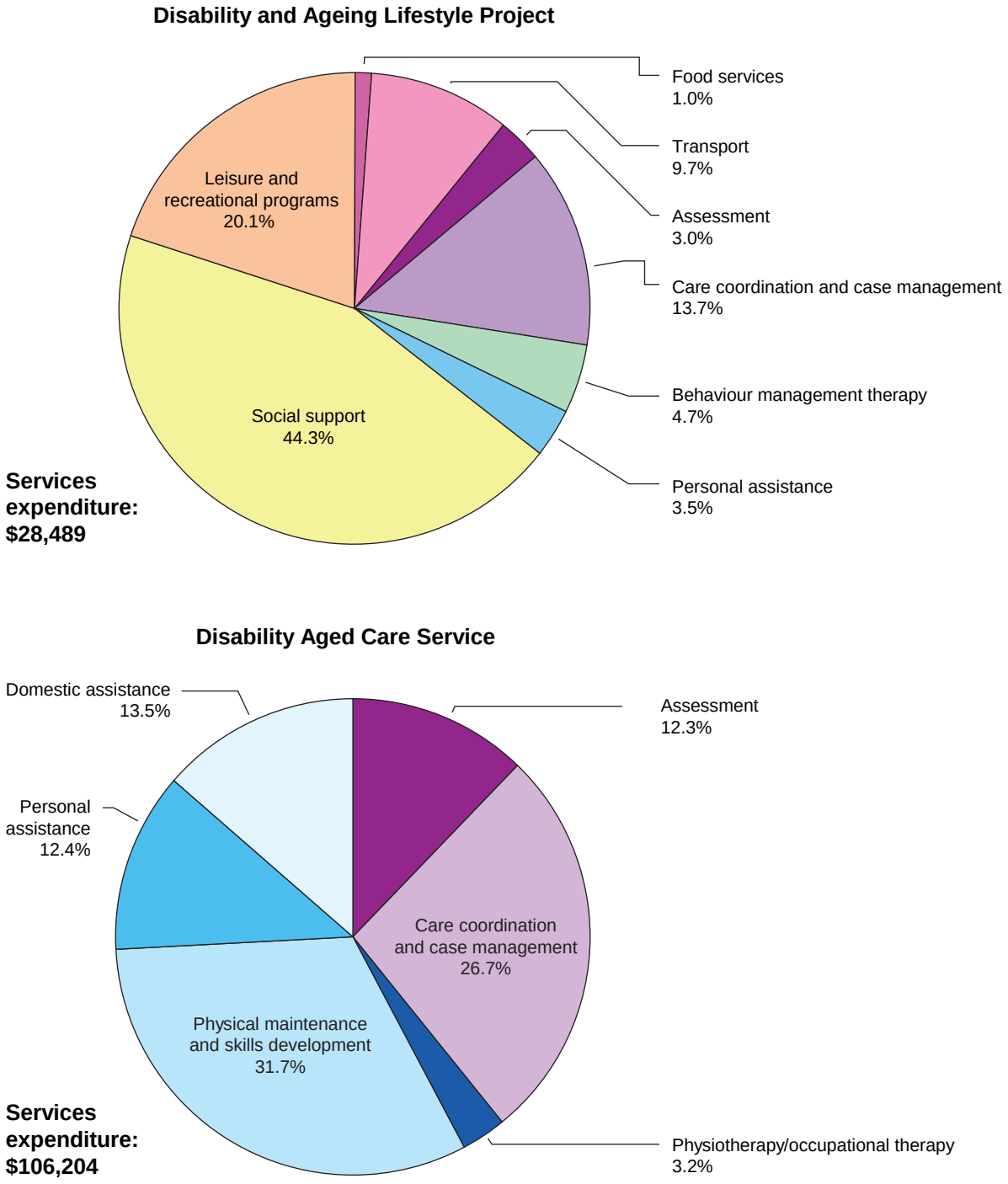
(continued)



Source: Appendix Tables C4a–b, C5.

Figure 5.2 (continued): Innovative Pool Disability Aged Care Interface Pilot, services expenditure by service type, by project, 1 July – 31 December 2004

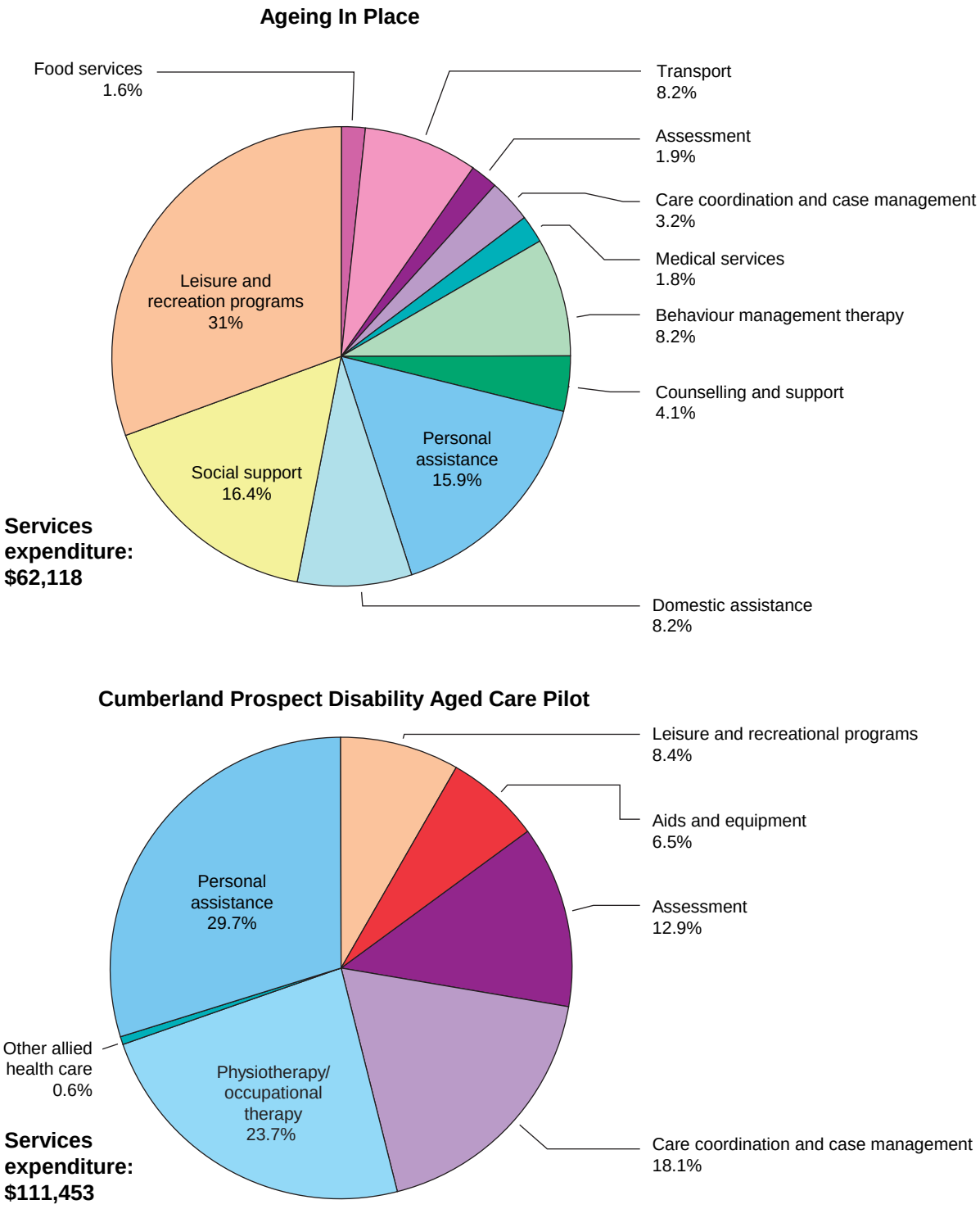
(continued)



Source: Appendix Tables C6–C7.

Figure 5.2 (continued): Innovative Pool Disability Aged Care Interface Pilot, services expenditure by service type, by project, 1 July – 31 December 2004

(continued)



Source: Appendix Tables C8–C9 (figures reported for the Cumberland Prospect Aged Care Pilot refer to the March and June 2005 financial quarters).

Figure 5.2 (continued): Innovative Pool Disability Aged Care Interface Pilot, services expenditure by service type, by project, 1 July – 31 December 2004

Provision of aids and equipment features in the service profiles of three projects in New South Wales and assessments of Ageing In Place (Tasmania) clients also led to the purchase of aids by the disability service provider, Oakdale Services (Table 5.4). Between these projects a total of $13,781 of project funds and an additional $4,813 of external funds were spent on aids and equipment for Pilot clients. Unspecified aids or equipment were purchased for 18 clients; seven clients received mobility aids. Access to funding for aids and equipment was cited by several project coordinators and disability service providers as a key benefit of the Pilot for individual clients. Expenditure on aids and equipment from project funds and other expenditure categories is shown in Appendix Table C1.

Table 5.4: Innovative Pool Disability Aged Care Interface Pilot, number of clients receiving aids and equipment and expenditure on aids and equipment, by aid/equipment type and project

	Project funding		External funding		Total	
Aids and equipment	**Clients**	**Dollars**	**Clients**	**Dollars**	**Clients**	**Dollars**
Mobility aids						
CPDAC, NSW	4	996	—	—	4	996
FNCDAC, NSW	2	745	—	—	2	745
NSDACP, NSW	1	1,041	—	—	1	1,041
Total mobility aids	*7*	*2,782*	—	—	*7*	*2,782*
Hearing aids						
AIP, Tas	—	—	2	32	2	32
Total hearing aids	—	—	*2*	*32*	*2*	*32*
Continence aids						
AIP, Tas	—	—	2	343	2	343
CPDAC, NSW	2	1,074	—	—	2	1,074
Total continence aids	*2*	*1,074*	*2*	*343*	*4*	*1,417*
Home modifications						
AIP, Tas	—	—	1	66	1	66
FNCDAC, NSW	1	765	—	—	1	765
Total home modifications	*1*	*765*	*1*	*66*	*2*	*831*
Other aids						
AIP, TAS	—	—	3	4,372	3	4,372
CPDAC, NSW	5	4,636	—	—	5	4,636
FNCDAC, NSW	5	1,990	—	—	5	1,990
NSDACP, NSW	5	2,534	—	—	5	2,534
Total other aids	*15*	*9,160*	*3*	*4,372*	*18*	*13,532*
Total aids and equipment expenditure		**13,781**		**4,813**		**18,594**

— Nil.

5.3 Main findings

Flexible care subsidy payments to Disability Aged Care Interface Pilot projects ranging between $30.73 to $68.50 per place day are at a somewhat higher rate than CACP subsidy but substantially lower than basic daily care subsidy for high level residential care (basic daily care subsidy does not necessarily fully cover the cost of care, however). Cost comparisons need to factor in the significant contributions of state governments towards the cost of maintaining people with disabilities in the community.

Currently no community care mainstream equivalent or alternative to the 'top-up' model of Pilot service is available to the target group. The cost of service delivery as reflected in project total expenditure observed during the evaluation reflects projects at different levels of maturity, some still completing initial needs assessment and further specialised assessments and others with most clients established in their care plans. It appears that once a project is established total expenditure closely approximates income from flexible care subsidy. Occupancy monitoring has meant that adjustments were made during, before and after the evaluation reporting period and these would invalidate estimates and comparisons of expenditure per client service day from data supplied for the evaluation.

Expenditure and service profiles support the broad separation of projects into distinct categories, being mainly social care intervention or mainly therapeutic intervention. Within these categories some or most clients received higher levels of personal assistance through the Pilot and some projects delivered a range of services spanning both categories of assistance. This separation can also be seen by considering the distribution of weekly hours per client on personal assistance and specific allied health care interventions[10] combined, depicted in Figure 5.3. Projects that have channelled higher proportions of expenditure into social interventions have nevertheless delivered high hours of additional personal assistance to small numbers of clients. Thus, the social care and therapeutic focuses are not mutually exclusive but are driven by the needs of the client group at the time.

10 Physiotherapy, occupational therapy, social work, psychological assessment and counselling, podiatry, dietetics and alternative therapies.

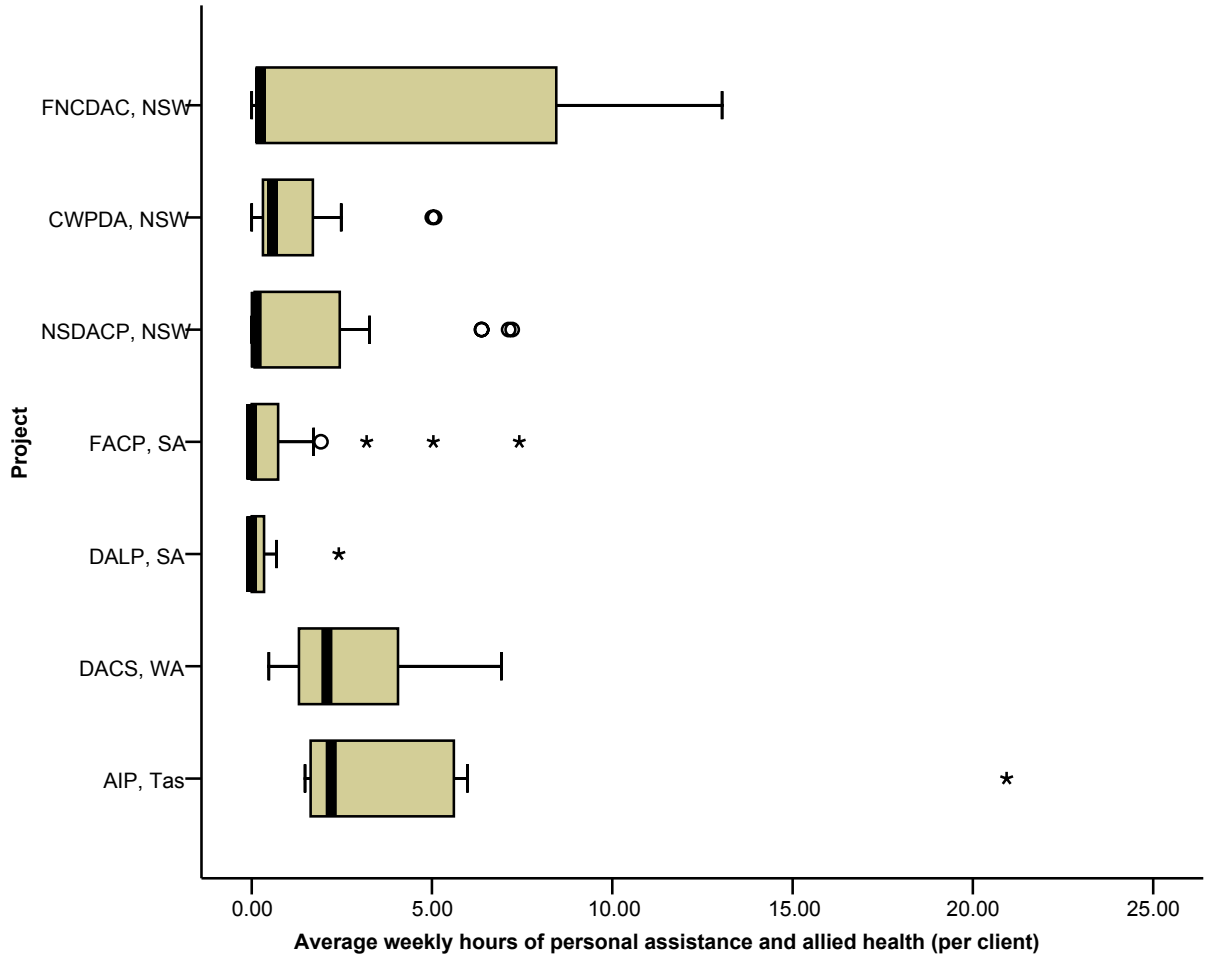


Figure 5.3: Innovative Pool Disability Aged Care Interface Pilot, distribution of average weekly hours per client for personal assistance and allied health care, by project

6 Care Experience Survey

6.1 Summary of results

Group home managers and disability support workers completed the bulk of questionnaires, with input from clients, family members or other advocates in a small number of cases. As such, responses largely reflect a disability services perspective of clients' care experiences and the experiences of staff in how projects interact with usual client care in the context of individual clients and the broader service environment. These perspectives may differ across geographical locations or even from one disability service to the next within an area.

Survey questions are a combination of multiple-choice, limited response and open-ended questions. Responses to open-ended questions were often quite detailed and specific to the relevant individual clients. In some cases themes that emerged in responses to open-ended questions appear inconsistent with responses to multiple-choice and limited response questions on the same form.

Identified needs

As expected, clients were identified as having needs across a wide range of areas that could be related to ageing (Disability Aged Care Interface Pilot clients are a group with longstanding needs for assistance, supervision and support; ACAT assessment has identified age-related needs in addition to pre-existing disability-related support needs). Survey respondents most commonly described progressive age-related needs, that is, needs related to ageing that are observed to be increasing over time, to include:

- mobility assistance
- behaviour management
- increased personal assistance
- assistance to encourage domestic and community participation as a means to arrest or prevent increasing social isolation.

Most respondents said that, prior to the Pilot, client needs in the areas of medication management, social support, transport, personal assistance and assistance to make appointments tended to be met. The areas most often referred to as areas of unmet need (where assistance was being received by the client before the Pilot but more help was needed) were leisure and recreation, transport to access the community, assistance to participate in household activities, personal assistance and physiotherapy. Allied health services (specifically speech therapy and physiotherapy), management of behavioural symptoms and social integration were the most commonly identified areas of unmet need (areas of need where no assistance was being received by the client prior to the Pilot).

Fully unmet need was not mentioned as frequently as partially met need, which is perhaps understandable given that clients are living in a supported accommodation environment. This may reflect disability service provider concerns that, while they are able to provide services to address a wide range of client needs, the level of those services may be insufficient to fully meet needs that are becoming more complex as clients age. In particular,

service gaps may appear as clients' needs change from episodic to continuous, for example, as mobility limitation, incontinence or dementia increase, the need for supervision and support increases from an occasional to continuous basis.

Areas of need identified through the Survey are broadly consistent with the services being provided by projects. Analysis of service utilisation data indicates that, though delivery varies across projects, most projects were focusing on the provision of allied health care or social support and participation in addition to increased personal assistance. Across all projects, survey responses suggest that clients were most commonly receiving help in the areas of personal assistance (50.4% of clients), occupational therapy (41.2% of clients), physiotherapy (36.6% of clients), social support (33.6% of clients), and recreation and leisure programs (31.3% of clients).[11]

Hopes and expectations of what the Pilot would deliver

Expressed hopes and expectations of the Pilot fall into two main categories. Some hopes and expectations relate to specific outcomes for individual clients, for example, 'to improve skill levels' and 'establish new networks and friends'. Others relate to benefits to the overall service delivery system, such as reduced stress for disability support staff: '…our service's duty of care around issues of personal safety and medication administration could be alleviated…'.

Project implementation

Respondents mostly gave positive ratings for project staffing, convenience, and planning and coordination. The majority of respondents believed that the projects meet previously unmet needs, and rated the amount of additional assistance provided as good to very good. Provision of more resources for care, increased client participation, access to specialist services, and maintaining or improving client wellbeing are the most frequently mentioned beneficial aspects of the projects.

Limited additional resources available through the project (funding, staffing, hours of care) was the most frequently levelled criticism. Level of provision of physiotherapy and speech therapy services, day and leisure programs, social support and transport services are cited as unsatisfactory in a number of projects, due to limited availability, staffing issues and other factors.

Staff education and skills transfer

One hypothesised benefit of the Pilot is the strengthening of the disability and aged care interface through skills transfer. Negative views about aspects of project implementation concentrate largely on this issue: whether disability support staff are provided with adequate education and training to implement client care plans, and whether a project helps to impart aged care skills and experience to disability support staff. Almost 50% of respondents failed

11 Percentages of clients receiving a service do not necessarily reflect service intensity. Although a high percentage of clients received some occupational therapy and/or physiotherapy, the amount of these services received by a client can be quite low (for example, all clients in a project may have received a routine one-hour physiotherapy assessment, but no active physiotherapy intervention).

to confirm that skills transfer was taking place. Negative, mixed and undecided responses to this question are distributed across the projects, including projects with an explicit training component. Responses from staff in homes participating in one project are not always consistent. For example, different staff from one group home participating in the Northern Sydney project consistently reported that the education and training to implement care plans was good to very good, yet more than half the staff from the same home suggested that the project did not facilitate the transfer of aged care skills and experience to disability support staff. Staff in another home participating in the Northern Sydney project rated education and training as unsatisfactory.

There is no obvious pattern of response to questions on education and skills transfer in relation to project staffing models. It is plausible that some project implementation models are not well suited to provide 'on-the-job' transfer of aged care skills—there may be a 'handover' from project coordinators to disability support staff who then function on a daily basis without interaction with aged care staff. In addition, disability support staff may not consider knowledge acquired for the implementation of a care plan for a specific client as 'knowledge and expertise in aged care'. Whether or not staff members believe that such specific learning will help them generally care for clients who are ageing is not clear in the survey responses.

Project model as a long-term care option

Messages on the viability and appropriateness of the 'top-up' model of aged care service delivery are mixed. Some respondents gave very positive responses about the projects and were cautiously optimistic about their potential in helping maintain clients at home as they age, stating a proviso that service levels would need to be able to respond to increasing client needs. Others indicated that the level of additional support provided by their project was insufficient to adequately manage a client's current age-related needs, making the project an inadequate form of support to allow the client to stay at home over the longer term, particularly in the context of needs which were observed to be increasing over time.

Over 90% of the 40 respondents who answered the question on whether projects are an appropriate longer term option for clients indicated that it is appropriate to support the client in the group home setting given their identified age-related needs. The remaining respondents were unsure whether this model of additional service provision is appropriate. No respondent indicated a belief that supporting the client within the group home was inappropriate; however, as more than 50% of respondents did not answer the question, it is hard to draw an overall conclusion on acceptance of the Pilot concept.

On a multiple choice item, the majority of respondents (76%) indicated that the projects were providing enough help to support disability staff in their role. Those who did not believe that the project was doing enough to assist mostly indicated that it is nevertheless appropriate to maintain the client in place as they age. For example, staff from three out of the four group homes participating in the Central West People with a Disability who are Ageing project (New South Wales) represented in the survey suggested that the project was not providing enough assistance to help disability support staff to manage clients' age-related needs. Yet all respondents from participating group homes in the Central West project said that it was appropriate to continue to care for the clients in their group homes.

Apparent contradictions may reflect a tension between a high motivation to maintain clients in the group home setting and consciousness of the reality of the increasingly complex care needs of ageing clients. There seems to be a pervasive belief within supported

accommodation services, evident in site visit interviews and the survey responses, that although transfer of a client from their familiar home environment into residential aged care may become necessary, it is rarely 'appropriate'. There is a keen awareness that clients are likely to experience increased need for assistance as they get older and that these needs are unlikely to be met within the constraints of current disability funding and/or operational arrangements. A strong emphasis on staffing ratios can be seen in responses to open-ended questions (without commensurate emphasis on the impact of staffing hours on older clients).

Implicit in survey responses is that disability funding is not responsive to the increasing needs of many older clients. Disability service providers appear to operate with static resources and care models, often predicated on a household of clients with similar lifestyles and routines who are able to spend time unsupervised and attend activities outside of the home. Some respondents are of the opinion that available funding alone is what constrains their ability to manage ageing clients. Others identified other impediments to managing increasing levels of support need, including the physical limitations of home environments, lack of staff training in age-related issues, and the disruption caused in households when some clients' needs and preferences become markedly different to those of other residents. Some respondents believe that an appropriately resourced 'top-up' aged care package delivered to the specific client could effectively address these problems, and others see increased resources within the disability sector as a better (and perhaps only real) solution.

According to the financial data provided for the evaluation, the majority of projects posted surpluses in 2004, some of which were substantial enough to prompt a reduction or suspension of their flexible care subsidy payments (most notably projects based in New South Wales). Survey responses include calls from staff in many of the group homes for higher levels of weekend support and/or increased capacity to supervise clients during the day, for example:

> 'Expand service to 7 days per week.'
>
> 'We have no weekend [service]. Client needs don't stop on Friday and commence again on Monday. I would like to see some hours given to weekends.'
>
> 'Assess the level of care required to keep the client in their home, i.e. Mon–Fri day staffing.'
>
> 'Day staff Monday to Friday in the group home.'

Disability services staff from group homes participating in the New South Wales projects were vocal about what they perceived as a service delivery shortfall, calling for 'more hours' or 'more money', not just for weekend services or increased daytime supervision. For example:

> 'Not enough assistance.'
>
> 'Individual services should be adequately funded to broker out for staff and acquire enough support (not just 3 hours a week but what each service actually needs) to provide ageing clients with an appropriate service.'
>
> '[Project could be improved if there were] more hours available [and] greater flexibility with the hours.'
>
> 'Not enough support…6 hours per week is not sufficient.'
>
> 'More funding?'

The fact of surpluses posted by projects in which disability support staff reported insufficient and/or inflexible levels of service provision to adequately cater for clients' age-related needs is difficult to reconcile. It is not clear whether such responses relate more to funding constraints in the disability sector as distinct from the level of additional support needed

from the Pilot to meet clients' identified age-related needs. This point is perhaps best illustrated in the feedback on one project: 'ten hours is not enough to keep anyone out of a nursing home' contrasted with the observation that 'an obvious benefit' is that clients are able to stay in their homes for longer. Thus, there may be differing viewpoints on the level of support delivered by the Pilot.

6.2 Survey aims, methodology and limitations

The Care Experience Survey was designed to elicit client, family and disability support worker perspectives on:

- levels of assistance required by ageing clients
- the extent to which age-related needs were met prior to the Disability Aged Care Interface Pilot project
- progress in meeting previously unmet or under-met age-related needs through the Pilot
- quality and appropriateness of Pilot services
- the suitability of Pilot services in the client's current living environment, for the foreseeable future.

Project coordinators were asked to issue the survey questionnaire for each participating client allowing for services to have been in place for the client for at least four weeks. The client or an advocate was to complete the form and mail it directly to the AIHW. The survey was anonymous but responses can be matched to de-identified client profile and assessment records using the unique client identification code recorded on the front of each questionnaire by project coordinators.

The questionnaire includes a combination of closed, limited response and open-ended questions. Respondents were asked to compare the care received from the project to usual care and to report whether the project was meeting previously unmet age-related needs. Respondents could comment on specific aspects of service delivery such as care planning and coordination; continuity of care; the range and availability of services; choice; convenience; privacy and security; and the physical environment. Disability support staff were asked to assess the feasibility of maintaining the client 'in place', and whether they believe that the project provides a suitable long-term care option for the care recipient. The questionnaire is available on request to the Ageing and Aged Care Unit, Australian Institute of Health and Welfare.

Analysis of the 92 completed questionnaires received by 31 January 2005 is summarised below. Thematic coding and data analysis were completed by Osman Consulting Pty Ltd, using the SPSS computer program.

Survey limitations

A number of points must be borne in mind in the interpretation of survey results.

Project coordinators were instructed to encourage completion of the questionnaire by the client and/or someone independent of project service delivery, wherever possible. However, as many of the clients have intellectual disability they were mostly unable to respond

without assistance and few family members were actively involved in usual care. As a result, disability support staff often responded on the client's behalf,[12] meaning that the majority of surveys were completed with the input of people who may have been directly involved in delivering project services. It cannot be assumed that a staff member would necessarily respond to questions as would the client or a family member. The survey largely provides a disability sector perspective on the Pilot concept and the individual projects, taking into account the familiar knowledge of clients.

Participation in the survey was voluntary, and there was less than 100% participation. The evaluation team received reports of resistance to completing the survey form related to concerns about the 'extra paperwork' for evaluation. It is possible that some response bias has resulted, as surveys are less likely to have been completed for clients residing in supported accommodation facilities where disability staff had difficulty finding the time to take part and particularly if more than one client within the facility was receiving project services necessitating multiple survey responses.

Throughout the evaluation stakeholders in all projects commented on the traditional tensions between the disability and aged care sectors. While they mostly perceived the Pilot as one solution to some of the challenges associated with disability and ageing, frustrations remain and are evident in survey responses. It is not possible to separate the relative influences on responses to survey questions of perceptions of project service provision to individual clients from perceptions of more systemic issues at the disability and aged care interface.

6.3 Response rates

A total of 148 questionnaires were distributed. As of 31 January 2005, 92 completed questionnaires had been returned (Table 6.1). Response rates for individual projects ranged between 21% and 100%, with an overall response rate of 62%.

Table 6.1: Care Experience Survey, surveys distributed and response rates[(a)] by project

Project	Surveys distributed	Surveys received	Facilities represented	Response rate (%)	Per cent of total response
Far North Coast Disability and Aged Care Consortium (NSW)	13	12	7	92.3	13.0
Central West People with a Disability who are Ageing (NSW)	33	7	6	21.2	7.6
Northern Sydney Disability Aged Care Pilot (NSW)	22	12	2	54.5	13.0
MS Changing Needs (Vic)	16	16	1	100.0	17.4
Flexible Aged Care Packages (SA)	31	27	16	87.1	29.3
Disability and Ageing Lifestyle Project (SA)	8	5	4	62.5	5.4
Disability Aged Care Service (WA)	18	8	4	44.4	8.7
Ageing In Place (Tas)	7	5	1	71.4	5.4
Total	**148**	**92**	**41**	**62.2**	**100.0**

(a) Response rate: number of care experience surveys received as a percentage of number of surveys distributed per project.

12 Project coordinators consulted disability support staff on who would complete the form.

6.4 Respondent identity

Respondents were asked to indicate who completed the questionnaire. More than one respondent could be indicated, for example, where a group home manager and a disability support worker contributed, both could be recorded, as could a client and relative or client and disability support worker. Thirty-one questionnaires (34%) were completed without the involvement of disability service staff or project coordinator, 19 of which were completed with client input (Table 6.2).

Far North Coast Disability and Aged Care Consortium was able to recruit some family members to assist clients to complete the questionnaire or to respond on behalf of clients.[13] Ageing In Place, Tasmania, arranged for an independent advocate from Advocacy Tasmania to assist clients to complete questionnaires together with disability support staff.

A high degree of consistency can be seen in the responses for clients living in the same group homes where surveys were completed by the group home manager and/or the same disability support staff. This is particularly the case for questions relating to the implementation of the project and the service model (questions about staffing, convenience and project coordination).

Fifteen questionnaires were completed with some level of input from a project coordinator. As the purpose was to obtain views of the projects from consumer and carer perspectives, a number of questions relate directly to aspects of project management and implementation. In analysing responses to these questions it was necessary to exclude those completed by or with the involvement of project coordinators.

There are too few completed forms from some projects to statistically compare responses across all of the projects (it was judged that at least 10 responses would be required for non-parametric statistical analysis). The exceptions were the Far North Coast Disability and Aged Care Consortium, Flexible Aged Care Packages, MS Changing Needs, and the Northern Sydney Disability Aged Care Pilot, each of which received more than 10 completed forms. Statistical comparisons between these four projects are reported for a number of variables.

13 Surveys were distributed to family members where possible and to disability support staff, so in some cases two questionnaires were completed for one client.

Table 6.2: Care Experience Survey, respondent identity by project

Project	Client with or without assistance— relative or independent advocate	Relative or independent advocate	Client with assistance— disability service staff	Client with assistance — disability service staff and project coordinator	Disability service staff and relative/ independent advocate	Disability service staff only	Project coordinator only	Total
				(number)				
Far North Coast Disability and Aged Care Consortium	—	4	—	—	1	7	—	**12**
Central West People with a Disability who are Ageing	—	—	—	—	—	7	—	**7**
Northern Sydney Disability Aged Care Pilot	—	—	—	—	—	12	—	**12**
MS Changing Needs	14	—	—	—	—	2	—	**16**
Flexible Aged Care Packages	—	2	4	5	—	6	10	**27**
Disability and Ageing Lifestyle Project	—	—	1	—	—	4	—	**5**
Disability Aged Care Service	—	—	1	—	—	7	—	**8**
Ageing In Place	5	—	—	—	—	—	—	**5**
Total	**19**	**6**	**6**	**5**	**1**	**45**	**10**	**92**
				(per cent)				
Far North Coast Disability Aged Care Consortium	—	33.3	—	—	8.3	58.3	—	**100.0**
Central West People with a Disability who are Ageing	—	—	—	—	—	100.0	—	**100.0**
Northern Sydney Disability Aged Care Pilot	—	—	—	—	—	100.0	—	**100.0**
MS Changing Needs	87.5	—	—	—	—	12.5	—	**100.0**
Flexible Aged Care Packages	—	7.4	14.8	18.5	—	22.2	37.0	**100.0**
Disability and Ageing Lifestyle Project	—	—	20.0	—	—	80.0	—	**100.0**
Disability Aged Care Service	—	—	12.5	—	—	87.5	—	**100.0**
Ageing in Place	100.0	—	—	—	—	—	—	**100.0**
Total	**20.7**	**6.5**	**6.5**	**5.4**	**1.1**	**48.9**	**10.9**	**100.0**

Note: Disability service staff can be disability support workers and/or group home managers.

— Nil.

6.5 Thematic framework

The AIHW engaged a statistical consultant to develop a thematic coding framework for responses to open-ended questions and perform content analysis.

Development of the thematic framework was an iterative process. The consultant completed a thematic analysis of a subset of hand-written responses to five key open-ended questions. The first two of these questions focus on needs and expectations. Two initial lists of 20 to 30 recurring themes were constructed, one by the consultant and one by the AIHW evaluation team. A high level of agreement was apparent and the process of cross-referencing the two lists produced a set of core themes for the initial framework. This list was further expanded and refined to accommodate responses to three more open-ended questions dealing with project services and staffing.

The AIHW evaluation team reviewed the resulting set of codes. A number of additional codes were subsequently added to the framework until it was shown that responses to the five key open-ended questions in 50 completed questionnaires could be coded satisfactorily. The final framework consists of:

- 30 core themes
- 10 themes specifically associated with how the projects meet or fail to meet client needs
- nine themes that deal specifically with staffing issues
- nine themes associated with aspects of the Pilot that attract positive feedback from respondents
- nine themes associated with aspects of the Pilot that attract negative feedback from respondents
- 15 themes to cover general comments, both positive and negative.

Over 80 themes were identified in the coding framework and used in the analysis. The framework has been designed so that specific themes can be combined into more general categories for reporting purposes.

6.6 Survey results

Identified needs of clients

Responses to Question 1 provide an indication of respondents' views of how well client needs were met prior to entering a Pilot project in areas related to ageing. Clients were said to have had high levels of identified need (met need, partially met need and unmet need, combined) across all activity areas, with between 58% and 99% of clients, by project, requiring assistance in each area of activity (Table 6.3).

The most common areas of fully met need include medication management (40 clients), social support (39 clients), transport (36 clients), personal assistance (32 clients) and assistance to make appointments (31 clients). Leisure and recreation (53 clients), transport to access the community (44 clients), assistance to participate in domestic life (43 clients), personal assistance (37 clients) and physiotherapy (33 clients) were commonly identified areas in which clients were receiving some assistance prior to the Pilot but needed more assistance.

Relatively few clients are identified as not receiving any assistance in areas where assistance was needed prior to the Pilot. The most commonly identified areas where clients needed assistance but were not receiving *any* help were speech therapy and management of behavioural symptoms (9 clients each), physiotherapy and social support (six clients each), and assistance to make appointments and nursing care at home (four clients each).

Responses to Question 1 for clients in the Far North Coast Disability and Aged Care Consortium, Flexible Aged Care Packages, MS Changing Needs, and the Northern Sydney Disability Aged Care Pilot projects were analysed to test whether differences exist between projects in the level of identified support needs prior to entering a project.[14] In all but one domain— physiotherapy—there are significant differences in the level of need between projects ($p < 0.05$), meaning that the client groups are reported as entering these projects at different average levels of support need.

Generally, respondents from the Far North Coast Disability and Aged Care Consortium and MS Changing Needs indicated higher levels of support need against most items in Question 1, whereas respondents from the Flexible Aged Care Packages project almost always indicated a lower level of need. The response patterns are different in some areas, for example, respondents from the Far North Coast Disability and Aged Care Consortium and Flexible Aged Care Packages projects indicated higher levels of need for social support than did respondents from the other two projects; respondents from the Flexible Aged Care Packages project and MS Changing Needs reported higher levels of need for leisure and recreation services.

14 The Kruskal Wallis non-parametric test was performed.

Table 6.3: Care Experience Survey, adequacy of assistance prior to project

Assistance type	Enough assistance	Some assistance received, but more needed	No assistance received, but assistance needed	Total identified need	Total identified unmet/under-met need	Not applicable[(a)]	Total
				(number)			
Personal assistance	32	37	3	72	40	4	76
Personal assistance at weekends	29	32	2	63	34	13	76
Continence management	30	27	3	60	30	16	76
Medication management	40	23	2	65	25	11	76
Provision of aids	26	30	2	58	32	18	76
Mobility assistance	23	30	1	54	31	22	76
Transport	36	31	1	68	32	8	76
Making appointments	31	26	4	61	30	15	76
Nursing care at home	18	28	4	50	32	26	76
Medical care	30	16	2	48	18	28	76
Speech therapy	14	21	9	44	30	32	76
Physiotherapy	16	33	6	55	39	21	76
Management of behavioural symptoms	19	29	9	57	38	19	76
Participate in domestic life	22	43	2	67	45	9	76
Leisure and recreation	20	53	2	75	55	1	76
Transport to community	25	44	2	71	46	5	76
Social support	39	25	6	70	31	6	76

(continued)

Table 6.3 (continued): Care Experience Survey, adequacy of assistance prior to project

Assistance type	Enough assistance	Some assistance received, but more needed	No assistance received, but assistance needed	Total identified need	Total identified unmet/under-met need	Not applicable[(a)]	Total
				(per cent)			
Personal assistance	42.1	48.7	3.9	94.7	52.6	5.3	100.0
Personal assistance at weekends	38.2	42.1	2.6	82.9	44.7	17.1	100.0
Continence management	39.5	35.5	3.9	78.9	39.5	21.1	100.0
Medication management	52.6	30.3	2.6	85.5	32.9	14.5	100.0
Provision of aids	34.2	39.5	2.6	76.3	42.1	23.7	100.0
Mobility assistance	30.3	39.5	1.3	71.1	40.8	28.9	100.0
Transport	47.4	40.8	1.3	89.5	42.1	10.5	100.0
Making appointments	40.8	34.2	5.3	80.3	39.5	19.7	100.0
Nursing care at home	23.7	36.8	5.3	65.8	42.1	34.2	100.0
Medical care	39.5	21.1	2.6	63.2	23.7	36.8	100.0
Speech therapy	18.4	27.6	11.8	57.9	39.5	42.1	100.0
Physiotherapy	21.1	43.4	7.9	72.4	51.3	27.6	100.0
Management of behavioural symptoms	25.0	38.2	11.8	75.0	50.0	25.0	100.0
Participate in domestic life	28.9	56.6	2.6	88.2	59.2	11.8	100.0
Leisure and recreation	26.3	69.7	2.6	98.7	72.4	1.3	100.0
Transport to community	32.9	57.9	2.6	93.4	60.5	6.6	100.0
Social support	51.3	32.9	7.9	92.1	40.8	7.9	100.0

(a) Includes missing values.

Age-related needs

Question 3 asks the respondent to describe the client's most pressing age-related needs. Age-related needs were defined on the questionnaire as 'needs that have emerged in recent times as a result of growing older, as distinct from long-standing disability-specific needs' (Box 6.1). Thematic analysis of responses to this question shows that non-specific 'progressive age-related' needs was most commonly identified (16 responses), followed by behaviour management (15 responses), mobility assistance (14 responses) and personal assistance (10 responses) (Table 6.4).

Responses are broadly consistent with responses to Question 1 (adequacy of prior level of assistance), although respondents communicated higher levels of need and identified more specific gaps in care relating to clients' age-related needs through the open-ended question compared to the closed format responses in Question 1.

Box 6.1: Examples of answers to Question 3—What activities do you [the client] need help with the MOST?

'1. Maintaining hygiene—particularly with regard to continent [sic] issues, body odour and having soiled hands. 2. Behavioural issues—mood swings, sudden loudness/yelling, increases stubbornness, crying and anger. Being intolerable to live with. Needs medication.'

'[Client] was suspected of acquiring Guillain-Barre Syndrome in 2002. She is now totally dependent on staff for all activities of daily living. She also is seen by a psychiatrist every month due to her depression and psychosis.'

'Palliative care to ensure her needs are being met. [Client] often refuses food. We have had a palliative care assessment who [sic] said this is OK but she is very underweight. The staff find this difficult emotionally to deal with.'

'Mobility assistance—especially to access the local community, mainly due to deterioration of eyesight and unsteadiness when walking.'

'Mobility and health care e.g. cataracts—vision impaired, exercise and hydrotherapy, memory loss.'

'Stiffness to joints and back pain, hearing impairment. Requires occasional help with personal care due to dizziness or health issues. Personal dignity due to the need for more assistance in areas of personal care and ADLs. Eyesight impairment as very involved in close craft work and knitting activities. Bones in feet deteriorating due to age.'

'[Client] has severe osteoporosis and has had a number of fractures. In the past [client] was able to walk around unaided. She can not do this due to her high falls risk. She must always be supported by a staff [sic].'

'Obsessive compulsive behaviours mean I need help with eating meals (currently 22 kg heavier). Dressing, bathing. Generally due to these activities taking so long not due to ability— able to do it.'

Table 6.4: Care Experience Survey, clients' most pressing age-related needs, analysis of open-ended question

Age-related need	Responses[(a)]	Per cent
Progressive age-related needs	20	26.3
Mobility	19	25.0
Behaviour management	16	21.1
Personal assistance	13	17.1
Participation	12	15.8
Continence management	11	14.5
Safety	6	7.9
Access to specialist/allied health services	6	7.9
Assistance with shopping	5	6.6
Assistance with meals	4	5.3
Nursing support	4	5.3
Confidence/reassurance	4	5.3
More resources for care/services	3	3.9
Independence	1	1.3
Respite care	1	1.3
Ability to change lifestyle	1	1.3
Exercise	1	1.3
Dementia-related needs	1	1.3
Support to pursue personal interests	1	1.3
No comment	20	26.3

(a) More than one age-related need could be recorded per client.

Expectations of what projects would deliver

Question 4 asks the respondent to describe their hopes and expectations of what the project would deliver in addition to the help and care that was already available to the client in the supported accommodation setting. Responses to this question are varied, and appear genuinely specific to individual clients (Box 6.2). These responses provide more information about an individual's needs that were not fully met prior to the project. The service gaps identified vary according to individual client and service context.

Box 6.2: Examples of answers to Question 4—At the outset, what did you *hope* or *expect* the pilot program would deliver [for the client]?

'More going out with friends, on day trips like for lunch and that. Time to do my shopping.' [emphasis original]

'I hoped this program would improve skill levels, I expected a vast improvement in quality of life.'

'Quality time with the client.'

'New friends and networks; meaningful activities and exercise; home management and nutrition; mobility assistance.'

'The pilot program offered a more regular routine for [client] around events of daily living (e.g. shopping, banking) which were not able to be addressed routinely prior to the program beginning. With 1:1 support (and familiar staff), it was hoped that [client's] levels of anxiety and frustration could be lowered, our service's duty of care around issues of personal safety and medication administration could be alleviated, and [client's] quality of life through social inclusion could be enhanced.' [emphasis original]

'Day care when I gave up work as the service is not funded to provide day care.'

'Continue and increase his growing support needs. Identify gaps in care levels and compensate with extra assistance and specialised care and allied health professionals.'

Quality and appropriateness of services

The majority of respondents (61%) believed that their project was addressing previously unmet needs (Table 6.5). Fifteen respondents across four projects stated that their project was addressing some areas of unmet need, but not to the extent that they had hoped, and 11 respondents across five projects were unsure about whether the project was effective in meeting previously unmet age-related needs. Three respondents across two projects indicated that the project was not addressing some important needs.

A majority of respondents rated the amount of additional assistance delivered by their project as satisfactory or good to very good (Table 6.6). Physiotherapy and occupational therapy services were most often rated as unsatisfactory (13 responses), followed by mobility assistance, assistance to participate in domestic life and transport to community and social events (10 responses each), and provision of aids and equipment and speech therapy (9 responses each). Unsatisfactory ratings were distributed across projects.

Table 6.5: Care Experience Survey, effectiveness in meeting previously unmet age-related needs, by project

Project	Yes	Partly	No	Unsure	Missing or not included	Total
			(number)			
Far North Coast Disability and Aged Care Consortium	6	5	1	—	—	**12**
Central West People with a Disability who are Ageing	2	4	—	1	—	**7**
Northern Sydney Disability Aged Care Pilot	5	4	—	3	—	**12**
MS Changing Needs	13	2	—	1	—	**16**
Flexible Aged Care Packages	8	—	—	3	16	**27**
Disability and Ageing Lifestyle Project	2	—	—	3	—	**5**
Disability Aged Care Service	8	—	—	—	—	**8**
Ageing In Place	3	—	—	—	2	**5**
Total	**47**	**15**	**1**	**11**	**18**	**92**
			(per cent of included responses)			
Far North Coast Disability and Aged Care Consortium	50.0	41.7	8.3	—	. .	100.0
Central West People with a Disability who are Ageing	28.6	57.1	—	14.3	. .	100.0
Northern Sydney Disability Aged Care Pilot	41.7	33.3	—	25.0	. .	100.0
MS Changing Needs	81.3	12.5	—	6.3	. .	100.0
Flexible Aged Care Packages	72.7	—	—	27.3	. .	100.0
Disability and Ageing Lifestyle Project	40.0	—	—	60.0	. .	100.0
Disability Aged Care Service	100.0	—	—	—	. .	100.0
Ageing In Place	100.0	—	—	—	. .	100.0
Total	**63.5**	**20.3**	**1.4**	**14.9**	. .	**100.0**

— Nil.
. . Not applicable

Table 6.6: Care Experience Survey, ratings of amount of additional assistance

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(number)		
Personal assistance	33	10	5	28	76
Weekend/evening personal assistance	22	11	7	36	76
Continence management	23	10	8	35	76
Medication management	22	11	7	36	76
Provision of aids and equipment	26	14	9	27	76
Mobility assistance	22	11	10	33	76
Transport to appointments	22	14	4	36	76
Making appointments and care coordination	26	9	6	35	76
Nursing care at home	23	10	3	40	76
Help to access medical care	14	9	5	48	76
Speech therapy	15	12	9	40	76
Physiotherapy/occupational therapy	23	10	13	30	76
Management of age-related behaviours	19	15	7	35	76
Assistance to participate in domestic life	30	9	10	27	76
Social support	27	16	8	25	76
Transport to community and social events	27	18	10	21	76
Day leisure and skills programs	13	13	8	42	76
Interpreting and translating services	1	2	2	71	76

(continued)

Table 6.6 (continued): Care Experience Survey, ratings of amount of additional assistance

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(per cent)		
Personal assistance	43.4	13.2	6.6	36.8	100.0
Weekend/evening personal assistance	28.9	14.5	9.2	47.4	100.0
Continence management	30.3	13.2	10.5	46.1	100.0
Medication management	28.9	14.5	9.2	47.4	100.0
Provision of aids and equipment	34.2	18.4	11.8	35.5	100.0
Mobility assistance	28.9	14.5	13.2	43.4	100.0
Transport to appointments	28.9	18.4	5.3	47.4	100.0
Making appointments and care coordination	34.2	11.8	7.9	46.1	100.0
Nursing care at home	30.3	13.2	3.9	52.6	100.0
Help to access medical care	18.4	11.8	6.6	63.2	100.0
Speech therapy	19.7	15.8	11.8	52.6	100.0
Physiotherapy/occupational therapy	30.3	13.2	17.1	39.5	100.0
Management of age-related behaviours	25.0	19.7	9.2	46.1	100.0
Assistance to participate in domestic life	39.5	11.8	13.2	35.5	100.0
Social support	35.5	21.1	10.5	32.9	100.0
Transport to community and social events	35.5	23.7	13.2	27.6	100.0
Day leisure and skills programs	17.1	17.1	10.5	55.3	100.0
Interpreting and translating service	1.3	2.6	2.6	93.4	100.0

Respondents were asked to indicate in what way services rated unsatisfactory did not meet expectation. Fifty-one aspects were specified within 13 different categories (Table 6.7). Physiotherapy and occupational therapy were most often identified as unsatisfactory, due to limited availability, high cost and 'other factors'. Speech therapy, transport services and day leisure and skills programs were also commonly cited as unsatisfactory (five responses each), due to limited availability, high cost, staffing issues and 'other factors'. Nominations of physiotherapy (five out of nine nominations) and speech therapy (three out of five nominations) were concentrated in the responses from one supported accommodation facility participating in the Northern Sydney project.

Table 6.7: Care Experience Survey, summary of areas rated unsatisfactory and stated reasons

Area of pilot rated as unsatisfactory	Number of responses	Reasons
Physiotherapy and occupational therapy	9	Limited availability; cost; other reason
Day and leisure skills/programs	5	Limited availability; cost; other reason
Speech therapy	5	Limited availability
Social support	4	Limited availability; staffing issues; other reason
Transport services	4	Limited availability; cost; staffing issues; other reason
Assistance to exercise	3	Limited availability; cost; not specified
Insufficient additional resources provided	3	Limited availability
Weekend/after hours support	3	Limited availability; cost; staffing issues
Assistance with domestic participation	2	Cost; staffing issues; other reason
Continence management	2	Limited availability; cost
General allied health services	2	Limited availability; staffing issues; other reason
Mobility assistance	2	Limited availability; other reason
Global dissatisfaction with pilot services	1	Cost; staffing issues; other reason
Help to make appointments	1	Unspecified
Management of age-related symptoms	1	Cost
Management of psychological and behavioural symptoms	1	Staffing issues
Personal assistance	1	Limited availability; staffing issues; other reason
Provision of aids and equipment	1	Cost
Unspecified	16	Limited availability; cost; staffing issues; not convenient; other reason

Project planning and coordination services were generally rated satisfactory or good to very good (Table 6.8). Training and education of disability support staff to facilitate the implementation of the client's care plan was rated as unsatisfactory by 11 respondents.

Fifty-six of the 76 respondents (74%) believed that the project services clients received were delivered in a manner that is always or mostly convenient to the client and the client's household (Table 6.9). Twelve respondents stated that service delivery was sometimes (though not often or always) inconvenient. Six respondents were undecided.

Table 6.8: Care Experience Survey, ratings for service planning and coordination

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(number)		
Assessment of client needs	55	18	1	2	76
Involvement of disability support staff	49	21	3	3	76
Selection of services	43	26	4	3	76
Liaison between project coordinator and disability support staff	43	21	3	9	76
Liaison with client's family	34	18	2	22	76
Training and education of disability support staff	42	17	11	6	76
			(per cent)		
Assessment of client needs	72.4	23.7	1.3	2.6	100.0
Involvement of disability support staff	64.5	27.6	3.9	3.9	100.0
Selection of services	56.6	34.2	5.3	3.9	100.0
Liaison between project coordinator and disability support staff	56.6	27.6	3.9	11.8	100.0
Liaison with client's family	44.7	23.7	2.6	28.9	100.0
Training and education of disability support staff	55.3	22.4	14.5	7.9	100.0

Table 6.9: Care Experience Survey, ratings for project convenience

Level of convenience	Responses	Per cent
Always or mostly convenient	56	73.7
Sometimes inconvenient	12	15.8
Undecided	6	7.9
Missing	2	2.6
Total	**76**	**100.0**

Ratings of project services as sometimes inconvenient are spread across five projects, each of which had a mix of positive and negative ratings from respondents across and within participating supported accommodation facilities. This suggests that the convenience of project services is affected by both household routines within participating supported accommodation facilities and individual client routines and preferences, as well as the service delivery model.

Question 11 asks respondents to comment on aspects of the project they did not like (Box 6.3). Nineteen respondents commented that there were no such aspects and 32 respondents did not comment. Thus, 67% of respondents did not identify any specific aspects of their project deemed as unsatisfactory (Table 6.10), suggesting that respondents had an overall positive, or at least not negative, view of the projects.

Box 6.3: Examples of answers to Question 11—Were there any aspects of the pilot program that you did NOT like?

'This [disability] service is not day-funded. Due to ageing issues clients (some) can not work during the day. The pilot program is one-on-one for 3 hours each client per week so it is not meeting the client or service needs.'[15]

'Not enough hours.'

'It would be helpful to have all approved funding in writing.'

'Yes and no. Pilot program in an excellent resource but because of client's ongoing need with ageing, personal care assistance and mobility, this program needs to be a permanent program.'

'It appeared that the worker designated to [client] was unaware and uninformed of what the allocated time was to be used for and what her role in this time would be.'

The most common criticism was of the level of service and resources available through a project (15 responses). These were not criticisms of the type or mode of service delivery *per se* but seem more a reflection of the belief of some respondents that more services and resources (funding, staffing levels and hours of care) are required to effectively meet client needs.

Question 12 offered respondents an opportunity to describe aspects of services that stood out as particularly effective in meeting the client's age-related needs (Box 6.4). All but 18 respondents provided some positive commentary, again illustrating that respondents had a mostly positive view of the projects (Table 6.11). The additional assistance provided by projects (21 responses), increased participation (15 responses), and access to specialist services and the optimisation and/or maintenance of wellbeing (8 responses each) were most frequently identified beneficial aspects of pilot services for clients. Thus, respondents identified aspects of service models and client outcomes.

15 Some supported accommodation providers involved with the projects reported that they were not funded to have a staff member in the house during the day. Clients who live in these group homes usually spend their days at work or in day programs. When clients 'retire' from day activities difficulties can arise because staff are not present in the home. During site visits several accommodation providers reported that they had hoped that projects would provide staff to stay at home during the day with clients who are no longer attending day activities.

Table 6.10: Care Experience Survey, aspects of the project that respondents did not like

Theme	Responses[(a)]	Per cent
None at all	19	25.0
Pilot services/funding/staffing levels/hours of care are insufficient	15	19.7
Hopes for the pilot to become permanent	2	2.6
Project services are fragmented	2	2.6
The pilot is helpful	2	2.6
Communication needs improving	1	1.3
Inadequate assistance with behaviour management	1	1.3
Inadequate assistance with meals	1	1.3
Inadequate assistance with shopping	1	1.3
Inadequate support for social needs	1	1.3
Inflexible service provision	1	1.3
Lack of professionalism	1	1.3
The pilot fails to meet some important needs	1	1.3
No comment/answer made	32	42.1

(a) More than one theme could be recorded per response.

Box 6.4: Examples of answers to Question 12—Which aspects of the pilot program stand out as particularly effective in meeting the client's age-related needs?

'Identification and assessment processes for age-related issues, introduction to age-related services through ACAT.'

'1) Reduction in the client's levels of confusion, anxiety, frustration and fatigue; 2) Opportunities have been created for the client to increase community contact and integration; 3) With 1:1 staff support the client is less vulnerable to risk of personal health and safety (especially since the client has epilepsy and regularly needed ambulance transport to hospital whilst he was unsupported out in the neighbourhood); 4) The cost for the client has been manageable.'

'Health care and mobility, falls prevention.'

'It provides quality time and care.'

'I like the staff—"nice" to me, "help me". Like to go out, with staff support, for example to BBQs. Like to go and visit people. Like to go and celebrate birthdays.' [emphasis original]

Table 6.11: Care Experience Survey, aspects of projects identified as particularly effective

Theme	Number of responses	Per cent
Provides more resources for care	21	27.6
Increased participation	15	19.7
Access to specialist services	8	10.5
Optimises/maintains wellbeing	8	10.5
Enhanced service/quality of care	6	7.9
Project staff characteristics	5	6.6
Allows clients to 'slow down' their lifestyle	4	5.3
Assistance with advancing age-related problems	4	5.3
Documented service delivery	4	5.3
Improves client safety	4	5.3
Personal assistance	4	5.3
Flexibility of the project	3	3.9
Assists with dementia-specific needs	2	2.6
Increased information	2	2.6
Mobility assistance	2	2.6
Provides clients with confidence/reassurance	2	2.6
Support from case manager	2	2.6
Continence management	1	1.3
Delays need for permanent care	1	1.3
Good GP and ACAT support	1	1.3
Insufficient services/funding	1	1.3
Nursing support	1	1.3
Pain management	1	1.3
Provides care on a one-on-one basis	1	1.3
The pilot is helpful	1	1.3
No	2	2.6
No comment/answer	16	21.1

Thirty-four responses reported that client care involved new staff in addition to the household's disability support staff (Table 6.12). Reporting of staffing models was not consistent within projects—responses were different between group homes in all projects except for Ageing In Place and MS Changing Needs (each is a fully integrated disability and aged care service model), and Disability and Ageing Lifestyle Project (for which only one participating group home responded to the question). Where projects introduced new staff into a client's household, respondents were asked to rate the staffing arrangements for the provision of additional assistance. More than 70% of respondents rated staffing arrangements as satisfactory or good to very good (Table 6.13). Nine respondents rated staffing arrangements as unsatisfactory.

Table 6.12: Care Experience Survey, project staffing models

New staff introduced into group home	Number	Per cent
Yes	34	44.7
No	30	39.5
Missing	12	15.8
Total	**76**	**100.0**

Table 6.13: Care Experience Survey, ratings of project staffing arrangements where project services introduced new staff into the client's household

Staffing arrangement	Number	Per cent
Good to very good	17	50.0
Satisfactory	7	20.6
Less than satisfactory	9	26.5
Missing	1	2.9
Total	**34**	**100.0**

A key potential benefit of the Pilot is the transfer of skills and experience between aged care and disability support staff. Forty responses (69%) reported that the project was successful in promoting skills transfer to disability support staff; 13 respondents (22%) reported that the Pilot had not delivered skills transfer; five respondents (9%) were undecided (Table 6.14). These responses are broadly consistent with responses to Question 9 in which 42 respondents (55%) rated the training and education of disability support staff to facilitate the implementation of the client's care plan as good to very good.

Table 6.14: Care Experience Survey, transfer of aged care skills and experience to disability support staff

	Skills transfer				
Project	Yes	No	Undecided	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	5	1	1	5	12
Central West People with a Disability who are Ageing	4	2	—	1	7
Northern Sydney Disability Aged Care Pilot	3	5	—	4	12
MS Changing Needs	14	1	1	—	16
Flexible Aged Care Packages	5	1	1	20	27
Disability and Ageing Lifestyle Project	3	—	—	2	5
Disability Aged Care Service	5	3	—	—	8
Ageing In Place	1	—	2	2	5
Total	**40**	**13**	**5**	**34**	**92**

(continued)

Table 6.14 (continued): Care Experience Survey, transfer of aged care skills and experience to disability support staff

Project	Skills transfer				
	Yes	No	Undecided	Missing or excluded	Total[(a)]
			(per cent)[(a)]		
Far North Coast Disability and Aged Care Consortium	71.4	14.3	14.3	. .	**100.0**
Central West People with a Disability who are Ageing	66.7	33.3	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	37.5	62.5	—	. .	**100.0**
MS Changing Needs	87.5	6.3	6.3	. .	**100.0**
Flexible Aged Care Packages	71.4	14.3	14.3	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	62.5	37.5	—	. .	**100.0**
Ageing In Place	33.3	—	66.7	. .	**100.0**
Total	**69.0**	**22.4**	**8.6**	**. .**	**100.0**

(a) Of non-missing, included responses.
— Nil.
. . Not applicable.

Negative, undecided and missing responses to the question on training and education are distributed across all projects, including projects with an explicit training component. Responses are inconsistent between group homes within each project. Staff in some group homes participating in each project believed that skills transfer was taking place, while at other homes in the same project, staff reported that the project was not helping to increase skills and experience in aged care. There is no evident association between these responses and the staffing model used to deliver project services (that is, whether or not the project introduced new staff or whether project services were delivered by existing disability support staff).

By far the majority of respondents (83%) reported that clients, families and disability support workers had an appropriate level of involvement in care planning (Table 6.15). Five respondents reported that, while clients and advocates were consulted about the care plan, they should have had a greater say. Five respondents reported that clients, their advocates and disability support staff were not adequately involved in care planning.

Table 6.15: Care Experience Survey, ratings of level of client, family or disability support staff involvement in care planning

Has the client, family members and household staff had adequate involvement in care planning for the project?		
Answer:	**Number**	**Per cent**
Yes	63	82.9
Partially	5	6.6
No	5	6.6
Missing	3	3.9
Total	**76**	**100.0**

Suitability of pilot services for long-term care provision

Approximately 85% of respondents who answered the question of the suitability of projects for long-term care indicated a belief that projects were providing disability support workers with an adequate level of support, information and practical assistance to manage clients' age-related needs at home (Table 6.16).

Seven respondents in two projects did not believe disability support staff were given adequate support from a project; another three respondents were undecided.

Table 6.16: Care Experience Survey, beliefs about whether the project provides disability workers with an adequate level of support, information and practical assistance in managing client age-related needs, by project

Project	Yes	No	Undecided	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	5	—	1	6	12
Central West People with a Disability who are Ageing	4	1	2	—	7
Northern Sydney Disability Aged Care Pilot	12	—	—	—	12
MS Changing Needs	10	6	—	—	16
Flexible Aged Care Packages	11	—	—	16	27
Disability and Ageing Lifestyle Project	5	—	—	—	5
Disability Aged Care Service	8	—	—	—	8
Ageing In Place	4	—	—	1	5
Total	**59**	**7**	**3**	**23**	**92**

(continued)

Table 6.16 (continued): Care Experience Survey, beliefs about whether the project provides disability workers with an adequate level of support, information and practical assistance in managing client age-related needs, by project

Project	Yes	No	Undecided	Missing or excluded	Total[(a)]
			(per cent[(a)])		
Far North Coast Disability and Aged Care Consortium	83.3	—	16.7	. .	**100.0**
Central West People with a Disability who are Ageing	57.1	14.3	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	100.0	—	—	. .	**100.0**
MS Changing Needs	62.5	37.5	—	. .	**100.0**
Flexible Aged Care Packages	100.0	—	—	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	100.0	—	—	. .	**100.0**
Ageing In Place	100.0	—	—	. .	**100.0**
Total	**85.5**	**10.1**	**4.4**	**. .**	**100.0**

(a) Of non-missing, included responses.

— Nil.

Respondents were asked whether, from the perspective of workers and residents in the client's household, it is appropriate to support the client in the group home setting given their existing age-related needs. The question was not answered on 47% of returned questionnaires, which is one of the lowest response rates for a single item.

Of the answers given, respondents overwhelmingly supported maintaining clients in the familiar home setting (93%) (Table 6.17). No respondent indicated that it was definitely not appropriate for the client to be cared for within the current home setting.

Table 6.17: Care Experience Survey, beliefs about the long-term appropriateness of projects for maintaining clients at home with assistance, by project

Project	Yes	Unsure	No	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	2	2	—	8	12
Central West People with a Disability who are Ageing	5	—	—	2	7
Northern Sydney Disability Aged Care Pilot	9	—	—	3	12
MS Changing Needs	—	—	—	16	16
Flexible Aged Care Packages	7	—	—	20	27
Disability and Ageing Lifestyle Project	2	—	—	3	5
Disability Aged Care Service	8	—	—	—	8
Ageing In Place	4	1	—	—	4
Total	**37**	**3**	**—**	**52**	**92**

(continued)

Table 6.17 (continued): Care Experience Survey, beliefs about the long-term appropriateness of projects for maintaining clients at home with assistance, by project

Project	Yes	Unsure	No	Missing or excluded	Total[(a)]
			(per cent[(a)])		
Far North Coast Disability and Aged Care Consortium	50.0	50.0	—	. .	**100.0**
Central West People with a Disability who are Ageing	100.0	—	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	100.0	—	—	. .	**100.0**
MS Changing Needs	—	—	—	. .	**100.0**
Flexible Aged Care Packages	100.0	—	—	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	100.0	—	—	. .	**100.0**
Ageing In Place	80.0	20.0	—	. .	**100.0**
Total	**92.5**	**7.5**	**0.0**	. .	**100.0**

(a) Of non-missing, included responses.

— Nil.

. . Not applicable.

Question 18 asks whether respondents believed the services offered by projects were an appropriate form of additional assistance for the client in the group home setting. Respondents were first asked to identify any aspects of a project which may make it unsuitable for long-term care of the client at home and then to describe how the project could be improved or expanded to better meet the client's age-related needs (Box 6.5).

Respondents mostly said that no aspect of service provision would make a project an unsuitable long-term care option; some did not answer the question (34 responses). Several respondents commented on positive aspects of projects (11 responses). Some respondents indicated that the additional assistance available from a project was adequate but might not be sufficient in the future if the client's needs increase (five responses), or that the project would need to continue indefinitely if the client were to remain at home (two responses).

Three respondents indicated that projects were not providing enough assistance to be effective as a long-term care option. Two of these responses indicated that the Pilot was viewed as a positive initiative but was somewhat disruptive for other members of the household and can create jealousy of the 'extra attention' received by Pilot clients.

Several risk factors for entry to residential aged care, even with Pilot services in place, were identified:

- deteriorating health and/or requiring nursing or medical services which cannot be provided in the home
- decline in physical functioning
- cognitive decline
- mental health issues and/or challenging behaviours
- mobility issues (for example, requiring two-person transfers when the disability service provider is not funded to provide these, or being insufficiently mobile to attend activities outside the home)

- limitations of the physical environment (for example, requiring a wheelchair when living in a privately rented house that cannot be adapted to accommodate a wheelchair)
- household dynamics (when meeting the client's needs in place unfairly impacts on the other members of the household)
- need for 24-hour supervision or staffing support and/or secure living areas to prevent injury or wandering.

Some respondents stated that, whether additional services were available through the Pilot or not, it would never be in the client's interests to be moved to another service.

When asked to indicate how the Pilot could be improved or expanded to better meet the client's age-related needs, the majority of people who responded indicated that additional funding for staffing, hours of care and access to other age-related services was needed (17 responses). Others were concerned that the Pilot (or some other source of increased funding for disability services) needs to become permanent in order to guarantee adequate service provision for the client (three responses), or indicated that the services delivered through the Pilot would need to remain flexible so that new and increasing needs can be catered for over time (13 responses). Twenty-four respondents did not comment or stated that they were unsure how the project could be improved. Five made positive statements about the project in its current form.

Some implementation aspects are mentioned as needing improvement. For example, some respondents requested that services be available on weekends (three responses); that services be delivered more flexibly (two responses); and that clearer, written guidelines about resource allocation under the project be provided (five responses). One respondent suggested that the project should be extended to ageing people with disabilities living in private residences and another remarked that the number of packages should be increased.

Six respondents were keen to receive more training in ageing issues.

Box 6.5: Examples of responses to Question 18—We would like to know if you think that the services offered by the pilot program are an appropriate form of additional assistance to the client in the group home setting.

(a) Please describe any aspects of the pilot program that you believe might make it unsuitable for long-term care of the client at home:

'If the client had high care needs which demanded nursing care on occasions and they could not participate in activities away from home.'

'Not enough support. As stated before, 6 hours a week is not sufficient.'

'[Client] has lived at [the group home] for most of her life. It would not be in [client's] interest to move to another facility.'

'No— no direct service as yet needed for my client to keep him at home.'

'Can't think of any. It's a good buddy/monitoring/keep your skills up programme.'

'Not enough assistance to adequately care for the client long term in their home.'

'Long term—lifting—requires two staff—unfunded.'

'Pilot program is <u>not</u> unsuitable but taking into account client's ongoing needs, should be considered for a permanent and ongoing program enabling client to age in place.' [emphasis original]

'Level of service provided may not be high enough if ageing related needs increased in the future…Assistance is appropriate as client's ADL needs were already being met and additional needs were social/community access. Access to therapy services is most beneficial.'

'I think that it's all positive…The break in their daily routine and the attention alone may help keep them in their home significantly longer.'

'The pilot program has been fantastic at enabling the client to participate in the local community and become a valued member.'

'The client may require more medical and mobility assistance in future.'

(b) How could the pilot program be improved or expanded to better meet the client's age-related needs?

'I think it's working beautifully. Clients are very happy with the activities and enjoy the quieter days too.'

'To develop a staff training package in age-related issues.'

'More hours.'

'This client's age related needs are becoming increasingly high due to the ageing process. She would benefit from any extra hours to allow staff to attend to her needs as well as access areas that best meet her needs. Permanent, ongoing funding needs to be secured for these needs.'

'All approved funding to be in writing with guidelines for the organisation to follow.'

'Remaining flexible to adapt to changing needs of client.'

'If the hours of support and assistance <u>could</u> be extended to better meet the identified (and projected) needs of the client, while support gaps in our service due to lack of funding still exist, this would be fantastic!' [emphasis original].

'Perhaps more hours for quality time and care.'

'Individual services should be adequately funded to broker out for staff and acquire enough support (not just 3 hours a week but what each service actually needs) to provide ageing clients with an appropriate service.'

'The pilot does not operate on the weekend. Client needs do not stop on Friday and commence again on Monday. I would like to see some hours given to weekends.'

'I think there is nothing that I can think of that could improve/expand the pilot program. I enjoy it! I used to work in a nursing home and it was like an assembly line. But this program is great for the carer AND the client! One-on-one is how it SHOULD be!' [emphasis original]

7 Conclusion

Pilot services represented a new care choice for ageing CSTDA consumers living in supported accommodation services—community-based aged care. Outside the Pilot, residential aged care is the only referral option open to ACATs in assessing clients in supported accommodation for aged care specific service. Leading examples of in-place progression models exist with the disability services sector (indeed one Pilot provider had commenced planning for an on-site disability-specific nursing home at the time of the evaluation) but these emerge only when there are sufficient resources to turn vision into reality.

The benefits of community-based aged care to individual clients and other household members and staff are obvious and have been described in this report. Thus, to the first of the three evaluation questions, *Do the pilot services offer new care choices which meet the needs of older Australians?*, the answer is an unequivocal 'yes'. In concluding the evaluation report, we summarise how the Pilot has benefited individuals and built capacity within the disability and aged care systems. We also touch on important issues at the boundary of disability and aged care programs that are not fully addressed by the top-up model of aged care funding trialled in the Innovative Pool Disability Aged Care Interface Pilot.

7.1 Benefits of the Pilot to individuals and service delivery systems

Additional funding for aged care has benefited Pilot clients in two main ways. First, it has introduced a new perspective to the provision of support as people age. The sharing of information and expertise between staff in disability and aged care services has meant that Pilot clients came to be viewed as people with disabilities who are ageing, not solely as people with disabilities, or CSTDA consumers. A client benefits in a tangible way from the insight into their living situation that comes from joint assessment by staff with expertise in disability support and aged care. Through the processes of joint assessment and care planning, the two service systems benefit from increased capacity of staff to understand the issues of supporting people with disabilities who are ageing. This increased capacity was demonstrated and valued by staff participating in the Pilot. Second, the Pilot delivered home- and community-based assistance to address functional decline in clients and to support client choice for lifestyle change to age-appropriate levels and types of activity. Increased access to generic aged care services has been a minor aspect of Pilot services. More commonly, projects delivered a highly individualised package of increased assistance to a client at home and therapeutic intervention and recreation and leisure activity to meet client preferences and needs.

Discussions held early in the evaluation focused on the question of what are the common age-related needs of clients of supported accommodation services. Needs were said to vary from client to client but to fall into the following broad categories:

- a need for higher level ADL support that was observed to be increasing over time
- dementia-specific care
- ongoing allied health supervision for care planning and guidance for physical therapy to help maintain living skills for as long as possible
- assistance with transitions to age-appropriate lifestyle

- the provision of ongoing support that is sensitive to the needs of the older person, that is, building capacity for service responsiveness to age-related functional change.

Higher levels of ADL support commensurate with increasing functional dependency

Aged care funding has led to the provision of additional personal assistance for many clients who had, over time, become unable to maintain simple self-care routines. One person's slowing due to loss of physical strength, cognitive decline or incontinence tends to impact on the whole household by placing extra pressure on staff during peak periods. Added support for a resident who no longer moves at the same pace helps relieve this pressure and provides the necessary level of support to the client. In addition, Pilot services have been able to provide personal assistance during daytime hours to clients who would otherwise be unattended for long periods.

Dementia care

Additional daytime assistance helps to support clients with dementia to spend longer periods at home. With the progression of dementia a resident typically needs longer periods in the calmer, less challenging environment of home while still having access to supervised activity. Most supported accommodation services do not have staff in attendance between the hours of 9.00 am and 3.00 pm, when residents would normally be at work or attending day programs. Flexible care subsidy in the Disability Aged Care Interface Pilot can help to fill some, but not all, of this gap.

Disrupted behaviour and sleep patterns associated with cognitive decline can lead to safety risks for the client, other residents and staff. Additional assistance from a Pilot project might not enable a person with this kind of need to remain at home if the accommodation service does not operate with active night staff. Assessment and behaviour management services delivered by projects help to identify dementia-specific needs that can be remedied as well as assisting support staff in the development of management plans.

Over the longer term, the progressive nature of dementia presents significant challenges to community living. Additional assistance at the levels delivered by Pilot projects helps to prolong ageing in place for people with disabilities as dementia symptoms emerge and begin to impact on disability services, but it does not provide for the continuous one-to-one support that is often required to maintain a person with advanced dementia at home. In the wider population of older community-dwelling people with dementia, the intensive support required to maintain a person with advanced dementia at home is provided by family carers, often supplemented by formal aged care services. It is widely recognised that a community care package alone, at current funding levels, does not provide an adequate level of support to a person with advanced dementia who is alone at home. Ultimately, some form of institutional care will be the future reality for many people with disabilities who have dementia-related high care needs if there is no 24-hour active staff in the community-based home setting.

Allied health care

Input from allied health professionals in the Pilot has taken two forms: assessment and the design and monitoring of physical maintenance programs. These interventions help to compensate for loss of physical function (for example, through recommendations for aids and equipment) and to improve or maintain levels of functioning at full potential (for example, physical activity programs).

Recommendations for aids and equipment are often made as a result of aged care assessment and follow-up allied health assessment, and in some instances projects have acquired aids to assist clients in daily living. State and territory governments have programs to deliver aids and appliances for people with disabilities but waiting times are said to be long in most areas. Pilot providers remarked that they have been able to respond immediately to identified needs, often for relatively inexpensive items that make a marked difference to client safety and quality of life. Sometimes only the assessment and identification of need is necessary because the disability service provider is able to make the acquisition. Consideration is given to the suitability of physical home environments and where necessary and possible, minor modifications are made to adapt homes according to the needs of residents who are ageing.

Transitioning to age-appropriate lifestyles

Lifestyle transitions have been another main focus of Pilot services and there appear to be several reasons why this was identified as an area of age-related need. Some clients needed to withdraw from employment or day programs because of diminished productivity and social functioning associated with the progression of dementia and/or physical frailty. People in this situation may have been continuing in long-standing routines prior to joining a Pilot project, even though this was not a lifestyle of personal choice or the most appropriate level of activity for an ageing person. The Disability Aged Care Interface Pilot has offered these people the choice of well managed lifestyle transition. Project staff and advocates have supported clients in the decision process and the additional resources from Pilot funding have facilitated gradual withdrawal from full-time or highly structured activity to activity plans that are more manageable for people with lower levels of cognitive and physical function. In the same category are those clients who were leading sedentary lifestyles prior to joining the Pilot because of earlier changes to daytime routines that had also occurred as a result of declining levels of functioning. The Pilot offered these people an opportunity for renewed social and community participation. Community and social services have mostly been delivered in parallel with additional personal assistance and other services as part of a total package of services from a Pilot project.

A small number of clients received recreation/leisure and transport services alone. This service profile is consistent with the provision of community access and support as a way to reduce the number of hours in a day in which clients are without companionship and activity.

Ongoing support that is responsive to the needs of the person who is ageing

Effective provision of additional aged care specific services relies on the expertise of staff from both the aged care and disability services sectors. For additional funding to make a real

difference to the quality of life of clients the service model should promote sharing of skills and knowledge so that a client's main service provider is responsive to their changing needs. Several models of aged care service provision have been trialled in the Disability Aged Care Interface Pilot which demonstrate that a range of expertise exists within disability services to support clients who are ageing.

The three projects with aged care teams sited or integrated within disability services (Ageing In Place, Tasmania; Disability Aged Care Service, Western Australia; and MS Changing Needs, Victoria;) demonstrated a high level of awareness of aged care specific needs of clients and aged care interventions within the project team. Ageing In Place and MS Changing Needs were uniquely positioned in different ways. Oakdale Services, the approved provider for Ageing In Place, is also the supported accommodation provider. Oakdale had for some years prior to the Pilot been monitoring functional change in older residents and working on the concept of an ageing in place service model. The historical barrier to ageing in place in this case was funding rather than lack of insight into the needs of older residents. MS Changing Needs is unique among the Pilot projects in that there is no obvious separation of disability support needs and aged care needs. As such, the knowledge and expertise required for the delivery of Pilot services is integral to the delivery of care for people with advanced MS and this exists within specialist MS disability services.

Disability Aged Care Service operated somewhat differently to Ageing In Place. Although the aged care project team was sited within one of the two accommodation services, pilot services were delivered by a dedicated aged care team working alongside disability support staff. Senses Foundation, the approved provider for Disability Aged Care Service, like Oakdale Services in Tasmania, has high level expertise in disability specific aged care intervention within the organisation's disability aged care division. Unlike Ageing In Place, Disability Aged Care Service delivered services into group homes and encountered the same sorts of issues in relation to referral and documentation practices as projects servicing group homes and supported accommodation facilities in other states.

Projects in New South Wales and South Australia have delivered services to clients of supported accommodation services operated by organisations other than the approved provider for the Pilot. Most of the project teams encountered early difficulties in obtaining referral documentation that accurately reflected clients' aged care specific needs. Over time problems were ironed out and steady flows of high quality referrals were established. If the Pilot is any measure, a widespread lack of awareness of ageing issues and aged care interventions appears to exist among disability workers who have daily caring responsibility for people in supported accommodation services. There is no suggestion that lack of awareness exists among specialist case managers; rather it appears more symptomatic of the low rates of pay, hence low qualification levels, of people working at the coalface of accommodation service provision. The Disability Aged Care Interface Pilot service models provided valuable opportunity for disability support staff to receive on-the-job exposure to aged care service delivery that would seem to provide long-term benefits to clients, other members of their households and the disability sector more generally. Moreover, the Pilot helped to highlight that community aged care workers with disability-specific experience are a rare species and that outreach service models therefore rely on a high level of cooperation and sharing of expertise between the sectors.

Impacts on residential aged care, disability and health systems

Through the provision of instrumental assistance (for example, personal assistance and community access) and service capacity building, 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 correspondingly circumstantial. Disability accommodation providers tend to resist pressure to transfer their clients into aged care facilities for as long as possible. That pressure builds as it becomes more and more difficult to maintain a client in a community-based setting. But the nature of the difficulty itself stems from the interaction of individual need factors and service capacity factors. Case studies presented throughout this report demonstrate that some difficulties are resolved with minimal expense but maximum insight; other issues require the ongoing injection of additional community-based resources; while in other cases, additional services at a cost of up to $70 per day may not be able to prevent entry to a residential care setting in the short to medium term. Much hinges on the style of accommodation and level of accommodation service in relation to an individual's aged care specific needs, the range and flexibility of specialist disability services to which a client has access, and the extent to which aged care funding can address the balance of a client's unmet need.

The area of allied health assessment and intervention is at the intersection of disability, aged care and health care systems. Pilot projects have in most cases delivered allied health therapies by purchasing services from private providers. Early attempts by projects to source allied health input from the public health system involved lengthy delays, which slowed assessment processes and the commencement of active therapy for clients. In a larger population this may relieve pressure on the public health system, although there is considerable doubt that members of the Pilot target group would ordinarily receive the observed levels of allied health assessment and therapy delivered by the Pilot as part of an aged care plan. 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.

People with disabilities and older people more generally who are eligible to receive HACC-funded services may receive allied health intervention through the HACC Program. The CACP Program does not fund allied health care. The main sources of allied health care for older people are private fee-for-service arrangements (which may be partly covered by private health insurance), the public health system, and the HACC and Day Therapy Centre programs, subject to program eligibility. Most members of the Pilot target group have limited access to allied health services to address aged care specific needs, first because of the way that access to public allied health services is prioritised and second, because of the cost involved in acquiring private services.

It is important to recognise that allied health interventions delivered by Pilot services are directed at arresting or slowing the functional decline that occurs as a result of ageing and at making environmental compensations that minimise the impact of increased disability due to ageing. This is not about fast-stream rehabilitation for injury-related conditions or major

medical events such as stroke; rather, the treatment intent in the Pilot context is strictly the management of increasing disability due to ageing. Although some might not consider allied health to be an aged care specific intervention, there is no escaping the high need for timely allied health intervention among older people because of the high rates of mobility and self-care limitation in older age groups. In demonstrating the positive effects of allied health assessment and related interventions on the quality of life for people with disabilities who are ageing, and therefore on their ability to remain in the community, the Pilot has highlighted an area of service need that is relevant to the care of all people who experience increasing disability as they age. The issue of access to allied health care for people who are ageing cuts across health care, aged care and disability programs.

7.2 Identified weaknesses of the Pilot model

As reflected in the Aged Care Innovative Pool 2002–03 Guidelines and Memoranda of Understanding between the Department and approved providers, Pilot projects were established with the aim of addressing the *aged care specific needs* of people with disabilities living in supported accommodation (Box 7.1). Notwithstanding the clear benefits of Pilot services to clients, a number of conceptual and practical difficulties are associated with the way in which this Pilot was conceived and implemented.

Box 7.1: People with disabilities who are ageing category of the Innovative Pool

This category of proposal is designed to meet the needs of people with disabilities who are at risk of being admitted to residential aged care because their increasing care needs cannot be met through disability support systems alone. They require additional services that are aged care specific in order to remain in their current disability funded living situation, be that a community setting such as a group home, or more institutional supported accommodation.

The aim is to enable the individual to remain part of their existing living and support relationships, in familiar surroundings, for as long as possible. Proposals must demonstrate that aged care related services would be incorporated into the care provided so that the individual's care needs are met in a seamless manner. Proposals should not be based on the withdrawal of other support services and should target identified individuals with ACAT assessments for residential care.

It is expected that, as people with disabilities age, both their aged care related needs and their disability support needs may increase. Proposals should consider the need for both aged care services and additional State/Territory disability support in the design of the project.

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

Open interpretation of aged care specific need

The idea that need for assistance should be defined as age related or disability related is worthy of discussion, both for its novelty and because it provides the underlying philosophy for assessment and service delivery in the Pilot. The idea has utility in providing a means of separating the respective financial responsibilities of disability and aged care programs. But

in speaking of aged care specific needs or age-related needs, what is really meant is age-onset *disability*. Many older people do not need aged care because they age without experiencing significant disability. Age is commonly used as a proxy for disability in the later stages of life because of assumptions—that do not apply equally for every individual—about ageing and disability. Policies and programs to promote 'healthy ageing' and 'ageing well, ageing productively' have gained prominence in recognition that a person can be old and free of significant disability. Where significant disability exists before a person gets 'old', in the conventional sense, difficulties inevitably arise in detecting changes that signal the increasing of disability due to ageing and the increasing of disability due to the fact that a person has had a disability for a long time.

Pilot project teams and participating ACATs have had to grapple with this issue on a practical level. They report that it is possible, though not always, to identify changes in a person with a disability that are associated with growing older as seen in the wider population. Typically, the process involves the description of an earlier 'steady state' (by considering what the person could do before and how he/she used to interact socially). This benchmark of normal life for the person with a disability is compared to how the person currently functions—physically, psychologically and socially. For some types of disability the process of detecting change is made easier by there being a discernible prior steady state. In the case of a person with Down syndrome, for example, the symptoms of dementia in Alzheimer's disease may present a stark contrast to the person's 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 corroborate social and behavioural changes as related to premature ageing. In addition, the effects of premature ageing in people with Down syndrome is well documented. 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 but well before they are 'old'.

A number of questions arise in connection with the idea of aged care specific needs in people with disabilities:

1. 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, or is it intended to mean only those needs that are routinely addressed by conventional aged care interventions?
2. Is an aged care specific need or aged care service defined to be consistent with the aged care needs of the wider population of older people or can allowance be made for different types of need that exist in conjunction with ageing with a disability and living in disability-funded supported accommodation?
3. How do these subtly different interpretations of aged care specific need 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?
    - 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?
4. Where do older people with disabilities who live in supported community accommodation (that is, those aged 65 years and over) who have unmet needs that are not assessed as strictly age related fit within this framework—where does ultimate responsibility for meeting *the needs* of older people with disabilities lie?

5. How much weight should be attached to chronological age in the assessment of needs related to premature ageing, especially in the context of chronic progressive disability?

While the Pilot has not provided answers to these questions, it has shown that different interpretations of *aged care specific need* exist and that these have practical implications. For instance, the service activity profiles of some Pilot projects during the evaluation might lead to questions of substitution of aged care funding for disability services funding in some projects. ACATs and project coordinators have 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 lifestyles is a case in point. When a person with a disability retires because they are no longer able, or no longer desire, to work full-time, they have an increased need for community access that is related to their stage in life (if a person retires from supported employment, then they potentially lose both social participation and access to daytime ADL assistance). An inability to receive an appropriate level of social support and supervised activity leads to an increased risk of future use of residential services. This risk is especially high if the person's home does not have staff attendance during daytime hours because it is expected that residents are attending workplaces and activities away from home. That the need for this type of support is believed to be age 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.

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. Yet, 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 that consumer, it is academic that the CSTDA funds community access services.

Perhaps the greatest conundrum for evaluation is the contrast between seven projects operating separate aged care and disability budgets and two, Ageing In Place and MS Changing Needs, that operate with aged care services fully integrated into the disability accommodation service using pooled aged care and disability budgets. To some extent the latter two projects were able to provide a more seamless service, but there were indications that pooled funding and full integration made the reporting of aged care specific expenditure more difficult. Both Ageing In Place and MS Changing Needs operate in accordance with the aims, target groups and service delivery models described in the respective Memoranda of Understanding; it is just that those two projects appear to have had scope to address a wider range of client needs. MS Changing Needs was established to provide high level nursing care to people who cannot access this through specialist disability services. In other words, MS Changing Needs was established because the disability services sector in the catchment area does/did not deliver the type of service needed by people with severe MS. What is not clear is whether this can be conceptually classified as an aged care specific service. Other Pilot projects have been required to adhere to stricter criteria for delivering aged care specific services. What is considered to place people with disabilities at

risk of admission to residential care and whether one takes a short- or long-term perspective are key issues.

Each of the other seven Pilot services was established to operate from a separate aged care budget with a strong emphasis on servicing aged care specific needs of clients (see Table 1.5). Memoranda of Understanding for the establishment of these services express the need to avoid substitution of aged care specific services for disability support services, the latter being variously described as services 'currently provided' by the disability service provider or 'program funding' for activities funded under the CSTDA. These differences of expression have possibly led to different interpretations of how project funds should and shouldn't be applied. Other differences between projects include age criteria, often decided by Steering Committees and in two cases also reflected in the Memorandum of Understanding, plus the meaning of 'aged care specific services', also within the jurisdiction of steering committees and specified in a Schedule of Aged Care Services for projects in New South Wales.

For comparison sake, contrast any one of the projects operating in New South Wales with Ageing In Place, Tasmania. Ageing In Place seemingly has greater capacity to address any of a client's most pressing support needs because greater flexibility was built into Pilot funding arrangements and scope for service provision. The accommodation service itself offers a hostel style of accommodation that is different in a number of respects to a group home for people with disabilities. By comparison, projects in New South Wales have a more aged care specific focus to service delivery, according to a Schedule of Aged Care Services, and have delivered services into a diverse range of group home settings and local disability service contexts to clients with varying levels of access to the range of available specialist services. Expenditure in these projects has been more closely tied to the processes of identifying and targeting aged care interventions to specific aged care needs of clients. In both cases the projects appear to have operated consistent with service aims and objectives reflected in the respective Memoranda of Understanding. However, Pilot design parameters give the projects in New South Wales a more limited sphere of influence and therefore the projects' ability to enable clients to live longer in the community is more subject to factors outside the Pilot sphere of influence.

The issue is further complicated by the inclusion of younger clients in projects that had a relatively high community access and social support component of expenditure (see Figure 5.2). Disability Ageing and Lifestyle Project and Ageing In Place recorded age homogeneous client groups that tended to be younger than other projects (excepting the special case of MS Changing Needs). Both of these projects delivered high levels of recreation and leisure activities and social support. Expenditure in Flexible Aged Care Packages reflects a similarly high social support component, although this project recorded a significantly higher median age and a greater spread of ages. Central West People with a Disability who are Ageing also recorded some younger clients who received mainly community access services. Excepting MS Changing Needs, 22 participants in the evaluation were aged under 50 years, all but two of whom were people with intellectual disability (two younger participants had physical disability). Sixteen of these younger clients were in the Disability and Ageing Lifestyle Project (four out of eight participants) and Central West People with a Disability who are Ageing (12 out of 33 participants).

The above discussion serves to demonstrate that people with disabilities who live in CSTDA-funded accommodation have needs that are intrinsically related to their disability service arrangements. People tend to spend more time at and around their home as they grow older. A critical driver for the need for increased formal service intervention in this group seems 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. The entrenched belief of many disability support staff that a person ageing with a disability is always better off in the disability supported accommodation setting because of higher staffing ratios in disability services denies the reality that the higher staff to client ratio, relative to residential aged care, is often for just a few hours in the day. All project teams emphasised that limited day and night supervision is a major contributor to the risk of admission to residential aged care in the target group. Pilot services were able to go some way towards addressing this risk, but a rethink of the funding and construction of specialist accommodation services for people ageing with a disability, more in line with a whole-person approach to social services, is clearly required if the risk is to be more systematically addressed.

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 CSTDA consumers.

From a system-wide perspective the top-up model of aged care funding seems to be an incomplete solution to the problem of limited choice in community-based aged care for people with disabilities in supported accommodation. It helps in individual cases by patching over 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. 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 are closely related to features of the disability support system. The evaluation concludes that 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. There is also the unresolved issue of people with disabilities aged over a certain age, say 60 or 65 years, who live in supported accommodation and whose risk of admission to residential aged care is assessed as mainly disability related. The needs of these older Australians are not addressed by the evaluated model.

Pilot exit strategies

The subject of exit strategies for the conclusion of the Pilot has caused high anxiety in project teams mainly because of the limited community-based options for clients. The concept of exit strategies assumes that clients will be able to return to day programs and employment services accessed before the Pilot (state disability authorities agreed to hold open places in mainstream programs for Pilot clients). Many clients' lifestyles have undergone fundamental change as a result of participating in the Pilot. For a proportion of Pilot clients, even

assuming the availability of mainstream service places, clients are unlikely to be able to resume their former daily schedules.

The Pilot effect

It is naïve to believe that increased funding for additional aged care specific services alone will deliver quality community aged care to people with disabilities living in supported accommodation. Across the projects, evaluation participants received a median of around 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 skills transfer between aged care and disability support staff in accommodation services where aged care expertise is more limited. A comprehensive strategy for delivering community based aged care to the target group therefore needs to factor in workforce and workplace practice considerations.

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 more usual ACAT referral arrangements.

7.3 Summation

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 Pilot gave ACATs a new referral option for members of the target group that has led to increased levels of personal assistance, active and passive physical therapies for improving or maintaining function, a focus on the special needs of clients who have dementia, and attention to needs for social participation.

A range of measures to improve access to community care for ageing clients living in disability supported accommodation is suggested as a result of the Disability Aged Care Interface Pilot:

1. The development of service models based on collaborative approaches to eligibility and needs assessment. Assessment by ACAT members with experience and professional interest in aged care assessment for people with disabilities proved

successful in the Pilot but the ground work performed by project coordinators and disability support staff was a core element of this success.

2. Consideration for the provision of routine dementia assessments of people aged 45 years or over with Down syndrome and other disorders that are known to cause or to be associated with dementia.
3. Care packages to provide higher levels of personal assistance and dementia-specific care to members of the target group with high and complex aged care specific needs.
4. Strategies to enable people with disabilities who are ageing to participate in community life on a flexible basis, including well managed retirement transition.
5. Adaptation of service and funding systems in recognition that home environments need to meet the needs of older residents who tend to spend longer periods of time at home.
6. A coordinated, whole-of-government approach to ensure consistency in approach 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.

The Pilot has helped to highlight a range of systemic issues that impact on consumers of CSTDA-funded accommodation services as they grow older. These are not all well addressed by the Pilot model of aged care specific funding and we caution that what works in a Pilot does not always translate well to mainstream service delivery environments unless close attention is paid to special Pilot conditions. Some important messages for the development of policies aimed at improving community living for older CSTDA consumers of supported accommodation services have emerged from the Innovative Pool Disability Aged Care Interface Pilot.

Weaknesses of the Pilot model should not detract from the obvious benefits of Pilot services to clients. The evaluation was unable to asses the impact of Pilot services on duration of community living in a strictly quantitative 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 and that these improvements are likely to have long-term benefits for individuals and service systems.

Appendix A: Overall client profiles

Table A1: Clients with intellectual disability, support needs related to mobility by age group

	Age group (years)				
Support need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	3	16	5	3	27
Needs help	10	25	21	10	66
Independent	6	12	11	1	30
Not stated	—	—	—	1	1
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	15.8	30.2	13.5	20.0	21.8
Needs help	52.6	47.2	56.8	66.7	53.2
Independent	31.6	22.6	29.7	6.7	24.2
Not stated	—	—	—	6.7	0.8
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A2: Clients with intellectual disability, support needs related to self-care by age group

	Age group (years)				
Support need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	11	39	24	9	83
Needs help	8	13	13	6	40
Independent	—	1	—	—	1
Not stated	—	—	—	—	—
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	57.9	73.6	64.9	60.0	66.9
Needs help	42.1	24.5	35.1	40.0	32.3
Independent	—	1.9	—	—	0.8
Not stated	—	—	—	—	—
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A3: Clients with intellectual disability, support needs related to domestic life by age group

	Age group (years)				
Support need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	13	45	32	12	102
Needs help	6	7	5	2	20
Independent	—	—	—	—	—
Not stated	—	1	—	1	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	68.4	84.9	86.5	80.0	82.3
Needs help	31.6	13.2	13.5	13.3	16.1
Independent	—	—	—	—	—
Not stated	—	1.9	—	6.7	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A4: Clients with intellectual disability, support needs related to community and social life by age group

	Age group (years)				
Support need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	16	46	31	14	107
Needs help	3	7	6	1	17
Independent	—	—	—	—	—
Not stated	—	—	—	—	—
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	84.2	86.8	83.8	93.3	86.3
Needs help	15.8	13.2	16.2	6.7	13.7
Independent	—	—	—	—	—
Not stated	—	—	—	—	—
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A5: Clients with intellectual disability, level of dependency in managing bowel continence, by age group

Dependency level	Age group (years)				Total
	Under 50	50–59	60–69	70+	
			(number)		
Incontinent	4	8	5	3	20
Occasional accident	3	9	11	4	27
Continent	11	36	20	8	75
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Incontinent	21.1	15.1	13.5	20.0	16.1
Occasional accident	15.8	17.0	29.7	26.7	21.8
Continent	57.9	67.9	54.1	53.3	60.5
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A6: Clients with intellectual disability, level of dependency in managing bladder continence, by age group

Dependency level	Age group (years)				Total
	Under 50	50–59	60–69	70+	
			(number)		
Incontinent	5	13	8	4	30
Occasional accident	6	17	14	6	43
Continent	7	23	14	5	49
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Incontinent	26.3	24.5	21.6	26.7	24.2
Occasional accident	31.6	32.1	37.8	40.0	34.7
Continent	36.8	43.4	37.8	33.3	39.5
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A7: Clients with intellectual disability, level of dependency in grooming, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	17	48	30	15	110
Independent	1	5	6	—	12
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	89.5	90.6	81.1	100.0	88.7
Independent	5.3	9.4	16.2	—	9.7
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A8: Clients with intellectual disability, level of dependency in toilet use, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	3	9	6	3	21
Needs some help	6	25	14	7	52
Independent	9	19	16	5	49
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	15.8	17.0	16.2	20.0	16.9
Needs some help	31.6	47.2	37.8	46.7	41.9
Independent	47.4	35.8	43.2	33.3	39.5
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A9: Clients with intellectual disability, level of dependency in feeding, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	1	5	1	—	7
Needs some help	9	31	21	10	71
Independent	8	17	14	5	44
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	5.3	9.4	2.7	—	5.6
Needs some help	47.4	58.5	56.8	66.7	57.3
Independent	42.1	32.1	37.8	33.3	35.5
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A10: Clients with intellectual disability, level of dependency in transfers, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	1	2	—	—	3
Needs some help	5	20	13	3	41
Independent	12	31	23	12	78
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	5.3	3.8	—	—	2.4
Needs some help	26.3	37.7	35.1	20.0	33.1
Independent	63.2	58.5	62.2	80.0	62.9
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A11: Clients with intellectual disability, level of dependency in mobility (level surface), by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Immobile	1	5	2	1	9
Needs some help	10	14	13	9	46
Independent	7	34	21	5	67
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Immobile	5.3	9.4	5.4	6.7	7.3
Needs some help	52.6	26.4	35.1	60.0	37.1
Independent	36.8	64.2	56.8	33.3	54.0
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A12: Clients with intellectual disability, level of dependency in dressing, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	3	18	8	4	33
Needs some help	12	25	18	6	61
Independent	3	10	10	5	28
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	15.8	34.0	21.6	26.7	26.6
Needs some help	63.2	47.2	48.6	40.0	49.2
Independent	15.8	18.9	27.0	33.3	22.6
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A13: Clients with intellectual disability, level of dependency in use of stairs, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	2	12	10	2	26
Needs some help	8	31	16	13	68
Independent	8	10	10	—	28
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	10.5	22.6	27.0	13.3	21.0
Needs some help	42.1	58.5	43.2	86.7	54.8
Independent	42.1	18.9	27.0	—	22.6
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A14: Clients with intellectual disability, level of dependency in bathing and showering, by age group

	Age group (years)				
Dependency level	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Dependent	8	34	25	11	78
Needs some help	8	11	7	2	28
Independent	2	8	4	2	16
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Dependent	42.1	64.2	67.6	73.3	62.9
Needs some help	42.1	20.8	18.9	13.3	22.6
Independent	10.5	15.1	10.8	13.3	12.9
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A15: Clients with intellectual disability, need for assistance with telephone use, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	8	36	22	13	79
Needs some help	8	15	13	2	38
Independent	2	1	1	—	4
Not stated	1	1	1	—	3
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	42.1	67.9	59.5	86.7	63.7
Needs some help	42.1	28.3	35.1	13.3	30.6
Independent	10.5	1.9	2.7	—	3.2
Not stated	5.3	1.9	2.7	—	2.4
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A16: Clients with intellectual disability, need for assistance to travel away from home outside walking distance, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	2	10	—	—	12
Needs some help	16	37	27	13	93
Independent	—	3	3	—	6
Not stated	1	3	7	2	13
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	10.5	18.9	—	—	9.7
Needs some help	84.2	69.8	73.0	86.7	75.0
Independent	—	5.7	8.1	—	4.8
Not stated	5.3	5.7	18.9	13.3	10.5
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A17: Clients with intellectual disability, need for assistance to shop for groceries or clothes, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	4	17	11	5	37
Needs some help	14	35	25	10	84
Independent	—	1	—	—	1
Not stated	1	—	1	—	2
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	21.1	32.1	29.7	33.3	29.8
Needs some help	73.7	66.0	67.6	66.7	67.7
Independent	—	1.9	—	—	0.8
Not stated	5.3	—	2.7	—	1.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A18: Clients with intellectual disability, need for assistance with meal preparation, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	7	33	16	11	67
Needs some help	11	16	14	2	43
Independent	—	—	—	—	—
Not stated	1	4	7	2	14
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	36.8	62.3	43.2	73.3	54.0
Needs some help	57.9	30.2	37.8	13.3	34.7
Independent	—	—	—	—	—
Not stated	5.3	7.5	18.9	13.3	11.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A19: Clients with intellectual disability, need for assistance with household chores, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	9	28	12	9	58
Needs some help	9	21	18	4	52
Independent	—	1	—	—	1
Not stated	1	3	7	2	13
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	47.4	52.8	32.4	60.0	46.8
Needs some help	47.4	39.6	48.6	26.7	41.9
Independent	—	1.9	—	—	0.8
Not stated	5.3	5.7	18.9	13.3	10.5
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A20: Clients with intellectual disability, need for assistance to use medications, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	10	26	16	6	58
Needs some help	8	25	20	9	62
Independent	—	1	—	—	1
Not stated	1	1	1	—	3
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	52.6	49.1	43.2	40.0	46.8
Needs some help	42.1	47.2	54.1	60.0	50.0
Independent	—	1.9	—	—	0.8
Not stated	5.3	1.9	2.7	—	2.4
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Table A21: Clients with intellectual disability, need for assistance to manage personal finances, by age group

	Age group (years)				
Level of need	**Under 50**	**50–59**	**60–69**	**70+**	**Total**
			(number)		
Unable	14	42	22	12	90
Needs some help	4	7	8	1	20
Independent	—	—	—	—	—
Not stated	1	4	7	2	14
Total	**19**	**53**	**37**	**15**	**124**
			(per cent)		
Unable	73.7	79.2	59.5	80.0	72.6
Needs some help	21.1	13.2	21.6	6.7	16.1
Independent	—	—	—	—	—
Not stated	5.3	7.5	18.9	13.3	11.3
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

— Nil.

Appendix B: Project profiles

Far North Coast Disability and Aged Care Consortium

Age and sex

FNCDAC supplied data on 13 clients, all of whom were aged 50 years or over at the start of the evaluation (Table B1.1).

Table B1.1: Far North Coast Disability Aged Consortium, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
50–59	6	6	12
60–69	—	1	1
Total	**6**	**7**	**13**
		(per cent)	
50–59	46	46	92
60–69	—	8	8
Total	**46**	**54**	**100**

— Nil.

Language and communication

Four FNCDAC clients had little or no effective means of communication with others and eight clients had effective spoken communication. Means of communication was not stated for one client. All clients are from an English-speaking background.

Accommodation and living arrangement

All FNCDAC clients were living in supported accommodation. Years at usual place of residence ranged from 2 to 32 years (mean 10.8 years), and five clients had been living in the same home for 15 or more years.

Income and concession status

All FNCDAC clients relied on the Disability Pension as their primary source of income and all clients held a health care concession card. FNCDAC does not charge client fees for the project.

Use of formal services

All clients were receiving assistance through the CSTDA when they entered the project. No client was on a waiting list for residential aged care.

Assessment and referral

All FNCDAC clients were referred to the project by their disability service provider. ACAT assessment was completed after referral to the project in all cases (Table B1.2). One client had recorded two ACAT assessments in the 12 months prior to entry.

The care of FNCDAC clients was managed by a social worker.

Waiting times for allied health care and specialist assessments through the public health system caused lengthy delays between ACAT assessment/referral and service commencement for some clients, stretching to months in a number of cases. By mid-2004, the project had moved to private providers for specialist assessment services in order to streamline assessment and service delivery.

Table B1.2: Far North Coast Disability and Aged Care Consortium, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
After referral to project	
Less than 21 days post referral	2
21–60 days post referral	3
61–90 days post referral	5
91–120 days post referral	1
121–180 days post referral	2
Total	**13**

Health conditions and health status on entry

The number of health conditions recorded for the FNCDAC clients at entry to the project ranged from three to eight, with modal values of four and seven (three clients each). Eight of the 13 clients had five or more health conditions. Table B1.3 lists the primary health conditions recorded for clients.

Table B1.3: Far North Coast Disability and Aged Care Consortium, number of clients by primary health condition

Primary health condition	Number of clients
Intellectual and developmental disorders	7
Congenital malformations, deformities and chromosomal abnormalities	4
Other[(a)]	2
Total	**13**

(a) Includes dementia and head injury.

Table B1.4: Far North Coast Disability and Aged Care Consortium, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	10
Vision impaired	8
Hearing impaired	5
Vision and hearing impaired	4
Diagnosis of depression	3
Total or partial paralysis	1
Missing or non-functional limbs	1

Clients were taking between one and nine different types of medication at the time of reporting. Ten of the 13 clients were taking four or more different types of medication. The modal number of medication types was six (recorded by four clients).

Disability support staff, family members or other advocates were asked to rate each client's health status and change in health status over the past 12 months using a 5-point Likert scale. Health status was reported for all clients, in each case by a disability support worker. Two clients' current health status was rated as very good, five as good, five were rated as being in fair health, and one client was rated as being in poor health. Three raters believed that the client's health was somewhat better than it was 12 months earlier, and two raters stated that their client's health was about the same as it was a year ago. Seven raters stated that the client's health was somewhat worse, and one reported that the client was in much worse health than one year earlier.

Level of core activity limitation

Around one-third of FNCDAC clients experienced severe or profound difficulty in self-care and communication activities and a further half experienced moderate difficulty in these areas (Table B1.5). Six clients had at least one type of severe or profound core activity limitation (self-care, mobility or communication).

Table B1.5: Far North Coast Disability and Aged Care Consortium, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	2	7	4	**13**
Mobility	4	3	3	3	**13**
Communication	1	1	6	5	**13**

— Nil.

Support needs

The majority of FNCDAC clients always needed help or supervision in seven out of nine life domains (Table B1.6). Most clients required help or supervision on a more intermittent basis in the areas of communication, mobility and interpersonal relationships. Constant help or supervision was required for all clients in performance of domestic tasks. Most clients always needed help with personal finances and community participation.

Table B1.6: Far North Coast Disability and Aged Care Consortium, number of clients by level of support need

	Level of support need				
Domain	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Not rated	Total
Self-care activities	—	4	9	—	**13**
Mobility	2	8	3	—	**13**
Communication	—	9	4	—	**13**
Domestic life	—	—	13	—	**13**
Community and social life	—	2	11	—	**13**
Relationships and interactions	—	9	4	—	**13**
Managing finances and employment	—	1	12	—	**13**
Learning and applying knowledge	—	5	8	—	**13**
Performing general tasks and demands	—	7	6	—	**13**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contained information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. All 13 clients had visited a medical practitioner at least once. The reported number of visits to a medical practitioner in this period varied from 4 to 20 per client, with a modal number of visits of 10. Cumulatively, the 13 clients recorded 168 visits to a medical practitioner outside of a hospital setting over an estimated 2,340 person days.

Eight clients were recorded as having used hospital services in the 6 months prior to entering the project, of whom five had visited the emergency department without subsequent admission; two had planned hospital admissions; and one client recorded a visit to the emergency department and an unplanned admission.

Four clients recorded a fall with injury, one of whom suffered another serious medical emergency in the pre-entry period.

Client baseline assessment results

Activities of daily living

Client Modified Barthel Index (MBI) scores at entry to the project range from 3 to 20 out of a total 20 points. The mean score was 11.7 points with a standard deviation of 4.7 (median of 12 points).

Using baseline MBI results, FNCDAC clients were classified into levels of dependency in ADL as follows: total dependency (one client); severe dependency (eight clients); moderate (two clients); slight (one client); independent (one client).

Five clients were always or sometimes bowel incontinent and 10 clients were always or sometimes bladder incontinent. Five clients were always or sometimes doubly incontinent. Most clients were unable to bathe or shower without assistance. The majority of clients needed help in the areas of grooming and feeding.

FNCDAC clients were totally dependent in between zero and six out of seven types of IADL at the time of entry to the project (total dependency recorded for a mean of 3.3 IADL). All clients either needed assistance or were unable to perform all IADL.

ADL and IADL data are summarised in Tables B1.7 and B1.8.

Table B1.7: Far North Coast Disability and Aged Care Consortium, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	8	3	2	**13**
Bladder management	3	6	4	**13**
Toilet use	5	7	1	**13**
Bathing/showering	2	. .	11	**13**
Dressing	2	7	4	**13**
Grooming	2	. .	11	**13**
Feeding	4	8	1	**13**
Mobility (level surface)	10	2	1	**13**
Transfers	5	8	—	**13**
Stairs	3	7	3	**13**

Notes

1. For bowel and bladder management, 'independent' equates to continent; partially dependent equates to occasional accident and fully dependent equates to incontinent.

2. Includes one client who is wheelchair independent.

— Nil.

. . Not applicable.

Table B1.8: Far North Coast Disability and Aged Care Consortium, number of clients by level of dependency in IADL as assessed at entry to the project

	Level of dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	3	10	**13**
Shop for groceries or clothes	—	9	4	**13**
Prepare meals	—	4	9	**13**
Household chores	—	5	8	**13**
Correctly administer own medications	—	12	1	**13**
Monetary transactions (e.g. pay bills)	—	2	11	**13**
Use the telephone	—	6	7	**13**

— Nil.

Psychological and behavioural symptoms

Data on behavioural and psychological symptoms as at entry to the project were reported for eight clients.[16] Five clients exhibited two or more behavioural symptoms on an intermittent or extensive basis. In two of these clients, verbal disruption, wandering and emotional symptoms manifested extensively (Figure B1.1).

16 These data were requested for clients whose initial needs assessment resulted in a behaviour management plan.

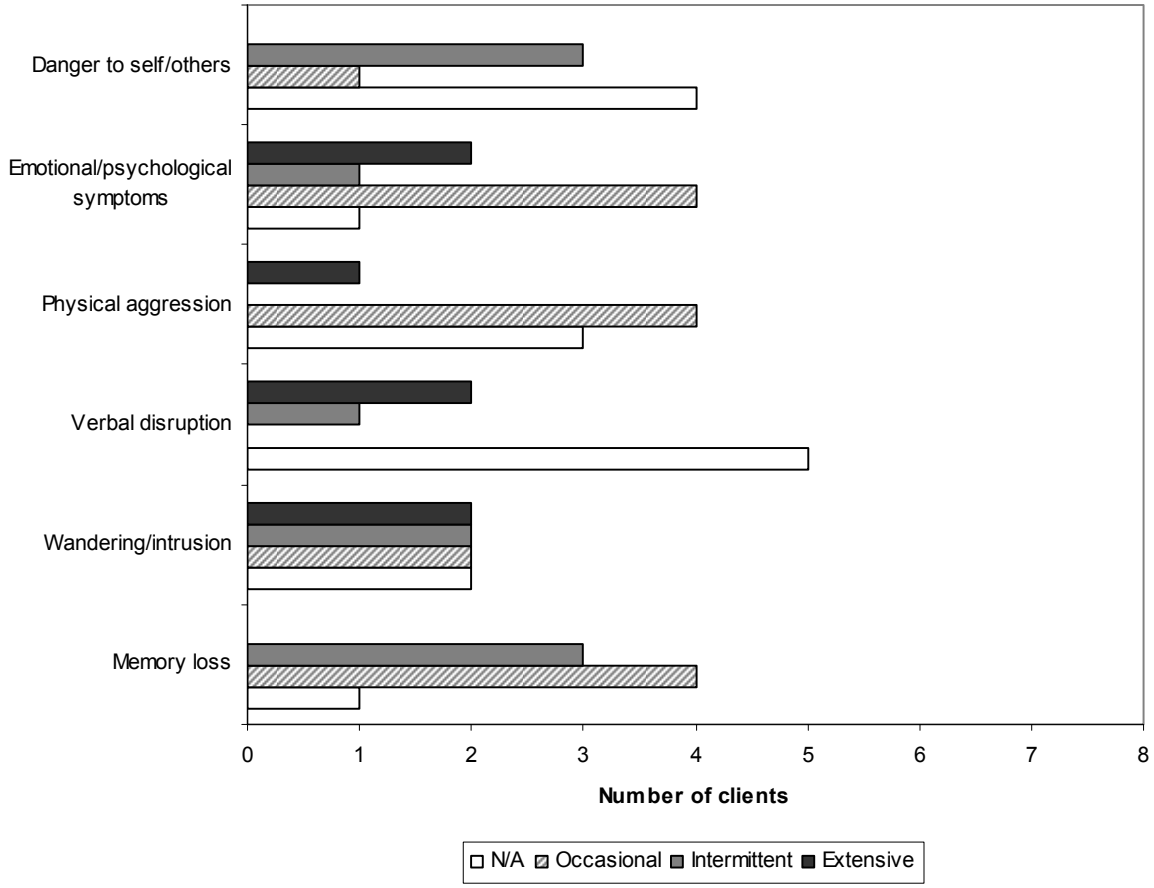


Figure B1.1: Far North Coast Disability and Aged Care Consortium, number of clients by frequency of psychological and behavioural symptoms

Broad Screen Checklist of Observed Changes

FNCDAC routinely conducts the Broad Screen Checklist of Observed Changes assessment, and has supplied between one and three scores collected over time for all clients taking part in the evaluation.

FNCDAC conducted the BSCOC at approximately 6-month intervals. The first reported assessments were conducted in late 2003 to mid-2004. BSCOC scores from these first assessments range from 13 points to 250 points, with an average score of 84 points (standard deviation 69.8). Figure B1.2 shows that five clients experienced significant functional change in the period preceding his/her first BSCOC assessment. Four clients experienced moderate change in functioning, and four clients experienced minor change.

Multiple assessment results are available for six clients. Four of these clients' BSCOC scores increased, suggesting that their rate of functional change was increasing over time. One of these clients transitioned from the moderate to the severe functional change category, and two transitioned from the minor to the moderate functional change category. The other two clients' rate of functional change decreased over time, with one client's score dropping by 200 points from the severe down to the moderate functional change category.

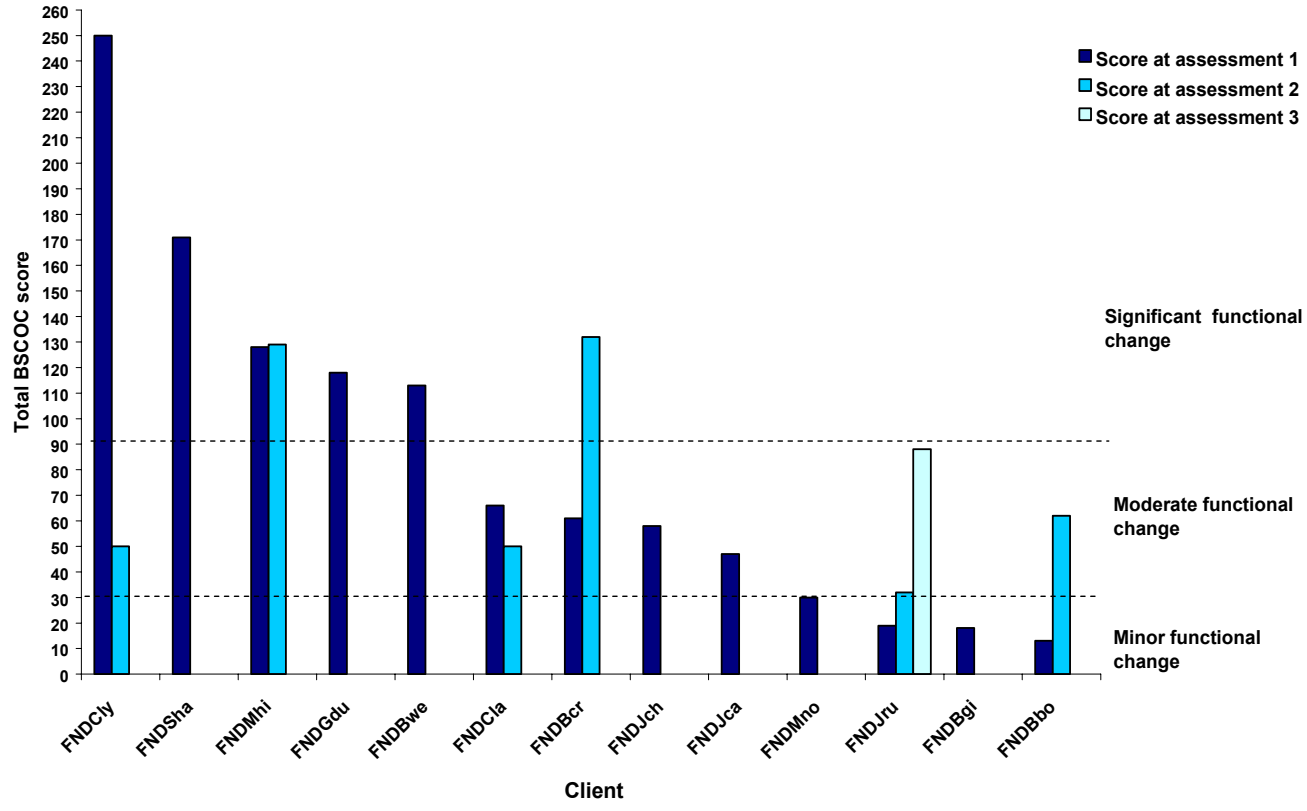


Figure B1.2: Far North Coast Disability and Aged Care Consortium, BSCOC total scores, by client

Client discharges

Four clients were discharged from the project during the evaluation period (Table B1.9).

Table B1.9: Far North Coast Disability and Aged Care Consortium, client discharge summaries

Discharged client	Discharge accommodation setting/ discharge reason	Length of stay (days)	Modified Barthel Index	
			Baseline	Final
1	Residential aged care (high care)	266	11	1
2	Residential aged care (high care)	175	3	0
3	Residential aged care (high care)	315	20	4
4	Additional assistance no longer needed	172	10	10

The three clients who entered residential aged care experienced deterioration in ADL functioning between the baseline and interim assessments. One client was completely dependent and another was severely dependent in ADL at time of entry to the project. The third client was independent in ADL at entry but exhibited extensive wandering and

intrusive behaviours and experienced a marked deterioration in self-care capacity during their time in the project.

Several other evaluation clients are said to be on a similar trajectory, with seizures often marking the onset of decline. Disability service providers have been found to be capable of absorbing much of the impact of extra care needs in such cases. The project has been able to provide additional staffing at peak periods, particularly for morning ablutions and around the evening meal time to help disability staff manage the household routine while also providing one-on-one support for high care clients. The need for night-time care in homes that do not have an active night-time staff roster has been a major factor in the decision to admit project clients to residential aged care.

Central West People with a Disability who are Ageing

Table B2.1: Central West People with a Disability who are Ageing, number of clients by disability group

Disability group	Number	Per cent
Intellectual	31	94
Psychiatric	1	3
Physical/diverse	1	3
Total	**33**	**100**

Age and sex

The mean age of clients was 54 years. Ages ranged from 37 years to 81 years, with 63% of clients aged 50 years or over (Table B2.2).

Table B2.2: Central West People with a Disability who are Ageing, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	1	—	1
40–49	6	5	11
50–59	4	7	11
60–69	7	2	9
70–89	1	—	1
Total	**19**	**14**	**33**
		(per cent)	
30–39	3	—	3
40–49	18	15	33
50–59	12	21	33
60–69	21	6	27
70–89	3	—	3
Total	**61**	**39**	**100**

— Nil.

Language and communication

Nine clients had little or no effective means of communication with other people, 22 clients had effective spoken communication, and one client used another method of communication. All clients are from an English-speaking background.

Accommodation and living arrangement

One client lived with family in a private residence and the remaining clients lived in supported accommodation. Years at place of residence ranged from 2 to 39 (mean 17.9 years). Twenty-one clients had been living in the same home for 15 or more years.

Income and concession status

All CWPDA clients relied solely on an Australian Government pension as their primary source of income. Thirty clients received the Disability Pension and three clients received the Age Pension. Twenty-five clients held a health care concession card. CWPDA does not charge client fees for the project.

Use of formal services

Twenty-six clients were receiving assistance through the CSTDA when they entered CWPDA. One client was receiving assistance from another unspecified source and five clients were not receiving government-funded assistance. Information on prior assistance was not available for one client.

Four clients were on a waiting list for residential aged care.

Assessment and referral

CWPDA clients were referred to the project by either the project provider (18 clients), an ACAT (nine clients) or another unspecified service or persons (six clients).

ACAT assessment was completed after or on referral to the project for 29 clients (Table B2.3). Two clients recorded two ACAT assessments in the 12 months prior to entry.

Case management for CWPDA clients was performed by a registered nurse.

Table B2.3: Central West People with a Disability who are Ageing, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
On or before referral to project	
Day of referral	1
121–180 days	1
181–365 days	3
Total	*5*
After referral to project	
Less than 21 days post referral	1
21–60 days post referral	6
61–90 days post referral	7
91–120 days post referral	10
121–180 days post referral	3
181–365 days post referral	1
Total	*28*
Total	**33**

Health conditions and health status on entry

CWPDA clients recorded between two and 11 health conditions as at entry to the project (nine clients recorded a modal value of three health conditions). Fifteen clients had five or more health conditions. Table B2.4 shows the primary health conditions recorded on the Aged Care Client Records for CWPDA clients.

Table B2.4: Central West People with a Disability who are Ageing, number of clients by primary health condition

Primary health condition	Number of clients
Congenital malformations, deformities and chromosomal abnormalities	17
Intellectual and developmental disorders	10
Arthritis	2
Other[(a)]	4
Total	**33**

(a) Includes cancer, diseases of the nervous system and hypertension.

Twenty-seven clients were assessed as being vision impaired and 23 clients were assessed as being at risk of falls due to impaired gait or balance (Table B2.5).

Table B2.5: Central West People with a Disability who are Ageing, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Vision impairment	27
Hearing impairment	4
Impaired gait or balance—at risk of falls	23
Missing or non-functional limbs	7
Total or partial paralysis	7
Diagnosis of depression	3

Clients were taking between one and 12 different types of medication at the time of reporting. Eighteen clients were taking four or more different types of medication. A mode of two types of medication per client was recorded.

Level of core activity limitation

One-half to two-thirds of clients had at least a moderate level of limitation in each of the core areas of daily activities (Table B2.6). In particular, 11 clients were reported to have experienced severe or profound limitation in self-care at the time of entry to the project.

Fourteen clients (42%) had a severe or profound core activity limitation.

Table B2.6: Central West People with a Disability who are Ageing, number of clients by level of core activity limitation

	Level of core activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	1	9	12	11	**33**
Mobility	6	11	8	8	**33**
Communication	3	14	10	6	**33**

Support needs

The majority of CWPDA clients always needed help or supervision in seven out of nine areas of activity in daily living (Table B2.7). Most clients needed constant help or supervision in self-care, domestic activities, managing personal finances and for participating in community and social life. Thus, the support needs of CWPDA clients were generally high across the activity domains.

Table B2.7: Central West People with a Disability who are Ageing, number of clients by level of support need

	Level of support need			
Domain	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Total
Self-care activities	—	9	24	**33**
Mobility	15	12	6	**33**
Communication	4	15	14	**33**
Domestic life	—	7	26	**33**
Community and social life	—	6	27	**33**
Relationships and interactions	—	17	16	**33**
Managing finances and employment	—	1	32	**33**
Learning and applying knowledge	—	11	22	**33**
Performing general tasks and demands	—	12	21	**33**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contained information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. Twenty-nine clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits varies from one to 25 per client.

Ten clients used hospital services in the 6 months prior to entering the project, of whom four had visited an emergency department without subsequent admission to hospital and six clients had been admitted (four on an unplanned basis).

Client baseline assessment results

Activities of daily living

Client MBI baseline scores ranged from zero to 19 out of a total 20 points, with a mean of 12.1 points and a standard deviation of 5.6 (median 14.0).

The results indicated that six clients were totally dependent in ADL when they entered the project and a further four clients were severely dependent. The remaining clients showed moderate (21 clients) or slight (two clients) dependency in ADL at entry.

Fourteen clients were either sometimes or always bowel incontinent and 19 clients were sometimes or always bladder incontinent. Thirteen clients were always or at times doubly incontinent. Most clients were unable to bathe or shower without assistance. The majority of clients needed help in the areas of grooming, dressing and feeding.

Approximately two-thirds of clients were independently mobile (with or without the use of a wheelchair) at time of entry.

At entry to the project, CWPDA clients were totally dependent in three out of seven areas of IADL on average. Most clients either needed assistance or were unable to perform in each of the IADL.

ADL and IADL data from the baseline assessment are summarised in Tables B2.8 and B2.9.

Table B2.8: Central West People with a Disability who are Ageing, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	19	11	3	**33**
Bladder management	14	12	7	**33**
Toilet use	17	8	8	**33**
Bathing/showering	5	. .	28	**33**
Dressing	8	19	6	**33**
Grooming	4	. .	29	**33**
Feeding	11	18	4	**33**
Mobility (level surface)	22	5	6	**33**
Transfers	22	8	3	**33**
Stairs	11	13	9	**33**

Notes

1. For bowel and bladder management, independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to 'incontinent'.
2. Includes two clients who are wheelchair independent.

. . Not applicable.

Table B2.9: Central West People with a Disability who are Ageing, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	2	23	8	**33**
Shop for groceries or clothes	1	25	7	**33**
Prepare meals	—	17	16	**33**
Household chores	1	20	12	**33**
Correctly administer own medications	—	21	12	**33**
Monetary transactions (e.g. pay bills)	—	13	20	**33**
Use the telephone	2	18	13	**33**

— Nil.

Client discharges

Two clients were discharged from the project in the evaluation period. One client entered an aged care facility (high care) and another client died in hospital.

Northern Sydney Disability Aged Care Pilot

Table B3.1: Northern Sydney Disability Aged Care Pilot, number of clients by disability group

Disability group	Number	Per cent
Intellectual	7	32
Physical	7	32
Other (ABI and multiple diverse)	8	36
Total	**22**	**100**

Age and sex

The overall mean age of NSDACP evaluation clients was 62 years. Ages ranged from 39 to 88 years, with 90% of clients aged 50 years or over (Table B3.2). Five clients were aged 70 years or over.

Table B3.2: Northern Sydney Disability Aged Care Pilot, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	—	1	1
40–49	1	—	1
50–59	2	7	9
60–69	2	4	6
70–89	1	4	5
Total	**6**	**16**	**22**
		(per cent)	
30–39	—	5	5
40–49	5	—	5
50–59	9	32	41
60–69	9	18	27
70–89	5	18	23
Total	**27**	**73**	**100**

— Nil.

Language and communication

Five NSDACP clients had little or no effective means of communication with others. Sixteen clients communicated effectively in spoken language, and one client used an effective non-spoken means of communication. All clients are from an English-speaking background.

Accommodation and living arrangement

All NSDACP clients resided in supported accommodation. Years at usual place of residence ranged from one to 80 years (mean 29.5 years), and five clients have been living in the same home for more than 50 years. After the recording of this information, clients at the Sunshine Home Gore Hill facility who recorded very long periods of residential tenure were relocated to group homes.

Income and concession status

Most NSDACP clients relied on the Disability Pension as a primary source of income and all clients held a health care concession card (Table B3.4). NSDACP did not charge client fees.

Table B3.3: Northern Sydney Disability Aged Care Pilot, number of clients by source of income, health care concession status and project concession status

Principal source of cash income	Number	Per cent
Disability Pension	15	68
Age Pension	4	18
Cash income—property	1	5
Other income	2	9
Total	**22**	**100**
Health care concession card holder	19	86
Project concession status	. .	. .

. . Not applicable.

Use of formal services

All clients were receiving assistance through the Commonwealth State/Territory Disability Agreement when they entered NSDACP. Two clients were on a waiting list for residential aged care.

Assessment and referral

All evaluation clients were referred to the project by their supported accommodation provider. After initial screening, and possibly resubmission, referrals completed according to the NSDACP-developed assessment pack are referred to the central ACAT contact point for routing to the appropriate area ACAT.

In the early weeks of project operation, delays between referral to NSDACP and completion of ACAT assessment often occurred because of the quality of referral information from accommodation provider to NSDACP (Table B3.4). A period of 'bedding down' the NSDACP referral and assessment processes through education of supported accommodation staff has produced a streamlined referral and assessment process. Hence, Table B3.4 reflects early project experience.

Table B3.4: Northern Sydney Disability Aged Care Pilot, number of days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
After referral to project	
Less than 21 days post referral	10
21–60 days post referral	6
61–90 days post referral	4
91–120 days post referral	2
Total	**22**

Health conditions and health status on entry

The number of health conditions recorded for the NSDACP clients at entry to the project ranged from two to eight. Eleven clients had four or more health conditions at entry. Table B3.5 lists the primary health conditions recorded on the Aged Care Client Records for NSDACP clients.

Table B3.5: Northern Sydney Disability Aged Care Pilot, number of clients by primary health condition

Primary health condition	Number of clients
Diseases of the nervous system, unspecified	6
Mental and behavioural disorders	3
Psychoses & depression, mood affective disorders	2
Disorders of the thyroid gland	2
Intestinal disease	2
Dementia[(a)]	2
Arthritis	2
Other diseases and disorders[(b)]	3
Total	**22**

(a) Includes dementia in Alzheimer's disease and dementia of other underlying causes.

(b) Includes diseases of the blood and blood-forming organs and immune mechanism, diabetes mellitus–type I and cerebrovascular disease.

Table B3.6: Northern Sydney Disability Aged Care Pilot, number of clients by disability group and presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	15
Vision impairment	17
Hearing impairment	8
Vision and hearing impairment	6
Diagnosis of depression	6
Confusion associated with delirium	2
Total or partial paralysis	7
Missing or non-functional limbs	9

Clients were taking between one and 11 different types of medication (modal numbers were four and seven types of medication, being taken by four clients each). Fourteen clients were taking five or more different medications.

Level of core activity limitation

The majority of NSDACP clients with physical disability (including those classified to the 'other' disability group) have severe or profound activity limitation in the areas of self-care and mobility (Table B3.7). Around half of the clients in the intellectual disability group have mild or moderate limitation in the areas of self-care, mobility and communication.

Fifteen clients (65%) have a severe or profound level of core activity limitation. Within the physical and 'other' disability groups, self-care and mobility limitations tend to cluster at the severe or profound level. Clients in the intellectual disability group are more likely than the other groups to exhibit mild core activity limitation.

Support needs

The majority of NSDACP clients always need help or supervision in seven out of nine areas of activity (Table B3.8). A high level of need for support in communication is less common and high level mobility support need is more common in NSDACP than in most other projects, reflecting a higher proportion of clients with physical disability (with the notable exception of the MS Changing Needs project).

Table B3.7: Northern Sydney Disability Aged Care Pilot, number of clients by disability group and level of core activity limitation

	Core activity		
Level of activity limitation	**Self-care**	**Mobility**	**Communication**
Intellectual disability group			
No limitation	1	—	2
Mild	3	5	4
Moderate	2	—	—
Severe or profound	1	2	1
Not stated	2	—	—
Total	*7*	*7*	*7*
Physical disability group			
No limitation	—	1	—
Mild	1	1	2
Moderate	1	—	4
Severe or profound	5	5	1
Not stated	—	—	—
Total	*7*	*7*	*7*
Other disability group			
No limitation	—	—	—
Mild	—	1	3
Moderate	1	—	3
Severe or profound	7	7	2
Not stated	—	—	—
Total	*8*	*8*	*8*
Total	**22**	**22**	**22**

— Nil.

Table B3.8: Northern Sydney Disability Aged Care Pilot, number of clients by disability group and level of support need, by area of support need

	Level of support need				
Domain	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Unable or always needs help or supervision	Not rated	Total
Self-care	—	6	15	1	**22**
Mobility	3	5	13	1	**22**
Communication	11	8	2	1	**22**
Domestic life	—	1	17	4	**22**
Community and social life	—	3	18	1	**22**
Relationships and interactions	1	5	15	1	**22**
Managing finances and employment	1	1	19	1	**22**
Learning and applying knowledge	—	4	15	3	**22**
Performing general tasks and demands	—	7	14	1	**22**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about client use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. All 22 clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner in this period varies from one to 90 per client. Eleven clients recorded use of hospital services in the 6 months prior to entering the project. Of these, five clients had presented at an emergency department and had been admitted to hospital and another four clients had been admitted without emergency department presentations. Three clients recorded a fall with injury, and one other client was rendered immobile without assistance for more than 30 minutes during the pre-entry period. Two other clients experienced other medical emergencies.

Client baseline assessment results

Activities of daily living

Baseline Modified Barthel Index (MBI) scores ranged from 1 to 18 out of a total 20 points. The mean baseline score for NSDACP was 6.4 points with a standard deviation of 5.9, reflecting a relatively low self-care functioning group. On the basis of the baseline MBI, 14 clients classify as totally dependent in ADL; three as severely dependent; and five as moderately dependent. However, the core activity limitation ratings and baseline MBI scores are inconsistent for 20% of clients.

NSDACP clients were totally dependent in between two and seven out of seven types of IADL at the time of entry to the project (mean 4.8; median 5.5 IADL with total dependency). On average, the physical and other disability groups exhibited greater dependency in ADL in comparison to the intellectual disability group. Overall, NSDACP clients were highly dependent in ADL at baseline, regardless of disability group. Similar levels of dependency in IADL are evident across the disability groups.

Table B3.9: Northern Sydney Disability Aged Care Pilot, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	10	3	9	**22**
Bladder management	5	5	12	**22**
Toilet use	4	5	13	**22**
Bathing/showering	2	. .	20	**22**
Dressing	4	2	16	**22**
Grooming	1	. .	21	**22**
Feeding	5	7	10	**22**
Mobility (level surface)	7	4	11	**22**
Transfers	7	9	6	**22**
Stairs	—	3	19	**22**

Note:. For bowel and bladder management, independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to incontinent.

— Nil.

. . Not applicable.

Table B3.10: Northern Sydney Disability Aged Care Pilot, number of clients by level of dependency in IADL as assessed at entry to project

	Dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	21	1	**22**
Shop for groceries or clothes	1	9	12	**22**
Prepare meals	—	1	21	**22**
Household chores	—	2	20	**22**
Correctly administer own medications	2	1	19	**22**
Monetary transactions (e.g. pay bills)	1	2	19	**22**
Use the telephone	3	5	14	**22**

— Nil.

Client discharges

One client died and no other clients were discharged from the project during the evaluation period.

Between commencement of services in May 2004 and 26 September 2005, NSDACP had provided service to 51 clients (an additional five clients were expected to commence on completion of ACAT assessment). Seven clients had left the service in that time (Table 3.11).

Table B3.11: Northern Sydney Disability Aged Care Pilot, status of ACAT approved clients, May 2004 to September 2005

		Discharges		
	Ongoing	Residential high care	Deceased	Total
DADHC	7	—	2	9
Sunshine Home	8	1	2	11
Sunnyfield	7	1	—	8
Spastic Centre	18	—	—	18
Crowle Foundation	2	1	—	3
Seton Villa	2	—	—	2
Inala	—	—	—	—
Total	**44**	**3**	**4**	**51**

— Nil.

MS Changing Needs

Age and sex

The mean age of clients was 47 years (ages ranged from 32 to 59 years; Table B4.1).

Table B4.1: MS Changing Needs, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	2	1	3
40–49	1	3	4
50–59	4	5	9
Total	**7**	**9**	**16**
		(per cent)	
30–39	13	6	19
40–49	6	19	25
50–59	25	31	56
Total	**44**	**56**	**100**

Language and communication

One client had little or no effective means of communication. The other clients communicated effectively using spoken language, 11 in English and one in Italian.

Accommodation and living arrangement

All Changing Needs clients live in MSV group homes. Years at usual place of residence ranged from less than one to 15 years (mean 4.8 years).

Income and concession status

All clients received the Disability Pension as their primary source of income. All clients held a health care concession card. MSV does not charge client fees for the project.

Use of formal services

All clients were receiving assistance through the CSTDA when they entered the project.

Two clients were on a waiting list for residential aged care.

Assessment and referral

ACAS assessment was completed approximately 9months before referral to the project for eight clients. Five clients completed ACAS assessment within 4months of referral to the project and assessment was completed more than 12 months following referral in three cases.

A registered nurse manages the care of all MS Changing Needs clients.

Health conditions and health status on entry

The number of health conditions recorded for the clients as at entry to the project ranges from one to three. Primary health condition was recorded as either multiple sclerosis (15 clients) or other disease of the nervous system (one client).

All clients were assessed as being at risk of falls due to problems with gait and/or balance, and all clients have non-functioning limbs. Fifteen clients have total or partial paralysis (Table B4.2).

Table B4.2: MS Changing Needs, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	16
Missing or non-functional limbs	16
Total or partial paralysis	15
Vision impairment	14
Diagnosis of depression	6

Clients were taking between two and 14 different types of medication. Fourteen clients were taking four or more different medications.

Clients were asked to rate their health status and change in health status over the past 12 months using a 5-point Likert scale. Nine clients reported good or very good health and seven reported fair health. Seven clients reported that their health was about the same as one year earlier; one client reported improved health status and eight clients reported worsened health status.

Level of core activity limitation

All clients experience severe or profound restriction in self-care and mobility (Table B4.3).

Table B4.3: MS Changing Needs, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	—	—	13	**13**
Mobility	—	—	—	13	**13**
Communication	7	3	2	1	**13**

— Nil.

Support needs

The majority of clients are either unable or always need help or supervision in eight out of nine areas of activity (Table B4.4).

Table B4.4: MS Changing Needs, number of clients by level of support need

	Level of support need			
Area of activity	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Total
Self-care	—	1	15	**16**
Mobility	—	7	9	**16**
Communication	13	2	1	**16**
Domestic life	—	—	16	**16**
Community and social life	—	4	12	**16**
Relationships and interactions	5	7	4	**16**
Managing finances and employment	—	4	12	**16**
Learning and applying knowledge	—	1	15	**16**
Performing general tasks and demands	—	3	13	**16**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about client use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. Fifteen clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner in this period varies from one to six per client. Three clients are recorded as having used hospital services in the 6 months prior to entering the project, of

whom one had visited the emergency department without an admission and two clients had both emergency department visits and unplanned hospital admissions.

Client baseline assessment results

Activities of daily living

Client Modified Barthel Index (MBI) scores at entry to the project range from zero to 5 out of a total 20 points, reflecting very high levels of ADL impairment in this client group. The mean score is 1.0 and the standard deviation is 1.3 points (median 1.0).

Fourteen clients exhibited total dependency in ADL and two clients were severely dependent at time of entry. As a group, MS Changing Needs clients recorded the highest levels of ADL dependency in the Pilot.

MS Changing Needs clients were totally dependent in between two and five (mean 3.5) out of seven IADL at the time of entry. Most clients either needed assistance or were unable to perform all or most IADL.

ADL and IADL baseline scores are summarised in Tables B4.5 and B4.6.

Table B4.5: MS Changing Needs, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	—	1	15	**16**
Bladder management	—	1	15	**16**
Toilet use	—	1	15	**16**
Bathing/showering	—	. .	16	**16**
Dressing	—	2	14	**16**
Grooming	1	. .	15	**16**
Feeding	2	8	6	**16**
Mobility (level surface)	4	—	12	**16**
Transfers	—	—	16	**16**
Stairs	—	—	16	**16**

Notes

1. For bowel and bladder management, independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to incontinent.

2. A person who uses a wheelchair independently is reported as independent for mobility.

(a) Nil.

. . Not applicable.

Table B4.6: MS Changing Needs, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	1	15	—	**16**
Shop for groceries or clothes	—	15	1	**16**
Prepare meals	—	—	16	**16**
Household chores	—	—	16	**16**
Correctly administer own medications	1	7	8	**16**
Monetary transactions (e.g. pay bills)	—	3	13	**16**
Use the telephone	3	11	2	**16**

— Nil.

Extent of, and satisfaction with, participation in life activities

Clients, family members and/or disability support workers were asked to rate the extent to which clients were participating *with the assistance currently available* in a range of life activities. In all cases, self-reports at the start of the evaluation period were provided.

Clients reported mostly moderate to complete participation restriction except in the areas of communication and interpersonal relationships, where lower levels of restriction are more common (Table B4.7). Not surprisingly, clients reported very little participation in self-care, activities that involve mobility, domestic life, employment and financial management (economic life), and general tasks and demands. Their level of disability severely limits opportunity to learn and apply knowledge. All clients reported restricted participation in community and social life.

Table B4.7: MS Changing Needs, number of clients by extent of participation restriction at baseline

	Extent of participation restriction					
Area of activity	No restriction	Mild restriction	Moderate restriction	Severe restriction	Complete restriction	Total
Self-care	—	—	1	1	14	**16**
Mobility	—	—	3	5	8	**16**
Communication	7	5	3	—	1	**16**
Domestic life	—	—	—	1	15	**16**
Community and social life	—	—	7	8	1	**16**
Relationships and interactions	1	4	8	2	1	**16**
Economic life	—	—	2	2	12	**16**
Learning and applying knowledge	—	—	2	9	5	**16**
Performing general tasks and demands	—	—	1	6	9	**16**

— Nil.

Clients were also asked to indicate current level of satisfaction with extent of participation. Table B4.8 summarises the satisfaction ratings. Just as extent of participation in each of the areas varies from client to client, so do clients' expressed satisfaction with their own circumstances. One client reported having complete participation restriction in every area of activity and indicated that they would like to be able to participate at least to some extent in each.

Table B4.8: MS Changing Needs, number of clients by level of satisfaction with participation at baseline

	Level of satisfaction with participation					
Area of activity	**No participation —participation desired**	**Extremely dissatisfied**	**Moderately dissatisfied**	**Satisfied**	**N/A or not stated**	**Total**
Self-care	6	—	1	8	1	**16**
Mobility	8	1	1	5	1	**16**
Communication	1	—	1	14	—	**16**
Domestic life	6	—	1	7	2	**16**
Community and social life	3	2	1	9	1	**16**
Relationships and interactions	2	—	2	11	1	**16**
Economic life	3	—	2	10	1	**16**
Learning and applying knowledge	5	1	1	9	—	**16**
General tasks and demands	5	1	2	7	1	**16**

— Nil.

Client discharges

No clients were discharged during the evaluation.

Interlink Flexible Aged Care Packages

Age and sex

The mean age of FACP clients was 64 years (ages ranged from 45 to 81 years). One client was aged younger than 50 years, and eight clients were aged 70 years or over (Table B5.1).

Table B5.1: Interlink FACP, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
40–49	—	1	1
50–59	5	3	8
60–69	7	6	13
70+	2	6	8
Total	**14**	**16**	**30**
		(per cent)	
40–49	—	3	3
50–59	17	10	27
60–69	23	20	43
70+	7	20	27
Total	**47**	**53**	**100**

— Nil.

Disability group

Table B5.2: Interlink FACP, number of clients by disability group

Disability group	Number	Per cent
Intellectual	27	90
Neurological	2	7
Acquired brain injury	1	3
Total	**30**	**100**

Language and communication

Twelve clients had little or no effective means of communication with others. Sixteen clients had effective spoken communication, and one client communicated effectively using other means. Method of communication was not stated for one client. All clients came from English-speaking backgrounds.

Accommodation and living arrangement

Clients' usual place of residence was a private residence (five clients) or supported community accommodation (25 clients; Table B5.3). Three clients lived in private residences with a spouse.

Table B5.3: Interlink FACP, number of clients by usual accommodation and living arrangement, and accommodation at time of referral to project

	Usual living arrangement					
Accommodation setting	Alone	With family	With others	Not stated	Total	Accomm'n at referral
Private residence (public rental)	—	3	2	—	5	6
Supported community accommodation	—	—	25	—	25	24
Total	**—**	**—**	**30**	**—**	**30**	**30**

— Nil.

Years at usual accommodation ranged from one to 24, with a mean of 11.5 years. Five clients have been living in the same home for 20 or more years. Three clients changed place of residence in the 2 years prior to entering the project.

Income and concession status

Interlink FACP clients relied on Australian Government pensions as their primary source of income—either the Age Pension (11 clients) or Disability Pension (19 clients). All clients hold a health care concession card, and all clients receive a discounted rate of co-payment to receive an Interlink package. Seven clients are not required to pay fees at all; the remaining 23 clients pay either $0.71 or $1.14 per day.

Use of formal services

Twenty-nine of the 30 clients were receiving assistance from government aged and community care programs when they entered FACP. Twenty-six clients were receiving assistance through the CSTDA, and three clients were receiving assistance from another unspecified government program.

One client was on a waiting list for residential aged care placement at time of entry to the project.

Assessment and referral

The majority of Interlink FACP clients were referred to the project by Helping Hand Inc. (18 clients). Another service agency referred 10 clients (Table B5.4). Nine clients had completed an ACAT assessment on the same day or prior to referral (Table B5.5). For these clients, the time between completion of an assessment and referral to the project varies from 3 to 359 days. ACAT assessment was completed after referral to the project for 21 clients.

Twenty-six clients are recorded as having an ACAT assessment, and four clients are reported as having had two ACAT assessments in the 12 months prior to entering the project.

Table B5.4: Interlink FACP, number of clients by source of referral

Referral source	Number of clients
Helping Hand Inc.	18
Other health or community service	10
Other agency	2
Total	**30**

The care of FACP clients is managed by a disability worker (18 clients), a social worker (two clients) or multidisciplinary team (10 clients).

Table B5.5: Interlink FACP, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
Before referral	
Less than 21 days	3
61–90 days	1
91–120 days	2
121–180 days	1
181–365 days	2
Total	*9*
After referral	
Less than 21 days post referral	7
30–39 days post referral	8
40–49 days post referral	6
Total	*21*
Total	**30**

Health conditions and health status on entry

The number of health conditions recorded for Interlink FACP clients as at entry to the project ranges from one to nine. Eight of the 30 clients had five or more health conditions. Table B5.6 shows the primary health conditions recorded on the Aged Care Client Records for Interlink clients.

Table B5.6: Interlink FACP, number of clients by primary health condition

Primary health condition	Number of clients
Intellectual and developmental disorders	19
Cerebrovascular disease	4
Diseases of the nervous system	3
Diabetes mellitus—type II	1
Mental and behavioural disorders	1
Diseases of the intestinal tract	1
Arthritis and related disorders	1
Total	**30**

Eighteen clients were assessed as being at risk of falls due to impaired gait or balance (Table B5.7). Three clients were both vision and hearing impaired.

Table B5.7: Interlink FACP, number of clients by selected sensory, mental and physical condition

Health condition	Number of clients
Impaired gait or balance—at risk of falls	18
Vision impairment	6
Hearing impairment	3
Vision and hearing impairment	3
Total or partial paralysis	4
Diagnosis of depression	6
Disorientation/confusion	1
Missing or non-functional limbs	1

Clients were taking between one and 13 different types of medication (a modal number of five medications is recorded for six clients). Ten of the 30 clients were taking seven or more different types of medication.

Disability support staff, family members or other advocates were asked to rate the client's health status and change in health status over the past 12 months using a 5-point Likert scale (Short-Form 36). Health status was reported for 15 clients, in each case by a disability support worker. Health status was rated as good (five clients), fair (nine clients) or poor (one client). One rater believed that the client's health was much better 12 months earlier and four raters stated that the client was in somewhat better health than a year before. Six clients were said to have been in about the same state of health, and four clients in somewhat worse health. Change in health status was not reported for 15 clients. Thus, according to disability support staff, the health status of around one-third of clients was comparable or somewhat better than 12 months earlier.

Level of core activity limitation

Most Interlink FACP clients experience mild or moderate activity restriction in the areas of self-care (19 clients), mobility (22 clients) and communication (16 clients). Where there is a severe or profound level of restriction, it is most likely to be in the area of self-care (Table B5.8). Thirteen clients (43%) had a severe or profound level of core activity restriction at time of entry to the project.

Table B5.8: Interlink FACP, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	1	6	13	10	**30**
Mobility	4	9	13	4	**30**
Communication	7	5	11	7	**30**

Support needs

Most Interlink FACP clients always needed help or supervision in seven out of nine major areas of activity (Table B5.9). Support needs tended to be more intermittent in the areas of communication and mobility.

Table B5.9: Interlink FACP, number of clients by level of support need

	Level of support need				
Area of activity	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Not rated	Total
Self-care	1	12	17	—	**30**
Mobility	5	23	2	—	**30**
Communication	4	20	6	—	**30**
Domestic life	—	7	22	1	**30**
Community and social life	—	7	23	—	**30**
Relationships and interactions	1	9	20	—	**30**
Managing finances and employment	—	4	26	—	**30**
Learning and applying knowledge	1	10	19	—	**30**
Performing general tasks and demands	1	11	18	—	**30**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. Of the 30 clients for whom data is reported, all but one had visited a medical practitioner at least once in the pre-entry

period. The reported number of visits to a medical practitioner in this period varies from one to 17 per client, with a mode of four visits recorded for four clients.

Six clients are recorded as having used hospital services in the 6 months prior to entering the project, of whom three recorded unplanned hospital admissions. These three clients collectively accumulated 48 unplanned hospital bed days over approximately 540 person days. Individually, they recorded between one and 42 days in hospital for unplanned admissions in the 6 month period.

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

- breathing difficulties/shortness of breath
- neurotic, stress-related or somatoform disorders
- intellectual and developmental disorders.

Four clients recorded a fall with injury, one client was rendered immobile and was without assistance for more than 30 minutes, and one client suffered another serious medical emergency during the pre-entry period.

Client baseline assessment results

Activities of daily living

Client Modified Barthel Index (MBI) scores at entry range from 8 to 20 out of a total 20 points. The mean score was 13.2 points with a standard deviation of 3.4 (median 13).

According to the baseline MBI results, the ADL functioning of FACP clients can be classified as follows: severe dependency in 14 clients; moderate dependency in 13 clients; and three clients were independent in ADL at time of entry. Twelve clients were always or at times incontinent of faeces and 18 clients were always or at times incontinent of urine. Ten clients were always or at times doubly incontinent. Twenty-five clients were unable to bathe or shower without assistance and 22 clients needed assistance to use the toilet. The majority of clients needed help in the areas of grooming, dressing and feeding; around one-third needed help with transfers.

Interlink FACP clients were totally dependent in between zero and seven types of IADL (out of seven) at the time of entry to the project. Most clients either needed assistance or were unable to perform all IADL.

ADL and IADL scores recorded at baseline assessments are summarised in Tables B5.10 and B5.11.

Table B5.10: Interlink FACP, number of clients with dependency in activities of daily living as assessed at entry to project.

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	19	9	3	**31**
Bladder management	13	14	4	**31**
Toilet use	9	17	5	**31**
Bathing/showering	6	. .	25	**31**
Dressing	9	17	5	**31**
Grooming	4	. .	27	**31**
Feeding	12	19	—	**31**
Mobility (level surface)	27	4	—	**31**
Transfers	22	8	1	**31**
Stairs	6	18	7	**31**

Notes

1. For bowel and bladder management, 'independent' equates to continent; 'partially dependent' equates to occasional accident; 'fully dependent' equates to incontinent.
2. A person who uses a wheelchair independently is recorded as independently mobile.

— Nil.

. . Not applicable.

Table B5.11: Interlink FACP, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency				
IADL	Help not needed	Help needed	Completely unable	Not assessable	Total
Get to places outside of walking distance	4	25	2	—	**31**
Shop for groceries or clothes	—	24	7	—	**31**
Prepare meals	1	15	15	—	**31**
Household chores	—	19	12	—	**31**
Self-medicate	1	23	6	1	**31**
Monetary transactions (e.g. pay bills)	—	9	22	—	**31**
Use the telephone	2	11	17	1	**31**

— Nil.

Psychological and behavioural symptoms

Data on behavioural and psychological symptoms at time of entry to the project were reported for two clients. One client displayed intermittent memory loss, occasional wandering or intrusive behaviour and was occasionally physically aggressive. The other client displayed wandering and/or intrusive behaviour and other behavioural and psychological symptoms on an extensive basis.

Client discharges

During the evaluation period, two clients transferred out of the project to another agency and remained living in their group home. Two clients died (Table B5.12). MBI scores for these clients were either stable or showed improvement. No behavioural data were recorded for these clients.

Table B5.12: Interlink FACP, client discharge summaries

Discharge client	Discharge accommodation setting/ discharge reason	Length of stay (days)	Modified Barthel Index	
			Baseline	Final
1	Transferred to another agency	232	10	10
2	Transferred to another agency	198	12	12
3	Deceased	277	11	16
5	Deceased	210	13	13

Disability and Ageing Lifestyle Project

Age and sex

The mean age of DALP clients was 47 years, with ages ranging from 35 years to 56 years (Table B6.1).

Table B6.1: Disability and Ageing Lifestyle Project, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	2	—	2
40–49	1	1	2
50–59	2	2	4
Total	**5**	**3**	**8**
		(per cent)	
30–39	25	—	25
40–49	13	13	25
50–59	25	25	50
Total	**63**	**38**	**100**

— Nil.

Language and communication

Three clients had little or no effective means of communication with others. Four clients communicated effectively using spoken language and one client used sign language. One client has a first language other than English.

Accommodation and living arrangement

All clients resided in supported accommodation. Years at usual accommodation ranged from 6 to 18 with a mean of 10 years.

Income and concession status

All DALP clients relied on the Disability Pension as their primary source of income and all clients held a health care concession card. DALP does not charge client fees for project services.

Use of formal services

All clients were receiving assistance through the CSTDA prior to entering the project.

No client was on a waiting list for residential aged care.

Assessment and referral

All clients were referred to the project by their accommodation service. Accommodation service staff complete forms in the DALP Referral Pack, which includes

- client referral form
- client consent form
- risk indicator form (medical conditions, transport and physical environment needs, nutrition, behaviour, personal safety and protection, financial vulnerability)
- assessment of support needs
- the Broad Screen Checklist of Observed Changes (Minda Inc.).

Forms are forwarded to Options Coordination, South Australia, for screening and referral to the Aged Care Assessment Team.

ACAT assessment of six clients was completed within 14 days of referral to the project (one client's ACAT assessment was completed within 23 days of referral).

A multidisciplinary team manages the care of DALP clients.

Health conditions and health status on entry

The number of health conditions recorded for the DALP clients at entry to the project ranges from four to 11. The primary health condition recorded on the Aged Care Client Records for all clients was mental retardation/intellectual disability.

Five clients were assessed as being at risk of falls due to impaired gait or balance at time of entry (Table B6.2). Four clients were vision impaired and five clients had a diagnosis of depression.

Table B6.2: Disability and Ageing Lifestyle Project, number of clients by presence of selected sensory, mental and physical condition

Health condition	Number of clients
Impaired gait or balance—at risk of falls	5
Vision impairment	4
Hearing impairment	—
Diagnosis of depression	5
Disorientation/delirium	3
Total or partial paralysis	1

— Nil.

One client was not taking medication on entry. The other six clients were taking between one and six different types of medication, two of whom were taking four or more different types of medication.

Disability support staff, family members or other advocates were asked to rate the client's health status and change in health status over the past 12 months using a 5-point Likert scale. Health status was reported for all clients, in each case by a disability support worker. Two clients were said to be in good health, four in fair health and two clients were said to be in poor health. The current health status was said to be somewhat worse than 12 months earlier for seven clients and the eighth client was said to be in a much worse state of health.

Level of core activity limitation

Half of the client group experienced severe/profound limitation in communication activities. Self-care limitations were more likely to be mild to moderate (six clients) than severe or profound (two clients; Table B6.3).

Four clients had a severe or profound level of activity limitation in at lease one of the core activities of daily living.

Table B6.3: Disability and Ageing Lifestyle Project, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self care	—	2	4	2	**8**
Mobility	2	1	4	1	**8**
Communication	3	—	1	4	**8**

— Nil.

Support needs

The majority of DALP clients always needed help or supervision in seven out of nine areas of activity (Table B6.4). For most clients, the level of support needed to achieve mobility is less than the level of support needed in other areas. Notably, five out of seven clients always need help with self-care tasks and six clients always need help with more general tasks and demands.

Use of medical and hospital services prior to entry

Baseline profiles contain information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. All seven clients had visited a medical practitioner at least once in the pre-entry period. The reported number of visits to a medical practitioner in this period varied from one to 20 per client. Cumulatively, the seven clients recorded 47 visits to a medical practitioner in the pre-entry period. One client had used hospital services in the 6 months prior to entering the project.

Three clients recorded a fall with injury, one of whom was rendered immobile and without help for more than 30 minutes.

Table B6.4: Disability and Ageing Lifestyle Project, number of clients by level of support need

Area of activity	Level of support need			Total
	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	
Self-care activities	—	3	5	**8**
Mobility	3	4	1	**8**
Communication	3	1	4	**8**
Domestic life	—	3	5	**8**
Community and social life	—	—	8	**8**
Relationships and interactions	—	1	7	**8**
Managing finances and employment	—	—	8	**8**
Learning and applying knowledge	—	2	6	**8**
Performing general tasks and demands	—	2	6	**8**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Client baseline assessment results

Activities of daily living

Client Modified Barthel Index (MBI) scores at entry ranged from 9 to 17 out of a total 20 points. The mean baseline score is 14.1 points with a standard deviation of 2.9 (median 14.5).

Classifying MBI scores to levels of dependency in ADL indicates that two clients were severely dependent and six clients were moderately dependent when they entered the project.

Most clients were unable to bathe or shower and dress without assistance. Most clients were independently mobile (walking or wheelchair use).

DALP clients were totally dependent in between one and six out of seven IADL at the time of entry to the project. At baseline, all clients were either unable or needed assistance to prepare meals and were unable to safely self-medicate.

ADL and IADL data from the baseline assessment are summarised in Tables B6.5 and B6.6.

Table B6.5: Disability and Ageing Lifestyle Project, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	6	2	—	**8**
Bladder management	4	3	1	**8**
Toilet use	5	3	—	**8**
Bathing/showering	1	. .	7	**8**
Dressing	2	5	1	**8**
Grooming	—	. .	8	**8**
Feeding	5	2	1	**8**
Mobility (level surface)	6	2	—	**8**
Transfers	5	3	—	**8**
Stairs	3	4	1	**8**

Note: For bowel and bladder management, independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to incontinent.

— Nil.

. . Not applicable.

Table B6.6: Disability and Ageing Lifestyle Project, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	—	7	1	**8**
Shop for groceries or clothes	—	5	3	**8**
Prepare meals	—	5	3	**8**
Household chores	—	4	4	**8**
Correctly administer own medications	—	—	8	**8**
Monetary transactions (e.g. pay bills)	—	—	8	**8**
Use the telephone	1	2	5	**8**

— Nil.

Psychological and behavioural symptoms

All eight clients exhibited three or more psychological or behavioural symptoms on an intermittent or extensive basis. Six clients exhibited two or three behavioural symptoms on an extensive basis. Most notably, six clients presented as a danger to themselves or others either intermittently or extensively (Figure B6.1). Periods without supervision pose a high risk for these clients.

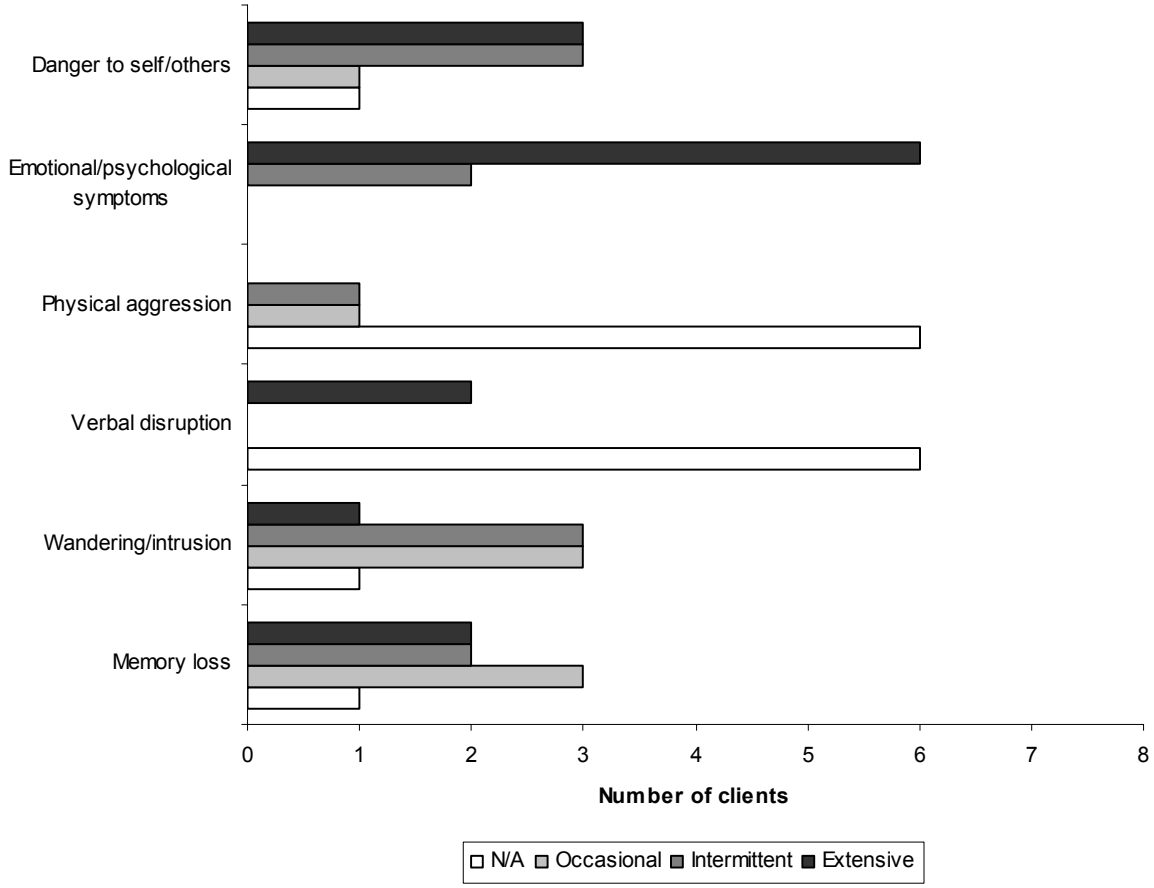


Figure B6.1: Disability and Ageing Lifestyle Project, number of clients by frequency of psychological and behavioural symptoms

Broad Screen Checklist of Observed Changes

DALP routinely conducts the BSCOC (Minda Inc.) assessment and has provided one assessment score for each client taking part in the evaluation. This assessment was conducted at approximately the same time as each client entered the project.

BSCOC scores at entry ranged from 37 to 96 points, with an average score of 65 points (standard deviation 23.7). All clients had registered functional change in the period prior to assessment. Figure B6.2 shows that one client experienced significant change and the remaining seven clients experienced moderate change.

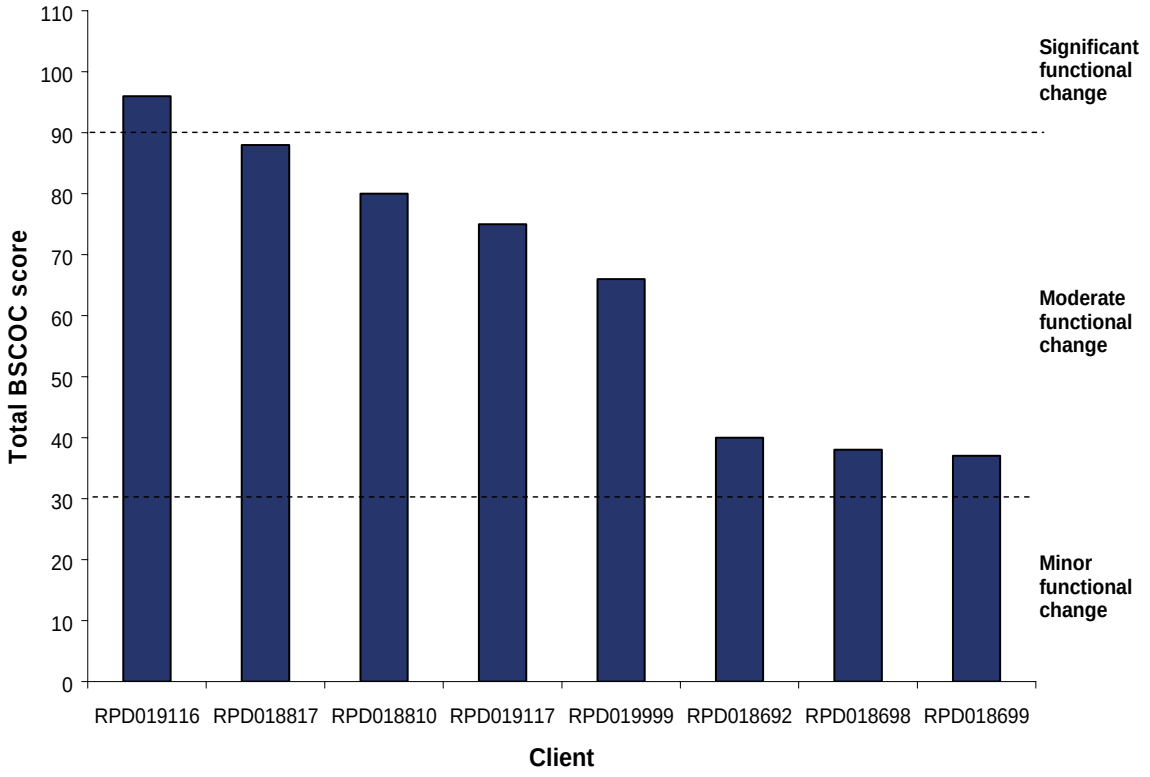


Figure B6.2: Disability and Ageing Lifestyle Project, BSCOC baseline scores

Client discharges

No clients were discharged during the evaluation.

Disability Aged Care Service

Age and sex

The mean age of DACS clients was 58.5 years; ages ranged from 47 years to 79 years (Table B7.1).

Table B7.1: Disability Aged Care Service, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
40–49	—	1	1
50–59	5	4	9
60–69	2	4	6
70–79	—	2	2
Total	**7**	**11**	**18**
		(per cent)	
40–49	—	6	6
50–59	28	22	50
60-69	11	22	33
70–79	—	11	11
Total	**39**	**61**	**100**

— Nil.

Language and communication

One client had little or no effective means of communication. Fourteen clients had effective spoken communication, 2 clients used sign language and one client used another method of communication. All clients are from an English-speaking background.

Accommodation and living arrangement

All DACS clients live in a Senses Foundation or Activ Foundation home. Years at usual place of residence ranged from two to 32 years (mean 10.8 years). Five clients had been living in the same home for 15 or more years.

Income and concession status

Most clients rely solely on the Disability Pension as their primary source of income (15 clients). Two clients receive income from other sources in addition to the Disability Pension and one client relies solely on private income. All but one client hold a health care concession card. Client fees are not charged for DACS services.

Use of formal services

Thirteen clients were receiving assistance through the CSTDA when they entered DACS. Four clients were receiving HACC services and one client was receiving assistance from both CSDA and HACC.

No client was on a waiting list for residential aged care when they entered the project.

Assessment and referral

Clients were referred to the project by the Senses and Activ disability services. ACAT assessment was completed after referral for all clients (Table B7.2). Three clients recorded two ACAT assessments in the 12 months prior to entry.

A registered mental health nurse manages the care of all clients.

Table B7.2: Disability Aged Care Service, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
After referral to project	
Less than 21 days post referral	3
21–60 days post referral	9
61–90 days post referral	4
91–120 days post referral	1
121–180 days post referral	1
Total	**18**

Health conditions and health status on entry

The number of health conditions recorded for DACS clients at entry to the project ranges from two to nine, with a mode of five medications recorded by six clients. Twelve of the 18 clients had five or more health conditions and three other clients had four or more health conditions at time of entry. Table B7.3 lists the primary health conditions recorded for DACS clients.

Table B7.3: Disability Aged Care Service, number of clients by primary health condition

Primary health condition	Number of clients
Congenital malformations, deformities and chromosomal abnormalities	9
Intellectual and developmental disorders	8
Poor vision	1
Total	**18**

All clients were assessed as being at risk of falls due to impaired gait or balance and there is a high prevalence of sensory impairment in the group (Table B7.4).

Table B7.4: Disability Aged Care Service, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	18
Vision impairment	10
Hearing impairment	6
Vision and hearing impairment	4
Diagnosis of depression	3
Disorientation/delirium	1

Clients were taking between two and 11 different types of medication at the time of reporting. Fifteen clients were taking four or more different types of medication (modal numbers of five and six different medication types were recorded by five clients in each case).

Level of core activity limitation

Senses clients are predominantly severely or profoundly limited in the areas of self-care, mobility and communication (Table B7.5). Only one client was recorded as not having had a severe or profound level of core activity limitation at time of entry. DACS is one of the more highly ADL impaired groups in the evaluation, with a high proportion of clients with severe or profound mobility limitation in addition to the often disability-related limitations in self-care and communication.

Table B7.5: Disability Aged Care Service, number of clients by level of core activity limitation

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	—	2	16	**18**
Mobility	—	1	4	13	**18**
Communication	—	1	3	14	**18**

— Nil.

Support needs

The majority of DACS clients always needed help or supervision in seven out of nine areas of activity (Table B7.6). In the areas of communication and mobility, half of the clients always needed help or supervision; the remaining nine clients needed help or supervision on a more intermittent basis. In other areas of activity, most notably self-care, financial management,

domestic life and learning and applying knowledge, all or nearly all DACS clients needed constant help and supervision.

Table B7.6: Disability Aged Care Service, number of clients by level of support needs

	Level of support need			
Domain	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Total
Self-care activities	—	—	18	**18**
Mobility	—	9	9	**18**
Communication	—	9	9	**18**
Domestic life	—	1	17	**18**
Community and social life	—	2	16	**18**
Relationships and interactions	—	5	13	**18**
Managing finances and employment	—	—	18	**18**
Learning and applying knowledge	—	1	17	**18**
Performing general tasks and demands	—	5	13	**18**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. All 18 clients had visited a medical practitioner at least once in this period. The reported number of visits varied from two to 15 per client.

Four clients were recorded as having used hospital services in the pre-entry period, of whom one had visited the emergency department only, two had unplanned hospital admissions (cumulatively spending 39 unplanned days in hospital) and one had a planned hospital admission.

One client sustained a fall with injury and another client suffered a serious medical emergency during the pre-entry period.

Client baseline assessment results

Activities of daily living

Client total Modified Barthel Index (MBI) scores at entry ranged from 5 to 18 out of a total 20 points. The mean baseline score for DACS clients was 12.2 with a standard deviation of 3.5 points (median 13). Classification of the baseline MBI scores into ADL dependency levels indicates that eight clients were severely dependent and 10 clients were moderately dependent in ADL at entry to the project.

Six clients were either always or at times bowel incontinent and nine clients were always or at times bladder incontinent. Five clients were at times or always doubly incontinent. Most

clients were unable to bathe or shower without assistance. The majority of clients needed help in the areas of grooming, dressing, toilet use and feeding. Over half of the clients were independently mobile (walking) although most needed help to negotiate stairs (Table B7.7).

Dependency in IADL varies, from some clients who are totally dependent in six out of seven IADL to others with no more than partial dependency. On average, DACS clients were completely dependent in four IADL at time of entry. Most clients were completely dependent in the areas of preparing meals, using the telephone, handling money and doing housework.

Table B7.7: Disability Aged Care Service, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	12	2	4	**18**
Bladder management	9	3	6	**18**
Toilet use	7	9	2	**18**
Bathing/showering	1	. .	17	**18**
Dressing	2	9	7	**18**
Grooming	3	. .	15	**18**
Feeding	6	12	—	**18**
Mobility (level surface)	11	7	—	**18**
Transfers	9	9	—	**18**
Stairs	3	12	3	**18**

Note: For bowel and bladder management, 'independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to incontinent.

— Nil.

. . Not applicable.

Table B7.8: Disability Aged Care Service, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency			
IADL	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	1	17	—	**18**
Shop for groceries or clothes	—	8	10	**18**
Prepare meals	—	3	15	**18**
Household chores	—	8	10	**18**
Correctly administer own medications	—	3	15	**18**
Monetary transactions (e.g. pay bills)	—	1	17	**18**
Use the telephone	—	3	15	**18**

— Nil.

Broad Screen Checklist of Observed Changes

DACS routinely conducts the BSCOC (Minda Inc.) assessment and has supplied one score for each client taking part in the evaluation. This assessment was conducted between April and June 2004.

BSCOC scores range from 44 to 130 points, with an average score of 86.4 points (standard deviation 24.1). Figure B7.1 shows that seven clients experienced a significant change in functioning in the period preceding assessment, and 11 clients experienced moderate functional change. The project team reported that these measured changes reflect functional decline in the period prior to entry.

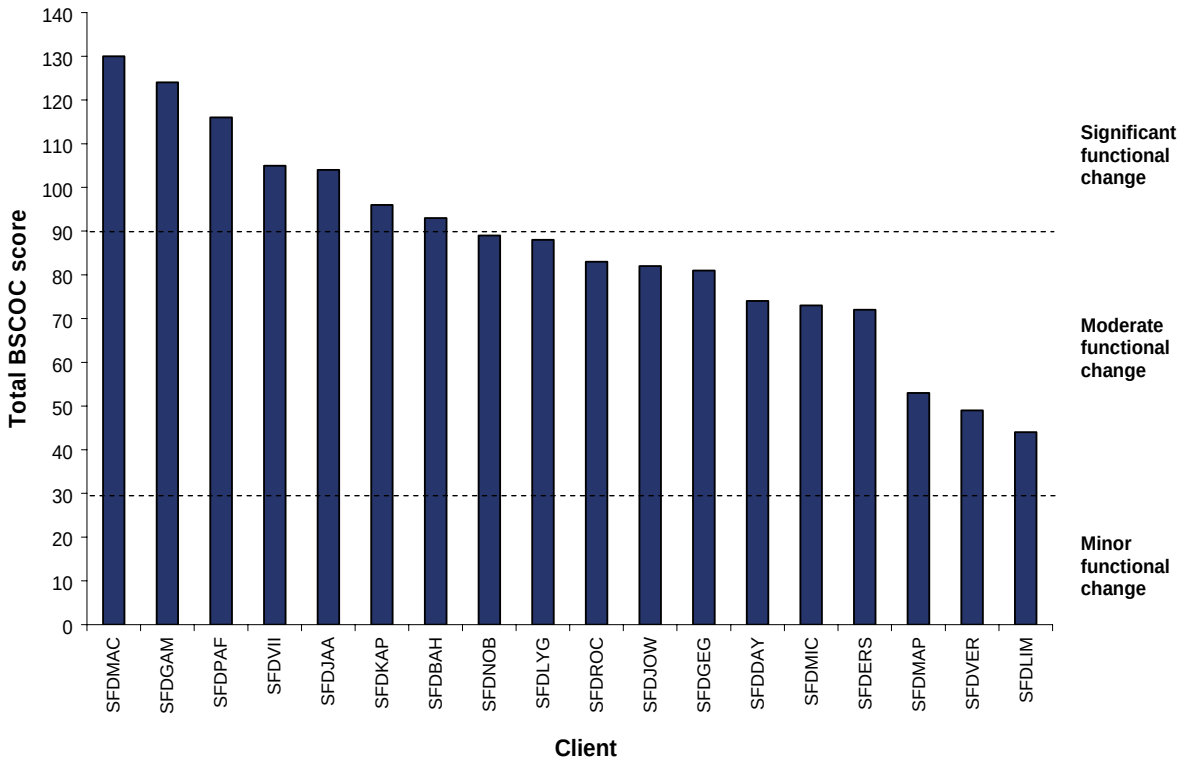


Figure 7.1: Disability Aged Care Service, *Broad Screen Checklist of Observed Changes* baseline scores

Client discharges

One evaluation client was discharged from DACS after 76 days with the project to enter high level residential aged care. This client was severely dependent in ADL on entry to the project and had registered significant functional decline in the period prior to entry. No other clients were discharged during the evaluation period.

Ageing In Place

Age and sex

The mean age of AIP clients was 52 years, with ages ranging from 40 to 62 years (Table B8.1).

Table B8.1: Ageing In Place, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
40–49	—	1	1
50–59	3	2	5
60–69	1	—	1
Total	**4**	**3**	**7**
		(per cent)	
40–49	—	14	14
50–59	43	29	71
60–69	14	—	14
Total	**57**	**43**	**100**

— Nil.

Language and communication

Six clients had effective spoken means of communication; one client was non-communicative. All clients were from English-speaking backgrounds.

Accommodation and living arrangement

Clients resided at Oakdale Lodge, a residential facility for people with disabilities. Years of residence ranged from 2 to 34. Four clients had been living at Oakdale Lodge for more than 20 years.

Income and concession status

The Australian Government Disability Pension was the primary source of income for all clients. All clients held a health care concession card. Client payments towards the cost of accommodation form part of the project budget; however, clients did not make additional payments to participate in AIP.

Use of formal services

All clients were receiving assistance funded through the CSTDA prior to entering AIP.

None of the clients was on a waiting list for residential aged care when they joined the project.

Assessment and referral

AIP clients were referred to the project by Oakdale Services. Clients had their ACAT assessments completed on 17 January 2003, 6 months prior to project establishment, during the project planning phase.

The care of AIP clients is managed by disability staff at Oakdale Lodge, in consultation with a representative of Advocacy Tasmania.

Health conditions and health status on entry

The number of health conditions recorded for AIP clients at entry to the project ranges from three to eight. Three clients had six or more health conditions.

Dementia in Alzheimer's disease was listed as the primary health condition for two clients and the primary disability *Intellectual and developmental disorde*r was given as the primary condition for the remaining five clients.

AIP clients were taking between zero and nine different types of medication at the time of entry. Two clients were taking three or more medications.

Three clients were reported to be in very good health when they entered the project. Two clients were rated as being in good health, and one client was rated as being in fair health. The health of five clients was rated as being about the same as it was 12 months earlier, and one client was rated as being in somewhat worse health than a year ago.

By comparison with clients in other projects, AIP clients were younger and fewer exhibited the range of sensory, physical and mental health conditions considered here; however, four of the seven clients were at risk of falls (Table B8.2).

Table B8.2: Ageing In Place, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Impaired gait or balance—at risk of falls	4
Total or partial paralysis	1
Missing or non-functional limbs	1
Vision impairment	—
Hearing impairment	1
Diagnosis of depression	—
Disorientation/confusion	—

— Nil.

Level of core activity limitations

AIP clients typically experienced moderate to severe or profound activity limitation in the areas of self-care, mobility and communication (Table B8.3). Five clients had a severe or profound level of limitation in at least one area of core activity.

Table B8.3: Ageing In Place, number of clients by level of core activity limitation at entry to project

	Level of activity limitation				
Core activity	No limitation	Mild	Moderate	Severe or profound	Total
Self-care	—	1	2	4	**7**
Mobility	2	1	3	1	**7**
Communication	1	—	2	4	**7**

— Nil.

Support needs

The level of support needed by AIP clients was highest in the areas of learning and applying knowledge, interpersonal relationships and managing finance and personal affairs (Table B8.4). Most clients sometimes or always needed help or supervision in all nine areas of activity.

Table B8.4: Ageing In Place, number of clients by level of support needs

	Level of support need			
Area of activity	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Total
Self-care	—	5	2	**7**
Mobility	2	4	1	**7**
Communication	1	3	3	**7**
Domestic life	—	3	4	**7**
Community and social life	—	1	6	**7**
Relationships and interactions	—	1	6	**7**
Managing finances and employment	—	—	7	**7**
Learning and applying knowledge	—	1	6	**7**
Performing general tasks and demands	—	3	4	**7**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about a client's use of medical and hospital services in the 6 months prior to entering the project—the 'pre-entry period'. All six clients had visited a medical practitioner between two and six times in the pre-entry period. There is no record of

hospital use and no client is recorded as having experienced a medical emergency in the pre-entry period.

Client baseline assessment results

Activities of daily living

Modified Barthel Index (MBI) scores at entry range from 11 to 19 out of a total 20 points. The mean baseline score is 15.9 points with a standard deviation of 2.6 (median 16.0 points). Five clients were unable to bathe or shower without assistance. All clients were mobile although one needed minor help with transfers (Table B8.5).

Table B8.5: Ageing In Place, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
	Independent	Partially dependent	Fully dependent	Total
Bowel management	7	—	—	**7**
Bladder management	5	2	—	**7**
Toilet use	6	1	—	**7**
Bathing/showering	2	. .	5	**7**
Dressing	1	3	3	**7**
Grooming	—	. .	7	**7**
Feeding	3	4	—	**7**
Mobility (level surface)	7	—	—	**7**
Transfers	6	1	—	**7**
Stairs	3	4	—	**7**

Note: For bowel and bladder management, independent equates to continent; partially dependent equates to occasional accident; fully dependent equates to incontinent.

— Nil.

. . Not applicable.

All clients showed some level of dependency in IADL when they entered the project (Table B8.6). On average, AIP clients were totally dependent in five out of seven IADL at the time of entry. Two clients were totally dependent in all seven IADL.

Table B8.6: Ageing in Place, number of clients by level of dependency in IADL as assessed at entry to project

	Level of dependency			
	Help not needed	Help needed	Completely unable	Total
Get to places outside of walking distance	1	6	—	**7**
Shop for groceries or clothes	—	5	2	**7**
Prepare meals	—	2	5	**7**
Household chores	—	3	4	**7**
Correctly administer own medications	—	—	7	**7**
Monetary transactions (e.g. pay bills)	—	1	6	**7**
Use the telephone	—	—	7	**7**

— Nil.

Participation in life activities

The client, family member or disability support worker rated the extent to which the client was able to participate *with the assistance currently available to them* in a range of life activity domains when they entered the project. In all cases, extent of participation ratings were provided by disability support staff (summarised in Table B8.7). The results show that, as at entry to the project, most clients experienced moderate to severe participation restriction across most areas of activity. Higher levels of participation restriction are apparent in activities involving high level cognition and mental processing (interpersonal and social interactions; financial management) than in the areas of self-care and mobility.

The project recorded no change in clients' levels of participation in any domain.

Table B8.7: Ageing In Place, number of clients by extent of participation

	Extent of participation restriction					
Area of activity	No restriction	Mild restriction	Moderate restriction	Severe restriction	Complete restriction	Total
Self-care activities	—	3	3	—	1	**7**
Mobility	—	5	1	—	—	**6**
Communication	—	2	2	3	—	**7**
Learning and applying knowledge	—	—	3	2	1	**6**
Performing general tasks and demands	—	3	1	3	—	**7**
Domestic life	—	—	4	3	—	**7**
Relationships and interactions	—	—	3	4	—	**7**
Managing finances and employment	—	—	2	3	2	**7**
Community and social life	—	1	—	6	—	**7**

— Nil.

Psychological and behavioural symptoms

Information on psychological and behavioural symptoms was collected for four clients (Figure B8.1). Two clients experienced memory loss and two clients tended to wander (one extensively). One client was at times verbally disruptive, and two clients were verbally

disruptive on an extensive basis. Four clients exhibited emotional or psychological symptoms and one client is at times physically aggressive.

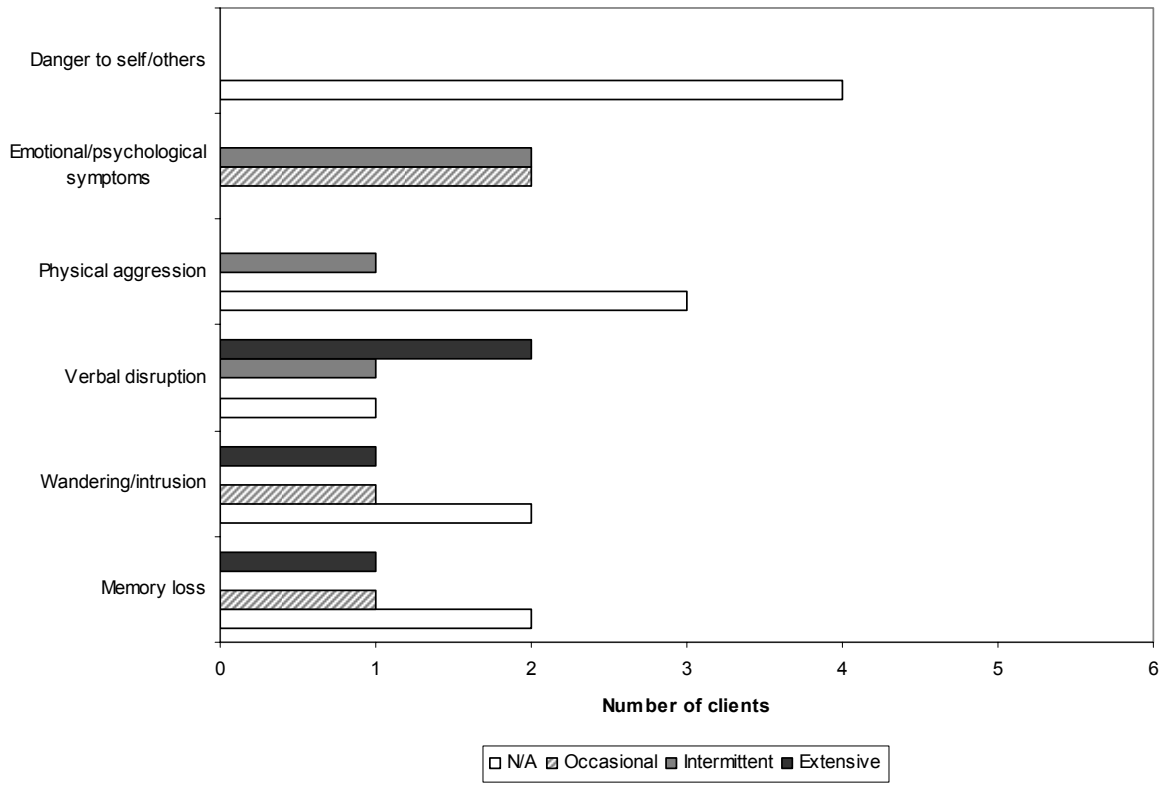


Figure B8.1: Ageing in Place, number of clients by frequency of psychological and behavioural symptoms at entry to project

Broad Screen Checklist of Observed Changes

AIP routinely conducts the BSCOC (Minda Inc.) and provided scores for all clients taking part in the evaluation.

AIP conducted the BSCOC at approximately 6-monthly intervals. The first reported assessments were conducted in July 2003, around the time that clients entered the project. BSCOC scores on this first assessment range from zero to 160 points, with an average of 48 points (standard deviation 58.5). Figure B8.2 shows that one client out of seven experienced a significant change in functioning in the period preceding his/her first BSCOC assessment. Two clients experienced moderate change in functioning, and three clients displayed minor change. Three clients' BSCOC scores increased across multiple assessments, suggesting that their rate of functional change was increasing over time. One of these clients transitioned from the moderate to the severe functional change category. The other clients' rates of functional change remained steady or decreased over time.

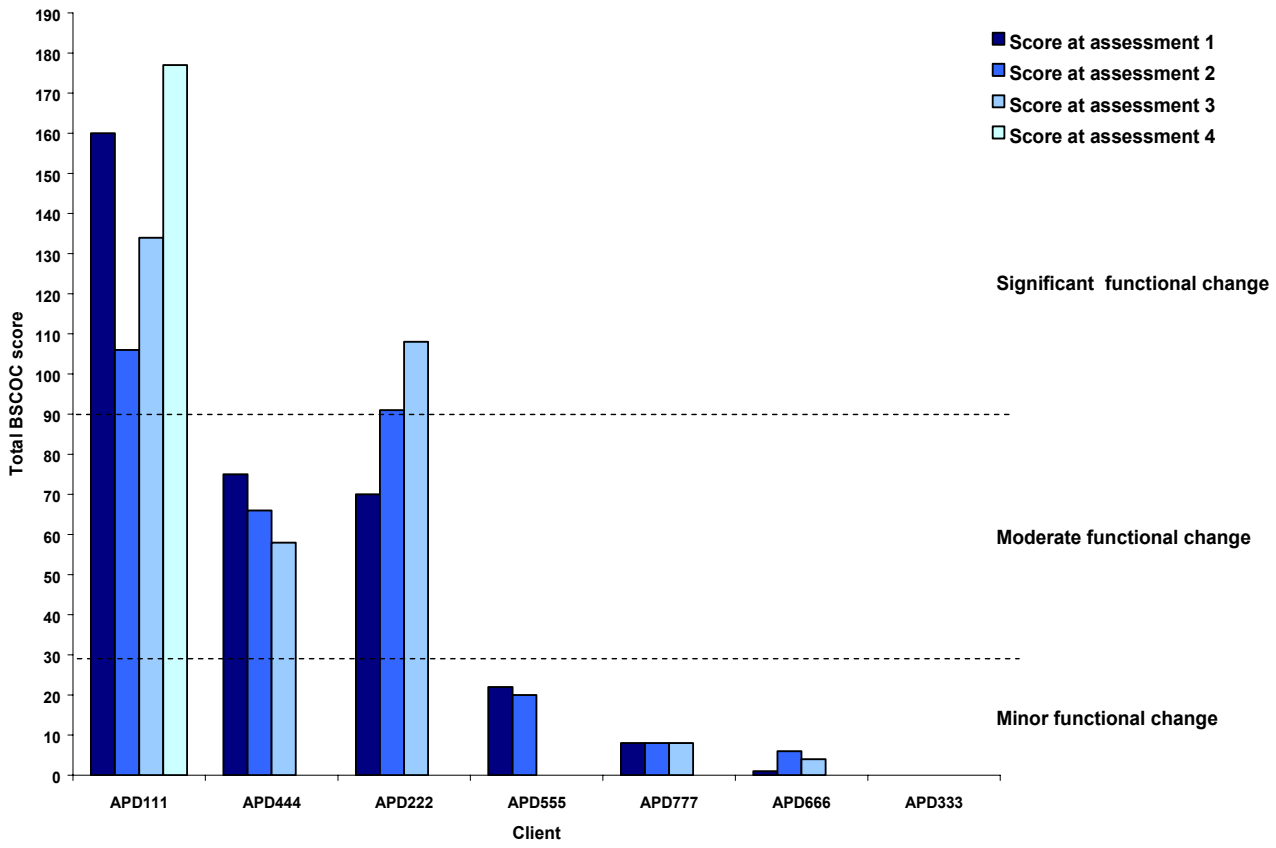


Figure B8.2: Ageing in Place, *Broad Screen Checklist of Observed Changes*, total scores

Client discharges

No clients were discharged from the project during the evaluation.

Cumberland Prospect Disability Aged Care Pilot

Cumberland Prospect Disability Aged Care Pilot serviced mostly clients with intellectual disability but the group also included people with multiple diverse disabilities (Table B9.1).

Table B9.1: Cumberland Prospect Disability Aged Care Pilot, number of clients by disability group

Disability group	Number	Per cent
Intellectual	17	94
Multiple/diverse	1	6
Total	**18**	**100**

Age and sex

The mean age of clients was 62 years. Ages ranged from 40 years to 82 years, with 63% of clients aged 50 years or over (Table B9.2).

Table B9.2: Cumberland Prospect Disability Aged Care Pilot, number of clients by age group and sex

Age (years)	Males	Females	Persons
		(number)	
30–39	—	—	—
40–49	1	—	1
50–59	3	3	6
60–69	7	1	8
70–89	3	—	3
Total	**14**	**4**	**18**
		(per cent)	
30–39	—	—	—
40–49	6	—	6
50–59	17	17	33
60–69	39	6	44
70–89	17	—	17
Total	**61**	**39**	**100**

— Nil.

Language and communication

Four clients had little or no effective means of communication with other people. Thirteen clients had effective spoken communication and one client used another method of communication. Two national languages were represented (Table B9.3).

Table B9.3: Cumberland Prospect Disability Aged Care Pilot, number of clients by language spoken at home, English and spoken language proficiency

	How well does client communicate in English?			
Language spoken at home	**Very well or well**	**Not well**	**Not at all**	**Total**
English	7	3	—	10
Danish	3	1	1	5
Non-verbal	—	—	3	3
Total	**10**	**4**	**4**	**18**

— Nil.

Accommodation and living arrangement

Six clients lived in group homes and 12 clients lived in larger residential accommodation facilities for people with disabilities. On average, CPDAC clients had been living at their home for approximately 28 years (ranging from under one year to 49 years).

Income and concession status

All CPDAC clients relied solely on an Australian Government pension as their primary source of income. Ten clients received the Disability Support Pension and eight received the Age Pension.

Thirteen clients held a health care concession card.

CPDAC does not charge client fees.

Use of formal services

One client was receiving assistance through the National Respite for Carers Program prior to joining the project.

No client was on a waiting list for residential aged care at the time of joining CPDAC.

Assessment and referral

Clients were referred to CPDAC from participating accommodation service providers in the New South Wales Department of Ageing, Disability and Home Care Cumberland/Prospect planning region, with the lead disability service provider, McCall Gardens, acting as an initial point of referral.

The project coordinator, a registered nurse, completes initial screening and manages client care for the project.

Referral is made to ACATs at the Auburn, Westmead and Blacktown hospitals as applicable. Each ACAT has a primary point of contact for the project. Thus, ACAT assessment is mostly completed after referral to the project (Table B9.4); 15 ACAT assessments were completed within 30 days of referral to ACAT.

One client recorded three ACAT assessments in the 12 months prior to entry.

Table B9.4: Cumberland Prospect Disability Aged Care Pilot, number of clients by days between completion of ACAT assessment and date of referral to project

Completion date of ACAT assessment	Number of clients
After referral to project	
Less than 21 days post referral	7
21–60 days post referral	11
Total	**18**

Health conditions and health status on entry

CPDAC clients recorded between two and eight health conditions at entry to the project (eight clients recorded a modal value of four conditions). Eleven clients were recorded as having four or more health conditions.

Table B9.5 shows the primary health conditions recorded on the Aged Care Client Records for CPDAC clients.

Table B9.5: Cumberland Prospect Disability Aged Care Pilot, number of clients by primary health condition

Primary health condition	Number of clients
Intellectual and developmental disorder	13
Diseases of the nervous system	2
Symptoms and signs concerning food and fluid intake	1
Heart disease	1
Not stated	1
Total	**18**

Table B9.6: Cumberland Prospect Disability Aged Care Pilot, number of clients by presence of selected sensory, mental and physical conditions

Health condition	Number of clients
Vision impairment	8
Hearing impairment	5
Impaired gait or balance—at risk of falls	16
Total or partial paralysis	2
Diagnosis of depression	1

Clients were taking between zero and eight different types of medication at the time of reporting. Half the clients were taking four or more different types of medication.

Level of core activity limitation

Eleven clients had a severe or profound level of core activity limitation. Between five and seven clients experienced severe or profound limitation in each of the areas of self-care, mobility and communication (Table B9.7).

Table B9.7: Cumberland Prospect Disability Aged Care Pilot, number of clients by level of core activity limitation

	Level of core activity limitation					
Core activity	No limitation	Mild	Moderate	Severe or profound	Not stated	Total
Self-care	—	1	9	7	1	**18**
Mobility	1	6	6	5	—	**18**
Communication	3	5	4	6	—	**18**

— Nil.

Support needs

In most areas of activity, the majority of CPDAC clients needed help or supervision at times or constantly (Table B9.8). Self-care, domestic life and activities involving social interaction and community participation typically involve constant help or supervision for nearly all clients.

Table B9.8: Cumberland Prospect Disability Aged Care Pilot, number of clients by level of support need

	Level of support need				
Domain	Does not need help or supervision[(a)]	Sometimes needs help or supervision	Always needs help or supervision	Not stated	Total
Self-care activities	—	6	12	—	**18**
Mobility	1	9	7	1	**18**
Communication	3	10	5	—	**18**
Domestic life	—	1	17	—	**18**
Community and social life	—	1	17	—	**18**
Relationships and interactions	1	6	11	—	**18**
Managing finances and employment	—	1	16	1	**18**
Learning and applying knowledge	—	5	13	—	**18**
Performing general tasks and demands	—	5	13	—	**18**

(a) Includes clients who do not need help or supervision but who use aids and/or equipment.

— Nil.

Use of medical and hospital services prior to entry

Baseline profiles contain information about a client's use of medical and hospital services in the six months prior to entering the project—the 'pre-entry period'. Fourteen clients visited a medical practitioner at least once during the pre-entry period, ranging from four to 16 consultations per client with an average of nine.

Five clients recorded hospital admissions during the pre-entry period, three via an emergency department. For the three unplanned admissions, a total of 55 patient days accrued plus 35 rehabilitation days for one client. Diagnoses recorded for the unplanned admissions include chronic lower respiratory disease, abnormalities of gait, and injury.

Client baseline assessment results

Activities of daily living

Baseline Modified Barthel Index (MBI) scores ranged from 5 to 18 out of a total 20 points for 16 clients. The mean baseline score was 10.9 points with a standard deviation of 3.3, reflecting a relatively low functioning group in the domain of self-care. On the basis of the baseline MBI, 12 clients were classified as severely dependent in ADL; two as completely dependent; and four as moderately dependent.

ADL scores recorded at the baseline assessment are summarised in Table B9.9.

The project was unable to assess clients in all IADL domains. Three domains had assessments of at least 15 clients. Fifteen clients were unable to manage their own medications. Fourteen clients were completely unable to use the telephone and another needed help to do so. Fourteen clients were able to shop with help but two other clients were completely unable to shop. Hence clients either needed help or were unable to perform in these three IADL.

Table B9.9: Cumberland Prospect Disability Aged Care Pilot, number of clients by level of dependency in activities of daily living as assessed at entry to project

	Dependency level			
ADL	Independent	Partially dependent	Fully dependent	Total
Bowel management	7	4	5	**16**
Bladder management	3	7	6	**16**
Toilet use	3	8	5	**16**
Bathing/showering	1	. .	15	**16**
Dressing	2	8	6	**16**
Grooming	—	. .	16	**16**
Feeding	3	13	—	**16**
Mobility (level surface)	13	2	1	**16**
Transfers	10	6	—	**16**
Stairs	2	11	3	**16**

Note: For bowel and bladder management, independent denotes continent; partially dependent denotes occasional accident; fully dependent denotes incontinent.

— Nil.

. . Not applicable.

Client discharges

No clients had been discharged by May 2005.

Appendix C: Services and expenditure tables

Table C1: Innovative Pool Disability Aged Care Interface Pilot, project combined services expenditure by service type ($), September and December quarters 2004[(a)]

Service type	September quarter	December quarter	Total
Assessment	12,697.95	10,720.10	23,418.05
Care coordination and case management	56,474.78	55,211.20	111,685.98
Medical services	1,174.50	621.50	1,796.00
Physiotherapy/occupational therapy	4,345.95	5,902.68	10,248.63
Behaviour management therapy	2,783.60	3,903.60	6,687.20
Counselling and support (client and carer)	1,273.00	1,273.00	2,546.00
Other allied health care	16,512.85	20,654.50	37,167.35
Personal assistance	75,236.01	91,341.41	166,577.42
Domestic assistance	15,443.46	15,320.89	30,764.35
Social support	94,704.49	113,701.44	208,405.94
Leisure and recreational programs	12,798.00	11,846.00	24,644.00
Food services	512.70	751.00	1,263.70
Transport	16,493.38	21,994.45	38,487.83
Home modifications	—	750.00	750.00
Provision of aids and equipment	2,939.45	27,876.48	30,815.93
Total	**313,390.12**	**381,868.24**	**695,258.38**

(a) Excludes MS Society Changing Needs and Cumberland Prospect Disability Aged Care Pilot.

— Nil.

Source: Project financial reports.

Table C2: Far North Coast Disability Aged Care Consortium, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Assessment	1,131.53	260.00	1,391.53
Care coordination and case management	4,417.32	3,604.60	8,021.92
Medical services	326.50	326.50	653.00
Physiotherapy/occupational therapy	987.04	3,135.58	4,122.62
Behaviour management therapy	108.40	162.60	271.00
Other allied health care	755.85	913.50	1,669.35
Personal assistance	33,031.16	20,638.86	53,670.02
Social support	3,120.17	3,250.19	6,370.35
Domestic assistance	5,490.46	1,873.89	7,364.35
Provision of aids and equipment	653.45	2,536.80	3,190.25
Total	**50,021.88**	**36,702.51**	**86,724.39**

Source: FNCDAC financial reports.

Table C3: Central West People with a Disability who are Ageing, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Assessment	2,204.73	1,831.10	4,035.83
Care coordination and case management	8,084.01	10,986.60	19,070.61
Physiotherapy/occupational therapy	734.91	1,831.10	2,566.01
Personal assistance	11,023.65	12,817.70	23,841.35
Social support	38,215.32	46,693.05	84,908.37
Transport	13,228.38	17,395.45	30,623.83
Total	**73,491.00**	**91,555.00**	**165,046.00**

Source: CWPDA financial reports.

Table C4a: Northern Sydney Disability Aged Care Pilot, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Care coordination and case management	21,481.00	23,307.00	44,788.00
Other allied health care	535.00	1,250.00	1,785.00
Personal assistance	11,430.00	37,521.85	48,951.85
Social support	337.00	5,000.00	5,337.00
Provision of aids and equipment	2,286.00	25,339.68	27,625.68
Total	**36,069.00**	**92,418.53**	**128,487.53**

Source: NSDACP financial reports.

Table C4b: Northern Sydney Disability Aged Care Pilot, quarterly expenditure on selected service types ($) between 1 April 2004 and 30 June 2005

	Quarter ending					Total to
Service type	**30.6.2004**	**30.9.2004**	**31.12.2004**	**31.3.2005**	**30.6.2005**	**30.6.2005**
Allied health assessment—physio.	2,691.00	1,944.00	1,971.00	4,059.00	264.00	10,929.00
Allied health assessment—occ. ther.	4,686.00	2,688.00	2,875.80	3,102.00	693.00	14,044.80
Personal assistance	4,688.76	16,676.11	29,349.77	37,870.45	52,348.53	140,933.62
Social support	649.44	884.28	8,200.07	13,594.26	13,608.58	36,936.63
Physiotherapy	0.00	6,714.00	13,630.84	14,926.60	21,802.08	57,073.52
Provision of aids and equipment	765.00	2,236.36	25,542.68	35,434.00	3,521.04	67,499.08
Other allied health	1,095.00	415.00	1,391.01	1,152.00	1,110.00	5,163.01
Hydrotherapy	—	—	—	174.24	4,193.52	4,367.76
Diversional therapy	—	—	—	—	748.00	748.00
Total	**14,575.20**	**31,557.75**	**82,961.17**	**110,312.55**	**98,288.75**	**337,695.42**

Notes

1. Quarterly expenditure reported by NSDACP in September 2005 is not intended to be all inclusive. For example, expenditure on needs assessment, case management and coordination by the NSDACP team is not included.
2. Discrepancies appear in the two reports of expenditure on personal assistance, social support, and provision of aids and equipment in the quarter ending 31 December 2004.

— Nil.

Source: NSDACP (New Horizons), 7 September 2005.

Table C5: Flexible Aged Care Packages, expenditure on services by service type ($), September and December quarters 2004

Service type	**September quarter**	**December quarter**	**Total**
Assessment	563.00	2,250.00	2,813.00
Care coordination and case management	4,545.00	1,000.00	5,545.00
Physiotherapy/occupational therapy	—	135.00	135.00
Personal assistance	10,095.00	5,903.00	15,998.00
Social support	45,368.00	43,620.00	88,988.00
Domestic assistance	1,680.00	2,280.00	3,960.00
Home maintenance	—	750.00	750.00
Total	**62,251.00**	**55,938.00**	**118,189.00**

— Nil.

Source: FACP financial reports.

Table C6: Disability and Ageing Lifestyle Project, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Assessment	669.69	182.00	851.69
Care coordination and case management	3,348.45	546.00	3,894.45
Behaviour management therapy	130.20	1,196.00	1,326.20
Personal assistance	130.20	871.00	1,001.20
Social support	2,574.00	10,048.20	12,622.22
Food services	21.70	260.00	281.70
Transport	720.00	2,054.00	2,774.00
Leisure and recreational programs	2,618.00	3,120.00	5,738.00
Total	**10,212.24**	**18,277.20**	**28,489.46**

Source: DALP financial reports.

Table C7: Disability Aged Care Service, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Assessment	6,918.00	6,197.00	13,115.00
Care coordination and case management	13,835.00	14,556.00	28,391.00
Physiotherapy/occupational therapy	2,624.00	801.00	3,425.00
Other allied health care	15,222.00	18,491.00	33,713.00
Personal assistance	5,708.00	7,502.00	13,210.00
Domestic assistance	5,728.00	8,622.00	14,350.00
Total	**50,035.00**	**56,169.00**	**106,204.00**

Source: DACS financial reports.

Table C8: Ageing in Place, expenditure on services by service type ($), September and December quarters 2004

Service type	September quarter	December quarter	Total
Assessment	1,211.00	—	1,211.00
Care coordination and case management	764.00	1,211.00	1,975.00
Medical services	848.00	295.00	1,143.00
Behaviour management therapy	2,545.00	2,545.00	5,090.00
Counselling and support (client and carer)	1,273.00	1,273.00	2,546.00
Personal assistance	3,818.00	6,087.00	9,905.00
Social support	5,090.00	5,090.00	1,180.00
Domestic assistance	2,545.00	2,545.00	5,090.00
Food services	491.00	491.00	982.00
Transport	2,545.00	2,545.00	5,090.00
Leisure and recreational programs	10,180.00	8,726.00	18,906.00
Total	**31,310.00**	**30,808.00**	**53,118.00**

— Nil.

Source: AIP financial reports.

Table C9: Cumberland Prospect Disability Aged Care Pilot, expenditure on services by service type ($), March and June quarters 2005

Service type	March quarter	June quarter	Total
Assessment	9,741.18	4,586.25	14,327.43
Care coordination and case management	9,378.00	10,845.00	20,223.00
Physiotherapy/occupational therapy	1,337.50	25,123.81	26,461.31
Other allied health care	—	681.70	681.70
Personal assistance	8,352.50	24,793.83	33,146.33
Provision of aids and equipment	3,478.00	3,806.10	7,284.10
Leisure and recreational programs	1,770.00	7,559.47	9,329.47
Total	**34,057.18**	**77,396.16**	**111,453.34**

— Nil.

Source: CPDAC financial reports.

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