

# 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).<sup>6</sup> 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.

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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**

<b>Project (acronym)</b>	<b>Approved provider</b>	<b>Service locations</b>	<b>Initial place allocation</b>	<b>Start date</b>	<b>Planned duration</b>	<b>Flexible care subsidy daily rate (\$)</b>
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)	UnitingCare 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)	UnitingCare 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.<sup>7</sup>
- 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).

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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**

<i>Accommodation support</i>	<i>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.</i>
<i>Advocacy</i>	<i>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.</i>
<i>Community support</i>	<i>Services that provide the support needed for a person with a disability to live in a non-institutional setting.</i>
<i>Community access</i>	<i>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.</i>
<i>Information services</i>	<i>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.</i>
<i>Print disability services</i>	<i>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.</i>
<i>Respite</i>	<i>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.</i>
<i>Employment</i>	<i>Services which provide employment assistance to people with disabilities to assist them obtain and/or retain employment.</i>

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)<sup>8</sup> (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

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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**

Primary disability	Age group (years)					Total
	30–39	40–49	50–59	60–69	70+	
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
<b>Total</b>	<b>3,004</b>	<b>2,780</b>	<b>1,843</b>	<b>685</b>	<b>287</b>	<b>8,599</b>

— 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<sup>(a)</sup>, Australia 2003**

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

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 'programmable 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 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](http://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**

<b>Result of ageing</b>	<b>Assistance potentially required</b>
<b>Biological ageing</b>	
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.
<b>Psychological ageing</b>	
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.
<b>Social ageing</b>	
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**

<b>Project</b>	<b>Place allocation</b>	<b>Location description</b>	<b>Approved provider</b>	<b>Number of accommodation provider partners</b>	<b>Siting of project team</b>	<b>Staffing model</b>
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 <sup>(a)</sup>	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
<i>Fully integrated models of disability and aged care service provision</i>		
Pooled aged care and disability funds	MS Changing Needs, Multiple Sclerosis Society of Victoria	<p>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.</p> <p>The intention of the project is to supply additional aged care services to meet the emerging aged care needs of the eligible participants.</p>
	Ageing In Place, Oakdale Services, Tasmania	<p>The service model will test the effectiveness and efficiency of pooling aged care funding and disability funding to provide ageing in place.</p> <p>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.</p>
<i>Collaborative models of disability and aged care service delivery</i>		
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.
	Central West people with a Disability who are Ageing, UnitingCare, New South Wales	Assist people with disabilities whose support needs are increasing due to conditions relating to their ageing, to maximise their independence and continue their lifestyle.
	Northern Sydney Disability Aged Care Pilot, New Horizons Limited, New South Wales	Examples of service scope:
	Interlink Flexible Aged Care Packages, Helping Hand Inc., South Australia	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.
	Disability and Ageing Lifestyle Project, Renmark Paringa District Hospital, South Australia	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.
	Disability Aged Care Service, Senses Foundation, Western Australia	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.
	Cumberland Prospect Disability Aged Care Pilot, UnitingCare, 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<sup>(a)</sup>**

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 <sup>(a)</sup>	Evaluation clients		Evaluation clients as per cent of active clients
			Profile records	Discharge records	
FNCDAC, NSW <sup>(b)</sup>	30	13	13	4	100.0
CWPDA, NSW <sup>(b)</sup>	40	33	33	2	100.0
NSDACP, NSW <sup>(b)</sup>	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 <sup>(c)</sup>	20	20	18	1	90.0
AIP, Tas	7	7	7	—	100.0
<i>Subtotal as at 30 November 2004</i>	<i>188</i>	<i>166</i>	<i>147</i>	<i>13</i>	<i>88.6</i>
CPDAC, NSW	30	28	18	—	64.3
<b>Total</b>	<b>228</b>	<b>194</b>	<b>165</b>	<b>13</b>	<b>85.1</b>

(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.