3 New care choices

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

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

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

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

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

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

Staffing aspects are discussed under each project, below.

3.1 Far North Coast Disability and Aged Care Consortium

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

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

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

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

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

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

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

Referral and assessment

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

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

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

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

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

Care planning

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

Client group

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

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

Project stakeholders believe that 65 years of age is too high a threshold for access to aged care services for clients who have disabilities. They feel that 50 years of age is a more appropriate age threshold for the target group, but they would prefer to see the threshold dispensed with altogether as there is no specific age at which age-related needs manifest. FNCDAC client group profiles are given in Appendix B (see Appendix Tables B1.1–B1.9).

Service model

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

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

In-home services funded by the pilot have been delivered by existing disability support staff. The project provides training including manual handling techniques appropriate for
individual clients. General training in aged care is provided, such as the use of aged care assessment tools and the identification and management of early cognitive decline.

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

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

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

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

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

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

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

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

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

.. Not applicable.

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

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

.. Not applicable.
Achievements and challenges

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

‘FNCDAC has facilitated the introduction of new and good practices which will benefit people with disabilities who are ageing on the Far North Coast:

• The Minda BSCOC has been implemented as standard practice for clients over a certain age, to be completed six-monthly. This is expected to gather baseline data, note the time of onset of change, and assist disability support staff to identify changes. In practice, the tool has proved to be quite subjective, and it was found that high reliance cannot always be placed on the raw scores. For example, one agency consistently recorded very high BSCOC scores, whilst others consistently recorded much lower scores. In another case, the BSCOC was administered twice, at a short interval, with the same interviewer interviewing different support workers for each BSCOC (same client). Scores varied markedly, which suggested low inter-rater reliability. However, the project did find that clients with very low scores (little evidence of functional change) were those who were rejected by ACAT at assessment. It was concluded that BSCOC is a useful tool for (a) Disability Service Providers to track changes in clients; and (b) providing a basis for discussion at ACAT assessment; BSCOC scores were found to be not informative in the absence of other detailed knowledge of a client.

• As part of the work-up for either ACAT assessment, or the assessments that follow, CT scans are occurring earlier in the lives of (relevant) clients than prior to the project.

• The project is currently investigating other screens and tests validated for this client group, with a view to using them to assist in the assessment process. The difficulty in determining what is age related has led to this search for better assessment tools. Tools need to be internationally validated, specific to this target group, and able to be administered by care staff or ACAT assessors.

A working party on screening tools identified further tools and the following were adopted as recommended standard practice:

• Minda BSCOC to chart change and for valuable information, particularly around ADL functioning.

• The DMR (Dementia questionnaire for person with intellectual disabilities, Holland) an internationally validated screening tool for dementia in people with intellectual disabilities. FNCDAC bought the tool and the project coordinator facilitated a short introductory training session with client service managers from participating disability service providers in April 2005 (some disability service providers started using it).

• PAS-ADD checklist—a screening tool for mental health disorders in people with disabilities. FNCDAC chose the Checklist, rather than the Mini-PAS-ADD, because (a) the Checklist can be used by support workers and (b) the Mini PAS-ADD required training that is not currently available in Australia as there is only one accredited trainer, who was occupied with research activity. Dr Steven Moss of England has developed all the PAS-ADD tools, which are internationally validated.

Additionally, FNCDAC continued with the Cornell Depression Scale and the Montgomery and Asberg Depression Rating Scale (MADRS). The project funded training in MADRS for staff from the relevant disability service providers as depression in the elderly is common and can parade as dementia. These two tools have been developed for people with impaired cognition. The whole area of screening has been raised through the ACAT assessments; ACAT assessors are careful to not reach a hasty conclusion that a client has dementia. Many referrals through the project have presented a complex and confusing picture, highlighting the important and
challenging issue of distinguishing dementia from other mental health and medication issues faced by members of the client group.

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

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

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

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

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

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

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

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

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

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

3.2 Central West People with a Disability who are Ageing

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

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

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

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

**Stakeholders**

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

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

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

**Target group, referral and assessment**

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

- can be supported in their current residence with additional aged care specific services (joining the project should not involve a change of residence)
- have their current disability service support guaranteed
- agree to participate
- have valid ACAT approval for residential aged care.
The main areas of age-related need that the project was designed to address are mobility, continence, sleep pattern, dementia, physiotherapy and occupational therapy needs, and socialisation.

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

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

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

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

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

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

**Staffing and service model**

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

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

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

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

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

. . . Not applicable.

Achievements and challenges

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

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

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

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

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

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

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

Staff turnover has been low in some locations, while in others the project has managed to maintain staffing with some difficulty. Clients in Bathurst and Orange have benefited from very low turnover of CWPDA aged care staff. Staff retention in Dubbo and Gilgandra posed a greater challenge. There is also high turnover in disability support staff at these locations. UnitingCare operates care packages in the wider community with a stable staff. In locations where difficulties exist, the challenge is in finding and retaining aged care staff with
expertise in the disability field. A disability client may fail to understand and accept staff changes and a change can exacerbate client behaviour and cause setback in the care plan.

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

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

Among other issues identified, travel time and costs across the large catchment area have proved to be an ongoing challenge. There is some difficulty with ‘remote’ management from DADHC in Sydney and the level of understanding of the respective roles of state and Australian Governments in program delivery among staff at the coalface of service delivery. Some consortium members believe that the evaluation should have been carried out towards the end of the project to gain more insight into its effectiveness and suggest that a longitudinal perspective would have provided a more detailed picture of the increase in ageing issues/needs and the increased hours over time to support a particular client.

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

### 3.3 Northern Sydney Disability Aged Care Pilot

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

NSDACP objectives are to:

- assist clients to maximise their independence and continue their lifestyle within their existing group home or institution
- demonstrate that flexible service delivery will meet individual client needs and prevent premature or inappropriate admission to residential aged care
• integrate aged-specific care with the client’s existing disability care plan.

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

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

**Stakeholders**

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

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

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

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

Established in 1952, the Sunnyfield Association offers support to people with a disability and their families living in Sydney and the Central Coast. Sunnyfield provides accommodation
services in over 30 group homes in the community, therapy services and day programs for people with a disability, respite and day programs, and training and employment services. Sunshine Home has been providing accommodation, day programs and employment opportunities for adults and adolescents with an intellectual disability for over 80 years. The organisation operates day options (including specific programs for seniors and younger people with intellectual disability), employment services and accommodation services. Until recently, Sunshine Home accommodation services comprised group homes and a larger hostel facility that accommodated approximately 100 residents at Gore Hill, the original Sunshine Home site. The hostel closed and several clients participating in the evaluation who were some of the earliest residents at Gore Hill moved into group home accommodation during the course of the evaluation.

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

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

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

**Target group**

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

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

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

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

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

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

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

The national evaluation coincided with a period of slow referral and assessment processes which, together with consent provisions, limited the number of evaluation participants to 22 of the 30 clients who had commenced by September 2004 (Figure 3.1). The number of group homes with one or more residents receiving NSDACP services rose from three in April 2004 to 11 by June and to 19 by November 2004. A proportion of early referrals from disability service providers was rejected by the NSDACP coordinator as inappropriate or incomplete. It has taken time to educate disability service staff on how to identify and document age-related needs, particularly in the area of dementia superimposed on Down syndrome. Initially the project relied on information disseminated at consortium meetings filtering down to staff in facilities but this proved to be an ineffective means of communicating NSDACP requirements to staff directly responsible for their implementation. Over time and with education, the referral and assessment process became streamlined and efficient. Major delays have not occurred at the ACAT end of the process.
A broad spectrum of aged care needs is seen in the referrals, requiring a range of assessment tools for screening and needs identification. NSDACP deals with clients who experience many of the common maladies of older age plus disability-specific health conditions that are age-related. NSDACP clients with cerebral palsy are at the high end of the spectrum of need for physical support. The Broad Screen Checklist of Observed Changes (Minda Inc.), used extensively across the Innovative Pool projects to inform assessments of clients with intellectual disability, cannot be used for this group. The Spastic Centre has made use of the Functional Independence Measure (FIM) for assessment of people identified for referral to the project and had routinely used the FIM over a period in the late 1990s. A comparison of the two sets of FIM scores revealed marked physical decline over the intervening period. The
FIM is recommended for use with this group of NSDACP clients and is found to facilitate communication with health care professionals due to its widespread application in the health sector. Spinal cord compression typically occurs in people with cerebral palsy who are aged over 30 years. This condition requires specialist diagnosis by a physiotherapist (a GP may not be equipped to diagnose spinal chord compression in a patient with cerebral palsy) and neurosurgical intervention.

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

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

Service model

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

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

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

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

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

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

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

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

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

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

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

— Nil or rounded to zero.
. . Not applicable.

A picture of service activity in the maturing NSDACP is reflected in the project’s September 2005 report of service expenditure (Table 3.6 and Figure 3.2), which shows increases in expenditure on personal assistance, physical therapy and the provision of aids and equipment as assessments were completed and care plans became established.
Table 3.6: Northern Sydney Disability Aged Care Pilot, quarterly expenditure on selected service types, 1 April 2004 – 30 June 2005

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

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

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

Achievements and challenges
NSDACP has been described as a ‘pressure reliever’. By taking responsibility for the management of age-related needs of clients, the project has freed up capacity within the participating disability services, allowing resources to be more evenly shared between all residents of a household. This reduces the burden on disability support staff and helps to improve the quality of life for project clients and other residents alike.
Disability service providers highlighted provision of aids and equipment, access to skilled dementia care and advice, and access to allied health care as three aspects of the NSDACP service model that are of major benefit to clients. The project demonstrates the need for aged care models of allied health support to be integrated into disability service settings. In this and a number of other respects NSDACP has helped a small number of people to overcome systemic barriers to service provision for people with disabilities. The NSCACP team and consortium pointed to issues that impact on the capacity of mainstream services to provide appropriate care for older people with disabilities:

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

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

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

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

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

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

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

   Many disability day programs cater primarily to the needs of people with intellectual disability and are reluctant to accept new clients who have a physical disability. Sometimes this reluctance is due to physical access barriers, for example, the lack of a ramp for wheelchair access. In other cases staff have been unwilling to accommodate a person with somewhat different needs to the rest of a group.
The project has highlighted the difficulties associated with placing a person with a disability into residential aged care to receive what disability service providers view as less appropriate care with a lower staff to client ratio than a client is accustomed to receiving. However, once age-related needs increase to the extent that a client needs high level nursing care or significant manual handling, group home accommodation becomes inappropriate. The project coordinator posited that potential solutions are to provide adequate training opportunities for staff in the aged care sector and training on ageing and aged care for staff in the disability sector to enable staff to deliver appropriate community care to people with disabilities who are ageing, and to provide specialist nursing homes for people with a disability.

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

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

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

### 3.4 MS Changing Needs

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

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

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

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

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

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

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

Target group

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

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

Most clients are immobile—hoists are already in place.

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

• swallowing problems that necessitate dietary changes, assistance with feeding or enteral feeding
• bowel and bladder incontinence
• high blood pressure
• skin integrity problems requiring wound dressing.

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

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

Service environment

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

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

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

Referral and assessment

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

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

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

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

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

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

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

— Nil or rounded to zero.

Achievements and challenges

MS Changing Needs is helping to show that both levels of government can cooperate to achieve a good outcome for clients. Most people with MS enter residential aged care via hospital. When a person needs to be hospitalised, often the group home cannot accept them
back because it is unable to provide 24-hour nursing care. The wait in hospital for a residential aged care bed can be long—delays of up to 18 months or more have occurred in the past.

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

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

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

3.5 Interlink Flexible Aged Care Packages

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

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

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

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

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

Stakeholders

The approved provider is Helping Hand Aged Care Incorporated, an organisation established in 1953 which provides residential care to older people along with rehabilitation, therapy and other support services for the aged. The project coordinator is employed by Helping Hand. The project consortium includes, apart from Helping Hand, the following partners: Adults with Physical and Neurological Disability Options Coordination; Barkuma
Inc.; Brain Injury Options Coordination; Hills Community Options Inc.; Minda Inc.; Orana Inc.; and the Intellectual Disability Services Council (supporting role).

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

**Client group**

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

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

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

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

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

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

**Service model**

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

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

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

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

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

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

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

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

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

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

— Nil or rounded to zero.

Achievements and challenges

Working with agencies with staff already attending clients has been the project’s major challenge. A large part of the project involves building relationships between the consortium members. The model is described as supporting disability services to help clients. As
outlined above, the project itself does not provide case management but develops a care plan which enables an existing disability services case manager to ensure that appropriate care is delivered to the client. It has been important for each sector to value the work of the other. Consortium members believe the model could be used anywhere once links are established and competition gives way to collaboration. Project staff identified initial challenges in working with consortium members but relationships have developed with the establishment of communication lines and training. Some group home staff seemed to find the arrival of new staff threatening.

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

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

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

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

### 3.6 Disability and Ageing Lifestyle Project

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

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

RPDH has significant experience in the delivery of a broad range of home-based services to a variety of clients with special needs. Current target groups of RPDH include frail older people, younger people with disabilities, people with challenging behaviours, people with mental health illness, people from culturally and linguistically diverse backgrounds, and carers of people in these groups. RPDH is involved in community aged care through the provision of CACPs in addition to operating an 89-bed residential aged care facility (high and low care).
RPDH employs local staff in the towns where services are delivered. Approximately 90% of RPDH staff work in some aspect of aged care or disability service provision. Options Coordination is an umbrella organisation for disability services in South Australia. The organisation comprises five agencies across the state. Options coordinators perform needs assessments for people (adults and children) with disabilities and assists clients to find places in specialist services. The case management of many disability services clients in the region is undertaken by Options Coordination and the Options coordinator involved with DALP is a respected source of knowledge of the needs of individuals in group homes in the DALP catchment area. The proposal for an innovative service received support from three disability services in the region: Lifestyle Assistance and Accommodation Service Inc., Dakota House—Riverland Group Housing Association, and Orana Inc. DALP was initially funded to operate 10 places and commenced operations in June 2004. The evaluation coincided with the project’s establishment phase; data on eight clients were supplied. The project achieved full occupancy in December 2004. As of mid-August 2005, no clients had been discharged from the service.

Service environment

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

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

Clients in group homes are not usually able to access CACPs or other types of community aged care. The project coordinators suggested that older disability clients in group homes would benefit from a community care package if accessible (three project clients from group homes were accessing a day activity program for older people at the time of the evaluation). There are no accommodation services in the area specifically designed for people with brain injury, neurological disorders or physical disabilities. People with these conditions are usually cared for in hostels or residential aged care facilities when they can no longer cope at home. This is a major service gap in the district. However, several aged care and disability service initiatives operate in the area and RPDH has established strong relationships with them.

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

Client group

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

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

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

Referral and assessment

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

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

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

All supported accommodation agencies with clients accepted into the project are required to complete an inter-agency brokerage service agreement with Renmark Paringa District Hospital. Clients (and their representatives) are also required to complete a client service
agreement with Renmark Paringa District Hospital prior to services commencing. A client service contract is agreed for each client once his/her care plan is finalised.

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

Service model

All services to be delivered are documented in advance. It was expected that clients would receive an average of 10 hours of additional assistance per week through the project. DALP was proposed to operate with a variety of different service delivery options. The program is open to a range of staffing options:

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

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

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

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

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

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

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

It was anticipated that over time DALP would work up to delivering an average of 10 hours of additional support per client each week.
Table 3.9: Disability and Ageing Lifestyle Project, minimum, median, maximum and mean service units per client per week, by service type

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

— Nil or rounded to zero.

Achievements and challenges

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

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

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

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

3.7 Disability Aged Care Service

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

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

- accommodation services—seven group homes for people with a disability funded by the Western Australia Disability Services Commission
- services for the deaf-blind
• aged care, including recreation programs.

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

Activ Foundation delivers services to people with intellectual disability.

The project aims to offer more care options to clients with age-related needs who live in group homes in order to avoid or delay transfer to residential aged care. Senses Foundation emphasised that the onset of cognitive decline is often a reason for clients transitioning to an aged care service. Managing clients with dementia presents a challenge to disability services, which generally do not offer secure built environments. Senses Foundation indicated that the community does not currently provide appropriate interventions for the target group.

Disability services provide about 4 hours of supervised care per day—breakfast and morning personal assistance plus evening meal preparation. DACS offers clients a minimum of 6.7 additional hours of assistance per week.

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

Client group

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

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

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

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

Referral and assessment

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

**Service model**

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

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

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

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

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

The project has found that Innovative Pool funding allows for one-to-one interaction between a client and staff, which has proven very beneficial. Activities with a client might focus on mobility, ADL performance, cognitive function or behaviour management. One client, for example, has concentrated on drawing and colouring activities to help restore fine motor skills.
Simple devices have been installed to promote independence in the home environment. In one case the project installed an urn to allow clients to independently prepare hot drinks as the kettle was too heavy to handle safely.

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

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

**Individual Specific Care Plan**

Name: **MISS S**

Issue Date: ________

Facility: **SENSES STREET**

Topic: **EXERCISES**

Review: Every 2 months.

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

Staff signature_______________________________________________________

Client signature_____________________________________________________

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

Staff signature ________________________________________________________________________________________________________________

Client signature_________________________________________________________________________

Review/evaluate care plan 2 months in progress notes. Sign and date over page.
<table>
<thead>
<tr>
<th>Date</th>
<th>Evaluation in progress notes</th>
<th>Signature</th>
<th>Date</th>
<th>Evaluation in progress notes</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>
The project can deliver intensive nursing care if required and employs a registered nurse and an enrolled nurse. Senses Foundation noted that hospitals find it difficult to manage patients with disabilities particularly where there is behavioural and/or speech impairment. On occasions, a patient has been sent home from hospital, requiring 24-hour care, to a supported accommodation setting that can provide only 4 hours of care per day. Senses Foundation anticipates an increase in the need for high level post-acute care within the disability sector as people with a disability live to ages that have not been reached in the past and experience levels of health service utilisation that are commonly observed in older populations.

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

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

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

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

— Nil or rounded to zero.

Achievements and challenges

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

A major positive aspect has been increased access to ACAT assessment for Senses and Activ clients. In the past, a client receiving disability services would not have had contact with an ACAT unless they experienced an acute episode or an urgent need for aged care placement. ACAT assessment is now viewed as a positive encounter. ACAT staff involved with the
DACS project have also reported that they are pleased to have a more positive option to offer disability services clients. One senior ACAT member remarked that assessment of clients for DACS demands a ‘flexibility of perspective’ that not all ACAT staff would have. DACS values highly the particular ACAT staff working with project staff and clients. In turn, ACAT members involved in the project remarked that it has been a professionally rewarding experience. The pre-screening procedure of DACS has meant that most referrals received by ACAT have been appropriate, with the clients showing obvious signs of age-related functional decline. The ACATs have been pleased to see that therapy needs of the clients are being met in a more timely fashion through the project and that clients’ medication regimes are well managed, which, in the past, could not always be said.

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

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

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

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

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

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

Oakdale Services Tasmania established the Ageing In Place pilot project at Oakdale Lodge, a residential facility for people with intellectual disability in Warrane, a suburb of Hobart. The project was established in June 2003 to cater to the ageing needs of seven residents. Service delivery commenced in July 2003 and was intended to operate for 3 years. Maximum funding from the Department of Health and Ageing will total $158,275 per year which is equivalent to $61.94 per allocated place per day.

Stakeholders

Oakdale Services Tasmania is the approved provider for Ageing In Place. Oakdale Services is a not-for-profit organisation established in 1970 that now delivers supported accommodation and other services to over 50 people with intellectual disability or acquired brain injury. The Tasmanian Department of Health and Human Services maintains the block grant payable to Oakdale Services Tasmania under the Commonwealth State/Territory Disability Agreement.

Client group, referral and assessment

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

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

Package recipients need to have been assessed by the ACAT as eligible to receive high level residential aged care and endorsed by Oakdale Services as suitable for participation in the project. Client selection involves the consent of the resident or a relative of the resident, the project coordinator and an advocate. Advocacy Tasmania Inc. plays an important role in client selection and care provision. The first clients commenced services in July 2003, comprehensive assessment having been completed as part of the development of the project proposal.
The project enjoys strong links with the South Tasmania ACAT, which were well established by the time the project began. The ACAT has staff experienced in assessment and care of both older people and people with a disability, lending valuable input to Ageing In Place. There is strong support for ACAT services playing an ongoing role in the assessment of people with a disability who are ageing. It is thought that ACAT services have a crucial role in educating the disability sector about aged care but also have a responsibility to learn about the assessment and care of people with disabilities. Standard ACAT assessment would find it difficult to set a benchmark of the ‘normal’ support needs for a client with intellectual disability. Comprehensive assessment involving both the ACAT and disability support staff who are familiar with a client’s history is considered essential.

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

**Service model**

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

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

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

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

A representative of Advocacy Tasmania attends quarterly project meetings to represent clients’ views of services and facilitates informal sessions between clients and Oakdale Services to discuss the project. Services to an individual client are constantly reviewed and refined if necessary through the input of Advocacy Tasmania which liaises with the project coordinator on the expressed needs and desires of individual clients.
AIP supplied evaluation data for seven clients, all people with intellectual disability. Ageing In Place is perhaps best described as a model of social care for people with a disability who are ageing. A main focus of the project is supporting lifestyle transition for clients in or approaching retirement. This is reflected in the project’s service activity profile, which featured high rates of service delivery for social support, domestic assistance, transport and recreation programs during the 2004 evaluation (Table 3.11).

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

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

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

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

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

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

— Nil or rounded to zero.

Service environment

The evaluation team discussed service provision for people with intellectual disability with management and staff at Oakdale Lodge, the referring ACAT team leader and the client advocate at Advocacy Tasmania. There is agreement that aged care needs cannot always be adequately addressed in conventional group home and hostel environments but that nor does residential aged care cater to the needs of this group. Transfer to residential aged care is often the only option for a disability services client who has high nursing care needs or who
needs 24-hour supervision because of high-risk behaviour. However, experience has shown that most aged care facilities have difficulty coping with residents who have intellectual disability.

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

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

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

Achievements and challenges

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

A major challenge for the project has been a lack of appreciation at state government level of the significance of the Disability Aged Care Interface Pilot. Oakdale Services management indicated it had received advice from the Tasmanian Government that specialist day places
for Ageing In Place clients would not be secured for the duration of the project. Thus, if the project is discontinued at the end of the 3-year funding period, clients will need to join the Disability Services waiting list and be assessed on the basis of need and priority at that time in order to resume daytime disability services. Oakdale Services and Advocacy Tasmania counselled potential clients on the long-term implications of joining the project. In some cases, clients needed to be given a trial period in Ageing In Place before fully committing.

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

3.9 Cumberland Prospect Disability Aged Care Pilot

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

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

CPDAC aims to:

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

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

Stakeholders and partners

UnitingCare NSW.ACT is an agency of The Uniting Church in Australia and is an approved aged care provider. While working with people with disabilities who are ageing through the
CPDAC project marks a new direction for the organisation, UnitingCare has a long history of providing mainstream aged care services, including residential care and Community Aged Care Packages.

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

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

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

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

**Client group**

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

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

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

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

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

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

Project coordinators visit clients weekly or fortnightly as appropriate.

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

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

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

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

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

— Nil or rounded to zero.

. . Not applicable.

Achievements and challenges

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

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

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

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

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

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

Case study 1

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

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

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

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

Additional areas of concern were:
- sleep disturbances
- intrusive and resistive behaviour.

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

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

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

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

The client also experienced problems getting up from a seated position and she also had problems getting out of bed, requiring an increase in staff intervention and manual handling.
The client required full assistance with all activities of daily living. Staff needed to attend to her hygiene needs, in terms of showering, grooming and oral care. Full assistance was also required to dress and undress. The client required continence management, continence aids and full staff assistance with toileting. The client was on a soft diet; staff were required to cut up meals and closely observe the client for choking as part of mealtime management.

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

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

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

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

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

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

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

Aspects of the client’s program included:

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

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

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

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

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

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

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

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

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

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

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

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

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

At this stage assessments and staff observation indicated that the client required and was receiving one-on-one assistance with all daily living activities on most occasions.
A sleep assessment was conducted due to documentation of a poor sleep pattern with wakeful episodes, incontinence and confusion. Aromatherapy was implemented to assist with relaxation and promotion of sleep (this is still being used and has proven helpful).

The client experienced more incontinent episodes despite the toileting program.

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

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

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

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

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

Case study 2

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

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

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

The ACAT recommended screening for depression and referral to the GP for possible anti-depression medication and to address peripheral circulation problems. It was also suggested that the client see a psychologist for cognitive behavioural therapy, a physiotherapist to develop a rehabilitation program. An investigation of opportunities for increased community participation to assist with mood, mobility and social isolation was recommended.
The client was the first and only client in the project who was able to consent to his own involvement in the Pilot and who had direct input into a care plan. He was very keen to commence a rehabilitation program in a gym but was not at all amenable to seeing a psychologist.

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

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

Outcomes

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

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

Case study 3

The client is a lady with intellectual disability, aged in her late 50s. She spent many years in a large institution and now lives in supported accommodation. She has been living in the same group home with the same housemates for more than a decade. Ms V was referred to the project in December 2003 with intellectual disability, osteoporosis, Bowen’s disease and epilepsy. Her challenging behaviours included non-compliant aggression, physical aggression and foul language. She was taking six different medications. The client scored 13 points on the BSCOC, indicating functional change had taken place before the client joined the project.
The client was assessed by ACAT in early 2004. Early cognitive change, weight loss, old fractures in the lumbar and thoracic spine, some episodes of urinary incontinence, and deteriorating skin integrity were noted. The ACAT recommended a series of allied health assessments including an occupational therapy assessment of the client’s home environment, a review of dietary and fluid intake, and the development of a physiotherapy program to maintain her strength, balance and bone density. It was also recommended that staff caring for the client be educated about the monitoring and management of early cognitive changes.

The necessary assessments were arranged. The client joined a community art class, and plans to expand her community participation. She is also taking part in an individual exercise program designed to strengthen her upper body, increase bone density and improve posture. Walking to art class has provided a further opportunity for exercise to improve balance and maintain bone density. The project funds a support worker to accompany the client and some exercise equipment has been purchased.

Outcomes
Though progress has been slow, the client showed early benefits from a regular exercise program, and enjoyed the contact with the women in her art class. She gradually extended her time at these activities. Disability support staff join the project coordinator for regular reviews with her health and allied health care professionals to ensure that the care plan remains appropriate to her changing needs.

Case study 4
The client is a man with Down syndrome aged in his mid-50s. He used to enjoy watching TV, reading magazines, playing cricket, swimming and music. He once had a wonderful memory and was a passionate fan of Elvis Presley. He has lived in his supported accommodation for only 2 years. Prior to this, the client lived independently in his own flat and attended work each day. He has been involved with the local disability service provider since he was a young child. His parents are both deceased—his sister takes responsibility for his welfare.

The client was referred to the project in October 2003 because of a dramatic increase in his personal care needs due to dementia and incontinence. His personal safety was compromised by his absconding and he could no longer be left unsupervised. He sometimes became aggressive when he was confused or disoriented. This decline to requiring 24-hour care was quite rapid. His BSCOC score was 118 with the highest scores being in the perceptual/cognitive, social/emotional and activities of daily living domains.

ACAT assessment identified Down syndrome, dementia, hypertension, cataracts, sleep apnoea and gout. It was noted that the client had ceased initiating tasks, and was becoming frustrated and resistant at times. He was unsteady on his feet and unable to judge changes in floor level, leading to a risk of falls even though he is able to walk unaided. He needs prompting to eat and requires a diet of soft foods. The client’s interaction with others had reduced to almost nil, whereas he used to be very social.

The client’s care plan in the project includes two hours of personal care per day, including time in the morning to enable him to do things at his own pace and go to his day program a little later, which has been successful in reducing resistance. He was assessed by a geriatrician and a gero-psychologist, which included a medication review. The project implemented daily walks to maintain mobility and the provision of aids and equipment. A manual handling expert was engaged to assess staff manual handling practices for this client and another client and to provide necessary training to staff. The client is also visited by a community nurse who treats his ulcerated ankle.
The client’s care plan evolved as his needs increased. For example, changes were initially made to his walking route to keep him away from crowds and public places that made him anxious. Then, as seizure activity increased, staff began taking him for walks in his wheelchair and ensuring that the route is within his ‘cognitive comfort zone’.

Outcomes

While the client’s health continued to deteriorate, the project made significant contributions to his quality of life and the decline is likely to have been far more rapid without the interventions of the project. As a consequence of the project, he is less resistant to staff performing personal care tasks, and is overall less grumpy and aggressive. The provision of equipment improved his physical safety and dignity and decreased the risk of pressure sores from increased hours in bed and chair. The client enjoys one-on-one walks with staff in the local neighbourhood to watch children playing sport or go to shops for a milkshake. The behaviour management plan and environmental interventions have decreased his anxiety. A minor reduction in his medications has resulted in a marked improvement in mood, and the client is an obviously happier person, with benefits for both him and the people he lives with.’

Case study 5

‘The client is a man with Down syndrome aged in his mid-50s. He commenced employment with his disability service provider in 1960 and worked for 37 years until his retirement in 1997. The client was also active outside work, riding his bicycle to and from work, being an active member of a local bowling club with his brother, and becoming a well-known identity in the local dancing fraternity through his love of ballroom dancing.

The client’s mother developed dementia and was placed in residential aged care in 1998. The client lived in respite care accommodation for 3 months before moving into supported accommodation with his disability service provider in 1999. After he retired from work, the client transferred to a day program for retired people with disabilities. He withdrew from this in 2002 due to deteriorating health. He developed myoclonic seizures in conjunction with progressive dementia. He deteriorated rapidly in the following 18 months and required high support for several months. His GP visited the home regularly, and the client was reviewed annually by the ACAT geriatrician.

The client was referred to the project in October 2003. Information at referral noted Down syndrome, progressive dementia, limited verbal communication, seizures, declining functional abilities, mobility problems, and low blood pressure. He had several consultations with the geriatrician prior to referral. In addition to the support and care offered by the disability service provider, the client was having weekly visits from community nurses for management of a wound resulting from the removal of a skin cancer, visits from a podiatrist and weekly leg and arm massage through a local university clinic. The client’s GP does home visits as required.

The client’s BSCOC score was 128, showing significant functional change, which was spread across each of the six sub-scales.

ACAT assessed the client and recommended several allied health assessments, including a physiotherapist to develop a mobility program, a speech therapist for swallowing, a dietician, and an occupational therapist to develop an ADL program and to advise on physical access in the home. Assistance from aged care specialists to manage continence, medication, skin integrity, manual handling and nutrition and to review practices for high level care provision was also recommended. The assessment highlighted a need for dementia education of staff and regular in-home respite to supplement staff resources because of the client’s high care needs.'
A detailed care plan was developed and incorporated into the client’s daily schedule. The client continues to receive regular home visits from the GP. The frequency of GP visits increased due to increased seizure activity and dental infection which required surgery in 2004.

Outcomes

In June 2004, the disability service manager met with the client’s family to discuss his increasing care needs and the constraints on the disability service provider in meeting those needs. The main constraints were said to be inadequate funding from the state disability department to support his high and increasing need for assistance, and the increasing risks for both the client and staff posed by occupational health and safety issues. The family agreed to a further ACAT assessment with the view to residential aged care. This assessment took place in August 2004 and the client was approved for residential care.

In September 2004, the family placed their brother in the aged care facility in which the client’s mother resides. Positive aspects of the move are that the client was closer to his mother (though contact with her is dependent on facility staff as she lives in a different wing), he has regular access to specialist diversional therapy, and there are nursing staff on site to provide wound care and other services. Other consequences of the move into residential aged care are that he is now living in an unfamiliar environment and is sharing a room with another resident, which he has never had to do. There is a lower staff-to-client ratio at the facility than in the previous group home and the staff are not familiar with his history. The move has impacted on the client’s social support system, as he has virtually no contact with friends and housemates.

This client had high needs at point of referral to the project. While the project was in a position to initiate a thorough health assessment (as recommended by ACAT) and provide additional personal care, the fact that the project only became available more than a year after the client’s health had begun to deteriorate meant that there was limited capacity to provide preventative or restorative care. The focus became one of supporting the disability service provider to support the client’s high care needs for as long as possible. Comprehensive and intensive assessments and a trial at supplementary care in the community ensured that all options to maintain the client at home in the community were exhausted before he entered an aged care facility.

Case study 6

‘The client was aged early 50s when the package commenced. The client fell over and as a result suffered a fractured neck of femur and was hospitalised. Post surgery, the Acute Health Service Team decided that the client was not a suitable candidate for rehabilitation due to intellectual disability. The client was transferred to an aged care facility for respite.

During this time the project provided physiotherapy and occupational therapy assessments. The client then received a rehabilitation program at the aged care facility with an ongoing physiotherapy support program.

The physiotherapist provided education to the staff working in the client’s supported accommodation service on how to perform correct passive movements. Further assessments were conducted by the occupational therapist at different stages of the client’s progress. Equipment was purchased to enable the client to return home.

Through a team approach the client was discharged after a period of 61 days respite and returned home. The familiar environment and the support of friends assist the client with their rehabilitation. The project provided two hours per day to assist with personal care, and the client continued with the physiotherapy program arranged by the project.’
Case study 7

The client was aged late 30s when the package commenced. The client’s mobility was deteriorating and this was impacting on all areas of the client’s life. It prevented the client from attending outings and participating in activities with friends. The use of a walking frame had proved to be inadequate on longer outings and, with decreased energy levels, the client was evidently frustrated and showed little motivation.

Once referred and accepted to the project, a series of assessments were completed. Following recommendations from the occupational therapist, a wheelchair was purchased for the client to use on longer outings. This enabled the client to maintain an active social life and be part of the community. Physiotherapy sessions commenced with strengthening exercises and a walking program was implemented. Staff were actively involved in all stages of the program and encouraged the client to continue with the strengthening exercise regime.

As the physiotherapy program progressed and the client’s motivation increased, hydrotherapy was introduced. The client had previously been reluctant to participate in hydrotherapy. Positive reinforcement and encouragement through the project has given the client a one-on-one focus and has increased the client’s motivation and confidence. Due to this increase in confidence and motivation the client continues to strive to reach their goal.”

Case study 8

The client is a lady in her 60s. She has congenital hypothyroidism and intellectual disability. She has been living in supported accommodation for 2 years, prior to which she was in the care of family. The client was referred to the project in January 2004, with congenital hypothyroidism, intellectual disability, anaemia, arthritis, Bakers cyst, hyperlipidaemia, hypertension and nocturnal insomnia. The referral noted that the client’s cognitive ability had declined rapidly and she was becoming emotionally dependent on individual members of staff. The decline in her physical abilities and health were of concern and required ongoing reassessment and monitoring. The client had numerous falls in the prior 6 months, leading to a fractured pelvis.

Her BSCOC score was high at 250, with the highest scores being in health, perceptual/cognitive and social/emotional sub-scales.

The client was assessed by ACAT in March 2004. The ACAT assessor sought further advice before making recommendations. Around this time, the client also had an annual medical check-up with her GP. Recommendations arising from the ACAT assessment and GP consultation were for the GP to review bloods for thyroid function, check sugars, check cough, and vision/hearing; referral to an occupational therapist for assessment of hand function, transfers, and requirement for aids, home visit to assess safety and provide education to staff about interventions for increasing her activities of daily living functioning; referral to a physiotherapist to assess balance and mobility; assessment for depression or other mood disturbances. A geriatrician was asked to review four separate problems—cognition, falls, medication and insomnia, in addition to existing medical conditions.

The geriatrician provided a further list of recommendations. Geriatrician recommendations for measures to improve mobility, anti-gravity muscle strength and balance and to reduce falls risk have not been acted on for various reasons. His recommendation for a walker was vetoed by the client’s brother, who was concerned that this would result in dependency (he had recently bought a pair of orthopaedic shoes to improve her gait). The client’s skin condition, a result of a fatty liver condition, has prevented her from taking up hydrotherapy. Her medication was adjusted to deal with the skin condition, insomnia, challenging behaviours, mood disturbance and incontinence. The client presents as a complex case because of so many medical conditions with possible medication side-effects and interactions.
The client’s social withdrawal and increasing dependency on staff was addressed by including her in a weekly small group of seniors who join various mainstream activities for older people. The project is funding additional support staff for her to join this group. It is envisaged that when she can attend hydrotherapy, staff will be brokered from another service to accompany her to the sessions in order to discourage further reliance on a few select staff.

**Outcomes**

The seniors group experience has been positive for the client, who now joins her friends to attend activities in the community each week. The group visits four different mainstream seniors groups in each week of the month and this has allowed the client to establish connections with four new groups of people.

A key outcome for the client has been access to the holistic assessment by ACAT and the various medical and allied health assessments flowing from that. For this client, the medication review, trialling of new medications and opportunity for ongoing review by the geriatrician has been an important part of her care plan.

**Case study 9**

'The client is a lady with Down syndrome aged in her late-50s. Since her parents’ deaths, a cousin has been responsible for her and maintains regular telephone contact. The client has been living in supported accommodation since 1979 and is currently residing with other older clients in a suitable house in the suburbs. The client worked for more than 20 years in the business service operated by her supported accommodation provider. She is now retired and attends a day program for people who are ageing with a disability on four mornings a week.

The client was referred to the project in October 2003 due to observed behavioural changes, including hiding or throwing out personal belongings of her own and her housemates. It was noted at the time that the client had Down syndrome, hypothyroidism, a pacemaker, asthma, scoliosis, a zinc deficiency and osteoporosis. She had a BSCOC score of 58. The BSCOC assessor noted that some of the client’s skills had deteriorated over a period of more than 6 months prior to the tool being administered on this occasion.

An ACAT assessed the client in January 2004 and the client was accepted into the project. The ACAT noted that the client presented with age-related problems in the area of vision, hearing, mobility, cognitive change, emotion/mood, activities of daily living and upper limb function. It was also noted that she had withdrawn from usual activities, and often refused to go to her day program, preferring to spend more time at home. This presented a problem because her supported accommodation service is not resourced to cater for this choice. ACAT recommendations included an assessment for depression, referral to a gero-psychologist for assessment and the development of a cognitive deficit plan and dementia education for staff; occupational therapy assessment for upper limb function; physiotherapy for mobility; the development of a behaviour management plan; and the continued involvement of the visiting podiatrist.

A care plan was implemented incorporating a behaviour management plan and physical therapies. The client commenced hydrotherapy sessions with the support of a care worker, and her socialisation improved as she was spending half-days at her day program. In late June 2004 the client was diagnosed with significant osteoporosis in her lumbar spine and proximal femur following a bone density scan. She fractured both elbows in separate falls soon afterwards. Toilet rails were installed as a preventative measure. The client’s osteoporosis and risk of falls will necessitate the involvement of rehabilitation services in the longer term.
The client has been a low needs client for the project. Financial assistance from the project involved mainly gero-psychology services and the additional support worker to attend hydrotherapy. Rehabilitation services are accessed through the local health service. The disability service provider continued with vision and hearing tests, regular podiatry appointments and assisting the client with her medications and nebuliser in addition to services provided through the project.

**Outcomes**

Thorough assessment by the gero-psychologist led to a provisional diagnosis of generalised anxiety disorder with agoraphobic and hoarding features. Early ‘sundowning’ behaviours were also noted, and the evening routine was adjusted to better manage these. The behaviour management strategy developed by the gero-psychologist and implemented by staff led to a 90% reduction in problematic behavioural symptoms.

Effective behaviour management has led to an increased engagement by the client in her day program and greater satisfaction with life for many months. However, the client is again withdrawing, becoming less compliant, and has had extremely high anxiety when going to the doctor.

The gero-psychologist will continue to monitor the client and adjust the management plan to meet changing needs. Staff have been alerted to the potential for further behaviours to emerge and these will be managed as they arise.

The rehabilitation centre was reluctant to see the client at the centre and preferred to devise an in-home program. However, as it is not the support worker’s role to act as physical therapist, nor is this their area of expertise, compliance with the exercise program was compromised. The client’s rehabilitation plan was adapted to focus on exercises that could be incorporated into her regular routine and take advantage of some her ritualised behaviours, for example, pegging the clothes on the line, and the disability service managers will be working with disability support staff to integrate exercise into her daily program.

Although the client is a low-care client in terms of project level of funding for additional supports, she continues to challenge staff. She has very clear likes and dislikes and refuses to participate in many activities which have come to include swimming, exercise, wearing glasses and wearing shoes. Non-compliance has complicated the implementation of an exercise program. The client also loves to wear socks, not shoes or slippers, which increases her risk of falls. Hydrotherapy has been discontinued because she began to refuse to go to the pool or once there, to get into the water. A private physiotherapist was engaged to work with the staff in identifying ways of incorporating weight-bearing exercise into the client’s daily routine, to replace the formal exercise program.

The need to assess the client and other clients for depression led to a two-hour training session for disability support staff, run by the ACAT gero-psychologist, on use of the Cornell Scale for Depression in Dementia and the Montgomery and Åsberg Depression Rating Scale.”
Case study 10

‘The client was aged late 50s when the package commenced. The client lived in supported accommodation with an ageing partner and received care assistance during the day. The client has diabetes and administers the injections independently.

The client’s overall health status had decreased and there was a concern about peripheral vascular disease in the leg. The insulin injections needed to be closely monitored due to the client’s memory loss. The client also regularly suffered from diabetic episodes. While staff members were present during the day, the client was most at risk during the evenings when staff members weren’t present.

On joining the project, the client underwent physiotherapy and occupational therapy assessments, followed by a dietician assessment. On the recommendation of the physiotherapist, a recliner chair was provided to increase comfort levels and provide a foot rest to elevate the legs, which helped with the peripheral vascular condition.

Due to the high risk of diabetic episodes during the evenings, the project provided two hours every evening to assist the client with evening meal preparation and insulin injections. The dietician supplied a sample daily menu and other suggested low glycaemic index foods to reduce the risk of diabetic episodes. With the ongoing support hours and the new menu options, the client experienced a reduction in diabetic episodes.’

Case study 11

‘The client was aged early 60s when the package commenced. Prior to being accepted into the project, the client lived in supported accommodation with a low support level. A fall resulted in a fracture. The client, unable to care for themself, was transferred to a residential aged care facility for 4 months and lost physical strength, mobility, some skills of daily living and gained a considerable amount of weight.

On return to disability supported accommodation, the client expected all activities of daily living to be performed by staff, as experienced in the aged care facility. Prior to the fracture the client was able to cook and manage aspects of their daily living under supervision. The client had become accustomed to living in an aged care facility; however, if the client could no longer be supported in the home, the client would have to be readmitted to an aged care facility, losing their independence. The client’s employment was also threatened.

On joining the project the client received physiotherapy and occupational therapy assessments. Through a dietician assessment, several menus were introduced so that the client, with staff support, could cook for themselves with the aim of reducing weight.

The client had another admission to hospital resulting in a four-day stay. The client returned home for three days and was then readmitted to hospital for 25 days.

Increased support levels encouraged the client to remember independent living skills to maintain independence. The staff support has also given the client one-on-one social interaction and increased confidence. Staff now report the client is more positive and happier. The client was able to return to work.’
Case study 12

‘The client was aged early 70s when the package commenced. The client previously enjoyed an active social life and going to work. Due to an unsafe incident, the client was no longer able to go out independently and retired from work. This caused the client distress and frustration—the client often expressed the wish to die.

Shortly after joining the project, the client was admitted to hospital with pneumonia where they aspirated and a PEG was inserted. The client had physiotherapy and occupational therapy assessments both prior to and after the hospital admission. A dietician assessment also occurred to address weight loss during the hospital stay.

Due to the 14-hour PEG feeds, the project provided a recliner chair to aid comfort and reduce the risk of skin breakdown. The chair enables the client time to rest and recover. An alternating air flow mattress and an electric hi-lo bed was also provided to minimise the risk of pressure areas. The knee-break in the bed also allowed the client to receive the enteral feeds at night in bed. The provision of the mattress has improved the quality of sleep. This has enabled the client to regain strength and energy.

Ongoing physiotherapy was provided to help increase mobility and muscle tone and to provide chest exercises to reduce the risk of pneumonia.

The project provided two hours to assist the client with personal care. An additional optional four hours per week assists the client in social outings and for one-on-one socialisation. Physiotherapy sessions are another outlet for socialisation, as the client attends with a group and enjoys the interaction with the physiotherapist and others.

The client now has a more positive outlook on life.’

Case study 13

‘The client is aged early-40s and has intellectual disability, hypothyroidism, and atrial fibrillation.

Client lives in a group home with two other males, visits family every other weekend and attends day options on five days per week.

Pre-project entry levels as per BSCOC (Minda Inc.): staff reported a moderate degree of functional change in the 6 months preceding involvement in the project, particularly in the areas of daily living skills, sensory integration, and perceptual cognitive functioning.

The original care plan was developed in August 2004 and provided for blocks of 1.5 hours every day which focused on recreational and social activities that appropriately support the client’s health and ageing issues. The plan included activities to encourage him to go slower, but provided opportunity for exercise.

On review in December 2004, the care plan was changed to one six-hour and one two-hour block weekly. Activities included low impact exercise in a heated pool, improving personal presentation skills and purchasing new clothes, learning to prepare nutritional foods and making healthy choices when eating out.

The client’s service review in April 2005 supported continuation of these activities and a further focus on helping him develop the garden at home. This will provide some low impact physical exercise under supervision, choice making and negotiation with other residents.’
The only challenges that have presented in the delivery of this service have been to ensure that the times are suitable for the client’s concentration and stamina, supporting rather than replacing his current activities.

Outcomes
At last review on 14 April 2005 the client stated that he was very happy. He especially enjoyed morning tea at the bakery, going to the pool and spa, and shopping for new clothes. He is looking forward to starting a new garden at his group home.

Case study 14
‘The client is aged mid 30s and has Down syndrome, mild heart failure, scarred oesophagus, hypotension, vision loss, dermatitis and disruptive behaviour.

The client lives in a group home with one other male and three females and visits family occasionally. The client works at a supported employment centre five days a week.

Pre-project entry levels are as per BSCOC (Minda Inc.). Staff reported a significant degree of functional change in the 6 months before the client joined the project, particularly in the areas of sensory integration, perceptual cognitive functioning and social and emotional function.

The original care plan, developed in September 2004, was for one hour on each of Monday, Wednesday and Friday mornings to develop a personal care regime, one hour of one-to-one behaviour management therapy and 7.5 hours fortnightly of social support to access gender appropriate activities. This project also negotiated for the client to be able to participate in a special day program one day a week, thereby reducing his work days to four.

On review in December 2004, personal care support was increased to five mornings a week, provided by a support worker. Social support was reduced to 6.5 hours a fortnight. Day program attendance one day per week continued. Behaviour management was reduced to half an hour per week.

On review in March 2005, the project negotiated for the client to reduce work days to attend a day activity program for older people. At the same time the behaviour management component was able to be dropped. Implementation of routines that supported choice and decision making had significantly reduced the incidence of behavioural issues.

This client had further reviews of health status that led to some interventions. At times this disruption has escalated the demanding and challenging behaviour. The client responded well to strategies that increase choice and visual cues to assist in routine management.

Outcomes
The services are primarily provided by a worker who enhances the client’s access to a positive gender role model. The incidence of challenging behaviours has significantly reduced particularly when the client has access to choice and routines. The transition from supported employment to a day activity centre and special purpose program reduced fatigue and aggression associated with the work environment and exposed the client to social interaction with a range of people.

This client reported being very happy with the care plan and eagerly looks forward to every session—even the morning personal care routine!’
Case study 15
'The client has intellectual disability, microcephaly, ectrodactyly, heart murmur, incontinence, severe foot abnormality, chronic back pain, and evidence of short-term memory loss and depression. The client is aged early 50s.

He lives in his own unit in a supported care hostel and works five days per week at a supported employment centre. He visits his sibling irregularly.

Pre-project entry levels are as per BSCOC (Minda Inc.). Staff reported significant functional change in the 6 months before the client joined the project, particularly in the areas of sensory integration, and perceptual cognitive functioning.

This client replaced three days per fortnight of work with 5.5 hour blocks of support that focus on community access, visits to farms and saleyards (a primary area of interest), taking photos for a chat book and going out for lunch. The program also focused on implementation of strategies to reduce aggressive and intolerant behaviour toward others.

A review in April 2005 revealed that the care plan was meeting the client’s needs and he expressed satisfaction. Support staff identified that he was tiring quickly and that they needed to closely monitor the pace and number of activities.

The care plan and its implementation has been without challenge—both client and support staff express very positive feedback.

Outcomes
The client is very happy with being able to sleep in on three days per fortnight while his peers go to work. He has also thrived on the one-to-one attention and ability to pursue personal interests. His photography is assisting him to record important people, events and objects in his life that assist him with both communication and memory.'

3.11 Main findings

Different staffing models have been used to provide clients with increased hours of personal assistance, physical maintenance therapies, and support for improved domestic and community participation. These models include the fully integrated staffing and service delivery model of Ageing In Place; the (mainly) dedicated aged care teams of NSDACP, DACS, CWPDA; the full brokerage model of FNCDAC; and mixed brokerage and agency staffing seen in FACP, DALP and CPDAC. Workforce has been a significant challenge for most projects.

Additional hours of personal assistance allow older clients to move at a different pace to younger members of a household whose routines are structured around full-time participation in disability services programs. At the time of the evaluation, clients were receiving a mean of 2.8 hours of additional personal assistance per week; additional personal assistance of up to 20.9 hours per week was recorded for one client (Table 3.13). Increasing hours of personal assistance could be expected as client groups mature. The injection of new personal care workers or the funding of additional personal assistance from disability support staff relieves pressure from household staff.

Therapeutic interventions have been developed following ACAT and allied health assessments to address loss of fine and gross motor skills that affect mobility and capacity to
participate in activities. Projects have delivered a range of other activities including ‘news groups’, story telling, individual pursuits and small group activities to promote mental activity, use of language and social interaction. This range of service types is thought to be important for people ageing with a disability who need to withdraw from long-term employment and day programs and who may face physical and psychological decline due to limited flexible daytime options.

Provision of aids and equipment has emerged as an important area of service delivery for small numbers of clients. Although vast sums have not been spent on aids and equipment it is clear from case studies provided to the evaluation that attention to the physical home environment of older clients can have a marked impact on quality of life, improve the relationship between client and disability support staff, and help to maintain ageing clients in their familiar home environment for longer. Often the pieces of equipment purchased have been small and inexpensive but have enabled clients to safely spend short periods at home without supervision. More expensive items such as a tilt chair or special purpose mattress have also been acquired and these are seen to benefit not only one client but potentially other members of a household (or accommodation service) who in future could experience similar needs.

Projects have also been conduits for the delivery of medical and other services because various types of referral have flowed from needs assessment processes.

By offering the new choice of community aged care, the projects assist clients to live longer in the community by helping to arrest or slow the physical and cognitive decline that occurs at older ages and by mitigating a range of factors that can prevent the longer term maintenance of a person with age-related needs at home such as need for a higher level of personal assistance, mobility assistance and continence management. Comprehensive, specialised assessment underpins these interventions and the Pilot has exposed high variation in the skills and experience within supported accommodation services for the identification of age-related needs in people with disabilities.
Table 3.13: Service units delivered to clients during the evaluation, by service type, all projects excluding MS Changing Needs

<table>
<thead>
<tr>
<th>Service type</th>
<th>Number of clients</th>
<th>Service unit</th>
<th>Minimum</th>
<th>Median</th>
<th>Maximum</th>
<th>Mean</th>
</tr>
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<tbody>
<tr>
<td>Initial needs assessment</td>
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<td>Hours/service episode</td>
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<td>Needs assessment other</td>
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<td>Events/service episode</td>
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<td>20</td>
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<td><strong>Nursing and medical care</strong></td>
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<td>Nursing care</td>
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<td>GP consultation</td>
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<td>Physiotherapy</td>
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<td>0.1</td>
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<td><strong>Social support, leisure and community access</strong></td>
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<td>Community transport</td>
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<td>One-way trips</td>
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<td>Mobility aids</td>
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<td>1,041</td>
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<td>640</td>
<td>1,825</td>
<td>610.70</td>
</tr>
<tr>
<td>Home modifications</td>
<td>1</td>
<td>Dollars/service episode</td>
<td>765</td>
<td>765</td>
<td>765</td>
<td>765.00</td>
</tr>
</tbody>
</table>

— Nil or rounded to zero.