6 Care Experience Survey

6.1 Summary of results

Group home managers and disability support workers completed the bulk of questionnaires, with input from clients, family members or other advocates in a small number of cases. As such, responses largely reflect a disability services perspective of clients' care experiences and the experiences of staff in how projects interact with usual client care in the context of individual clients and the broader service environment. These perspectives may differ across geographical locations or even from one disability service to the next within an area.

Survey questions are a combination of multiple-choice, limited response and open-ended questions. Responses to open-ended questions were often quite detailed and specific to the relevant individual clients. In some cases themes that emerged in responses to open-ended questions appear inconsistent with responses to multiple-choice and limited response questions on the same form.

Identified needs

As expected, clients were identified as having needs across a wide range of areas that could be related to ageing (Disability Aged Care Interface Pilot clients are a group with longstanding needs for assistance, supervision and support; ACAT assessment has identified age-related needs in addition to pre-existing disability-related support needs). Survey respondents most commonly described progressive age-related needs, that is, needs related to ageing that are observed to be increasing over time, to include:

- mobility assistance
- behaviour management
- increased personal assistance
- assistance to encourage domestic and community participation as a means to arrest or prevent increasing social isolation.

Most respondents said that, prior to the Pilot, client needs in the areas of medication management, social support, transport, personal assistance and assistance to make appointments tended to be met. The areas most often referred to as areas of unmet need (where assistance was being received by the client before the Pilot but more help was needed) were leisure and recreation, transport to access the community, assistance to participate in household activities, personal assistance and physiotherapy. Allied health services (specifically speech therapy and physiotherapy), management of behavioural symptoms and social integration were the most commonly identified areas of unmet need (areas of need where no assistance was being received by the client prior to the Pilot).

Fully unmet need was not mentioned as frequently as partially met need, which is perhaps understandable given that clients are living in a supported accommodation environment. This may reflect disability service provider concerns that, while they are able to provide services to address a wide range of client needs, the level of those services may be insufficient to fully meet needs that are becoming more complex as clients age. In particular,

service gaps may appear as clients' needs change from episodic to continuous, for example, as mobility limitation, incontinence or dementia increase, the need for supervision and support increases from an occasional to continuous basis.

Areas of need identified through the Survey are broadly consistent with the services being provided by projects. Analysis of service utilisation data indicates that, though delivery varies across projects, most projects were focusing on the provision of allied health care or social support and participation in addition to increased personal assistance. Across all projects, survey responses suggest that clients were most commonly receiving help in the areas of personal assistance (50.4% of clients), occupational therapy (41.2% of clients), physiotherapy (36.6% of clients), social support (33.6% of clients), and recreation and leisure programs (31.3% of clients).[11]

Hopes and expectations of what the Pilot would deliver

Expressed hopes and expectations of the Pilot fall into two main categories. Some hopes and expectations relate to specific outcomes for individual clients, for example, 'to improve skill levels' and 'establish new networks and friends'. Others relate to benefits to the overall service delivery system, such as reduced stress for disability support staff: '…our service's duty of care around issues of personal safety and medication administration could be alleviated…'.

Project implementation

Respondents mostly gave positive ratings for project staffing, convenience, and planning and coordination. The majority of respondents believed that the projects meet previously unmet needs, and rated the amount of additional assistance provided as good to very good. Provision of more resources for care, increased client participation, access to specialist services, and maintaining or improving client wellbeing are the most frequently mentioned beneficial aspects of the projects.

Limited additional resources available through the project (funding, staffing, hours of care) was the most frequently levelled criticism. Level of provision of physiotherapy and speech therapy services, day and leisure programs, social support and transport services are cited as unsatisfactory in a number of projects, due to limited availability, staffing issues and other factors.

Staff education and skills transfer

One hypothesised benefit of the Pilot is the strengthening of the disability and aged care interface through skills transfer. Negative views about aspects of project implementation concentrate largely on this issue: whether disability support staff are provided with adequate education and training to implement client care plans, and whether a project helps to impart aged care skills and experience to disability support staff. Almost 50% of respondents failed

11 Percentages of clients receiving a service do not necessarily reflect service intensity. Although a high percentage of clients received some occupational therapy and/or physiotherapy, the amount of these services received by a client can be quite low (for example, all clients in a project may have received a routine one-hour physiotherapy assessment, but no active physiotherapy intervention).

to confirm that skills transfer was taking place. Negative, mixed and undecided responses to this question are distributed across the projects, including projects with an explicit training component. Responses from staff in homes participating in one project are not always consistent. For example, different staff from one group home participating in the Northern Sydney project consistently reported that the education and training to implement care plans was good to very good, yet more than half the staff from the same home suggested that the project did not facilitate the transfer of aged care skills and experience to disability support staff. Staff in another home participating in the Northern Sydney project rated education and training as unsatisfactory.

There is no obvious pattern of response to questions on education and skills transfer in relation to project staffing models. It is plausible that some project implementation models are not well suited to provide 'on-the-job' transfer of aged care skills—there may be a 'handover' from project coordinators to disability support staff who then function on a daily basis without interaction with aged care staff. In addition, disability support staff may not consider knowledge acquired for the implementation of a care plan for a specific client as 'knowledge and expertise in aged care'. Whether or not staff members believe that such specific learning will help them generally care for clients who are ageing is not clear in the survey responses.

Project model as a long-term care option

Messages on the viability and appropriateness of the 'top-up' model of aged care service delivery are mixed. Some respondents gave very positive responses about the projects and were cautiously optimistic about their potential in helping maintain clients at home as they age, stating a proviso that service levels would need to be able to respond to increasing client needs. Others indicated that the level of additional support provided by their project was insufficient to adequately manage a client's current age-related needs, making the project an inadequate form of support to allow the client to stay at home over the longer term, particularly in the context of needs which were observed to be increasing over time.

Over 90% of the 40 respondents who answered the question on whether projects are an appropriate longer term option for clients indicated that it is appropriate to support the client in the group home setting given their identified age-related needs. The remaining respondents were unsure whether this model of additional service provision is appropriate. No respondent indicated a belief that supporting the client within the group home was inappropriate; however, as more than 50% of respondents did not answer the question, it is hard to draw an overall conclusion on acceptance of the Pilot concept.

On a multiple choice item, the majority of respondents (76%) indicated that the projects were providing enough help to support disability staff in their role. Those who did not believe that the project was doing enough to assist mostly indicated that it is nevertheless appropriate to maintain the client in place as they age. For example, staff from three out of the four group homes participating in the Central West People with a Disability who are Ageing project (New South Wales) represented in the survey suggested that the project was not providing enough assistance to help disability support staff to manage clients' age-related needs. Yet all respondents from participating group homes in the Central West project said that it was appropriate to continue to care for the clients in their group homes.

Apparent contradictions may reflect a tension between a high motivation to maintain clients in the group home setting and consciousness of the reality of the increasingly complex care needs of ageing clients. There seems to be a pervasive belief within supported

accommodation services, evident in site visit interviews and the survey responses, that although transfer of a client from their familiar home environment into residential aged care may become necessary, it is rarely 'appropriate'. There is a keen awareness that clients are likely to experience increased need for assistance as they get older and that these needs are unlikely to be met within the constraints of current disability funding and/or operational arrangements. A strong emphasis on staffing ratios can be seen in responses to open-ended questions (without commensurate emphasis on the impact of staffing hours on older clients).

Implicit in survey responses is that disability funding is not responsive to the increasing needs of many older clients. Disability service providers appear to operate with static resources and care models, often predicated on a household of clients with similar lifestyles and routines who are able to spend time unsupervised and attend activities outside of the home. Some respondents are of the opinion that available funding alone is what constrains their ability to manage ageing clients. Others identified other impediments to managing increasing levels of support need, including the physical limitations of home environments, lack of staff training in age-related issues, and the disruption caused in households when some clients' needs and preferences become markedly different to those of other residents. Some respondents believe that an appropriately resourced 'top-up' aged care package delivered to the specific client could effectively address these problems, and others see increased resources within the disability sector as a better (and perhaps only real) solution.

According to the financial data provided for the evaluation, the majority of projects posted surpluses in 2004, some of which were substantial enough to prompt a reduction or suspension of their flexible care subsidy payments (most notably projects based in New South Wales). Survey responses include calls from staff in many of the group homes for higher levels of weekend support and/or increased capacity to supervise clients during the day, for example:

> 'Expand service to 7 days per week.'
>
> 'We have no weekend [service]. Client needs don't stop on Friday and commence again on Monday. I would like to see some hours given to weekends.'
>
> 'Assess the level of care required to keep the client in their home, i.e. Mon–Fri day staffing.'
>
> 'Day staff Monday to Friday in the group home.'

Disability services staff from group homes participating in the New South Wales projects were vocal about what they perceived as a service delivery shortfall, calling for 'more hours' or 'more money', not just for weekend services or increased daytime supervision. For example:

> 'Not enough assistance.'
>
> 'Individual services should be adequately funded to broker out for staff and acquire enough support (not just 3 hours a week but what each service actually needs) to provide ageing clients with an appropriate service.'
>
> '[Project could be improved if there were] more hours available [and] greater flexibility with the hours.'
>
> 'Not enough support…6 hours per week is not sufficient.'
>
> 'More funding?'

The fact of surpluses posted by projects in which disability support staff reported insufficient and/or inflexible levels of service provision to adequately cater for clients' age-related needs is difficult to reconcile. It is not clear whether such responses relate more to funding constraints in the disability sector as distinct from the level of additional support needed

from the Pilot to meet clients' identified age-related needs. This point is perhaps best illustrated in the feedback on one project: 'ten hours is not enough to keep anyone out of a nursing home' contrasted with the observation that 'an obvious benefit' is that clients are able to stay in their homes for longer. Thus, there may be differing viewpoints on the level of support delivered by the Pilot.

6.2 Survey aims, methodology and limitations

The Care Experience Survey was designed to elicit client, family and disability support worker perspectives on:

- levels of assistance required by ageing clients
- the extent to which age-related needs were met prior to the Disability Aged Care Interface Pilot project
- progress in meeting previously unmet or under-met age-related needs through the Pilot
- quality and appropriateness of Pilot services
- the suitability of Pilot services in the client's current living environment, for the foreseeable future.

Project coordinators were asked to issue the survey questionnaire for each participating client allowing for services to have been in place for the client for at least four weeks. The client or an advocate was to complete the form and mail it directly to the AIHW. The survey was anonymous but responses can be matched to de-identified client profile and assessment records using the unique client identification code recorded on the front of each questionnaire by project coordinators.

The questionnaire includes a combination of closed, limited response and open-ended questions. Respondents were asked to compare the care received from the project to usual care and to report whether the project was meeting previously unmet age-related needs. Respondents could comment on specific aspects of service delivery such as care planning and coordination; continuity of care; the range and availability of services; choice; convenience; privacy and security; and the physical environment. Disability support staff were asked to assess the feasibility of maintaining the client 'in place', and whether they believe that the project provides a suitable long-term care option for the care recipient. The questionnaire is available on request to the Ageing and Aged Care Unit, Australian Institute of Health and Welfare.

Analysis of the 92 completed questionnaires received by 31 January 2005 is summarised below. Thematic coding and data analysis were completed by Osman Consulting Pty Ltd, using the SPSS computer program.

Survey limitations

A number of points must be borne in mind in the interpretation of survey results.

Project coordinators were instructed to encourage completion of the questionnaire by the client and/or someone independent of project service delivery, wherever possible. However, as many of the clients have intellectual disability they were mostly unable to respond

without assistance and few family members were actively involved in usual care. As a result, disability support staff often responded on the client's behalf,[12] meaning that the majority of surveys were completed with the input of people who may have been directly involved in delivering project services. It cannot be assumed that a staff member would necessarily respond to questions as would the client or a family member. The survey largely provides a disability sector perspective on the Pilot concept and the individual projects, taking into account the familiar knowledge of clients.

Participation in the survey was voluntary, and there was less than 100% participation. The evaluation team received reports of resistance to completing the survey form related to concerns about the 'extra paperwork' for evaluation. It is possible that some response bias has resulted, as surveys are less likely to have been completed for clients residing in supported accommodation facilities where disability staff had difficulty finding the time to take part and particularly if more than one client within the facility was receiving project services necessitating multiple survey responses.

Throughout the evaluation stakeholders in all projects commented on the traditional tensions between the disability and aged care sectors. While they mostly perceived the Pilot as one solution to some of the challenges associated with disability and ageing, frustrations remain and are evident in survey responses. It is not possible to separate the relative influences on responses to survey questions of perceptions of project service provision to individual clients from perceptions of more systemic issues at the disability and aged care interface.

6.3 Response rates

A total of 148 questionnaires were distributed. As of 31 January 2005, 92 completed questionnaires had been returned (Table 6.1). Response rates for individual projects ranged between 21% and 100%, with an overall response rate of 62%.

Table 6.1: Care Experience Survey, surveys distributed and response rates[(a)] by project

Project	Surveys distributed	Surveys received	Facilities represented	Response rate (%)	Per cent of total response
Far North Coast Disability and Aged Care Consortium (NSW)	13	12	7	92.3	13.0
Central West People with a Disability who are Ageing (NSW)	33	7	6	21.2	7.6
Northern Sydney Disability Aged Care Pilot (NSW)	22	12	2	54.5	13.0
MS Changing Needs (Vic)	16	16	1	100.0	17.4
Flexible Aged Care Packages (SA)	31	27	16	87.1	29.3
Disability and Ageing Lifestyle Project (SA)	8	5	4	62.5	5.4
Disability Aged Care Service (WA)	18	8	4	44.4	8.7
Ageing In Place (Tas)	7	5	1	71.4	5.4
Total	**148**	**92**	**41**	**62.2**	**100.0**

(a) Response rate: number of care experience surveys received as a percentage of number of surveys distributed per project.

12 Project coordinators consulted disability support staff on who would complete the form.

6.4 Respondent identity

Respondents were asked to indicate who completed the questionnaire. More than one respondent could be indicated, for example, where a group home manager and a disability support worker contributed, both could be recorded, as could a client and relative or client and disability support worker. Thirty-one questionnaires (34%) were completed without the involvement of disability service staff or project coordinator, 19 of which were completed with client input (Table 6.2).

Far North Coast Disability and Aged Care Consortium was able to recruit some family members to assist clients to complete the questionnaire or to respond on behalf of clients.[13] Ageing In Place, Tasmania, arranged for an independent advocate from Advocacy Tasmania to assist clients to complete questionnaires together with disability support staff.

A high degree of consistency can be seen in the responses for clients living in the same group homes where surveys were completed by the group home manager and/or the same disability support staff. This is particularly the case for questions relating to the implementation of the project and the service model (questions about staffing, convenience and project coordination).

Fifteen questionnaires were completed with some level of input from a project coordinator. As the purpose was to obtain views of the projects from consumer and carer perspectives, a number of questions relate directly to aspects of project management and implementation. In analysing responses to these questions it was necessary to exclude those completed by or with the involvement of project coordinators.

There are too few completed forms from some projects to statistically compare responses across all of the projects (it was judged that at least 10 responses would be required for non-parametric statistical analysis). The exceptions were the Far North Coast Disability and Aged Care Consortium, Flexible Aged Care Packages, MS Changing Needs, and the Northern Sydney Disability Aged Care Pilot, each of which received more than 10 completed forms. Statistical comparisons between these four projects are reported for a number of variables.

13 Surveys were distributed to family members where possible and to disability support staff, so in some cases two questionnaires were completed for one client.

Table 6.2: Care Experience Survey, respondent identity by project

Project	Client with or without assistance— relative or independent advocate	Relative or independent advocate	Client with assistance— disability service staff	Client with assistance — disability service staff and project coordinator	Disability service staff and relative/ independent advocate	Disability service staff only	Project coordinator only	Total
				(number)				
Far North Coast Disability and Aged Care Consortium	—	4	—	—	1	7	—	**12**
Central West People with a Disability who are Ageing	—	—	—	—	—	7	—	**7**
Northern Sydney Disability Aged Care Pilot	—	—	—	—	—	12	—	**12**
MS Changing Needs	14	—	—	—	—	2	—	**16**
Flexible Aged Care Packages	—	2	4	5	—	6	10	**27**
Disability and Ageing Lifestyle Project	—	—	1	—	—	4	—	**5**
Disability Aged Care Service	—	—	1	—	—	7	—	**8**
Ageing In Place	5	—	—	—	—	—	—	**5**
Total	**19**	**6**	**6**	**5**	**1**	**45**	**10**	**92**
				(per cent)				
Far North Coast Disability Aged Care Consortium	—	33.3	—	—	8.3	58.3	—	**100.0**
Central West People with a Disability who are Ageing	—	—	—	—	—	100.0	—	**100.0**
Northern Sydney Disability Aged Care Pilot	—	—	—	—	—	100.0	—	**100.0**
MS Changing Needs	87.5	—	—	—	—	12.5	—	**100.0**
Flexible Aged Care Packages	—	7.4	14.8	18.5	—	22.2	37.0	**100.0**
Disability and Ageing Lifestyle Project	—	—	20.0	—	—	80.0	—	**100.0**
Disability Aged Care Service	—	—	12.5	—	—	87.5	—	**100.0**
Ageing in Place	100.0	—	—	—	—	—	—	**100.0**
Total	**20.7**	**6.5**	**6.5**	**5.4**	**1.1**	**48.9**	**10.9**	**100.0**

Note: Disability service staff can be disability support workers and/or group home managers.

— Nil.

6.5 Thematic framework

The AIHW engaged a statistical consultant to develop a thematic coding framework for responses to open-ended questions and perform content analysis.

Development of the thematic framework was an iterative process. The consultant completed a thematic analysis of a subset of hand-written responses to five key open-ended questions. The first two of these questions focus on needs and expectations. Two initial lists of 20 to 30 recurring themes were constructed, one by the consultant and one by the AIHW evaluation team. A high level of agreement was apparent and the process of cross-referencing the two lists produced a set of core themes for the initial framework. This list was further expanded and refined to accommodate responses to three more open-ended questions dealing with project services and staffing.

The AIHW evaluation team reviewed the resulting set of codes. A number of additional codes were subsequently added to the framework until it was shown that responses to the five key open-ended questions in 50 completed questionnaires could be coded satisfactorily. The final framework consists of:

- 30 core themes
- 10 themes specifically associated with how the projects meet or fail to meet client needs
- nine themes that deal specifically with staffing issues
- nine themes associated with aspects of the Pilot that attract positive feedback from respondents
- nine themes associated with aspects of the Pilot that attract negative feedback from respondents
- 15 themes to cover general comments, both positive and negative.

Over 80 themes were identified in the coding framework and used in the analysis. The framework has been designed so that specific themes can be combined into more general categories for reporting purposes.

6.6 Survey results

Identified needs of clients

Responses to Question 1 provide an indication of respondents' views of how well client needs were met prior to entering a Pilot project in areas related to ageing. Clients were said to have had high levels of identified need (met need, partially met need and unmet need, combined) across all activity areas, with between 58% and 99% of clients, by project, requiring assistance in each area of activity (Table 6.3).

The most common areas of fully met need include medication management (40 clients), social support (39 clients), transport (36 clients), personal assistance (32 clients) and assistance to make appointments (31 clients). Leisure and recreation (53 clients), transport to access the community (44 clients), assistance to participate in domestic life (43 clients), personal assistance (37 clients) and physiotherapy (33 clients) were commonly identified areas in which clients were receiving some assistance prior to the Pilot but needed more assistance.

Relatively few clients are identified as not receiving any assistance in areas where assistance was needed prior to the Pilot. The most commonly identified areas where clients needed assistance but were not receiving *any* help were speech therapy and management of behavioural symptoms (9 clients each), physiotherapy and social support (six clients each), and assistance to make appointments and nursing care at home (four clients each).

Responses to Question 1 for clients in the Far North Coast Disability and Aged Care Consortium, Flexible Aged Care Packages, MS Changing Needs, and the Northern Sydney Disability Aged Care Pilot projects were analysed to test whether differences exist between projects in the level of identified support needs prior to entering a project.[14] In all but one domain— physiotherapy—there are significant differences in the level of need between projects ($p < 0.05$), meaning that the client groups are reported as entering these projects at different average levels of support need.

Generally, respondents from the Far North Coast Disability and Aged Care Consortium and MS Changing Needs indicated higher levels of support need against most items in Question 1, whereas respondents from the Flexible Aged Care Packages project almost always indicated a lower level of need. The response patterns are different in some areas, for example, respondents from the Far North Coast Disability and Aged Care Consortium and Flexible Aged Care Packages projects indicated higher levels of need for social support than did respondents from the other two projects; respondents from the Flexible Aged Care Packages project and MS Changing Needs reported higher levels of need for leisure and recreation services.

14 The Kruskal Wallis non-parametric test was performed.

Table 6.3: Care Experience Survey, adequacy of assistance prior to project

Assistance type	Enough assistance	Some assistance received, but more needed	No assistance received, but assistance needed	Total identified need	Total identified unmet/under-met need	Not applicable[(a)]	Total
				(number)			
Personal assistance	32	37	3	72	40	4	76
Personal assistance at weekends	29	32	2	63	34	13	76
Continence management	30	27	3	60	30	16	76
Medication management	40	23	2	65	25	11	76
Provision of aids	26	30	2	58	32	18	76
Mobility assistance	23	30	1	54	31	22	76
Transport	36	31	1	68	32	8	76
Making appointments	31	26	4	61	30	15	76
Nursing care at home	18	28	4	50	32	26	76
Medical care	30	16	2	48	18	28	76
Speech therapy	14	21	9	44	30	32	76
Physiotherapy	16	33	6	55	39	21	76
Management of behavioural symptoms	19	29	9	57	38	19	76
Participate in domestic life	22	43	2	67	45	9	76
Leisure and recreation	20	53	2	75	55	1	76
Transport to community	25	44	2	71	46	5	76
Social support	39	25	6	70	31	6	76

(continued)

Table 6.3 (continued): Care Experience Survey, adequacy of assistance prior to project

Assistance type	Enough assistance	Some assistance received, but more needed	No assistance received, but assistance needed	Total identified need	Total identified unmet/under-met need	Not applicable[(a)]	Total
				(per cent)			
Personal assistance	42.1	48.7	3.9	94.7	52.6	5.3	100.0
Personal assistance at weekends	38.2	42.1	2.6	82.9	44.7	17.1	100.0
Continence management	39.5	35.5	3.9	78.9	39.5	21.1	100.0
Medication management	52.6	30.3	2.6	85.5	32.9	14.5	100.0
Provision of aids	34.2	39.5	2.6	76.3	42.1	23.7	100.0
Mobility assistance	30.3	39.5	1.3	71.1	40.8	28.9	100.0
Transport	47.4	40.8	1.3	89.5	42.1	10.5	100.0
Making appointments	40.8	34.2	5.3	80.3	39.5	19.7	100.0
Nursing care at home	23.7	36.8	5.3	65.8	42.1	34.2	100.0
Medical care	39.5	21.1	2.6	63.2	23.7	36.8	100.0
Speech therapy	18.4	27.6	11.8	57.9	39.5	42.1	100.0
Physiotherapy	21.1	43.4	7.9	72.4	51.3	27.6	100.0
Management of behavioural symptoms	25.0	38.2	11.8	75.0	50.0	25.0	100.0
Participate in domestic life	28.9	56.6	2.6	88.2	59.2	11.8	100.0
Leisure and recreation	26.3	69.7	2.6	98.7	72.4	1.3	100.0
Transport to community	32.9	57.9	2.6	93.4	60.5	6.6	100.0
Social support	51.3	32.9	7.9	92.1	40.8	7.9	100.0

(a) Includes missing values.

Age-related needs

Question 3 asks the respondent to describe the client's most pressing age-related needs. Age-related needs were defined on the questionnaire as 'needs that have emerged in recent times as a result of growing older, as distinct from long-standing disability-specific needs' (Box 6.1). Thematic analysis of responses to this question shows that non-specific 'progressive age-related' needs was most commonly identified (16 responses), followed by behaviour management (15 responses), mobility assistance (14 responses) and personal assistance (10 responses) (Table 6.4).

Responses are broadly consistent with responses to Question 1 (adequacy of prior level of assistance), although respondents communicated higher levels of need and identified more specific gaps in care relating to clients' age-related needs through the open-ended question compared to the closed format responses in Question 1.

Box 6.1: Examples of answers to Question 3—What activities do you [the client] need help with the MOST?

'1. Maintaining hygiene—particularly with regard to continent [sic] issues, body odour and having soiled hands. 2. Behavioural issues—mood swings, sudden loudness/yelling, increases stubbornness, crying and anger. Being intolerable to live with. Needs medication.'

'[Client] was suspected of acquiring Guillain-Barre Syndrome in 2002. She is now totally dependent on staff for all activities of daily living. She also is seen by a psychiatrist every month due to her depression and psychosis.'

'Palliative care to ensure her needs are being met. [Client] often refuses food. We have had a palliative care assessment who [sic] said this is OK but she is very underweight. The staff find this difficult emotionally to deal with.'

'Mobility assistance—especially to access the local community, mainly due to deterioration of eyesight and unsteadiness when walking.'

'Mobility and health care e.g. cataracts—vision impaired, exercise and hydrotherapy, memory loss.'

'Stiffness to joints and back pain, hearing impairment. Requires occasional help with personal care due to dizziness or health issues. Personal dignity due to the need for more assistance in areas of personal care and ADLs. Eyesight impairment as very involved in close craft work and knitting activities. Bones in feet deteriorating due to age.'

'[Client] has severe osteoporosis and has had a number of fractures. In the past [client] was able to walk around unaided. She can not do this due to her high falls risk. She must always be supported by a staff [sic].'

'Obsessive compulsive behaviours mean I need help with eating meals (currently 22 kg heavier). Dressing, bathing. Generally due to these activities taking so long not due to ability— able to do it.'

Table 6.4: Care Experience Survey, clients' most pressing age-related needs, analysis of open-ended question

Age-related need	Responses[(a)]	Per cent
Progressive age-related needs	20	26.3
Mobility	19	25.0
Behaviour management	16	21.1
Personal assistance	13	17.1
Participation	12	15.8
Continence management	11	14.5
Safety	6	7.9
Access to specialist/allied health services	6	7.9
Assistance with shopping	5	6.6
Assistance with meals	4	5.3
Nursing support	4	5.3
Confidence/reassurance	4	5.3
More resources for care/services	3	3.9
Independence	1	1.3
Respite care	1	1.3
Ability to change lifestyle	1	1.3
Exercise	1	1.3
Dementia-related needs	1	1.3
Support to pursue personal interests	1	1.3
No comment	20	26.3

(a) More than one age-related need could be recorded per client.

Expectations of what projects would deliver

Question 4 asks the respondent to describe their hopes and expectations of what the project would deliver in addition to the help and care that was already available to the client in the supported accommodation setting. Responses to this question are varied, and appear genuinely specific to individual clients (Box 6.2). These responses provide more information about an individual's needs that were not fully met prior to the project. The service gaps identified vary according to individual client and service context.

Box 6.2: Examples of answers to Question 4—At the outset, what did you *hope* or *expect* the pilot program would deliver [for the client]?

'More going out with friends, on day trips like for lunch and that. Time to do my shopping.' [emphasis original]

'I hoped this program would improve skill levels, I expected a vast improvement in quality of life.'

'Quality time with the client.'

'New friends and networks; meaningful activities and exercise; home management and nutrition; mobility assistance.'

'The pilot program offered a more regular routine for [client] around events of daily living (e.g. shopping, banking) which were not able to be addressed routinely prior to the program beginning. With 1:1 support (and familiar staff), it was hoped that [client's] levels of anxiety and frustration could be lowered, our service's duty of care around issues of personal safety and medication administration could be alleviated, and [client's] quality of life through social inclusion could be enhanced.' [emphasis original]

'Day care when I gave up work as the service is not funded to provide day care.'

'Continue and increase his growing support needs. Identify gaps in care levels and compensate with extra assistance and specialised care and allied health professionals.'

Quality and appropriateness of services

The majority of respondents (61%) believed that their project was addressing previously unmet needs (Table 6.5). Fifteen respondents across four projects stated that their project was addressing some areas of unmet need, but not to the extent that they had hoped, and 11 respondents across five projects were unsure about whether the project was effective in meeting previously unmet age-related needs. Three respondents across two projects indicated that the project was not addressing some important needs.

A majority of respondents rated the amount of additional assistance delivered by their project as satisfactory or good to very good (Table 6.6). Physiotherapy and occupational therapy services were most often rated as unsatisfactory (13 responses), followed by mobility assistance, assistance to participate in domestic life and transport to community and social events (10 responses each), and provision of aids and equipment and speech therapy (9 responses each). Unsatisfactory ratings were distributed across projects.

Table 6.5: Care Experience Survey, effectiveness in meeting previously unmet age-related needs, by project

Project	Yes	Partly	No	Unsure	Missing or not included	Total
			(number)			
Far North Coast Disability and Aged Care Consortium	6	5	1	—	—	**12**
Central West People with a Disability who are Ageing	2	4	—	1	—	**7**
Northern Sydney Disability Aged Care Pilot	5	4	—	3	—	**12**
MS Changing Needs	13	2	—	1	—	**16**
Flexible Aged Care Packages	8	—	—	3	16	**27**
Disability and Ageing Lifestyle Project	2	—	—	3	—	**5**
Disability Aged Care Service	8	—	—	—	—	**8**
Ageing In Place	3	—	—	—	2	**5**
Total	**47**	**15**	**1**	**11**	**18**	**92**
			(per cent of included responses)			
Far North Coast Disability and Aged Care Consortium	50.0	41.7	8.3	—	. .	100.0
Central West People with a Disability who are Ageing	28.6	57.1	—	14.3	. .	100.0
Northern Sydney Disability Aged Care Pilot	41.7	33.3	—	25.0	. .	100.0
MS Changing Needs	81.3	12.5	—	6.3	. .	100.0
Flexible Aged Care Packages	72.7	—	—	27.3	. .	100.0
Disability and Ageing Lifestyle Project	40.0	—	—	60.0	. .	100.0
Disability Aged Care Service	100.0	—	—	—	. .	100.0
Ageing In Place	100.0	—	—	—	. .	100.0
Total	**63.5**	**20.3**	**1.4**	**14.9**	. .	**100.0**

— Nil.
. . Not applicable

Table 6.6: Care Experience Survey, ratings of amount of additional assistance

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(number)		
Personal assistance	33	10	5	28	76
Weekend/evening personal assistance	22	11	7	36	76
Continence management	23	10	8	35	76
Medication management	22	11	7	36	76
Provision of aids and equipment	26	14	9	27	76
Mobility assistance	22	11	10	33	76
Transport to appointments	22	14	4	36	76
Making appointments and care coordination	26	9	6	35	76
Nursing care at home	23	10	3	40	76
Help to access medical care	14	9	5	48	76
Speech therapy	15	12	9	40	76
Physiotherapy/occupational therapy	23	10	13	30	76
Management of age-related behaviours	19	15	7	35	76
Assistance to participate in domestic life	30	9	10	27	76
Social support	27	16	8	25	76
Transport to community and social events	27	18	10	21	76
Day leisure and skills programs	13	13	8	42	76
Interpreting and translating services	1	2	2	71	76

(continued)

Table 6.6 (continued): Care Experience Survey, ratings of amount of additional assistance

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(per cent)		
Personal assistance	43.4	13.2	6.6	36.8	100.0
Weekend/evening personal assistance	28.9	14.5	9.2	47.4	100.0
Continence management	30.3	13.2	10.5	46.1	100.0
Medication management	28.9	14.5	9.2	47.4	100.0
Provision of aids and equipment	34.2	18.4	11.8	35.5	100.0
Mobility assistance	28.9	14.5	13.2	43.4	100.0
Transport to appointments	28.9	18.4	5.3	47.4	100.0
Making appointments and care coordination	34.2	11.8	7.9	46.1	100.0
Nursing care at home	30.3	13.2	3.9	52.6	100.0
Help to access medical care	18.4	11.8	6.6	63.2	100.0
Speech therapy	19.7	15.8	11.8	52.6	100.0
Physiotherapy/occupational therapy	30.3	13.2	17.1	39.5	100.0
Management of age-related behaviours	25.0	19.7	9.2	46.1	100.0
Assistance to participate in domestic life	39.5	11.8	13.2	35.5	100.0
Social support	35.5	21.1	10.5	32.9	100.0
Transport to community and social events	35.5	23.7	13.2	27.6	100.0
Day leisure and skills programs	17.1	17.1	10.5	55.3	100.0
Interpreting and translating service	1.3	2.6	2.6	93.4	100.0

Respondents were asked to indicate in what way services rated unsatisfactory did not meet expectation. Fifty-one aspects were specified within 13 different categories (Table 6.7). Physiotherapy and occupational therapy were most often identified as unsatisfactory, due to limited availability, high cost and 'other factors'. Speech therapy, transport services and day leisure and skills programs were also commonly cited as unsatisfactory (five responses each), due to limited availability, high cost, staffing issues and 'other factors'. Nominations of physiotherapy (five out of nine nominations) and speech therapy (three out of five nominations) were concentrated in the responses from one supported accommodation facility participating in the Northern Sydney project.

Table 6.7: Care Experience Survey, summary of areas rated unsatisfactory and stated reasons

Area of pilot rated as unsatisfactory	Number of responses	Reasons
Physiotherapy and occupational therapy	9	Limited availability; cost; other reason
Day and leisure skills/programs	5	Limited availability; cost; other reason
Speech therapy	5	Limited availability
Social support	4	Limited availability; staffing issues; other reason
Transport services	4	Limited availability; cost; staffing issues; other reason
Assistance to exercise	3	Limited availability; cost; not specified
Insufficient additional resources provided	3	Limited availability
Weekend/after hours support	3	Limited availability; cost; staffing issues
Assistance with domestic participation	2	Cost; staffing issues; other reason
Continence management	2	Limited availability; cost
General allied health services	2	Limited availability; staffing issues; other reason
Mobility assistance	2	Limited availability; other reason
Global dissatisfaction with pilot services	1	Cost; staffing issues; other reason
Help to make appointments	1	Unspecified
Management of age-related symptoms	1	Cost
Management of psychological and behavioural symptoms	1	Staffing issues
Personal assistance	1	Limited availability; staffing issues; other reason
Provision of aids and equipment	1	Cost
Unspecified	16	Limited availability; cost; staffing issues; not convenient; other reason

Project planning and coordination services were generally rated satisfactory or good to very good (Table 6.8). Training and education of disability support staff to facilitate the implementation of the client's care plan was rated as unsatisfactory by 11 respondents.

Fifty-six of the 76 respondents (74%) believed that the project services clients received were delivered in a manner that is always or mostly convenient to the client and the client's household (Table 6.9). Twelve respondents stated that service delivery was sometimes (though not often or always) inconvenient. Six respondents were undecided.

Table 6.8: Care Experience Survey, ratings for service planning and coordination

Service type	Good to very good	Satisfactory	Less than satisfactory	Not applicable	Total
			(number)		
Assessment of client needs	55	18	1	2	76
Involvement of disability support staff	49	21	3	3	76
Selection of services	43	26	4	3	76
Liaison between project coordinator and disability support staff	43	21	3	9	76
Liaison with client's family	34	18	2	22	76
Training and education of disability support staff	42	17	11	6	76
			(per cent)		
Assessment of client needs	72.4	23.7	1.3	2.6	100.0
Involvement of disability support staff	64.5	27.6	3.9	3.9	100.0
Selection of services	56.6	34.2	5.3	3.9	100.0
Liaison between project coordinator and disability support staff	56.6	27.6	3.9	11.8	100.0
Liaison with client's family	44.7	23.7	2.6	28.9	100.0
Training and education of disability support staff	55.3	22.4	14.5	7.9	100.0

Table 6.9: Care Experience Survey, ratings for project convenience

Level of convenience	Responses	Per cent
Always or mostly convenient	56	73.7
Sometimes inconvenient	12	15.8
Undecided	6	7.9
Missing	2	2.6
Total	**76**	**100.0**

Ratings of project services as sometimes inconvenient are spread across five projects, each of which had a mix of positive and negative ratings from respondents across and within participating supported accommodation facilities. This suggests that the convenience of project services is affected by both household routines within participating supported accommodation facilities and individual client routines and preferences, as well as the service delivery model.

Question 11 asks respondents to comment on aspects of the project they did not like (Box 6.3). Nineteen respondents commented that there were no such aspects and 32 respondents did not comment. Thus, 67% of respondents did not identify any specific aspects of their project deemed as unsatisfactory (Table 6.10), suggesting that respondents had an overall positive, or at least not negative, view of the projects.

Box 6.3: Examples of answers to Question 11—Were there any aspects of the pilot program that you did NOT like?

'This [disability] service is not day-funded. Due to ageing issues clients (some) can not work during the day. The pilot program is one-on-one for 3 hours each client per week so it is not meeting the client or service needs.'[15]

'Not enough hours.'

'It would be helpful to have all approved funding in writing.'

'Yes and no. Pilot program in an excellent resource but because of client's ongoing need with ageing, personal care assistance and mobility, this program needs to be a permanent program.'

'It appeared that the worker designated to [client] was unaware and uninformed of what the allocated time was to be used for and what her role in this time would be.'

The most common criticism was of the level of service and resources available through a project (15 responses). These were not criticisms of the type or mode of service delivery *per se* but seem more a reflection of the belief of some respondents that more services and resources (funding, staffing levels and hours of care) are required to effectively meet client needs.

Question 12 offered respondents an opportunity to describe aspects of services that stood out as particularly effective in meeting the client's age-related needs (Box 6.4). All but 18 respondents provided some positive commentary, again illustrating that respondents had a mostly positive view of the projects (Table 6.11). The additional assistance provided by projects (21 responses), increased participation (15 responses), and access to specialist services and the optimisation and/or maintenance of wellbeing (8 responses each) were most frequently identified beneficial aspects of pilot services for clients. Thus, respondents identified aspects of service models and client outcomes.

15 Some supported accommodation providers involved with the projects reported that they were not funded to have a staff member in the house during the day. Clients who live in these group homes usually spend their days at work or in day programs. When clients 'retire' from day activities difficulties can arise because staff are not present in the home. During site visits several accommodation providers reported that they had hoped that projects would provide staff to stay at home during the day with clients who are no longer attending day activities.

Table 6.10: Care Experience Survey, aspects of the project that respondents did not like

Theme	Responses[(a)]	Per cent
None at all	19	25.0
Pilot services/funding/staffing levels/hours of care are insufficient	15	19.7
Hopes for the pilot to become permanent	2	2.6
Project services are fragmented	2	2.6
The pilot is helpful	2	2.6
Communication needs improving	1	1.3
Inadequate assistance with behaviour management	1	1.3
Inadequate assistance with meals	1	1.3
Inadequate assistance with shopping	1	1.3
Inadequate support for social needs	1	1.3
Inflexible service provision	1	1.3
Lack of professionalism	1	1.3
The pilot fails to meet some important needs	1	1.3
No comment/answer made	32	42.1

(a) More than one theme could be recorded per response.

Box 6.4: Examples of answers to Question 12—Which aspects of the pilot program stand out as particularly effective in meeting the client's age-related needs?

'Identification and assessment processes for age-related issues, introduction to age-related services through ACAT.'

'1) Reduction in the client's levels of confusion, anxiety, frustration and fatigue; 2) Opportunities have been created for the client to increase community contact and integration; 3) With 1:1 staff support the client is less vulnerable to risk of personal health and safety (especially since the client has epilepsy and regularly needed ambulance transport to hospital whilst he was unsupported out in the neighbourhood); 4) The cost for the client has been manageable.'

'Health care and mobility, falls prevention.'

'It provides quality time and care.'

'I like the staff—"nice" to me, "help me". Like to go out, with staff support, for example to BBQs. Like to go and visit people. Like to go and celebrate birthdays.' [emphasis original]

Table 6.11: Care Experience Survey, aspects of projects identified as particularly effective

Theme	Number of responses	Per cent
Provides more resources for care	21	27.6
Increased participation	15	19.7
Access to specialist services	8	10.5
Optimises/maintains wellbeing	8	10.5
Enhanced service/quality of care	6	7.9
Project staff characteristics	5	6.6
Allows clients to 'slow down' their lifestyle	4	5.3
Assistance with advancing age-related problems	4	5.3
Documented service delivery	4	5.3
Improves client safety	4	5.3
Personal assistance	4	5.3
Flexibility of the project	3	3.9
Assists with dementia-specific needs	2	2.6
Increased information	2	2.6
Mobility assistance	2	2.6
Provides clients with confidence/reassurance	2	2.6
Support from case manager	2	2.6
Continence management	1	1.3
Delays need for permanent care	1	1.3
Good GP and ACAT support	1	1.3
Insufficient services/funding	1	1.3
Nursing support	1	1.3
Pain management	1	1.3
Provides care on a one-on-one basis	1	1.3
The pilot is helpful	1	1.3
No	2	2.6
No comment/answer	16	21.1

Thirty-four responses reported that client care involved new staff in addition to the household's disability support staff (Table 6.12). Reporting of staffing models was not consistent within projects—responses were different between group homes in all projects except for Ageing In Place and MS Changing Needs (each is a fully integrated disability and aged care service model), and Disability and Ageing Lifestyle Project (for which only one participating group home responded to the question). Where projects introduced new staff into a client's household, respondents were asked to rate the staffing arrangements for the provision of additional assistance. More than 70% of respondents rated staffing arrangements as satisfactory or good to very good (Table 6.13). Nine respondents rated staffing arrangements as unsatisfactory.

Table 6.12: Care Experience Survey, project staffing models

New staff introduced into group home	Number	Per cent
Yes	34	44.7
No	30	39.5
Missing	12	15.8
Total	**76**	**100.0**

Table 6.13: Care Experience Survey, ratings of project staffing arrangements where project services introduced new staff into the client's household

Staffing arrangement	Number	Per cent
Good to very good	17	50.0
Satisfactory	7	20.6
Less than satisfactory	9	26.5
Missing	1	2.9
Total	**34**	**100.0**

A key potential benefit of the Pilot is the transfer of skills and experience between aged care and disability support staff. Forty responses (69%) reported that the project was successful in promoting skills transfer to disability support staff; 13 respondents (22%) reported that the Pilot had not delivered skills transfer; five respondents (9%) were undecided (Table 6.14). These responses are broadly consistent with responses to Question 9 in which 42 respondents (55%) rated the training and education of disability support staff to facilitate the implementation of the client's care plan as good to very good.

Table 6.14: Care Experience Survey, transfer of aged care skills and experience to disability support staff

	Skills transfer				
Project	Yes	No	Undecided	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	5	1	1	5	12
Central West People with a Disability who are Ageing	4	2	—	1	7
Northern Sydney Disability Aged Care Pilot	3	5	—	4	12
MS Changing Needs	14	1	1	—	16
Flexible Aged Care Packages	5	1	1	20	27
Disability and Ageing Lifestyle Project	3	—	—	2	5
Disability Aged Care Service	5	3	—	—	8
Ageing In Place	1	—	2	2	5
Total	**40**	**13**	**5**	**34**	**92**

(continued)

Table 6.14 (continued): Care Experience Survey, transfer of aged care skills and experience to disability support staff

Project	Skills transfer				
	Yes	No	Undecided	Missing or excluded	Total[(a)]
			(per cent)[(a)]		
Far North Coast Disability and Aged Care Consortium	71.4	14.3	14.3	. .	**100.0**
Central West People with a Disability who are Ageing	66.7	33.3	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	37.5	62.5	—	. .	**100.0**
MS Changing Needs	87.5	6.3	6.3	. .	**100.0**
Flexible Aged Care Packages	71.4	14.3	14.3	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	62.5	37.5	—	. .	**100.0**
Ageing In Place	33.3	—	66.7	. .	**100.0**
Total	**69.0**	**22.4**	**8.6**	**. .**	**100.0**

(a) Of non-missing, included responses.
— Nil.
. . Not applicable.

Negative, undecided and missing responses to the question on training and education are distributed across all projects, including projects with an explicit training component. Responses are inconsistent between group homes within each project. Staff in some group homes participating in each project believed that skills transfer was taking place, while at other homes in the same project, staff reported that the project was not helping to increase skills and experience in aged care. There is no evident association between these responses and the staffing model used to deliver project services (that is, whether or not the project introduced new staff or whether project services were delivered by existing disability support staff).

By far the majority of respondents (83%) reported that clients, families and disability support workers had an appropriate level of involvement in care planning (Table 6.15). Five respondents reported that, while clients and advocates were consulted about the care plan, they should have had a greater say. Five respondents reported that clients, their advocates and disability support staff were not adequately involved in care planning.

Table 6.15: Care Experience Survey, ratings of level of client, family or disability support staff involvement in care planning

Has the client, family members and household staff had adequate involvement in care planning for the project?		
Answer:	**Number**	**Per cent**
Yes	63	82.9
Partially	5	6.6
No	5	6.6
Missing	3	3.9
Total	**76**	**100.0**

Suitability of pilot services for long-term care provision

Approximately 85% of respondents who answered the question of the suitability of projects for long-term care indicated a belief that projects were providing disability support workers with an adequate level of support, information and practical assistance to manage clients' age-related needs at home (Table 6.16).

Seven respondents in two projects did not believe disability support staff were given adequate support from a project; another three respondents were undecided.

Table 6.16: Care Experience Survey, beliefs about whether the project provides disability workers with an adequate level of support, information and practical assistance in managing client age-related needs, by project

Project	Yes	No	Undecided	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	5	—	1	6	12
Central West People with a Disability who are Ageing	4	1	2	—	7
Northern Sydney Disability Aged Care Pilot	12	—	—	—	12
MS Changing Needs	10	6	—	—	16
Flexible Aged Care Packages	11	—	—	16	27
Disability and Ageing Lifestyle Project	5	—	—	—	5
Disability Aged Care Service	8	—	—	—	8
Ageing In Place	4	—	—	1	5
Total	**59**	**7**	**3**	**23**	**92**

(continued)

Table 6.16 (continued): Care Experience Survey, beliefs about whether the project provides disability workers with an adequate level of support, information and practical assistance in managing client age-related needs, by project

Project	Yes	No	Undecided	Missing or excluded	Total[(a)]
			(per cent[(a)])		
Far North Coast Disability and Aged Care Consortium	83.3	—	16.7	. .	**100.0**
Central West People with a Disability who are Ageing	57.1	14.3	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	100.0	—	—	. .	**100.0**
MS Changing Needs	62.5	37.5	—	. .	**100.0**
Flexible Aged Care Packages	100.0	—	—	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	100.0	—	—	. .	**100.0**
Ageing In Place	100.0	—	—	. .	**100.0**
Total	**85.5**	**10.1**	**4.4**	**. .**	**100.0**

(a) Of non-missing, included responses.

— Nil.

Respondents were asked whether, from the perspective of workers and residents in the client's household, it is appropriate to support the client in the group home setting given their existing age-related needs. The question was not answered on 47% of returned questionnaires, which is one of the lowest response rates for a single item.

Of the answers given, respondents overwhelmingly supported maintaining clients in the familiar home setting (93%) (Table 6.17). No respondent indicated that it was definitely not appropriate for the client to be cared for within the current home setting.

Table 6.17: Care Experience Survey, beliefs about the long-term appropriateness of projects for maintaining clients at home with assistance, by project

Project	Yes	Unsure	No	Missing or excluded	Total
			(number)		
Far North Coast Disability and Aged Care Consortium	2	2	—	8	12
Central West People with a Disability who are Ageing	5	—	—	2	7
Northern Sydney Disability Aged Care Pilot	9	—	—	3	12
MS Changing Needs	—	—	—	16	16
Flexible Aged Care Packages	7	—	—	20	27
Disability and Ageing Lifestyle Project	2	—	—	3	5
Disability Aged Care Service	8	—	—	—	8
Ageing In Place	4	1	—	—	4
Total	**37**	**3**	**—**	**52**	**92**

(continued)

Table 6.17 (continued): Care Experience Survey, beliefs about the long-term appropriateness of projects for maintaining clients at home with assistance, by project

Project	Yes	Unsure	No	Missing or excluded	Total[(a)]
			(per cent[(a)])		
Far North Coast Disability and Aged Care Consortium	50.0	50.0	—	. .	**100.0**
Central West People with a Disability who are Ageing	100.0	—	—	. .	**100.0**
Northern Sydney Disability Aged Care Pilot	100.0	—	—	. .	**100.0**
MS Changing Needs	—	—	—	. .	**100.0**
Flexible Aged Care Packages	100.0	—	—	. .	**100.0**
Disability and Ageing Lifestyle Project	100.0	—	—	. .	**100.0**
Disability Aged Care Service	100.0	—	—	. .	**100.0**
Ageing In Place	80.0	20.0	—	. .	**100.0**
Total	**92.5**	**7.5**	**0.0**	. .	**100.0**

(a) Of non-missing, included responses.

— Nil.

. . Not applicable.

Question 18 asks whether respondents believed the services offered by projects were an appropriate form of additional assistance for the client in the group home setting. Respondents were first asked to identify any aspects of a project which may make it unsuitable for long-term care of the client at home and then to describe how the project could be improved or expanded to better meet the client's age-related needs (Box 6.5).

Respondents mostly said that no aspect of service provision would make a project an unsuitable long-term care option; some did not answer the question (34 responses). Several respondents commented on positive aspects of projects (11 responses). Some respondents indicated that the additional assistance available from a project was adequate but might not be sufficient in the future if the client's needs increase (five responses), or that the project would need to continue indefinitely if the client were to remain at home (two responses).

Three respondents indicated that projects were not providing enough assistance to be effective as a long-term care option. Two of these responses indicated that the Pilot was viewed as a positive initiative but was somewhat disruptive for other members of the household and can create jealousy of the 'extra attention' received by Pilot clients.

Several risk factors for entry to residential aged care, even with Pilot services in place, were identified:

- deteriorating health and/or requiring nursing or medical services which cannot be provided in the home
- decline in physical functioning
- cognitive decline
- mental health issues and/or challenging behaviours
- mobility issues (for example, requiring two-person transfers when the disability service provider is not funded to provide these, or being insufficiently mobile to attend activities outside the home)

- limitations of the physical environment (for example, requiring a wheelchair when living in a privately rented house that cannot be adapted to accommodate a wheelchair)
- household dynamics (when meeting the client's needs in place unfairly impacts on the other members of the household)
- need for 24-hour supervision or staffing support and/or secure living areas to prevent injury or wandering.

Some respondents stated that, whether additional services were available through the Pilot or not, it would never be in the client's interests to be moved to another service.

When asked to indicate how the Pilot could be improved or expanded to better meet the client's age-related needs, the majority of people who responded indicated that additional funding for staffing, hours of care and access to other age-related services was needed (17 responses). Others were concerned that the Pilot (or some other source of increased funding for disability services) needs to become permanent in order to guarantee adequate service provision for the client (three responses), or indicated that the services delivered through the Pilot would need to remain flexible so that new and increasing needs can be catered for over time (13 responses). Twenty-four respondents did not comment or stated that they were unsure how the project could be improved. Five made positive statements about the project in its current form.

Some implementation aspects are mentioned as needing improvement. For example, some respondents requested that services be available on weekends (three responses); that services be delivered more flexibly (two responses); and that clearer, written guidelines about resource allocation under the project be provided (five responses). One respondent suggested that the project should be extended to ageing people with disabilities living in private residences and another remarked that the number of packages should be increased.

Six respondents were keen to receive more training in ageing issues.

Box 6.5: Examples of responses to Question 18—We would like to know if you think that the services offered by the pilot program are an appropriate form of additional assistance to the client in the group home setting.

(a) Please describe any aspects of the pilot program that you believe might make it unsuitable for long-term care of the client at home:

'If the client had high care needs which demanded nursing care on occasions and they could not participate in activities away from home.'

'Not enough support. As stated before, 6 hours a week is not sufficient.'

'[Client] has lived at [the group home] for most of her life. It would not be in [client's] interest to move to another facility.'

'No— no direct service as yet needed for my client to keep him at home.'

'Can't think of any. It's a good buddy/monitoring/keep your skills up programme.'

'Not enough assistance to adequately care for the client long term in their home.'

'Long term—lifting—requires two staff—unfunded.'

'Pilot program is <u>not</u> unsuitable but taking into account client's ongoing needs, should be considered for a permanent and ongoing program enabling client to age in place.' [emphasis original]

'Level of service provided may not be high enough if ageing related needs increased in the future…Assistance is appropriate as client's ADL needs were already being met and additional needs were social/community access. Access to therapy services is most beneficial.'

'I think that it's all positive…The break in their daily routine and the attention alone may help keep them in their home significantly longer.'

'The pilot program has been fantastic at enabling the client to participate in the local community and become a valued member.'

'The client may require more medical and mobility assistance in future.'

(b) How could the pilot program be improved or expanded to better meet the client's age-related needs?

'I think it's working beautifully. Clients are very happy with the activities and enjoy the quieter days too.'

'To develop a staff training package in age-related issues.'

'More hours.'

'This client's age related needs are becoming increasingly high due to the ageing process. She would benefit from any extra hours to allow staff to attend to her needs as well as access areas that best meet her needs. Permanent, ongoing funding needs to be secured for these needs.'

'All approved funding to be in writing with guidelines for the organisation to follow.'

'Remaining flexible to adapt to changing needs of client.'

'If the hours of support and assistance <u>could</u> be extended to better meet the identified (and projected) needs of the client, while support gaps in our service due to lack of funding still exist, this would be fantastic!' [emphasis original].

'Perhaps more hours for quality time and care.'

'Individual services should be adequately funded to broker out for staff and acquire enough support (not just 3 hours a week but what each service actually needs) to provide ageing clients with an appropriate service.'

'The pilot does not operate on the weekend. Client needs do not stop on Friday and commence again on Monday. I would like to see some hours given to weekends.'

'I think there is nothing that I can think of that could improve/expand the pilot program. I enjoy it! I used to work in a nursing home and it was like an assembly line. But this program is great for the carer AND the client! One-on-one is how it SHOULD be!' [emphasis original]

7 Conclusion

Pilot services represented a new care choice for ageing CSTDA consumers living in supported accommodation services—community-based aged care. Outside the Pilot, residential aged care is the only referral option open to ACATs in assessing clients in supported accommodation for aged care specific service. Leading examples of in-place progression models exist with the disability services sector (indeed one Pilot provider had commenced planning for an on-site disability-specific nursing home at the time of the evaluation) but these emerge only when there are sufficient resources to turn vision into reality.

The benefits of community-based aged care to individual clients and other household members and staff are obvious and have been described in this report. Thus, to the first of the three evaluation questions, *Do the pilot services offer new care choices which meet the needs of older Australians?*, the answer is an unequivocal 'yes'. In concluding the evaluation report, we summarise how the Pilot has benefited individuals and built capacity within the disability and aged care systems. We also touch on important issues at the boundary of disability and aged care programs that are not fully addressed by the top-up model of aged care funding trialled in the Innovative Pool Disability Aged Care Interface Pilot.

7.1 Benefits of the Pilot to individuals and service delivery systems

Additional funding for aged care has benefited Pilot clients in two main ways. First, it has introduced a new perspective to the provision of support as people age. The sharing of information and expertise between staff in disability and aged care services has meant that Pilot clients came to be viewed as people with disabilities who are ageing, not solely as people with disabilities, or CSTDA consumers. A client benefits in a tangible way from the insight into their living situation that comes from joint assessment by staff with expertise in disability support and aged care. Through the processes of joint assessment and care planning, the two service systems benefit from increased capacity of staff to understand the issues of supporting people with disabilities who are ageing. This increased capacity was demonstrated and valued by staff participating in the Pilot. Second, the Pilot delivered home- and community-based assistance to address functional decline in clients and to support client choice for lifestyle change to age-appropriate levels and types of activity. Increased access to generic aged care services has been a minor aspect of Pilot services. More commonly, projects delivered a highly individualised package of increased assistance to a client at home and therapeutic intervention and recreation and leisure activity to meet client preferences and needs.

Discussions held early in the evaluation focused on the question of what are the common age-related needs of clients of supported accommodation services. Needs were said to vary from client to client but to fall into the following broad categories:

- a need for higher level ADL support that was observed to be increasing over time
- dementia-specific care
- ongoing allied health supervision for care planning and guidance for physical therapy to help maintain living skills for as long as possible
- assistance with transitions to age-appropriate lifestyle

- the provision of ongoing support that is sensitive to the needs of the older person, that is, building capacity for service responsiveness to age-related functional change.

Higher levels of ADL support commensurate with increasing functional dependency

Aged care funding has led to the provision of additional personal assistance for many clients who had, over time, become unable to maintain simple self-care routines. One person's slowing due to loss of physical strength, cognitive decline or incontinence tends to impact on the whole household by placing extra pressure on staff during peak periods. Added support for a resident who no longer moves at the same pace helps relieve this pressure and provides the necessary level of support to the client. In addition, Pilot services have been able to provide personal assistance during daytime hours to clients who would otherwise be unattended for long periods.

Dementia care

Additional daytime assistance helps to support clients with dementia to spend longer periods at home. With the progression of dementia a resident typically needs longer periods in the calmer, less challenging environment of home while still having access to supervised activity. Most supported accommodation services do not have staff in attendance between the hours of 9.00 am and 3.00 pm, when residents would normally be at work or attending day programs. Flexible care subsidy in the Disability Aged Care Interface Pilot can help to fill some, but not all, of this gap.

Disrupted behaviour and sleep patterns associated with cognitive decline can lead to safety risks for the client, other residents and staff. Additional assistance from a Pilot project might not enable a person with this kind of need to remain at home if the accommodation service does not operate with active night staff. Assessment and behaviour management services delivered by projects help to identify dementia-specific needs that can be remedied as well as assisting support staff in the development of management plans.

Over the longer term, the progressive nature of dementia presents significant challenges to community living. Additional assistance at the levels delivered by Pilot projects helps to prolong ageing in place for people with disabilities as dementia symptoms emerge and begin to impact on disability services, but it does not provide for the continuous one-to-one support that is often required to maintain a person with advanced dementia at home. In the wider population of older community-dwelling people with dementia, the intensive support required to maintain a person with advanced dementia at home is provided by family carers, often supplemented by formal aged care services. It is widely recognised that a community care package alone, at current funding levels, does not provide an adequate level of support to a person with advanced dementia who is alone at home. Ultimately, some form of institutional care will be the future reality for many people with disabilities who have dementia-related high care needs if there is no 24-hour active staff in the community-based home setting.

Allied health care

Input from allied health professionals in the Pilot has taken two forms: assessment and the design and monitoring of physical maintenance programs. These interventions help to compensate for loss of physical function (for example, through recommendations for aids and equipment) and to improve or maintain levels of functioning at full potential (for example, physical activity programs).

Recommendations for aids and equipment are often made as a result of aged care assessment and follow-up allied health assessment, and in some instances projects have acquired aids to assist clients in daily living. State and territory governments have programs to deliver aids and appliances for people with disabilities but waiting times are said to be long in most areas. Pilot providers remarked that they have been able to respond immediately to identified needs, often for relatively inexpensive items that make a marked difference to client safety and quality of life. Sometimes only the assessment and identification of need is necessary because the disability service provider is able to make the acquisition. Consideration is given to the suitability of physical home environments and where necessary and possible, minor modifications are made to adapt homes according to the needs of residents who are ageing.

Transitioning to age-appropriate lifestyles

Lifestyle transitions have been another main focus of Pilot services and there appear to be several reasons why this was identified as an area of age-related need. Some clients needed to withdraw from employment or day programs because of diminished productivity and social functioning associated with the progression of dementia and/or physical frailty. People in this situation may have been continuing in long-standing routines prior to joining a Pilot project, even though this was not a lifestyle of personal choice or the most appropriate level of activity for an ageing person. The Disability Aged Care Interface Pilot has offered these people the choice of well managed lifestyle transition. Project staff and advocates have supported clients in the decision process and the additional resources from Pilot funding have facilitated gradual withdrawal from full-time or highly structured activity to activity plans that are more manageable for people with lower levels of cognitive and physical function. In the same category are those clients who were leading sedentary lifestyles prior to joining the Pilot because of earlier changes to daytime routines that had also occurred as a result of declining levels of functioning. The Pilot offered these people an opportunity for renewed social and community participation. Community and social services have mostly been delivered in parallel with additional personal assistance and other services as part of a total package of services from a Pilot project.

A small number of clients received recreation/leisure and transport services alone. This service profile is consistent with the provision of community access and support as a way to reduce the number of hours in a day in which clients are without companionship and activity.

Ongoing support that is responsive to the needs of the person who is ageing

Effective provision of additional aged care specific services relies on the expertise of staff from both the aged care and disability services sectors. For additional funding to make a real

difference to the quality of life of clients the service model should promote sharing of skills and knowledge so that a client's main service provider is responsive to their changing needs. Several models of aged care service provision have been trialled in the Disability Aged Care Interface Pilot which demonstrate that a range of expertise exists within disability services to support clients who are ageing.

The three projects with aged care teams sited or integrated within disability services (Ageing In Place, Tasmania; Disability Aged Care Service, Western Australia; and MS Changing Needs, Victoria;) demonstrated a high level of awareness of aged care specific needs of clients and aged care interventions within the project team. Ageing In Place and MS Changing Needs were uniquely positioned in different ways. Oakdale Services, the approved provider for Ageing In Place, is also the supported accommodation provider. Oakdale had for some years prior to the Pilot been monitoring functional change in older residents and working on the concept of an ageing in place service model. The historical barrier to ageing in place in this case was funding rather than lack of insight into the needs of older residents. MS Changing Needs is unique among the Pilot projects in that there is no obvious separation of disability support needs and aged care needs. As such, the knowledge and expertise required for the delivery of Pilot services is integral to the delivery of care for people with advanced MS and this exists within specialist MS disability services.

Disability Aged Care Service operated somewhat differently to Ageing In Place. Although the aged care project team was sited within one of the two accommodation services, pilot services were delivered by a dedicated aged care team working alongside disability support staff. Senses Foundation, the approved provider for Disability Aged Care Service, like Oakdale Services in Tasmania, has high level expertise in disability specific aged care intervention within the organisation's disability aged care division. Unlike Ageing In Place, Disability Aged Care Service delivered services into group homes and encountered the same sorts of issues in relation to referral and documentation practices as projects servicing group homes and supported accommodation facilities in other states.

Projects in New South Wales and South Australia have delivered services to clients of supported accommodation services operated by organisations other than the approved provider for the Pilot. Most of the project teams encountered early difficulties in obtaining referral documentation that accurately reflected clients' aged care specific needs. Over time problems were ironed out and steady flows of high quality referrals were established. If the Pilot is any measure, a widespread lack of awareness of ageing issues and aged care interventions appears to exist among disability workers who have daily caring responsibility for people in supported accommodation services. There is no suggestion that lack of awareness exists among specialist case managers; rather it appears more symptomatic of the low rates of pay, hence low qualification levels, of people working at the coalface of accommodation service provision. The Disability Aged Care Interface Pilot service models provided valuable opportunity for disability support staff to receive on-the-job exposure to aged care service delivery that would seem to provide long-term benefits to clients, other members of their households and the disability sector more generally. Moreover, the Pilot helped to highlight that community aged care workers with disability-specific experience are a rare species and that outreach service models therefore rely on a high level of cooperation and sharing of expertise between the sectors.

Impacts on residential aged care, disability and health systems

Through the provision of instrumental assistance (for example, personal assistance and community access) and service capacity building, community-based aged care for people with disabilities reduces the risk of early admission to residential aged care. It delivers the important benefit of maintaining continuity of care for those individuals who can continue to be supported primarily by specialist disability services, and their families. Increased awareness of ageing processes among disability support staff will pay longer term dividends if it means that aged care interventions occur in a timely fashion for other clients in a supported accommodation service.

However, the level of risk of early admission to residential aged care is highly individual and because of this the impact of Pilot-type services on the residential aged care system is thought to be correspondingly circumstantial. Disability accommodation providers tend to resist pressure to transfer their clients into aged care facilities for as long as possible. That pressure builds as it becomes more and more difficult to maintain a client in a community-based setting. But the nature of the difficulty itself stems from the interaction of individual need factors and service capacity factors. Case studies presented throughout this report demonstrate that some difficulties are resolved with minimal expense but maximum insight; other issues require the ongoing injection of additional community-based resources; while in other cases, additional services at a cost of up to $70 per day may not be able to prevent entry to a residential care setting in the short to medium term. Much hinges on the style of accommodation and level of accommodation service in relation to an individual's aged care specific needs, the range and flexibility of specialist disability services to which a client has access, and the extent to which aged care funding can address the balance of a client's unmet need.

The area of allied health assessment and intervention is at the intersection of disability, aged care and health care systems. Pilot projects have in most cases delivered allied health therapies by purchasing services from private providers. Early attempts by projects to source allied health input from the public health system involved lengthy delays, which slowed assessment processes and the commencement of active therapy for clients. In a larger population this may relieve pressure on the public health system, although there is considerable doubt that members of the Pilot target group would ordinarily receive the observed levels of allied health assessment and therapy delivered by the Pilot as part of an aged care plan. Based on anecdotal reports and case studies submitted to the evaluation it is concluded that limited access to allied health intervention contributes to use of residential aged care services by members of the target group.

People with disabilities and older people more generally who are eligible to receive HACC-funded services may receive allied health intervention through the HACC Program. The CACP Program does not fund allied health care. The main sources of allied health care for older people are private fee-for-service arrangements (which may be partly covered by private health insurance), the public health system, and the HACC and Day Therapy Centre programs, subject to program eligibility. Most members of the Pilot target group have limited access to allied health services to address aged care specific needs, first because of the way that access to public allied health services is prioritised and second, because of the cost involved in acquiring private services.

It is important to recognise that allied health interventions delivered by Pilot services are directed at arresting or slowing the functional decline that occurs as a result of ageing and at making environmental compensations that minimise the impact of increased disability due to ageing. This is not about fast-stream rehabilitation for injury-related conditions or major

medical events such as stroke; rather, the treatment intent in the Pilot context is strictly the management of increasing disability due to ageing. Although some might not consider allied health to be an aged care specific intervention, there is no escaping the high need for timely allied health intervention among older people because of the high rates of mobility and self-care limitation in older age groups. In demonstrating the positive effects of allied health assessment and related interventions on the quality of life for people with disabilities who are ageing, and therefore on their ability to remain in the community, the Pilot has highlighted an area of service need that is relevant to the care of all people who experience increasing disability as they age. The issue of access to allied health care for people who are ageing cuts across health care, aged care and disability programs.

7.2 Identified weaknesses of the Pilot model

As reflected in the Aged Care Innovative Pool 2002–03 Guidelines and Memoranda of Understanding between the Department and approved providers, Pilot projects were established with the aim of addressing the *aged care specific needs* of people with disabilities living in supported accommodation (Box 7.1). Notwithstanding the clear benefits of Pilot services to clients, a number of conceptual and practical difficulties are associated with the way in which this Pilot was conceived and implemented.

Box 7.1: People with disabilities who are ageing category of the Innovative Pool

This category of proposal is designed to meet the needs of people with disabilities who are at risk of being admitted to residential aged care because their increasing care needs cannot be met through disability support systems alone. They require additional services that are aged care specific in order to remain in their current disability funded living situation, be that a community setting such as a group home, or more institutional supported accommodation.

The aim is to enable the individual to remain part of their existing living and support relationships, in familiar surroundings, for as long as possible. Proposals must demonstrate that aged care related services would be incorporated into the care provided so that the individual's care needs are met in a seamless manner. Proposals should not be based on the withdrawal of other support services and should target identified individuals with ACAT assessments for residential care.

It is expected that, as people with disabilities age, both their aged care related needs and their disability support needs may increase. Proposals should consider the need for both aged care services and additional State/Territory disability support in the design of the project.

Source: Aged Care Innovative Pool 2002–03 Guidelines, Australian Government Department of Health and Ageing.

Open interpretation of aged care specific need

The idea that need for assistance should be defined as age related or disability related is worthy of discussion, both for its novelty and because it provides the underlying philosophy for assessment and service delivery in the Pilot. The idea has utility in providing a means of separating the respective financial responsibilities of disability and aged care programs. But

in speaking of aged care specific needs or age-related needs, what is really meant is age-onset *disability*. Many older people do not need aged care because they age without experiencing significant disability. Age is commonly used as a proxy for disability in the later stages of life because of assumptions—that do not apply equally for every individual—about ageing and disability. Policies and programs to promote 'healthy ageing' and 'ageing well, ageing productively' have gained prominence in recognition that a person can be old and free of significant disability. Where significant disability exists before a person gets 'old', in the conventional sense, difficulties inevitably arise in detecting changes that signal the increasing of disability due to ageing and the increasing of disability due to the fact that a person has had a disability for a long time.

Pilot project teams and participating ACATs have had to grapple with this issue on a practical level. They report that it is possible, though not always, to identify changes in a person with a disability that are associated with growing older as seen in the wider population. Typically, the process involves the description of an earlier 'steady state' (by considering what the person could do before and how he/she used to interact socially). This benchmark of normal life for the person with a disability is compared to how the person currently functions—physically, psychologically and socially. For some types of disability the process of detecting change is made easier by there being a discernible prior steady state. In the case of a person with Down syndrome, for example, the symptoms of dementia in Alzheimer's disease may present a stark contrast to the person's previous level of domestic and social functioning. Other visible signs of physiological ageing at relatively young chronological ages in people with Down syndrome help to corroborate social and behavioural changes as related to premature ageing. In addition, the effects of premature ageing in people with Down syndrome is well documented. More complex cases have surfaced in the Pilot, principally related to chronic progressive disability, such as multiple sclerosis, or physical and diverse disabilities that lead to complications over time, as a person ages but well before they are 'old'.

A number of questions arise in connection with the idea of aged care specific needs in people with disabilities:

1. Is the term *aged care specific needs* (or *age-related needs*) intended to encompass the range of needs that emerge as a person with a disability gets older, or is it intended to mean only those needs that are routinely addressed by conventional aged care interventions?
2. Is an aged care specific need or aged care service defined to be consistent with the aged care needs of the wider population of older people or can allowance be made for different types of need that exist in conjunction with ageing with a disability and living in disability-funded supported accommodation?
3. How do these subtly different interpretations of aged care specific need reconcile with a whole-person approach to social services and the primary objective of enabling people with disabilities to live in the community for as long as possible?
    - If aged care funding is directed towards servicing aged care specific needs but significant unmet need remains, then what is the likely marginal impact of community-based aged care on use of residential aged care services by the target group and how is this limited impact to be balanced against improvements in quality of life for individuals?
4. Where do older people with disabilities who live in supported community accommodation (that is, those aged 65 years and over) who have unmet needs that are not assessed as strictly age related fit within this framework—where does ultimate responsibility for meeting *the needs* of older people with disabilities lie?

5. How much weight should be attached to chronological age in the assessment of needs related to premature ageing, especially in the context of chronic progressive disability?

While the Pilot has not provided answers to these questions, it has shown that different interpretations of *aged care specific need* exist and that these have practical implications. For instance, the service activity profiles of some Pilot projects during the evaluation might lead to questions of substitution of aged care funding for disability services funding in some projects. ACATs and project coordinators have approached the assessment of people referred for Pilot services from the point of view of their risk of admission to residential aged care. In assessing a person's risk exposure it is necessary to consider the needs of the individual and what services she or he can access through disability services.

Supporting age-appropriate lifestyles is a case in point. When a person with a disability retires because they are no longer able, or no longer desire, to work full-time, they have an increased need for community access that is related to their stage in life (if a person retires from supported employment, then they potentially lose both social participation and access to daytime ADL assistance). An inability to receive an appropriate level of social support and supervised activity leads to an increased risk of future use of residential services. This risk is especially high if the person's home does not have staff attendance during daytime hours because it is expected that residents are attending workplaces and activities away from home. That the need for this type of support is believed to be age related is reflected in the service activity profiles of a number of Pilot projects. Ageing In Place expended approximately 31% of total expenditure on leisure and recreation activities for clients, 16% on social support and 8.2% on transport services; Disability and Ageing Lifestyle Project expended approximately 44% of total expenditure on social support, 20% on leisure and recreation activities and almost 10% on transport services for clients; 75% of expenditure in the Flexible Aged Care Packages project was directed to social support services.

Community access services for people with disabilities are funded under the CSTDA and it is an objective of the CSTDA to provide lifelong opportunity for people with disabilities to participate in their communities. Yet, an individual CSTDA consumer might not have access to individual funding for community access (rates of individualised funding are lowest in the youngest and oldest age groups of CSTDA consumers) and there may be no places available in local day programs. To that consumer, it is academic that the CSTDA funds community access services.

Perhaps the greatest conundrum for evaluation is the contrast between seven projects operating separate aged care and disability budgets and two, Ageing In Place and MS Changing Needs, that operate with aged care services fully integrated into the disability accommodation service using pooled aged care and disability budgets. To some extent the latter two projects were able to provide a more seamless service, but there were indications that pooled funding and full integration made the reporting of aged care specific expenditure more difficult. Both Ageing In Place and MS Changing Needs operate in accordance with the aims, target groups and service delivery models described in the respective Memoranda of Understanding; it is just that those two projects appear to have had scope to address a wider range of client needs. MS Changing Needs was established to provide high level nursing care to people who cannot access this through specialist disability services. In other words, MS Changing Needs was established because the disability services sector in the catchment area does/did not deliver the type of service needed by people with severe MS. What is not clear is whether this can be conceptually classified as an aged care specific service. Other Pilot projects have been required to adhere to stricter criteria for delivering aged care specific services. What is considered to place people with disabilities at

risk of admission to residential care and whether one takes a short- or long-term perspective are key issues.

Each of the other seven Pilot services was established to operate from a separate aged care budget with a strong emphasis on servicing aged care specific needs of clients (see Table 1.5). Memoranda of Understanding for the establishment of these services express the need to avoid substitution of aged care specific services for disability support services, the latter being variously described as services 'currently provided' by the disability service provider or 'program funding' for activities funded under the CSTDA. These differences of expression have possibly led to different interpretations of how project funds should and shouldn't be applied. Other differences between projects include age criteria, often decided by Steering Committees and in two cases also reflected in the Memorandum of Understanding, plus the meaning of 'aged care specific services', also within the jurisdiction of steering committees and specified in a Schedule of Aged Care Services for projects in New South Wales.

For comparison sake, contrast any one of the projects operating in New South Wales with Ageing In Place, Tasmania. Ageing In Place seemingly has greater capacity to address any of a client's most pressing support needs because greater flexibility was built into Pilot funding arrangements and scope for service provision. The accommodation service itself offers a hostel style of accommodation that is different in a number of respects to a group home for people with disabilities. By comparison, projects in New South Wales have a more aged care specific focus to service delivery, according to a Schedule of Aged Care Services, and have delivered services into a diverse range of group home settings and local disability service contexts to clients with varying levels of access to the range of available specialist services. Expenditure in these projects has been more closely tied to the processes of identifying and targeting aged care interventions to specific aged care needs of clients. In both cases the projects appear to have operated consistent with service aims and objectives reflected in the respective Memoranda of Understanding. However, Pilot design parameters give the projects in New South Wales a more limited sphere of influence and therefore the projects' ability to enable clients to live longer in the community is more subject to factors outside the Pilot sphere of influence.

The issue is further complicated by the inclusion of younger clients in projects that had a relatively high community access and social support component of expenditure (see Figure 5.2). Disability Ageing and Lifestyle Project and Ageing In Place recorded age homogeneous client groups that tended to be younger than other projects (excepting the special case of MS Changing Needs). Both of these projects delivered high levels of recreation and leisure activities and social support. Expenditure in Flexible Aged Care Packages reflects a similarly high social support component, although this project recorded a significantly higher median age and a greater spread of ages. Central West People with a Disability who are Ageing also recorded some younger clients who received mainly community access services. Excepting MS Changing Needs, 22 participants in the evaluation were aged under 50 years, all but two of whom were people with intellectual disability (two younger participants had physical disability). Sixteen of these younger clients were in the Disability and Ageing Lifestyle Project (four out of eight participants) and Central West People with a Disability who are Ageing (12 out of 33 participants).

The above discussion serves to demonstrate that people with disabilities who live in CSTDA-funded accommodation have needs that are intrinsically related to their disability service arrangements. People tend to spend more time at and around their home as they grow older. A critical driver for the need for increased formal service intervention in this group seems to be the structuring of supported accommodation services for residents who are away from

home during the day which may not be a suitable accommodation model for ageing residents. The need for part-time or casual community participation has implications for transport assistance and flexibility in the hours of staff attendance within the accommodation service. The entrenched belief of many disability support staff that a person ageing with a disability is always better off in the disability supported accommodation setting because of higher staffing ratios in disability services denies the reality that the higher staff to client ratio, relative to residential aged care, is often for just a few hours in the day. All project teams emphasised that limited day and night supervision is a major contributor to the risk of admission to residential aged care in the target group. Pilot services were able to go some way towards addressing this risk, but a rethink of the funding and construction of specialist accommodation services for people ageing with a disability, more in line with a whole-person approach to social services, is clearly required if the risk is to be more systematically addressed.

This evaluation did not explore how people gain access to specialist day services administered by state and territory governments following retirement from supported employment services administered by the Australian Government but this is another area within the disability services system that needs to be considered in the context of ageing CSTDA consumers.

From a system-wide perspective the top-up model of aged care funding seems to be an incomplete solution to the problem of limited choice in community-based aged care for people with disabilities in supported accommodation. It helps in individual cases by patching over systemic problems at the interface of disability and aged care programs and at the interfaces between different types of specialist disability services. There is a risk that some groups will fall through gaps in services modelled on separate aged care and disability funding. The high degree of overlap between the types of assistance delivered by Pilot projects and those funded under the CSTDA means that criteria are required to establish how aged care funding is to be used. The Pilot has shown that individual care planning will tend to address areas of need that are implicated in an individual's risk of entry to residential aged care and that these areas are closely related to features of the disability support system. The evaluation concludes that eligibility criteria based on interpretations of aged care specific need or age-related need, which have been demonstrated to vary, may lead to program management rules such as those which currently prevent access to HACC-funded services for the target group. Using subjective eligibility criteria, the only way to avoid questions of 'double dipping' and 'cost shifting' is for program managers to trust the processes that determine eligibility for aged care. There is also the unresolved issue of people with disabilities aged over a certain age, say 60 or 65 years, who live in supported accommodation and whose risk of admission to residential aged care is assessed as mainly disability related. The needs of these older Australians are not addressed by the evaluated model.

Pilot exit strategies

The subject of exit strategies for the conclusion of the Pilot has caused high anxiety in project teams mainly because of the limited community-based options for clients. The concept of exit strategies assumes that clients will be able to return to day programs and employment services accessed before the Pilot (state disability authorities agreed to hold open places in mainstream programs for Pilot clients). Many clients' lifestyles have undergone fundamental change as a result of participating in the Pilot. For a proportion of Pilot clients, even

assuming the availability of mainstream service places, clients are unlikely to be able to resume their former daily schedules.

The Pilot effect

It is naïve to believe that increased funding for additional aged care specific services alone will deliver quality community aged care to people with disabilities living in supported accommodation. Across the projects, evaluation participants received a median of around 6 additional hours of assistance during the reporting period in addition to aged care planning and ancillary services such as transport (Table 4.2). Some projects delivered higher median weekly hours per client; evaluation results reflect both maturity and the service focus of a project. At the time of the evaluation very few clients were receiving in excess of 10 additional service hours per week through the Pilot and while projects had capacity to increase service levels to some extent it is clear that with all places filled it would not generally be possible for a project to deliver more than 10 hours to a high proportion of clients. These results emphasise the importance of skills transfer between aged care and disability support staff in accommodation services where aged care expertise is more limited. A comprehensive strategy for delivering community based aged care to the target group therefore needs to factor in workforce and workplace practice considerations.

One reason the top-up model has worked well for clients in the Disability Aged Care Interface Pilot is because the localised nature of the Pilot produced special arrangements that are conducive to a high level of cooperation and shared vision. Project coordinators were hand-picked for their experience, creativity and personal qualities. In most projects referrals were channelled to or through specific ACAT members with specialist experience. Difficulties were encountered where the relationship with ACAT was built on more usual ACAT referral arrangements.

7.3 Summation

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

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

The Pilot gave ACATs a new referral option for members of the target group that has led to increased levels of personal assistance, active and passive physical therapies for improving or maintaining function, a focus on the special needs of clients who have dementia, and attention to needs for social participation.

A range of measures to improve access to community care for ageing clients living in disability supported accommodation is suggested as a result of the Disability Aged Care Interface Pilot:

1. The development of service models based on collaborative approaches to eligibility and needs assessment. Assessment by ACAT members with experience and professional interest in aged care assessment for people with disabilities proved

successful in the Pilot but the ground work performed by project coordinators and disability support staff was a core element of this success.

2. Consideration for the provision of routine dementia assessments of people aged 45 years or over with Down syndrome and other disorders that are known to cause or to be associated with dementia.
3. Care packages to provide higher levels of personal assistance and dementia-specific care to members of the target group with high and complex aged care specific needs.
4. Strategies to enable people with disabilities who are ageing to participate in community life on a flexible basis, including well managed retirement transition.
5. Adaptation of service and funding systems in recognition that home environments need to meet the needs of older residents who tend to spend longer periods of time at home.
6. A coordinated, whole-of-government approach to ensure consistency in approach across the country and across the sectors on training requirements and opportunities for staff at all levels who are working with people with a disability who are ageing.

The Pilot has helped to highlight a range of systemic issues that impact on consumers of CSTDA-funded accommodation services as they grow older. These are not all well addressed by the Pilot model of aged care specific funding and we caution that what works in a Pilot does not always translate well to mainstream service delivery environments unless close attention is paid to special Pilot conditions. Some important messages for the development of policies aimed at improving community living for older CSTDA consumers of supported accommodation services have emerged from the Innovative Pool Disability Aged Care Interface Pilot.

Weaknesses of the Pilot model should not detract from the obvious benefits of Pilot services to clients. The evaluation was unable to asses the impact of Pilot services on duration of community living in a strictly quantitative sense, but there are strong indications in case studies, informant interviews and the Care Experience Survey that additional assistance delivered with an aged care focus has significantly improved the quality of life of individual clients and that these improvements are likely to have long-term benefits for individuals and service systems.