

## 2 A profile of Pilot clients

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

### 2.1 Socio-demographic snapshot

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

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

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

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

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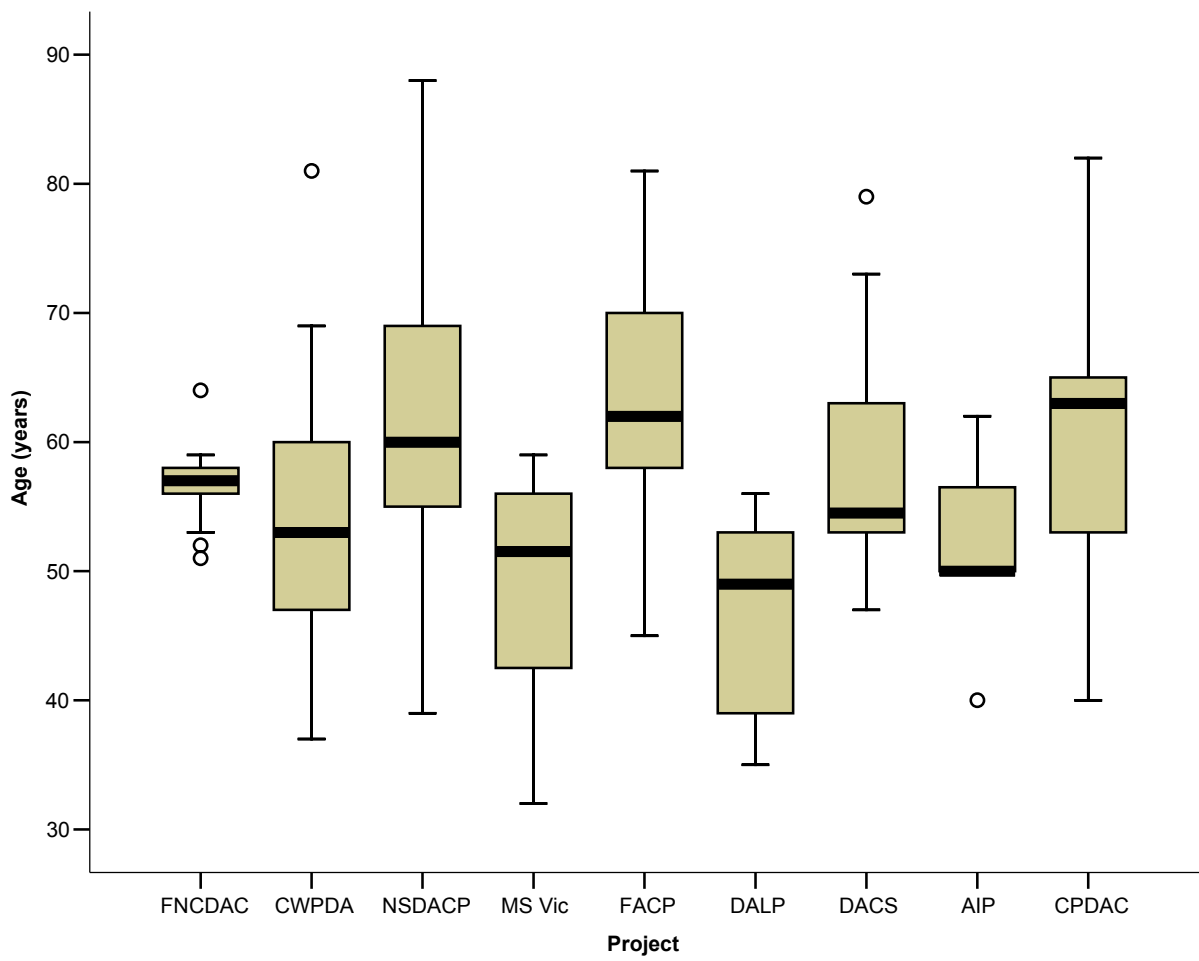
9 Excluding clients from the Cumberland Prospect Disability Aged Care Project, none of whom commenced before January 2005.

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

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

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

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



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

## Disability groups

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

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

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

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

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

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

— Nil.

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

## 2.2 Core activity limitations

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

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

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

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

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

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

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

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

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

— Nil.

## 2.3 Activities of daily living measures

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

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

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

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

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

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

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

— Nil.

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

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

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

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

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

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

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



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

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

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

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

## 2.4 Participation measures

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

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

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

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

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

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

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

— Nil.

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

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

— Nil.

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

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

— Nil.

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

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

— Nil.

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

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

— Nil.

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

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

— Nil.

## 2.5 Corollary: clients with intellectual disability

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

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

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

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

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

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

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

— Nil.

## Accommodation and living arrangement

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

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

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

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

— Nil.

## Health conditions and health status on entry

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

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

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

— Nil.

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

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

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

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

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

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

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

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

— Nil.

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

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

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

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

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



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

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

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

— Nil.

## Level of core activity limitation

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

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

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

— Nil.

### Support needs

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

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

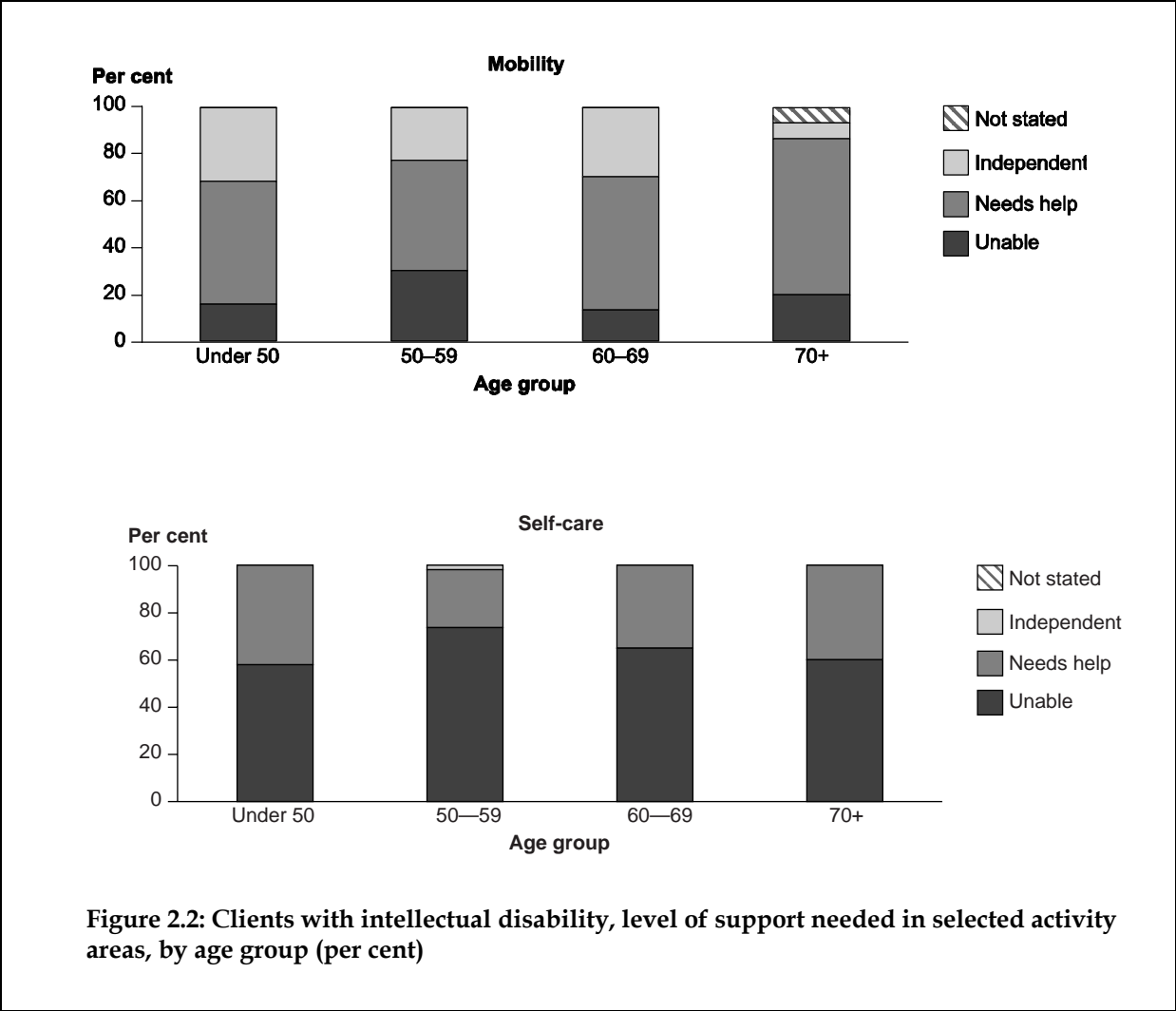
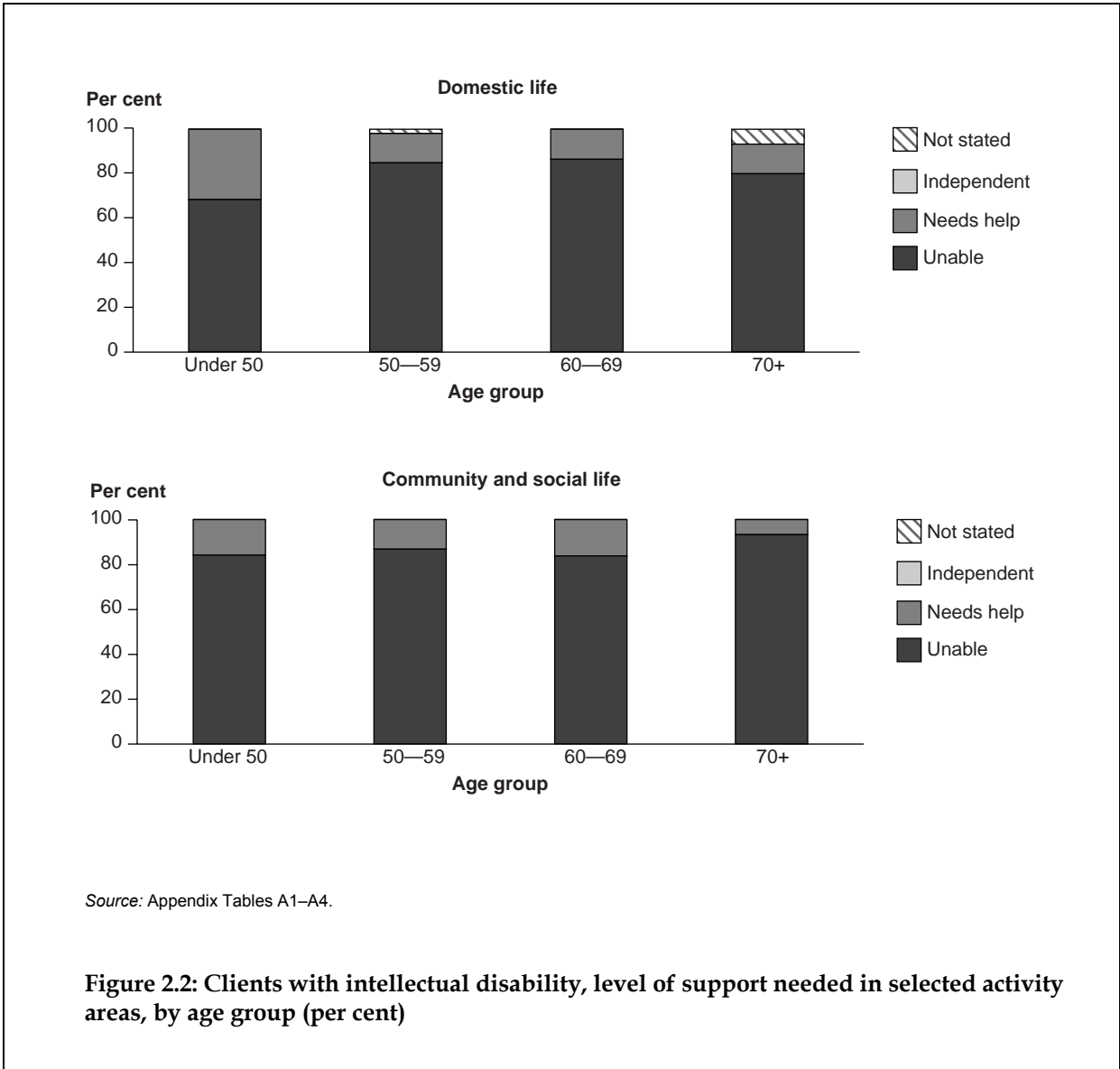


Figure 2.2: Clients with intellectual disability, level of support needed in selected activity areas, by age group (per cent)

(continued)



### Activities of daily living

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

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

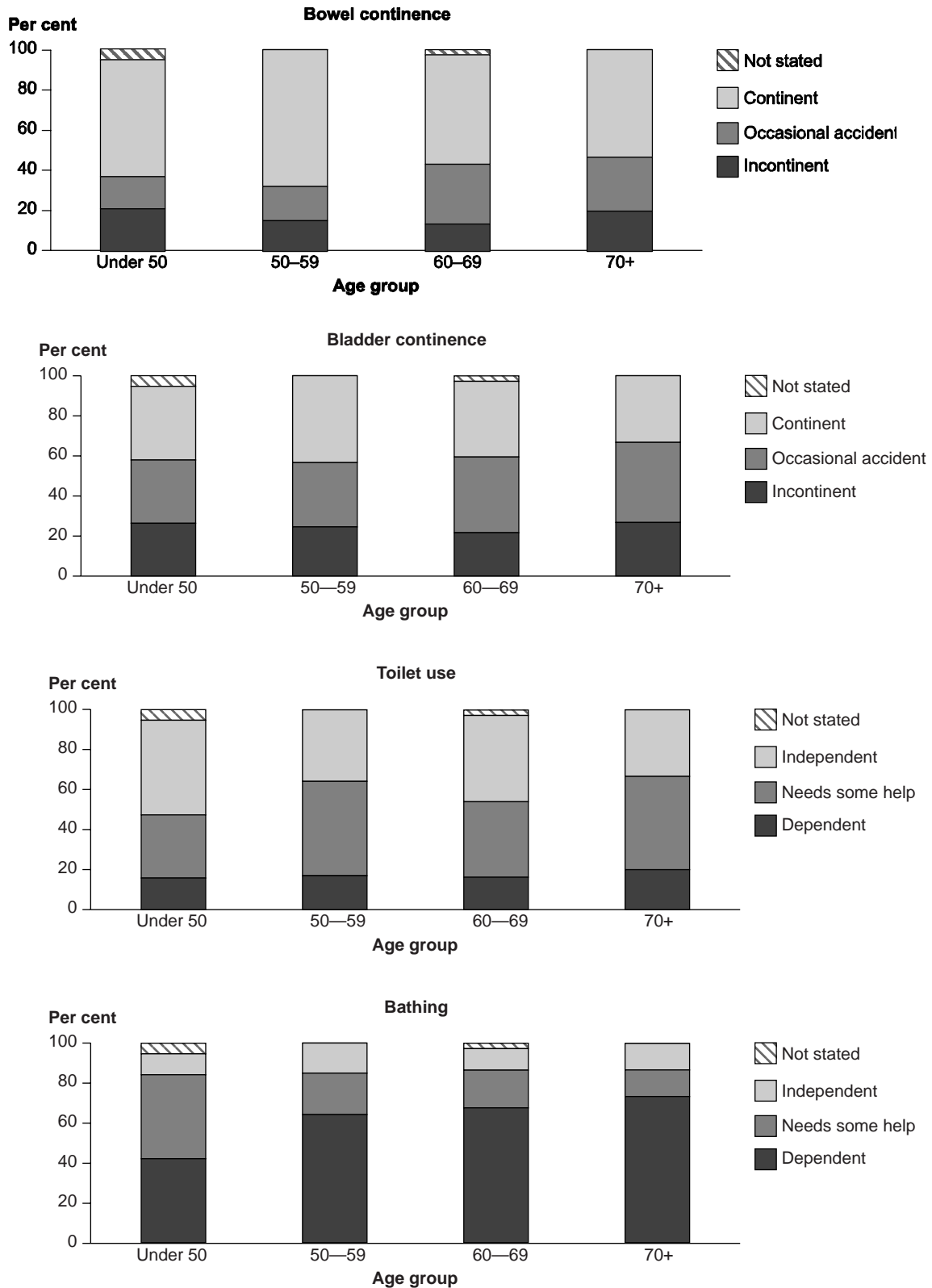
Age group (years)	Number	Minimum	Median	Maximum	Mean	Standard deviation
Under 50	18	0	14	18	12.8	4.5
50–59	53	0	13	20	12.1	4.7
60–69	36	1	13	20	12.8	4.2
70+	15	4	13	18	12.4	3.6
<b>All clients</b>	<b>122</b>	<b>0</b>	<b>13</b>	<b>20</b>	<b>12.4</b>	<b>4.4</b>

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

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

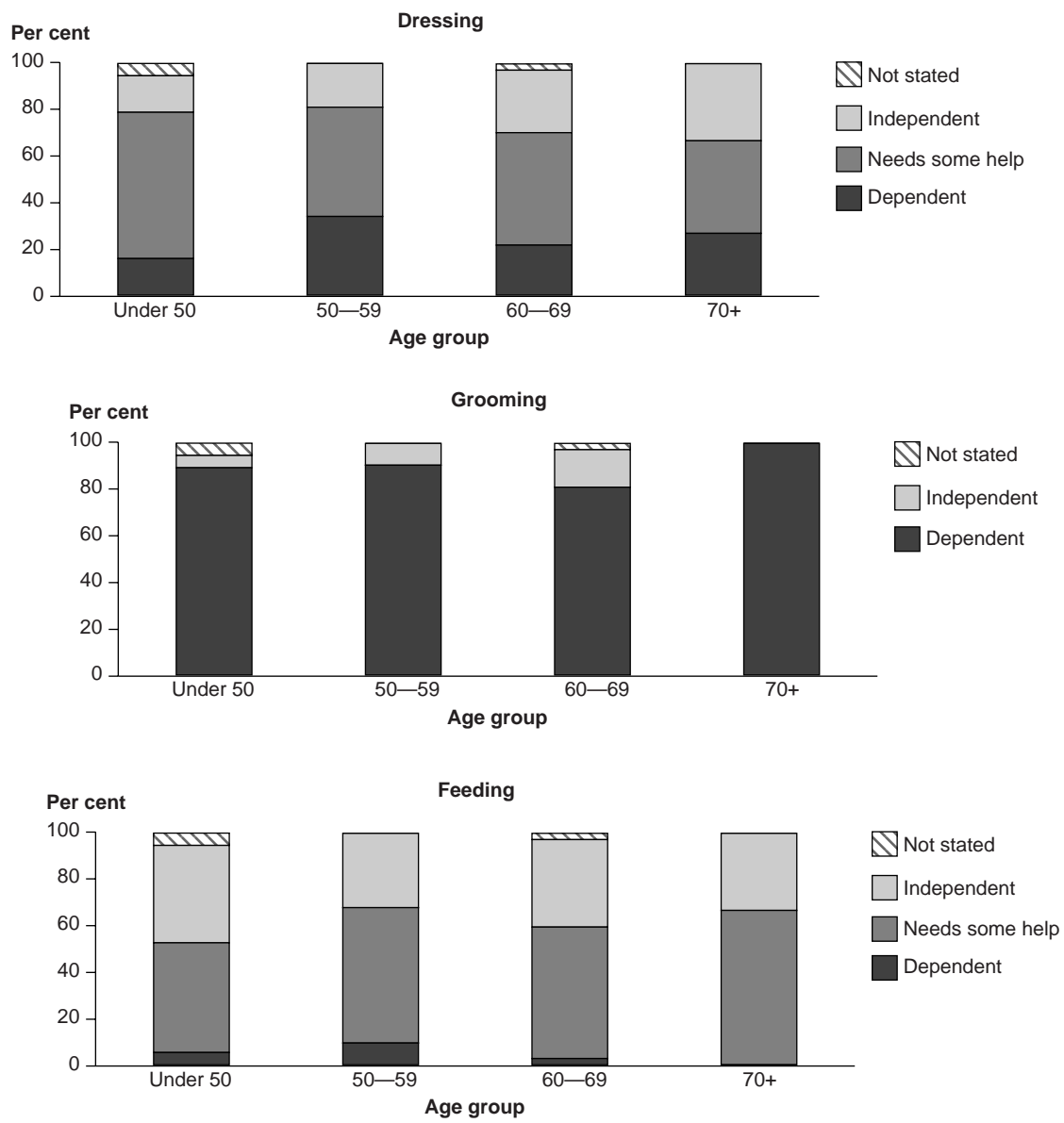
Age group (years)	Independent	Slight dependency	Moderate dependency	Severe dependency	Total dependency	Total
(number)						
Under 50	0	0	13	4	2	19
50–59	2	1	24	21	5	53
60–69	1	3	16	15	2	37
70+	0	0	8	6	1	15
<b>All clients</b>	<b>3</b>	<b>4</b>	<b>61</b>	<b>46</b>	<b>10</b>	<b>124</b>
(per cent)						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

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



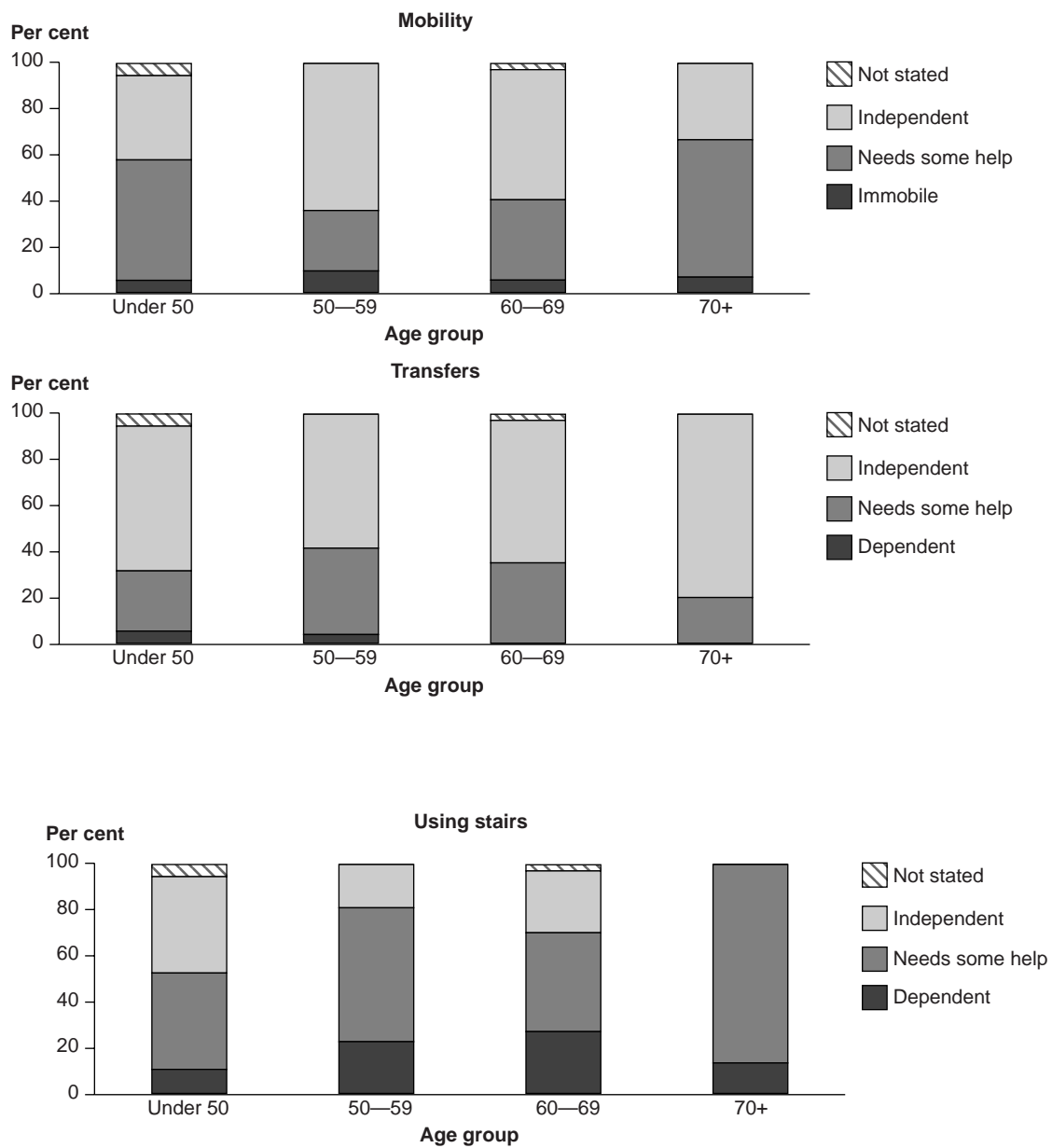
**Figure 2.3: Clients with intellectual disability, per cent of clients by level of dependency in self-care and mobility tasks, by age group**

*(continued)*



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

*(continued)*



Source: Appendix Tables A5-A14.

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

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

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

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

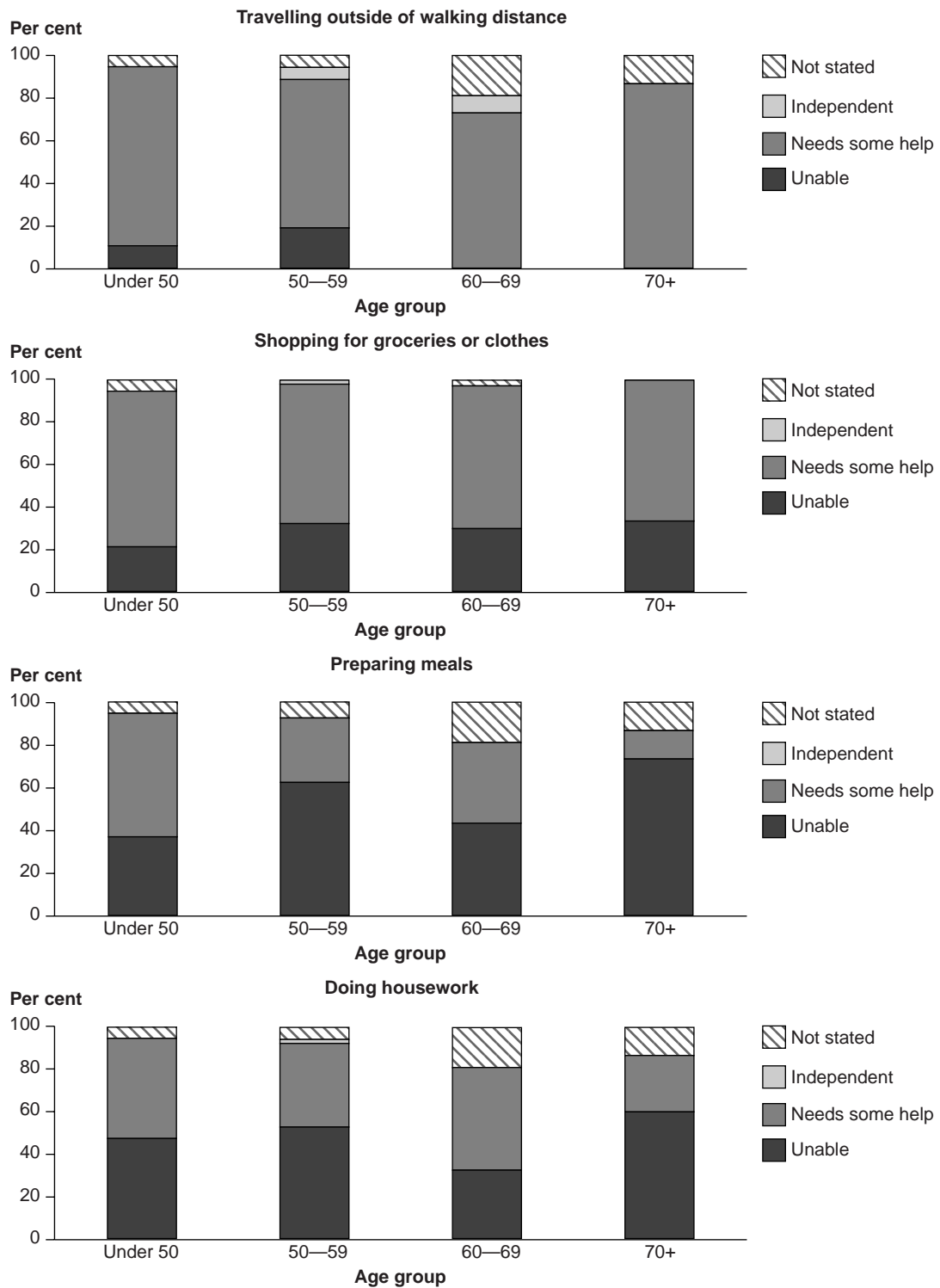
Clients with intellectual disability exhibited dependency in between zero and seven out of seven IADL at the time of entry to the Pilot (median number of items for which a client records total dependency is four). Overall, the 110 clients for whom baseline IADL data were provided scored between zero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

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

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

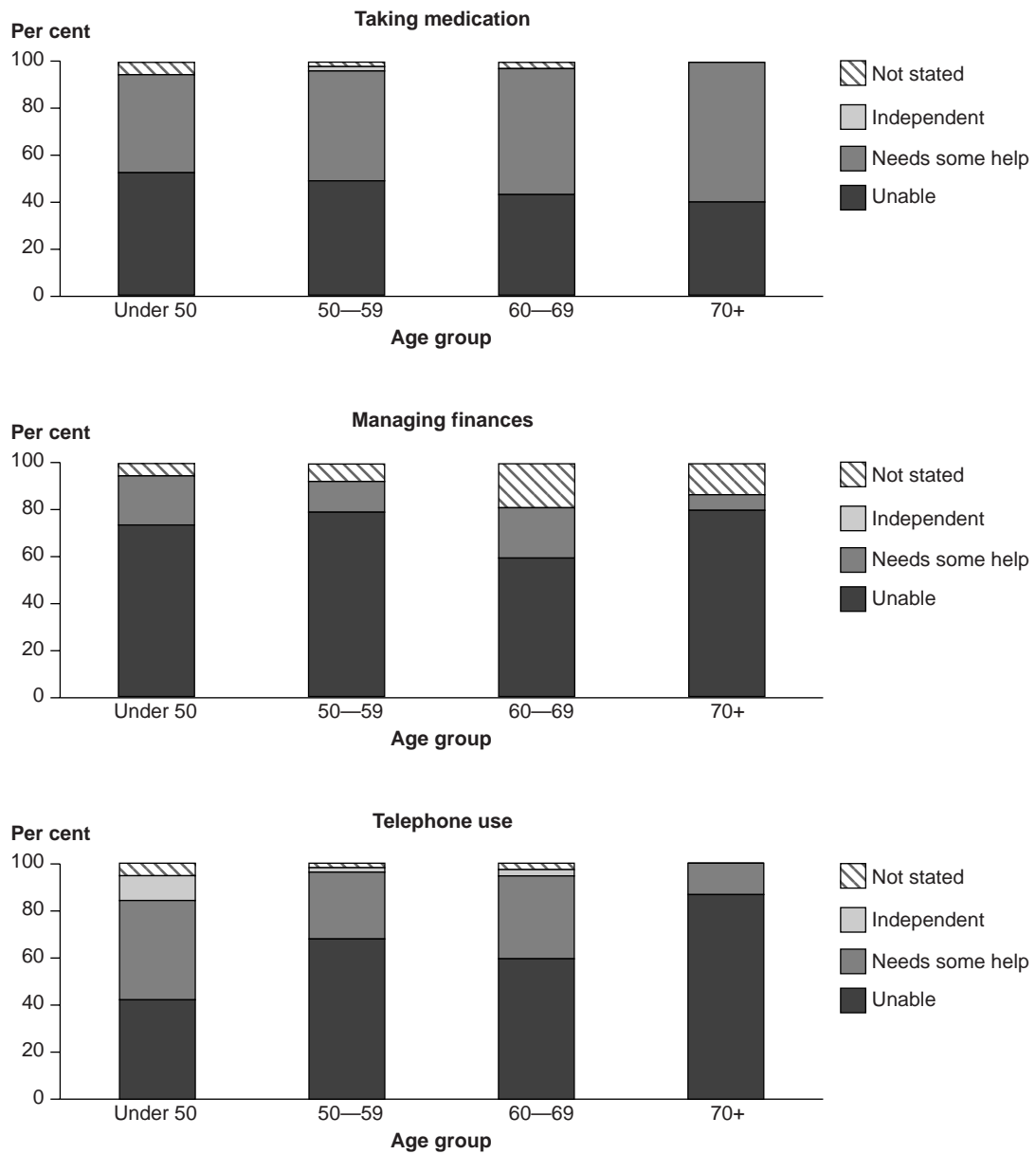
Figure 2.4 shows the proportion of clients who were dependent, partially dependent or independent on specific IADL. Almost all clients for whom data were provided required assistance in each IADL. As for ADL, the distribution of levels of functioning within each age group is similar across the items.





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

*(continued)*



Source: Appendix Tables A15-A21.

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

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

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

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

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

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