

4 Informal carers, support needs and living arrangements

This chapter presents information relating to informal care, support needs and living arrangements for CSTDA-funded service users during 2004–05.

4.1 Presence of an informal carer

An informal carer is defined as a person such as a family member, friend or neighbour who provides unpaid care and assistance on a regular and sustained basis (AIHW 2004b). Of the 200,493 service users accessing services during 2004–05, 84,964 (42%) reported the existence of an informal carer, and 74,536 service users (37%) reported that they did not have such a carer (Table 4.1). For around one-fifth of service users (40,993 or 20%) this information was not stated or not collected.

Service users accessing respite services were the most likely to report the existence of an informal carer (86%), followed by community support (54%). Service users accessing employment services were the least likely to report the presence of such a carer (30%).

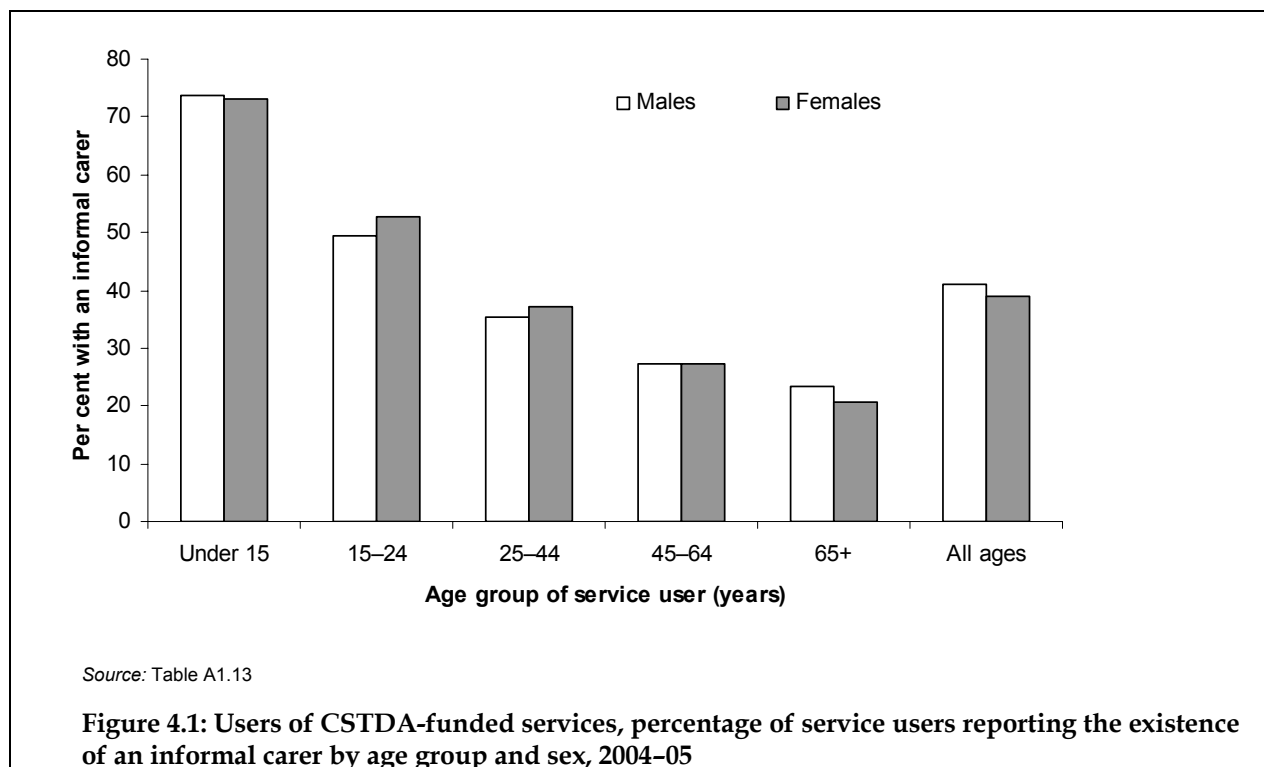
Table 4.1: Users of CSTDA-funded services, existence of an informal carer by service group, 2004–05

Service group	Has an informal carer		Does not have an informal carer		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%
Accommodation support	11,583	34.3	18,928	56.0	3,276	9.7	33,787	100.0
Community support	49,922	53.9	16,233	17.5	26,455	28.6	92,610	100.0
Community access	19,119	43.3	19,904	45.1	5,143	11.6	44,166	100.0
Respite	20,658	86.3	2,000	8.4	1,293	5.4	23,951	100.0
Employment	19,364	29.9	37,354	57.6	8,117	12.5	64,835	100.0
Total	84,964	42.4	74,536	37.2	40,993	20.4	200,493	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Column totals may not be the sum of components since individuals may have accessed services in more than one service group over the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

The existence of an informal carer was less likely in older age groups – service users aged 0–14 years were most likely to report the existence of a carer (74% for males; 73% for females), whereas those aged 65 years and over were least likely (23% and 21% respectively) (Figure 4.1). The proportion of service users with an informal carer was very similar overall between males and females, with the largest difference being in the 15–24 year age group (49% for males; 53% for females).



Service users located in major cities and inner regional areas were approximately equally likely to report the existence of an informal carer (both around 43%) (Table 4.2). The likelihood of reporting an informal carer was higher in more remote areas – rates ranged from 50% for service users in outer regional areas, to 62% for those in remote areas and 67% for those in very remote areas.

Table 4.2: Users of CSTDA-funded services, existence of an informal carer by location, 2004-05

Service group	Has an informal carer		Does not have an informal carer		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%
Major cities	52,107	42.9	47,111	38.8	22,252	18.3	121,471	100.0
Inner regional	19,258	43.0	18,426	41.2	7,069	15.8	44,753	100.0
Outer regional	9,634	50.2	7,231	37.6	2,341	12.2	19,206	100.0
Remote	1,592	61.5	633	24.5	362	14.0	2,587	100.0
Very remote	776	67.2	216	18.7	162	14.1	1,155	100.0
Not stated/collected	1,596	14.1	918	8.1	8,807	77.8	11,321	100.0
Total	84,964	42.4	74,536	37.2	40,993	20.4	200,493	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Column totals may not be the sum of components since individuals may have accessed services in more than one service group over the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

4.2 Carer age and relationship to service user

Of the 84,964 service users with an informal carer, 57,712 (68%) reported that this carer was their mother (Table 4.3). The next most commonly reported carer relationships were father (6.5%), other female relative (6.3%), wife/female partner (4.6%) and husband/male partner (4.3%).

Mothers were the most common informal carers for all age groups except those aged 65 years and over – almost half (47%) of these service users reported that their spouse or partner was their informal carer (28% wife/female partner; 20% husband/male partner), and a further 15% reported being cared for by their daughter.

Of the 62,479 informal carers whose age was reported, almost half (30,875 or 49%) were in the 25–44 year age group (Table 4.4). A further 22,909 (37%) were aged 45–64 years, and 7,245 (12%) 65 years and over. There were also 230 carers reported to be under 15 years of age.

Around one-third (28,291 of 84,964, or 33%) of service users with an informal carer were aged under 15 years (Table 4.5). More than three-quarters (78%) of service users in this age group were cared for by a person aged 25–44 years. Service users in the age groups 15–24 years, 25–44 years and 45–64 years were most likely to be cared for by a person aged 45–64 years (38%, 36% and 33% respectively) and service users in the oldest age group, 65 years and over, were most likely cared for by another person aged 65 years or over (42%).

Table 4.3: CSTDA-funded service users with an informal carer, relationship of carer to service user by service user age, 2004–05

Relationship of carer to service user	Age group of service user (years)						Total
	0–14	15–24	25–44	45–64	65+	Not stated	
	Number						
Wife/female partner	0	75	1,059	1,969	780	2	3,885
Husband/male partner	0	117	1,290	1,666	552	3	3,628
Mother	24,733	15,324	14,445	3,072	69	69	57,712
Father	1,252	1,577	2,063	569	19	10	5,490
Daughter	0	18	106	356	425	1	906
Son	0	25	83	233	199	3	543
Daughter-in-law	0	2	1	10	26	0	39
Son-in-law	0	0	4	2	1	0	7
Other female relative	954	1,007	1,539	1,595	240	5	5,340
Other male relative	80	134	393	516	79	1	1,203
Friend/neighbour—female	121	242	495	432	111	1	1,402
Friend/neighbour—male	5	68	275	235	45	0	628
Not stated/not collected	1,146	635	1,217	882	280	21	4,181
Total	28,291	19,224	22,970	11,537	2,826	116	84,964
	Per cent						
Wife/female partner	—	0.4	4.6	17.1	27.6	1.7	4.6
Husband/male partner	—	0.6	5.6	14.4	19.5	2.6	4.3
Mother	87.4	79.7	62.9	26.6	2.4	59.5	67.9
Father	4.4	8.2	9.0	4.9	0.7	8.6	6.5
Daughter	—	0.1	0.5	3.1	15.0	0.9	1.1
Son	—	0.1	0.4	2.0	7.0	2.6	0.6
Daughter-in-law	—	0.0	0.0	0.1	0.9	—	0.0
Son-in-law	—	—	0.0	0.0	0.0	—	0.0
Other female relative	3.4	5.2	6.7	13.8	8.5	4.3	6.3
Other male relative	0.3	0.7	1.7	4.5	2.8	0.9	1.4
Friend/neighbour—female	0.4	1.3	2.2	3.7	3.9	0.9	1.7
Friend/neighbour—male	0.0	0.4	1.2	2.0	1.6	—	0.7
Not stated/not collected	4.1	3.3	5.3	7.6	9.9	18.1	4.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. Service users with missing age who responded 'child aged under 5 years (not applicable)' to the *communication method* data item were included in the 0–4 years age group.
3. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

Table 4.4: CSTDA-funded service users with an informal carer, relationship of carer to service user by age group of carer, 2004–05

Relationship of carer to service user	Age group of carer (years)					Not stated/ not collected	Total
	0–14	15–24	25–44	45–64	65+		
	Number						
Wife/female partner	0	42	766	1,501	573	1,003	3,885
Husband/male partner	0	37	834	1,508	644	605	3,628
Mother	0	758	25,943	14,896	4,222	11,893	57,712
Father	0	12	1,199	1,765	920	1,594	5,490
Daughter	37	123	259	269	27	191	906
Son	24	101	155	124	9	130	543
Daughter-in-law	0	1	10	18	2	8	39
Son-in-law	0	0	1	4	0	2	7
Other female relative	10	78	822	1,614	555	2,261	5,340
Other male relative	2	27	235	399	100	440	1,203
Friend/neighbour—female	1	13	257	441	96	594	1,402
Friend/neighbour—male	0	4	125	148	57	294	628
Not stated/not collected	156	24	269	222	40	3,470	4,181
Total	230	1,220	30,875	22,909	7,245	22,485	84,964
	Per cent						
Wife/female partner	—	3.4	2.5	6.6	7.9	4.5	4.6
Husband/male partner	—	3.0	2.7	6.6	8.9	2.7	4.3
Mother	—	62.1	84.0	65.0	58.3	52.9	67.9
Father	—	1.0	3.9	7.7	12.7	7.1	6.5
Daughter	16.1	10.1	0.8	1.2	0.4	0.8	1.1
Son	10.4	8.3	0.5	0.5	0.1	0.6	0.6
Daughter-in-law	—	0.1	0.0	0.1	0.0	0.0	0.0
Son-in-law	—	—	0.0	0.0	—	0.0	0.0
Other female relative	4.3	6.4	2.7	7.0	7.7	10.1	6.3
Other male relative	0.9	2.2	0.8	1.7	1.4	2.0	1.4
Friend/neighbour—female	0.4	1.1	0.8	1.9	1.3	2.6	1.7
Friend/neighbour—male	—	0.3	0.4	0.6	0.8	1.3	0.7
Not stated/not collected	67.8	2.0	0.9	1.0	0.6	15.4	4.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories. Service users who accessed employment services only (service types 5.01–5.03) and did not submit a response are also included in the 'not collected' category for 'age group of carer'. These service users were not required to complete this data item.

Table 4.5: CSTDA-funded service users with an informal carer, age of service user by age of carer, 2004–05

Age group of service user (years)	Age group of carer (years)						Total
	0–14	15–24	25–44	45–64	65+	Not stated/ not collected	
	Number						
0–14	128	796	22,099	2,855	278	2,135	28,291
15–24	24	78	5,460	7,262	356	6,044	19,224
25–44	52	137	2,200	8,188	2,975	9,418	22,970
45–64	23	196	877	3,756	2,458	4,227	11,537
65+	2	11	223	820	1,174	596	2,826
Not stated	1	2	16	28	4	65	116
Total	230	1,220	30,875	22,909	7,245	22,485	84,964
	Per cent						
0–14	0.5	2.8	78.1	10.1	1.0	7.5	100.0
15–24	0.1	0.4	28.4	37.8	1.9	31.4	100.0
25–44	0.2	0.6	9.6	35.6	13.0	41.0	100.0
45–64	0.2	1.7	7.6	32.6	21.3	36.6	100.0
65+	0.1	0.4	7.9	29.0	41.5	21.1	100.0
Not stated	0.9	1.7	13.8	24.1	3.4	56.0	100.0
Total	0.3	1.4	36.3	27.0	8.5	26.5	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. Service users with missing age who responded 'child aged under 5 years (not applicable)' to the *communication method* data item were included in the 0–14 years age group.
3. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories. Service users who accessed employment services only (service types 5.01–5.03) and did not submit a response are also included in the 'not collected' category for 'age group of carer'. These service users were not required to complete this data item.

4.3 Carer primary status and co-residency

A carer was considered to be a 'primary carer' if he or she assisted the service user in one or more of the three activities of daily living – self-care, mobility or communication (AIHW 2004b). Just over two-thirds (67%) of service users with a carer reported that he or she was a primary carer (Table 4.6). A similar proportion of service users (57,061 of 84,964, or 67%) reported that their carer was co-resident. The vast majority (90%) of primary carers were reported to be co-resident carers, and less than half (49%) of non-primary carers were reported as being co-resident.

Table 4.6: CSTDA-funded service users with an informal carer, residency status of carer by primary status of carer, 2004–05

Residency status of carer	Primary status of carer							
	Yes		No		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%
Co-resident carer	51,249	89.6	4,665	48.6	1,147	6.3	57,061	67.2
Non-resident carer	4,618	8.1	3,703	38.6	527	2.9	8,848	10.4
Not stated/not collected	1,354	2.4	1,224	12.8	16,477	90.8	19,055	22.4
Total	57,221	100.0	9,592	100.0	18,151	100.0	84,964	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom informal carer data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories. Service users who accessed employment services only (service types 5.01–5.03) and did not submit a response are also included in the 'not collected' category for both 'primary status of carer' and 'residency status of carer'. These service users were not required to complete either of these data items.

4.4 Support needs

Data on the support needs of service users, in nine main life areas, are collected as part of the CSTDA NMDS (see question 11 of the service user form in Appendix 2). There is a wide range of assessment tools and methods currently used in the disability services field. The support needs data item was designed so that such information could be transcribed into a common framework that is consistent with national data standards and international classification standards, including the International Classification of Functioning, Disability and Health (ICF) (see AIHW 2003: Chapter 8). The support needs data item also relates to the concepts used in population surveys about disability (see, for example, ABS 2004b).

The support needs question had a high rate of 'not stated/not collected' responses – up to 23% for some categories – and data should be interpreted in this context.

For simplicity of analysis, data on the overall support needs of service users are further grouped into three main areas:

- activities of daily living (ADL) – self-care; mobility; and communication
- activities of independent living (AIL) – interpersonal interactions and relationships; learning, applying knowledge and general tasks and demands; and domestic life
- activities of work, education and community living (AWEC) – education; community (civic) and economic life; and working. This category is analysed for service users aged 5 years and over, as service users under 5 years are allowed to respond 'not applicable due to age' for all three of these life areas. In Table 4.7, however, all age groups are shown for life areas in this category to show responses over all ages.

Of all reported life areas, the largest proportion of service users who reported that they always needed support (or were unable to undertake that activity) were found in the three AWEC groups – working (24%), education (22%) and community (civic) and economic life (21%) (Table 4.7). In contrast, the life areas with the smallest proportion of service users always needing support were mobility (14%), communication (16%), and interpersonal interactions (each 17%).

Overall, CSTDA service users have high support needs. Around 90% always or sometimes needed support in activities of work, education and community living (AWEC) and activities of independent living (AIL), and just over 70% in activities of daily living (ADL) (Figure 4.2).

The proportion of service users always needing support was highest for AWEC (33% of those aged 5 years and over), followed by AIL (28%) and ADL (24%) (Table 4.8). When missing data are excluded, comparisons between the three broad categories are quite similar – 30% of service users reported always needing support for ADL, 35% for AIL and 44% for AWEC (Figure 4.2).

Table 4.7: Users of CSTDA-funded services, life area by frequency of support or assistance needed, 2004–05

Frequency of support needed	Always or unable to do		Sometimes		None but uses aids		None		Not applicable		Not stated/not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Activities of daily living (ADL)														
Self-care	35,588	17.8	52,485	26.2	6,108	3.0	61,130	30.5	0	—	45,182	22.5	200,493	100.0
Mobility	27,301	13.6	47,131	23.5	10,187	5.1	72,108	36.0	0	—	43,766	21.8	200,493	100.0
Communication	32,889	16.4	61,921	30.9	5,621	2.8	57,008	28.4	0	—	43,054	21.5	200,493	100.0
<i>Any ADL</i>	<i>47,607</i>	<i>23.7</i>	<i>71,575</i>	<i>35.7</i>	<i>7,184</i>	<i>3.6</i>	<i>31,670</i>	<i>15.8</i>	<i>0</i>	<i>—</i>	<i>42,457</i>	<i>21.2</i>	<i>200,493</i>	<i>100.0</i>
Activities of independent living (AIL)														
Interpersonal interactions ^(a)	34,144	17.0	80,551	40.2	4,346	2.2	35,821	17.9	0	—	45,631	22.8	200,493	100.0
Learning ^(b)	37,722	18.8	79,464	39.6	5,336	2.7	27,153	13.5	9,797	4.9	41,021	20.5	200,493	100.0
Domestic life	35,747	17.8	56,431	28.1	5,046	2.5	35,223	17.6	18,440	9.2	49,606	24.7	200,493	100.0
<i>Any AIL</i>	<i>55,183</i>	<i>27.5</i>	<i>83,143</i>	<i>41.5</i>	<i>3,725</i>	<i>1.9</i>	<i>14,136</i>	<i>7.1</i>	<i>8,046</i>	<i>4.0</i>	<i>36,260</i>	<i>18.1</i>	<i>200,493</i>	<i>100.0</i>
Activities of work, education and community living (AWEC)														
Education	44,731	22.3	68,451	34.1	5,747	2.9	27,315	13.6	10,083	5.0	44,166	22.0	200,493	100.0
Community (civic) and economic life	41,756	20.8	64,108	32.0	5,848	2.9	33,103	16.5	10,388	5.2	45,290	22.6	200,493	100.0
Working	48,609	24.2	62,607	31.2	4,286	2.1	13,774	6.9	21,241	10.6	49,976	24.9	200,493	100.0
<i>Any AWEC</i>	<i>66,168</i>	<i>33.0</i>	<i>70,944</i>	<i>35.4</i>	<i>4,345</i>	<i>2.2</i>	<i>9,364</i>	<i>4.7</i>	<i>12,103</i>	<i>6.0</i>	<i>37,569</i>	<i>18.7</i>	<i>200,493</i>	<i>100.0</i>

(a) The full name for the life area 'interpersonal interactions' is 'interpersonal interactions and relationships'.

(b) The full name for the life area 'learning' is 'learning, applying knowledge and general tasks and demands'.

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. The frequency of support needed for a service user for each of the three broad groups (ADL, AIL and AWEC) is based on the highest support need category of the service user for that group. For example, if a service user reports 'always or unable to do' for the life area of self-care (one of the ADL areas) then that service user will be placed into the 'always or unable to do' category for ADL, regardless of their support needs for mobility or communication (the other two ADL areas). Therefore the totals for each of the broad groups (ADL, AIL and AWEC) cannot be calculated by adding totals from the three component life areas.
3. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom support needs data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

Accommodation support and respite service users were more likely than other users to report always needing assistance in each of the three broad life areas. Rates ranged from 42% in ADL to 60% in AWEC for accommodation support service users, and from 44% in ADL to 57% in AWEC for respite service users (Table 4.8). Users of employment services were the

least likely to report always needing assistance in each of the three life areas (25% in AWEC, 17% in AIL and 11% in ADL, compared with 35% in AWEC, 28% in AIL and 24% in ADL across all service groups).

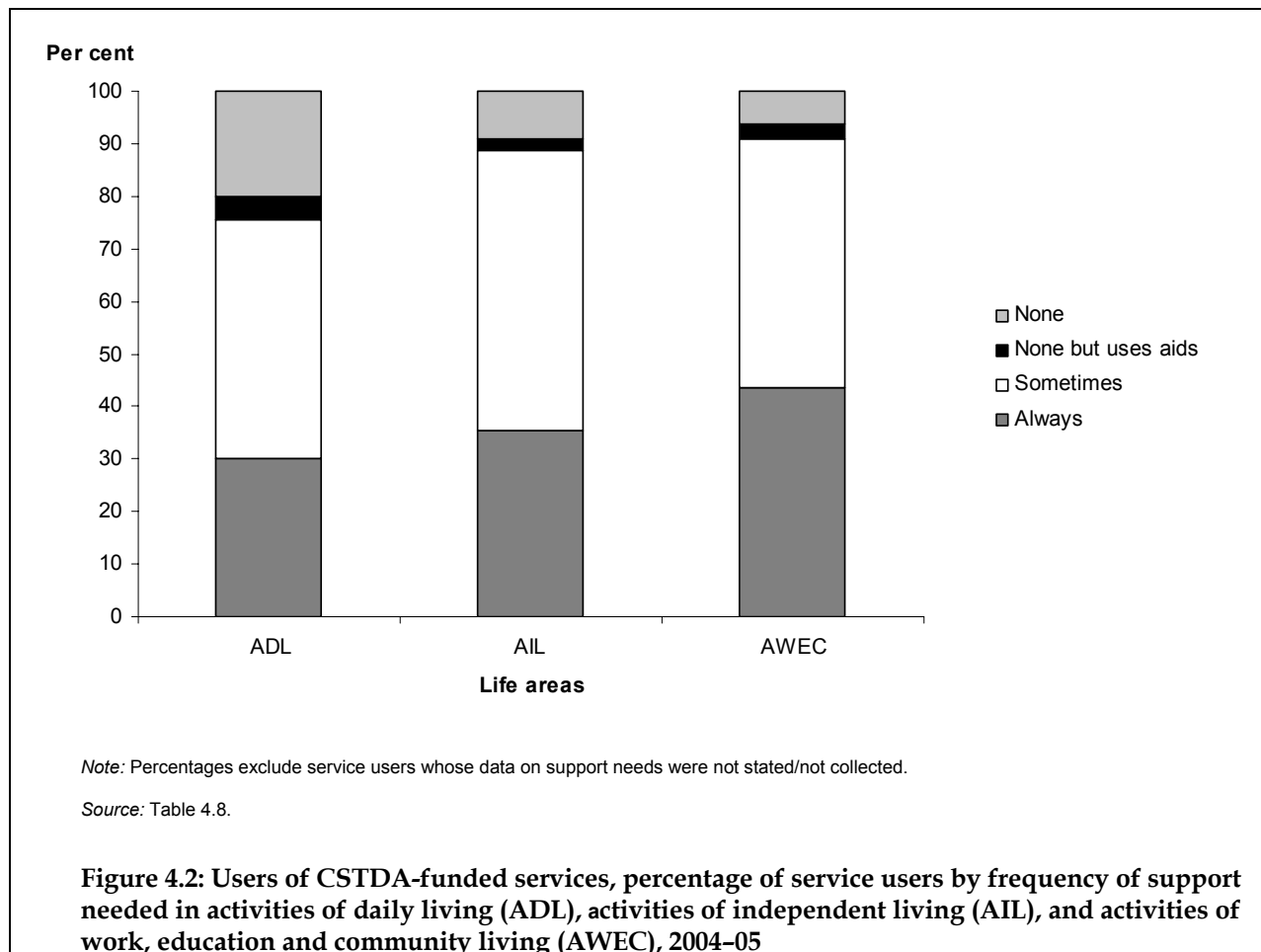


Table 4.8: Users of CSTDA-funded services, service group by frequency of support needed in activities of daily living (ADL), activities of independent living (AIL) and activities of work, education and community living (AWEC), 2004-05

Frequency of support needed	Accommodation support		Community support		Community access		Respite		Employment		All service groups	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
ADL												
Always or unable to do	14,180	42.0	28,108	30.4	14,539	32.9	10,428	43.5	7,231	11.2	47,607	23.7
Sometimes	12,744	37.7	24,583	26.5	16,163	36.6	8,099	33.8	33,236	51.3	71,575	35.7
None but uses aids	813	2.4	2,853	3.1	1,681	3.8	299	1.2	2,958	4.6	7,184	3.6
None	3,993	11.8	6,769	7.3	5,700	12.9	1,721	7.2	19,407	29.9	31,670	15.8
Not stated/not collected	2,057	6.1	30,297	32.7	6,083	13.8	3,404	14.2	2,003	3.1	42,457	21.2
Total	33,787	100.0	92,610	100.0	44,166	100.0	23,951	100.0	64,835	100.0	200,493	100.0
AIL												
Always or unable to do	16,197	47.9	29,795	32.2	17,014	38.5	11,378	47.5	11,230	17.3	55,183	27.5
Sometimes	13,781	40.8	26,174	28.3	17,227	39.0	8,330	34.8	42,058	64.9	83,143	41.5
None but uses aids	386	1.1	1,161	1.3	1,146	2.6	155	0.6	1,532	2.4	3,725	1.9
None	1,273	3.8	3,966	4.3	2,350	5.3	588	2.5	7,742	11.9	14,136	7.1
Not stated/not collected/ not applicable	2,150	6.4	31,514	34.0	6,429	14.6	3,500	14.6	2,273	3.5	44,306	22.1
Total	33,787	100.0	92,610	100.0	44,166	100.0	23,951	100.0	64,835	100.0	200,493	100.0
AWEC (5 years and over)												
Always or unable to do	20,126	59.9	31,129	40.4	22,334	50.8	13,268	56.9	15,925	24.6	65,350	35.4
Sometimes	9,407	28.0	19,384	25.1	11,362	25.8	5,856	25.1	41,722	64.4	70,573	38.2
None but uses aids	475	1.4	1,394	1.8	1,642	3.7	186	0.8	1,287	2.0	4,312	2.3
None	1,372	4.1	2,920	3.8	2,198	5.0	504	2.2	3,639	5.6	9,320	5.0
Not stated/not collected/ not applicable	2,210	6.6	22,268	28.9	6,452	14.7	3,506	15.0	2,262	3.5	35,043	19.0
Total	33,590	100.0	77,095	100.0	43,988	100.0	23,320	100.0	64,835	100.0	184,598	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Row totals may not be the sum of components since individuals may have accessed more than one service type during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom support needs data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

4.5 Living arrangements and residential setting

A total of 111,705 service users (56%) reported that they lived with their family, 37,227 (19%) with others, and 24,645 (12%) reported that they lived alone (Table 4.9). Service users accessing respite services were most likely to report living with family (77%) and accommodation support service users were most likely to report living with others (58%). Of all service users, those using employment services were most likely to report living alone (19%).

Service users living with people other than their family were the most likely users to always need support in all three of the broad life area groupings, ranging from 42% in ADL to 60% in AWEC (Figure 4.3 and Table A1.14). A high proportion of users living with family also reported always needing support, ranging from 26% for ADL to 36% for AWEC. In contrast,

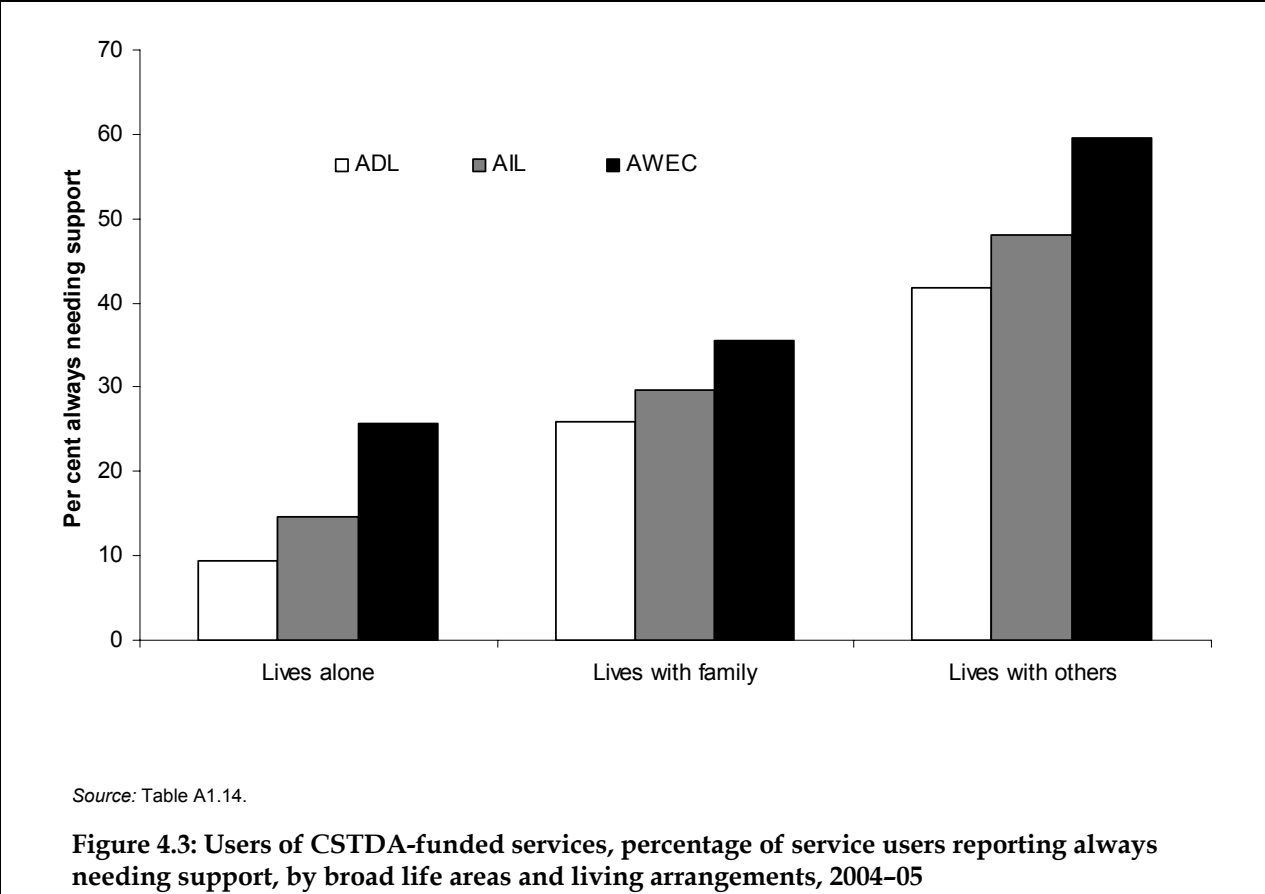
service users living alone were the least likely to always need support, with rates ranging from 10% for ADL to 26% for AWEC.

Table 4.9: Users of CSTDA-funded services, living arrangements by service group, 2004–05

Service group	Lives alone		Lives with family		Lives with others		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Accommodation support	6,046	17.9	7,165	21.2	19,496	57.7	1,080	3.2	33,787	100.0
Community support	6,470	7.0	53,790	58.1	14,253	15.4	18,097	19.5	92,610	100.0
Community access	5,684	12.9	18,631	42.2	14,989	33.9	4,862	11.0	44,166	100.0
Respite	1,282	5.4	18,508	77.3	2,581	10.8	1,580	6.6	23,951	100.0
Employment	12,044	18.6	40,987	63.2	10,069	15.5	1,735	2.7	64,835	100.0
Total	24,645	12.3	111,705	55.7	37,227	18.6	26,916	13.4	200,493	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Column totals may not be the sum of components since individuals may have accessed more than one service type during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom living arrangement data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.



The most commonly reported residential setting was a private residence (137,238 of 200,493 service users, or 68%). Just over three-quarters (76%) of service users living in a private residence were living with family, and a further 16% alone. The next most common residential setting was domestic-scale supported accommodation (13,770 or 7%) and supported accommodation facilities (10,727 or 5%); the vast majority of users residing in these settings were living with others (96% and 95% respectively) (Table 4.10).

Table 4.10: Users of CSTDA-funded services, living arrangement by residential setting, 2004–05

Residential setting	Lives alone		Lives with family		Lives with others		Not stated/ not collected		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%
Private residence	21,731	15.8	104,056	75.8	9,160	6.7	2,291	1.7	137,238	100.0
Aboriginal/Torres Strait Islander community	38	4.9	619	80.0	63	8.1	54	7.0	774	100.0
Domestic-scale supported	275	2.0	202	1.5	13,236	96.1	57	0.4	13,770	100.0
Supported accommodation facility	333	3.1	106	1.0	10,238	95.4	50	0.5	10,727	100.0
Boarding house/private hotel	270	18.0	196	13.0	994	66.1	44	2.9	1,504	100.0
Independent unit (retirement village)	267	58.0	118	25.7	70	15.2	5	1.1	460	100.0
Residential aged care	53	4.8	46	4.2	990	89.4	19	1.7	1,108	100.0
Psychiatric community care	73	6.5	60	5.4	498	44.5	488	43.6	1,119	100.0
Hospital	30	9.7	24	7.7	236	76.1	20	6.5	310	100.0
Short-term crisis accommodation	267	26.8	168	16.9	386	38.8	174	17.5	995	100.0
Public place/temporary shelter	74	40.2	43	23.4	60	32.6	7	3.8	184	100.0
Other	687	23.3	959	32.5	602	20.4	699	23.7	2,947	100.0
Not stated/not collected	547	1.9	5,108	17.4	694	2.4	23,008	78.4	29,357	100.0
Total	24,645	12.3	111,705	55.7	37,227	18.6	26,916	13.4	200,493	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom living arrangement and residential setting data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

Two-thirds (66%) of service users who reported always needing help with ADL had an informal carer (Table 4.11). But more than a quarter (27%) of these service users did not have an informal carer. Of service users reporting sometimes needing help, 49% reported the presence of a carer and 43% had no carer.

When considering the 137,238 service users living in a private residence, the proportion of service users reporting the existence of an informal carer was higher than for all service users (53% compared with 42% overall) (Tables 4.1 and 4.11). In particular, the proportion of service users always needing help with ADL was 85%, with only 12% reporting they did not have such a carer. For those service users in a private residence sometimes needing help with ADL, 53% reported they had an informal carer.

Table 4.11: Users of CSTDA-funded services, existence of an informal carer by frequency of support needed in activities of daily living (ADL), 2004–05

Frequency of support needed in ADL	Has an informal carer		Does not have an informal carer		Not stated/not collected		Total	
	No.	%	No.	%	No.	%	No.	%
All service users								
Always or unable to do	31,382	65.9	12,830	26.9	3,395	7.1	47,607	100.0
Sometimes	34,931	48.8	30,802	43.0	5,842	8.2	71,575	100.0
None but uses aids	2,348	32.7	4,288	59.7	548	7.6	7,184	100.0
None	7,908	25.0	20,470	64.6	3,292	10.4	31,670	100.0
Not stated/not collected	8,395	19.8	6,146	14.5	27,916	65.8	42,457	100.0
Total	84,964	42.4	74,536	37.2	40,993	20.4	200,493	100.0
Service users living in a private residence								
Always or unable to do	26,975	85.3	3,621	11.5	1,013	3.2	31,609	100.0
Sometimes	31,177	53.3	22,888	39.1	4,458	7.6	58,523	100.0
None but uses aids	2,142	33.6	3,776	59.2	456	7.2	6,374	100.0
None	7,171	25.5	18,036	64.1	2,915	10.4	28,122	100.0
Not stated/not collected	5,796	46.0	1,949	15.5	4,865	38.6	12,610	100.0
Total	73,261	53.4	50,270	36.6	13,707	10.0	137,238	100.0

Notes

1. Service user data are estimates after use of a statistical linkage key to account for individuals who received services from more than one service type outlet during the 12-month period. Service user data were not collected for all CSTDA service types (see Section 2.2 for details).
2. 'Not stated/not collected' includes both service users accessing only 3.02 services for whom support needs data were not collected (see Section 2.2) and other service users with no response. Refer to Table A1.1 for a breakdown of these two categories.

5 Service outlets

During 2004–05, a total of 8,448 service type outlets were identified as providing CSTDA-funded services nationwide (Table 5.1). Data items collected about these outlets are provided mainly by the funded agencies themselves. However, selected items are provided by funding jurisdictions (for example, service type and agency sector information). See Appendix 2 for more details.

5.1 Agency sector

Approximately two-thirds (67%) of the 8,448 service type outlets providing CSTDA-funded services during 2004–05 were classified as non-government and just under one-third (32%) as government (Table 5.1).

The 5,697 non-government service type outlets consisted of 3,847 (46% of all service type outlets) income tax exempt charities and 1,850 (22% of all service type outlets) non-income tax exempt (Table 5.1). Of the 2,724 government service type outlets, 2,552 (30% of all service type outlets) were provided by state/territory governments, and 169 (2% of all service type outlets) by local governments. A further 3 outlets were directly provided by the Australian Government.

5.2 State distribution and service type

State/territory-funded outlets

Of the 8,448 CSTDA-funded service type outlets, 7,651 (91%) were funded by state/territory governments (Table 5.2). The largest numbers of outlets were in Victoria (2,570), followed by New South Wales (1,600) and Queensland (1,513).

Service type outlets providing accommodation support services made up almost half (3,637 of 7,651, or 48%) of state/territory-funded outlets during 2004–05 (Table 5.2). A further 1,551 service type outlets (20%) provided community access services, 1,301 (17%) provided community support and 709 (9%) were respite services. Advocacy, information and print disability services were provided by a total of 299 outlets (4%) and other support services (such as training and research) were provided by the remaining 154 outlets (2%).

The proportions of state/territory-funded service type outlets providing particular services were similar across jurisdictions. Advocacy, information and print disability services were notably low in New South Wales with only 1 of their 1,600 outlets providing these services (Table 5.2).

Australian government-funded outlets

A total of 797 service type outlets were funded by the Australian Government during 2004–05 (Table 5.3). The vast majority (711, or 89%) of these outlets provided employment support services – 378 provided supported employment, 297 open employment, and 36 open and supported employment services. The remaining 86 service type outlets (11%) provided advocacy, information and print disability services.

Table 5.1: CSTDA-funded service type outlets, service type by agency sector, 2004–05

Service type	Government			Non-government					Total
	Aus Gov	State/territory	Local	Sub-total	Income tax exempt (charity)	Non-income tax exempt	Sub-total	Not stated	
Large residential/institution	0	26	0	26	19	12	31	0	0
Small residential/institution	0	8	0	8	13	58	71	0	0
Hostels	0	3	0	3	14	7	21	0	0
Group homes	0	1,318	40	1,358	748	307	1,055	0	0
Attendant care/personal care	0	8	7	15	44	87	131	0	0
In-home accommodation support	0	104	7	111	413	278	691	8	0
Alternative family placement	0	3	0	3	23	14	37	0	0
Other accommodation support	0	7	4	11	44	13	57	0	0
Total accommodation support	0	1,477	58	1,535	1,318	776	2,094	8	3,637
Therapy support for individuals	0	49	0	49	65	24	89	4	142
Early childhood intervention	0	94	8	102	113	11	124	0	226
Behaviour/specialist intervention	0	68	0	68	24	12	36	0	104
Counselling (individual/family/group)	0	14	0	14	14	16	30	0	44
Regional resource and support teams	0	53	0	53	2	3	5	0	58
Case management, local coord. & development	0	377	11	388	178	88	266	2	656
Other community support	0	14	2	16	32	23	55	0	71
Total community support	0	669	21	690	428	177	605	6	1,301
Learning and life skills development	0	118	14	132	630	358	988	0	1,120
Recreation/holiday programs	0	13	7	20	57	53	110	0	130
Other community access	0	80	7	87	144	64	208	6	301
Total community access	0	211	28	239	831	475	1,306	6	1,551
Own home respite	0	5	3	8	34	35	69	0	77
Centre-based respite/respite homes	0	110	3	113	101	65	166	1	280
Host family respite/peer support respite	0	7	0	7	16	12	28	0	35
Flexible respite	0	24	19	43	152	81	233	3	279
Other respite	0	6	1	7	17	14	31	0	38
Total respite	0	152	26	178	320	207	527	4	709
Open employment	2	0	1	3	282	12	294	0	297
Supported employment	1	5	2	8	368	2	370	0	378
Open and supported employment	0	1	0	1	34	1	35	0	36
Total employment	3	6	3	12	684	15	699	0	711
Advocacy	0	0	0	0	96	33	129	1	130
Information/referral	0	18	0	18	44	36	80	0	98
Combined information/advocacy	0	0	0	0	12	21	33	0	33
Mutual support/self-help groups	0	0	1	1	62	34	96	1	98
Alternative formats of communication	0	0	0	0	18	8	26	0	26
Total advocacy, information and print disability	0	18	1	19	232	132	364	2	385
Research and evaluation	0	2	0	2	2	0	2	0	4
Training and development	0	2	1	3	4	5	9	0	12
Peak bodies	0	3	0	3	3	8	11	0	14
Other support services	0	12	31	43	25	55	80	1	124
Total other support	0	19	32	51	34	68	102	1	154
Total	3	2,552	169	2,724	3,847	1,850	5,697	27	8,448
Total per cent	0.0	30.2	2.0	32.2	45.5	21.9	67.4	0.3	100.0

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. Australian government-related employment services are not directly provided services, but funded organisations such as universities classified as 'Australian government-related'.
3. 'Open and supported' employment services ceased to be operational from 1 December 2004.

Table 5.2: State/territory-funded CSTDA service type outlets, service type by state/territory, 2004–05

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Large residential/institution	22	4	12	9	7	3	0	0	57
Small residential/institution	6	2	57	12	1	1	0	0	79
Hostels	4	14	0	0	1	5	0	0	24
Group homes	688	847	293	231	214	34	65	41	2,413
Attendant care/personal care	3	33	41	1	34	31	1	2	146
In-home accommodation support	116	244	232	144	49	14	6	5	810
Alternative family placement	3	9	16	8	2	0	0	2	40
Other accommodation support	16	33	11	5	1	2	0	0	68
Total accommodation support	858	1,186	662	410	309	90	72	50	3,637
Therapy support for individuals	15	51	30	23	15	1	1	6	142
Early childhood intervention	95	89	17	12	12	0	0	1	226
Behaviour/specialist intervention	23	41	26	4	7	0	0	3	104
Counselling (individual/family/group)	3	0	25	2	13	0	0	1	44
Regional resource and support teams	44	0	1	2	5	4	0	2	58
Case management, local coordination and development	49	208	168	141	59	7	17	7	656
Other community support	25	0	10	18	13	0	2	3	71
Total community support	254	389	277	202	124	12	20	23	1,301
Learning and life skills development	172	520	248	96	53	22	6	3	1,120
Recreation/holiday programs	26	6	22	29	37	6	3	1	130
Other community access	144	64	49	3	8	27	2	4	301
Total community access	342	590	319	128	98	55	11	8	1,551
Own home respite	1	13	25	14	21	2	0	1	77
Centre-based respite/respite homes	63	99	54	28	18	8	6	4	280
Host family respite/peer support respite	8	14	5	0	6	1	0	1	35
Flexible respite	65	78	64	48	17	0	4	3	279
Other respite	6	9	11	2	8	1	0	1	38
Total respite	143	213	159	92	70	12	10	10	709
Advocacy	0	24	10	10	3	6	5	0	58
Information/referral	0	38	12	4	17	16	7	2	96
Combined information/advocacy	0	9	7	4	5	7	1	0	33
Mutual support/self-help groups	0	69	19	0	9	0	1	0	98
Alternative formats of communication	1	0	6	0	1	3	3	0	14
Total advocacy, information and print disability	1	140	54	18	35	32	17	2	299
Research and evaluation	0	0	2	1	0	1	0	0	4
Training and development	0	6	2	1	0	1	1	1	12
Peak bodies	0	3	3	1	1	3	1	2	14
Other support services	2	43	35	13	25	3	3	0	124
Total other support	2	52	42	16	26	8	5	3	154
Total	1,600	2,570	1,513	866	662	209	135	96	7,651

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. ACT therapy support for individuals represents an agency count and is therefore understated. This agency consists of 7 service type outlets providing services in different geographical locations.

Table 5.3: Australian Government-funded CSTDA service type outlets, service type by state and territory, 2004–05

Service type	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Total
Open employment	87	65	70	27	28	13	4	3	297
Supported employment	141	91	46	24	48	19	5	4	378
Open and supported employment	13	6	2	5	3	3	1	3	36
Total employment support	241	162	118	56	79	35	10	10	711
Advocacy	19	22	8	8	7	3	3	2	72
Information/referral	1	—	—	—	—	—	1	—	2
Alternative formats of communication	3	3	1	2	1	1	1	—	12
Total advocacy, information and print disability	23	25	9	10	8	4	5	2	86
Total	264	187	127	66	87	39	15	12	797

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. 'Open and supported' employment services ceased to be operational from 1 December 2004.

5.3 Period of operation

Of the 8,071 service type outlets providing information about their operating hours, 6,427 (80%) were operating for 7 hours or more a day and 3,058 (38%) were operating for 24 hours a day (Table 5.4). Around 10% of outlets (847 of 8,135) reported having no regular pattern of daily operation.

Three-quarters (2,594 of 3,481, or 75%) of service type outlets providing accommodation support and almost half (302 of 653, or 46%) of outlets providing respite services were open 24 hours a day (Table 5.4). For all other outlets, the most common number of operating hours was 7–9 hours – proportions ranged from 44% of outlets providing community access services to 93% of outlets providing employment services. Service type outlets providing community access services were more likely than other outlets to operate for less than 7 hours a day, with over one-third (487 of 1,450, or 34%) reporting less than 7 operating hours a day.

Most service type outlets operated for either 5 days a week (40%, or 3,282 of 8,135) or 7 days a week (46%, or 3,735 of 8,135) (Table 5.5). As with hours per day of operation, service type outlets providing either accommodation support or respite services most commonly reported operating for the maximum period, 7 days a week (87% and 54% respectively). The most common number of days of operation was 5 for all other service type outlets, with proportions ranging from 65% (250 of 382) for outlets providing advocacy, information and print disability services to 92% (654 of 711) for outlets providing employment services.

A total of 7,507 service type outlets (92% of all outlets) were operating for 48 weeks or more a year, including 5,692 (70% of all outlets) that were operating for the full 52 weeks a year (Table 5.6). For all service groups other than community access, the most commonly reported number of operating weeks per year was the maximum 52, with rates ranging from 50% (190 of 381) for outlets providing advocacy, information and print disability services to 93% (654 of 3,305) for outlets providing accommodation support services. Outlets providing community access most commonly reported operating for 48–51 weeks (712 of 1,442, or 49%).

Table 5.4: CSTDA-funded service type outlets, number of operating hours per day by service group, 2004–05

Hours of operation per day	Accommodation support	Community support	Community access	Respite	Employment	Advocacy, info. & print disability	Other	Total
Less than 3 hours	15	13	6	5	0	2	3	44
3–6 hours	97	36	481	32	19	81	7	753
7–9 hours	246	986	637	105	661	257	109	3,001
10–12 hours	75	24	38	17	19	3	1	177
13–18 hours	98	6	12	12	1	0	0	129
19–23 hours	49	3	2	7	0	0	1	62
24 hours	2,594	70	82	302	3	5	2	3,058
No regular pattern	307	110	192	173	8	34	23	847
Total	3,481	1,248	1,450	653	711	382	146	8,071

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. Column totals exclude 377 service type outlets for which hours of operation per day were missing.

Table 5.5: CSTDA-funded service type outlets, number of operating days per week by service group, 2004–05

Days of operation per week	Accommodation support	Community support	Community access	Respite	Employment	Advocacy, info. & print disability	Other	Total
1 day	5	21	30	20	0	55	2	133
2 days	15	20	20	16	2	8	1	82
3 days	20	26	35	17	5	11	4	118
4 days	11	21	29	21	10	19	6	117
5 days	219	964	999	84	654	250	112	3,282
6 days	58	12	60	18	9	3	5	165
7 days	3,076	97	169	353	25	11	4	3,735
No regular pattern	139	85	111	124	6	25	13	503
Total	3,543	1,246	1,453	653	711	382	147	8,135

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. Column totals exclude 313 service type outlets for which days of operation per week were missing.

Table 5.6: CSTDA-funded service type outlets, number of operating weeks per year by service group, 2004–05

Weeks of operation per year	Accommodation support	Community support	Community access	Respite	Employment	Advocacy, info. & print disability	Other	Total
1–39 weeks	36	10	30	33	4	7	5	125
40–47 weeks	22	61	162	11	11	7	3	277
48–51 weeks	132	346	712	112	290	173	50	1,815
52 weeks	3,305	779	495	438	403	190	82	5,692
No regular pattern	53	52	43	62	3	4	9	226
Total	3,548	1,248	1,442	656	711	381	149	8,135

Notes

1. A service type outlet may, in some cases, represent two or more locations that provide the same service type. (See Section 2.4 for discussion of the definition of 'service type outlet').
2. Column totals exclude 313 service type outlets for which weeks of operation per year were missing.