

4 Demographic characteristics of families, finances and service use

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This chapter describes the demographic characteristics of the sample of carers, the people with a disability for whom they care and other family members in the carers' households from the FCPDS. Information about the number of years for which they have been caring, hours of care and care needs of the person with a disability are also provided. The chapter also documents the financial situation of carers' families and the use of services by carers, the people with a disability and other members of the family.

The demographic characteristics of carers

Table 4.1 documents the demographic characteristics of the 1,002 carers in the FCPDS. Throughout this chapter, only the more notable features of tables will be highlighted. Most carers received only Carer Allowance (74.8%), while 22.8% of carers received both Carer Allowance and Carer Payment. The remaining 2.5% of the carers indicated that they received Carer Payment only. In future analyses, we will combine this last group of carers with those receiving both Carer Allowance and Carer Payment and refer to this category hereafter as "Carer Payment". It should also be noted that a greater percentage of male carers (40.0%) than female carers (21.0%) received Carer Payment (or both Carer Payment and Carer Allowance), whereas a greater percentage of female carers (79.0%) than male carers (60.0%) received only Carer Allowance.

A little over three-quarters of the carers in the FCPDS were female, a finding consistent with the population of recipients of government assistance to carers, as well as other Australian and international data. Moreover, there was a statistically significant difference in the age of female and male carers that is consistent with the view that carers who are male are typically caring for their wife/partner. As Figure 4.1 (on p. 22) shows, 41.8% of male carers were over 65 years of age, with a further 33.8% in the 51 to 65 year age category. Only 21.3% of male carers were aged 36 to 50 years and 3.1% were under 35 years of age. In contrast, 40.1% of female carers were aged 36 to 50, followed by 29.8% aged 51 to 65 years. Fewer than one in five female carers were either over 65 years of age (16.1%) or under 35 years of age (14.1%).

Aboriginal or Torres Strait Islander people comprised 1.9% of the sample. Over two-thirds of all carers were partnered, slightly less than one-third had a year 12 secondary education and 55.7% also had another educational qualification. Twenty-two per cent of carers wanted to work but were not looking for work, 4.5% wanted to work and were looking for work and 14.4% of carers were not employed and were not seeking employment. A further 29.0% of carers were employed and 30.0% were retired. Employment issues will be discussed more fully in Chapter 11. The other interesting point to note is that a number of carers had care responsibilities for family members who did not have a disabling condition. By far the most common of these caring responsibilities was caring for children (31.9%).

Characteristics of people with a disability

Table 4.2 (on p. 23) presents demographic information for the people with a disability in the FCPDS. Carers could be asked about up to three people with a disability for whom they cared. Therefore, demographic information on 1,140 people with a disability was collected. Eighty-

Table 4.1 The demographic characteristics of carers

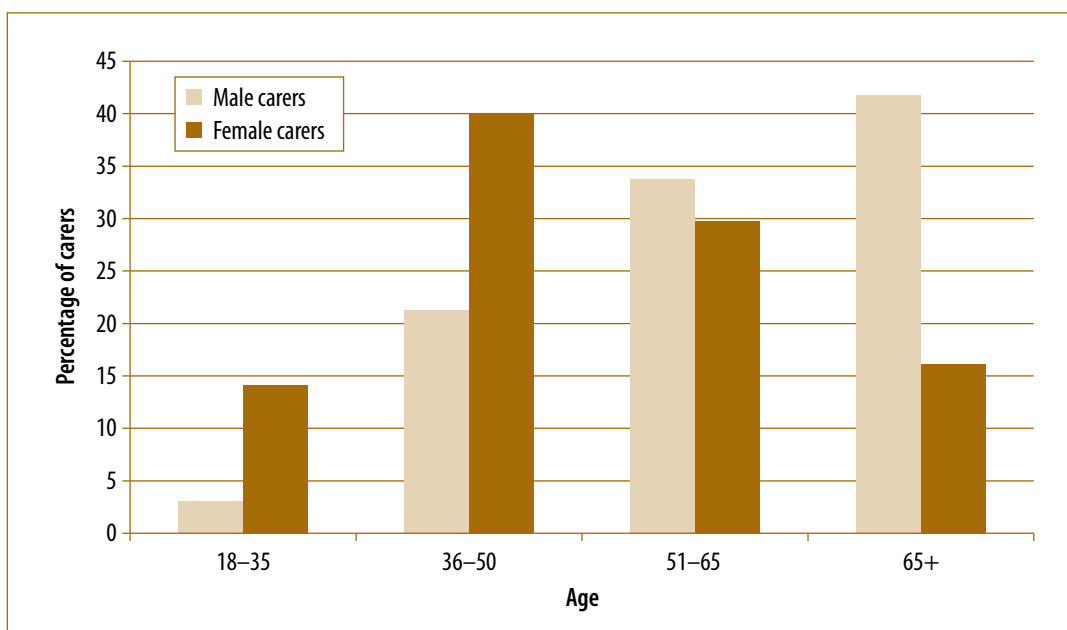
Variables	Percentage
Age	
18–35 years	11.6
36–50 years	35.7
51–65 years	30.6
66 years or more	21.9
Gender	
Male	22.5
Female	77.5
Aboriginal or Torres Strait Islander origin	
	1.9
Carer's relationship status	
Partnered	68.7
Not partnered	22.5
Highest year of primary or secondary school	
Year 12	31.3
Year 11	10.9
Year 10	29.2
Year 9	12.1
Year 8	14.1
Never attended school	0.9
Don't know	1.1
No answer	0.4
Highest qualification completed	
Postgraduate degree	3.2
Bachelor degree (including Honours)	7.9
Diploma	8.5
Certificate level	17.5
Trade, apprenticeship or workplace training	15.3
School qualification only	44.3
Other, don't know, no answer	3.3
Employment status	
Employed full-time	7.2
Employed part-time	21.8
Retired	30.0
Wants to work and is looking for work	4.5
Wants to work but not looking for work	22.2
Not in the labour force and doesn't want to work	14.4
Other care responsibilities	
Children	31.9
Parents/parents-in-law	3.5
Other relative(s)	3.5
Other person/people	2.0

Note: Percentages may not total 100% due to rounding.

Source: FCPDS 2006

seven per cent of families ($n = 876$) were caring for one person with a disability, 11.0% of families cared for two, and 1.2% of families cared for three people with a disability.

The general pattern of the age distribution was bimodal, with children and older people the two largest groups receiving care. In total, there were 406 people under the age of 18 in the sample (35.6%). Only a small number of preschool children were being cared for (4.7%); however, (22.7%) of people with a disability were primary-school aged children, and 8.7% were secondary-school aged children. Less than one-fifth of the sample of people with a disability were aged between 18 and 50 (15.5%), over half were over 50 years, and one-third were over 66 years.



Notes: $\chi^2(3) = 88.28, p < .001$

Source: FCPDS 2006

Figure 4.1 Age of female and male carers surveyed

Approximately two in five people with a disability were partners of their carer (37.3%) and a further 43.5% were the children of the carer. Combined with demographic information on the age of people with a disability, we can see that the sample of families comprises two main groups: (a) older families, where the carer is caring for their partner; and (b) younger families, where the carer is caring for their child and may have additional care responsibilities for children without a disability (see Table 4.1). People with a disability were also the parents or parents-in-law of the carer in 13.7% of cases.

Approximately three-fifths of people with a disability were males (58.7%) and 2.4% were of Aboriginal or Torres Strait Islander origin. Most people with a disability lived with the carer (94.7%).

The number of years of caring for the person with a disability highlights the extended nature of caring. Close to half of the people with a disability had been receiving care for 7 years or more, and a further one-quarter for between 4 and 6 years. The distribution of hours of caring is even more remarkable. Only 11.6% of carers were caring for the person with a disability for 20 hours or less a week, and 58% reported that they cared for the person with a disability for more than 100 hours per week. Bittman, Fisher, Hill, and Thomson (2005) have discussed issues associated with asking carers to report the hours they spend caring for a person with a disability. They concluded that global estimates of the hours spent caring (such as in the FCPDS and the ABS Survey of Disability and Carers) are likely to include the time associated with direct care as well as the time that would be associated with monitoring the person with a disability (or being “on call”). The high proportion of carers reporting caring for more than 100 hours per week may be explained by these factors.

As was stated in the method (Chapter 3), we coded the medical conditions reported using the five major categories in the National Community Services Data Dictionary (National Data Services Dictionary Committee, 2006), but also included a category for multiple medical conditions and an unassigned category when there was insufficient information provided to categorise the person’s disabling condition. Close to half of people with a disability had some form of physical disability (47.4%), and 14.5% were in the multiple disability category. Sixteen per cent of people with a disability had an intellectual/learning disability, while 11.2% had a psychiatric

Table 4.2 Demographic characteristics of the people with a disability

Variables	Percentage
Age	
0–4 years	4.1
5–12 years	22.7
13–17 years	8.7
18–35 years	8.1
36–50 years	7.5
51–65 years	16.6
66 years or more	32.2
Gender	
Males	58.7
Females	41.3
Aboriginal or Torres Strait Islander origin	
	2.4
House of residence	
Lives in same house as carer	94.7
Sometimes lives in the same house as carer	0.8
Does not live in same house as carer	4.6
Relationship to carer	
Partner	37.3
Son/daughter	43.5
Parent or parent-in-law	13.7
Grandparent	0.3
Grandchild	0.6
Sibling	1.2
Other	3.4
Type of disability	
Intellectual/learning	16.6
Physical	47.4
Psychiatric	11.2
Sensory/speech	4.9
Acquired brain injury	2.8
Multiple	14.5
Unassigned	2.6
Years of being cared for	
0–1 years	10.0
2–3 years	16.8
4–6 years	23.9
7–12 years	23.3
13 years or more	26.1
Hours of caring by primary carer per week	
1–20 hours	11.6
21–39 hours	10.7
40–59 hours	9.2
60–100 hours	10.6
101 hours or more	58.0
Care needs	
Low	46.1
Medium	38.3
High	15.6
Number of observations	1,140

Note: Percentages may not total 100% due to rounding.

Source: FCPDS 2006

disability. Only 4.9% of people with a disability had a sensory or speech impairment, and 2.8% had acquired brain injury.

For each person with a disability, the carer was asked whether that person needed assistance in relation to each of six areas: self-care, body movement, communication, making friendships, and coping with feelings or emotions. Based on carers' responses, the care needs of people with a disability were categorised as "low", "medium" or "high" (see Chapter 3 for a detailed description of the care needs and the process of deriving a care needs score). A high level of care needs would require the carer to indicate that the person with a disability always needed assistance in at least three of the six areas of care needs and sometimes needed assistance in the three other areas of care needs. One in six people with a disability were classified as having high care needs. Two out of five people with a disability were classified as having medium care needs, and almost half of the people with a disability were classified as having low care needs. However, it should be noted that the low rating of care needs was of care needs relative to other people with a disability and does not reflect a trivial amount of care required. For example, people with a disability could be rated as having low care needs even if they always needed assistance on two care needs. It was also possible to have a low rating on care needs if the person with a disability sometimes needed assistance on four of the six care needs.

Demographic characteristics of other family members in the household

The majority of carers had at least one other family member living with them in addition to a person or persons with a disability (56.3%). Two hundred and thirty households had one additional family member (30.0%), 185 had two (18.5%), 103 had three (10.3%) and 49 households had four or more (4.9%). In total, demographic information was collected on 1,133 family members who were not the primary carer or the person with a disability.

The demographic characteristics of these family members are described in Table 4.3. Almost half of these family members were under the age of 18 years, with almost one-quarter of family members being aged between 5 and 12. A further 40% of family members were aged between 18 and 50. These age patterns are more explicable when one considers the family members' relationships to the carer—family members were almost exclusively either the carer's partner or child (89.0%).

Carers were only asked about the employment status of other family members when the latter were aged 15 or more. Seventy-four per cent of working-aged family members were employed.

The financial situation of the household

Carers were asked about their gross household income. From these data, we calculated household income using the OECD equivalence scale, which accounts for the number of adults and children in the household (see Chapter 3).

Figure 4.2 displays equivalised household weekly income for households with carers with Carer Payment and carers receiving only Carer Allowance. The first point to note is that 22.6% of carers receiving Carer Allowance and 17.8% receiving Carer Payment were not able or refused to provide their household income. Many carers would have simply not been able to provide an estimate, given that precise knowledge of other household members' income would be required. The second point to note is that the range of equivalised household weekly income is more restricted for households where the carer was receiving the means-tested payment (Carer Payment) than the income of households where the carer was only receiving Carer Allowance. For example, 43.1% of households had an equivalised household income of \$100 to \$200 per week when the carer was receiving the Caring Payment, compared to 22.4% of households on the same amount when the carer was only receiving Carer Allowance.

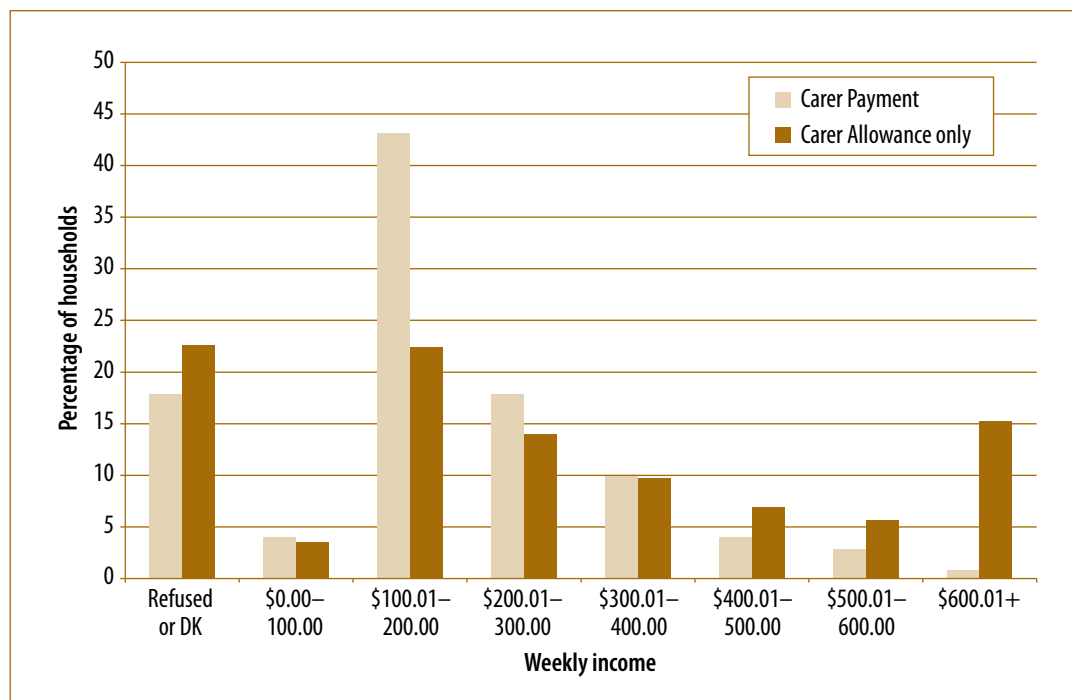
Another measure of the financial wellbeing of the family caring for a person with a disability was a series of questions focusing on financial hardship. Carers were asked whether their family had experienced four financial hardship events this year because of a shortage of money (see Figure 4.3 for a description of these events). Compared to the general population, higher percentages of

Table 4.3 Demographic characteristics of other family members in the household

Variables	Percentage
Age	
0–4 years	9.3
5–12 years	23.3
13–17 years	16.0
18–35 years	17.5
36–50 years	21.5
51–65 years	8.8
66 years or more	3.6
Gender	
Males	64.5
Females	35.5
Employment status	
Employed	41.9
Not employed	14.7
Not applicable (aged under 15 years)	43.3
Relationship to carer	
Partner	30.6
Son/daughter	58.4
Parent or parent-in-law	2.5
Grandparent	0.1
Grandchild	2.3
Sibling	1.6
Other	4.6
Number of observations	1,133

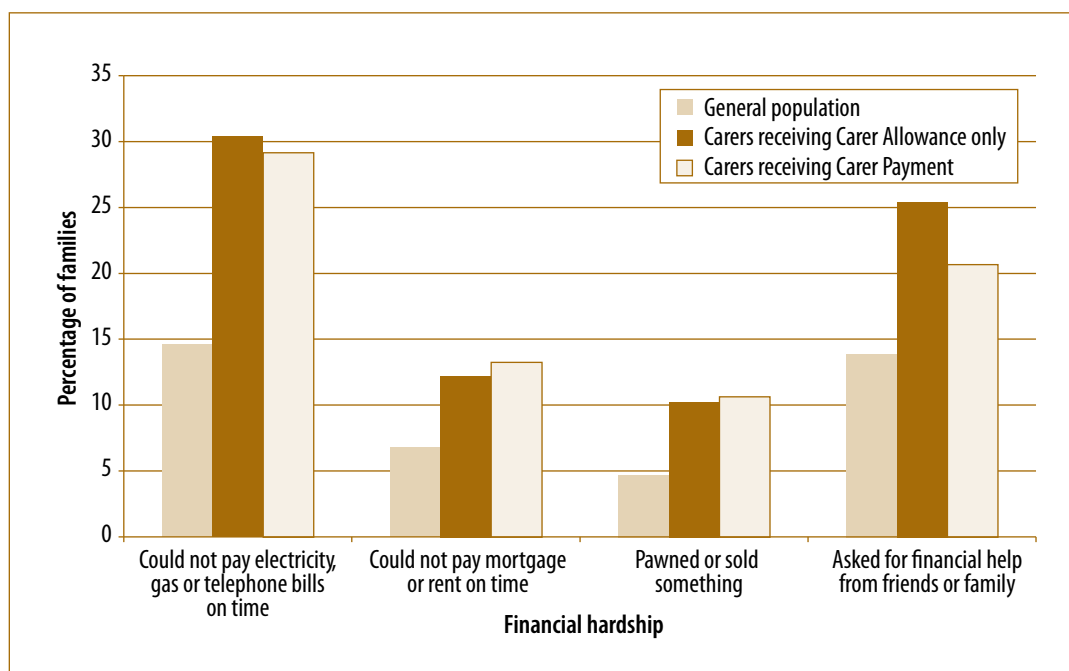
Note: Percentages may not total 100% due to rounding.

Source: FCPDS 2006



Source: FCPDS 2006

Figure 4.2 Equivalised household weekly income for carers' households, by payment type



Notes: In this instance, the data for carers from the FCPDS have been weighted by gender and age to match the gender and age characteristics of the general population in HILDA Wave 4.1. Statistical tests suggested that, compared to the general population, significantly higher percentages of households caring for a person with a disability “could not pay electricity, gas or telephone bills on time” ($\chi^2(2) = 161.40, p < .001$), “could not pay the rent or mortgage on time” ($\chi^2(2) = 43.38, p < .001$), “pawned or sold something” ($\chi^2(2) = 59.60, p < .001$) and “asked for financial help from friends or family” ($\chi^2(2) = 80.01, p < .001$).

Sources: FCPDS 2006, HILDA Wave 4.1

Figure 4.3 Financial hardships in carers’ families, by type of hardship and caring responsibilities

households caring for a person with a disability “could not pay electricity, gas or telephone bills on time”, “could not pay the rent or mortgage on time”, “pawned or sold something” and “asked for financial help from friends or family”. All of these differences were statistically significant. Not being able to pay electricity, gas or telephone bills on time was the greatest area of difficulty. Thirty per cent of families with a carer receiving Carer Allowance and 29.2% of families with a carer receiving Carer Payment experienced financial hardship in this area. Only 14.6% of the general population indicated that they had experienced difficulty in paying electricity, gas or telephone bills on time. It is also worth noting that a greater percentage of carers receiving Carer Allowance had “asked for financial help from friends or family” (25.4%) than carers receiving Carer Payment (20.7%).

Use of services

As service use was not a major focus of the study, we asked one open-ended question: “Could you please tell me whether you [or the person with a disability] (or anyone else in your household) uses any disability services like respite, counselling, disability employment services or carer support services”. Interviewers coded carers’ responses into several categories that, with the exception of “no service use”, were not mutually exclusive (see Table 4.4). The most notable feature of these results was that almost half of the carers said that the person with a disability, the carer and other family members did not use any disability support services. It is likely that the number of carers who indicated that they did not use any services may be an overestimate, as memory recall is hardest with open-ended questions and no prompts.

The most commonly used services were respite and consulting a general practitioner. Ten per cent of carers indicated use of an “other” service. There was a range of services used in the “other” category and included aged care, specialist societies and services, and services provided

by hospitals. One in ten carers reported their families also used some form of psychological service, such as counselling,²⁶ a psychiatrist or a psychologist.

Table 4.4 Use of services by people with a disability, their carer and other family members

Services used	Percentage
None	47.9
Respite	13.0
General Practitioner	11.2
Other	10.6
Community support services	6.5
Counselling	6.5
Attendant care or personal care	5.6
In-home accommodation support	5.2
Therapy	4.8
Physiotherapist	3.1
Psychiatrist	2.2
Community access services	2.1
Learning and life skills development	1.7
Recreation/holiday programs	1.6
Equipment or mobility aides	1.5
Paediatrician	1.1
Other specialist medical practitioners	1.1
Psychologists	1.1
Self-help groups	1.1
Disability employment services	1.0
Advocacy	1.0
Behaviour/specialist intervention	0.3
Case management	0.2
Carer education or training	0.2
Alternative forms of communication	0.1
Number of observations	1,002

Source: FCPDS 2006

Carers who used respite ($n = 124$)²⁷ were also asked how many hours of respite their families used per month. Over one-third of families used 10 hours or less a month (37.1%) and one in five used 11 to 20 hours per month (21.0%). The other main group was the 16.9% of families that used respite 51 hours or more a month.

Table 4.5 Hours of respite per month

Hours of respite per month	Percentage
0–10 hours	37.1
11–20 hours	21.0
21–30 hours	12.1
31–40 hours	5.6
41–50 hours	7.3
51 hours or more	16.9
Total number	124

Source: FCPDS 2006

26. The term “counselling” is somewhat vague. Moreover, the amount of counselling received could also range from a single 30-minute session to weekly psychotherapy for years. Unfortunately, time limits on the length of the interview precluded the collection of detailed information on the nature of the services used by people with a disability, their carer and other family members.

27. Although 130 carers indicated their family used respite, six respondents couldn’t say how many hours were used.

Conclusion

The majority of carers received Carer Allowance only (74.8%), whereas 25.3% received Carer Payment. Carers were mainly female (77.6%). Almost one out of five carers (22.0%) wanted to work but were not looking for work, 14.4% of carers were not employed and were not seeking employment, 29.0% of carers were employed and 30.0% were retired. Almost one in three cared for at least one child with no disability along with the person with a disability (who could also be a child).

Most families cared for one person with a disability; however, 13% of families cared for two or three people with a disability. Slightly more people with a disability were men (58.7%). Over a third were children and close to half were people over 50 years of age. Almost half had some form of physical disability (47.4%) and 14.5% had multiple disabling conditions. The two other more prevalent disabling conditions were an intellectual/learning disability (16.6%) and a psychiatric disability (11.2%). Almost half of the carers had been caring for the person with a disability for 7 years or more (49.4%) and 58% of carers reported that they cared for the person with a disability for more than 100 hours per week.

The majority of families caring for a person with a disability also had other family members residing in the household apart from the primary carer and the person or persons with a disability (56.3%). Most of these family members were either the child of the carer (58.4%) or their partner (30.6%). Of those family members who were of working age, 74% were employed.

Almost half of the carers' families did not use any support services (47.9%). For those who did, the most commonly used services were respite care or a general practitioner. For the few who did use respite services, the most common amount of respite care use was 20 hours or less a month (57.6%), with 17.8% using it for 51 hours or more a month.

Compared to families from the general population, a greater proportion of families of carers suffered from financial hardship. Irrespective of which payment carers received, a higher percentage of carers' families experienced difficulties in the four financial events that were assessed than families who did not care for a person with a disability.