THE NATURE AND IMPACT OF CARING FOR FAMILY MEMBERS WITH A DISABILITY IN AUSTRALIA

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Foreword by Professor Alan Hayes

While central to family life, caring can be invisible to those beyond the home. This can especially be the case in families caring for a member with a disability. In order to frame effective policies, research is needed on the extent of caring within families and the impacts that it can have, both within and beyond the family. The current report does this by analysing the results of a survey undertaken in late 2006 of over 1,000 carers receiving government payments. The report shows the impacts of caring for a family member with a disability on both physical and mental health. Caring is shown to have physical, emotional and relational impacts, as well as broader effects on finances and engagement in paid employment. These impacts are amplified in families caring for more than one person with a disability and with other dependent members. As such, the report makes a very valuable contribution to our understanding of the informal care provided by Australian families.

I am particularly pleased that this has been a first, very fruitful, collaboration involving staff of the Department of Families, Community Services and Indigenous Affairs (now the Department of Families, Housing, Community Services and Indigenous Affairs) and the Institute. As members of the research team from the department, Dr Norbert Zmijewski and Marcia Kingston wrote and contributed to chapters of the report, provided the sample frame for the study, contributed to the interview schedule and assisted in the training of interviewers. I congratulate the authors on an excellent report that is the product of a most successful joint venture. Of course, a survey of this scope could not have been undertaken without the generous assistance of the many participants who were willing to share their insights and experiences.

Thank you!

Professor Alan Hayes
Director
Australian Institute of Family Studies
Family carers make an invaluable contribution to the care and wellbeing of people who need assistance due to disability, severe medical conditions or ageing. This contribution also provides enormous benefits for the Australian community.

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) acknowledges the importance of a strong evidence base in underpinning good policy development. This report provides valuable new information about family perceptions of the impact of caring for a person with a disability on a significant group of informal carers: those receiving Australian Government payments in recognition of their caring responsibilities.

This research will also provide valuable input to FaHCSIA’s review of support for pensioners and carers, which is part of the Government’s review of Australia’s tax system.

The study is based on a survey of a random sample of people receiving Carer Payment and/or Carer Allowance, which are the major payments available for people who provide informal care for family members or friends. The major findings in the report illustrate the enormous personal sacrifices carers make through their selflessness and hard work.

I would like to express appreciation to the carers who willingly and enthusiastically gave their time to participate in this study. These carers provided important insights into the family impact of caring for a person with a disability, including physical, emotional, social and financial impacts, and the effects on family relationships and labour force participation.

FaHCSIA is pleased to have collaborated with the Australian Institute of Family Studies on this highly worthwhile project.

Dr Jeff Harmer
Secretary
Department of Families, Housing, Community Services and Indigenous Affairs
About the authors

**Dr Ben Edwards** is a Research Fellow at the Australian Institute of Family Studies (AIFS). He joined the Institute in 2004. His PhD focused on the psychological impact of a cancer diagnosis with patients and families and was supported by a scholarship from the National Health and Medical Research Council. Since joining the Institute, Ben’s research has focused on how neighbourhoods and communities influence children and their families, as well as how ill health such as disability and cancer affects families. Ben also has expertise in the statistical analysis of complex data, including longitudinal and family data, and provides statistical advice to other researchers at the Institute.

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**Dr Matthew Gray** was appointed Deputy Director (Research) at the Australian Institute of Family Studies in 2005. He is also the Executive Project Manager of *Growing Up in Australia: the Longitudinal Study of Australian Children*. Dr Gray has published widely on economic and social policy issues, including the determinants of labour force status, welfare reform in the United States, economic consequences of divorce, work and family, and changes in the living arrangements of Australian children since 1946. He has also worked on economic and social policy issues related to Indigenous Australians. Dr Gray was a member of the Ministerial Taskforce on Child Support.

**Dr Norbert Zmijewski** was, until recently, the Section Manager, Research and Data Section, Disability Policy and Coordination Branch in the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). Dr Zmijewski had been a manager in FaHCSIA since 2000. His areas of responsibility included undertaking research and data analysis that contribute to building an evidence base, and supporting development and evaluation of policies for people with a disability and their carers. He is now Research Manager, Business Regulation Benchmarking, at the Productivity Commission.

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- Social Research Centre—the fieldwork agency employed to conduct and manage the computer-assisted telephone interviews. Particular thanks go to Graham Challice and Nikki Honey, and to all of the interviewers whose skill and enthusiasm ensured a smooth data collection process and a positive experience for the carers being interviewed.

- Dr Julie Kos—Dr Kos, who at the time was employed in the Disability and Carers Branch of FaHCSIA was instrumental in developing some of the early ideas for the project and establishing the collaboration between FaHCSIA and AIFS.

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The interview schedule was developed through extensive consultations with FaHCSIA staff. Other parties were also consulted during the development process:

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- research staff from the Functioning and Disability section of the Australian Institute of Health and Welfare;

- AIFS staff with experience in conducting CATI interviews and/or expertise in the area of disability;

- Dr Erin Wilson, Research Coordinator, Scope Victoria, an organisation that provides disability services; and

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This report was reviewed by Professor Robert Cummins, School of Psychology, Deakin University, and Professor Sidney Bloch, Department of Psychiatry, University of Melbourne. We thank them for their insightful comments and suggestions, which were incorporated into the final version of the report. Expert editing was provided by Lan Wang.

And, finally, our greatest appreciation goes to the carers who participated—for their wisdom, insight, enthusiasm, and willingness to share their stories and their time.
Executive summary

It is estimated that in 2003 there were 474,600 primary carers providing care to a person because of disability or old age. In coming decades, as the Australian population ages, the number of carers is projected to increase. Despite the large number of carers in Australia and the likely increase in their numbers, relatively little is known about the impact upon families of providing care. This report begins to fill the gap.

The analysis is based upon data from a nationally representative survey, conducted in 2006, of 1,002 carers who receive an Australian Government payment directed towards carers (Carer Payment and/or Carer Allowance). Carers were selected from a random sample of 5,000 carers from Centrelink records who, at June 2006, were receiving Carer Payment and/or Carer Allowance.\(^1\)

This research was a collaborative project between the Australian Institute of Family Studies (AIFS) and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The aims of this report are to:

- examine the effect of caring on family and social relationships;
- document the social, emotional, physical and financial impact on families of caring for a person with a disability;
- examine the effect of caring on labour force status.

Key findings

Mental health

One of the key issues to emerge from this research is that carers and their families experience high rates of mental health problems. Carers had significantly worse mental health and vitality and higher rates of depression than the general population. Differences between carers and the general population on these variables were evident for carers of all age groups, except when carers were 65 years or older.

When we used the mental health scale as an indicator of clinical levels of depression, the rates of clinical levels of depression in the previous 4-week period were 19% of female carers and 13% of male carers, while for females and males in the general population they were 11% and 8% respectively. Fifty-one per cent of female carers and 30.7% of males also reported that they had been depressed for 6 months or more since they started caring (we henceforth refer to this period of depression as a “depressive episode”).

Family members also experienced high levels of depression, with 27.3% of partners, 12.1% of parents and 10.6% of offspring of carers experiencing a depressive episode of 6 months or more since caring began. Moreover, the carer’s experience of depression was associated with other family members’ experiences. Regardless of whether they had a disability, partners and children of carers were two to five times more likely to experience a depressive episode when the carer had also experienced a depressive episode of 6 months or more since they started caring. Higher rates of depressive episodes for partners with no disabling condition and children with and without a disability were also evident when there were problems in family functioning.

The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring. The risk of carers experiencing a first depressive episode of at least 6 months’ duration was greatest in the first year of caring (over 13% of carers), but over the next 20 years was fairly stable at about 3%. For other family members, the first year of caring

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1. Sample records contained information on contact details and payment type only.
accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members.

Several factors were associated with carers having more mental health problems, worse vitality and higher rates of depression than people from the general population. These included: caring for a child with a disability; caring for a person with a disability with high care needs; caring for more than one person with a disability; having another care role (that is, also looking after children who did not have a disabling condition); experiencing one or more problems in dimensions of family functioning; and needing more support than they were currently receiving.

**Physical health**

Almost twice as many carers were in poor physical health than the general population. These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories, except when aged 65 years or more.2

Several factors were associated with higher self-ratings of poor physical health of carers. These included: caring for a person with a disability who has high care needs, caring for more than one person with a disability, and having one or more problems in dimensions of family functioning. Carers who indicated that they needed more support also had higher rates of poor physical health than carers who said the support they received was “about right”. As many of the risk factors for poor physical health of carers were the same as those for poor mental health, a coordinated biopsychosocial intervention may best meet the needs of carers and their families.

**Employment**

The employment chapter of this report provides direct evidence on the changes in labour force status since starting caring. It is clear that many carers had stopped working since commencing caring and, when asked why, a large majority said that it was because of their caring responsibilities. Interestingly, at least among non-employed carers, there was little difference in the employment rates prior to commencing caring between those who received only Carer Allowance and those who received Carer Payment. The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment suggests that policies that support carers who want to be in paid employment may be worthwhile.

**Financial hardship**

Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship. Irrespective of which payment the carers’ families received, families who cared for a person with a disability experienced a higher level of financial hardship than the general population. For example, 30% of families with a carer receiving Carer Allowance and 29.2% of families with a carer receiving Carer Payment had experienced difficulty in paying electricity, gas or telephone bills on time. Only 14.6% of the general population indicated that they experienced financial hardship in this area.

**Relationships and support networks**

Carers’ support networks, carers’ relationships, relationship breakdown and family functioning were a major focus of the study. Although most carers had supportive people around them, there was a substantial minority of carers (one in five) who had no assistance from other people in caring for the person or people with a disability. For the majority of carers who did have support, the support provided was not without some issues attached. Even when carers had people to support them and the person with a disability, one in five carers had disagreements with others about caring. Of those carers who had support people, one in five had support people who had some problems with cooperating with other supporters about the care for the person with a disability. These findings highlight that coordination, disagreement and conflict can ensue.

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2. There were insufficient numbers of male carers in the different age categories to conduct the same comparisons for male carers.
from caring for a person with a disability and these can be barriers to the effective provision of informal care.

Carers were satisfied with their relationships with their partners, or at least they were as satisfied as non-carers from the general population—even when their partner was the person with a disability. Although provision of care for a person with a disability was not associated with dissatisfaction with carers’ relationships (that is, the relationship between carers and their partners, their children and their parents, and the relationship between carers’ partners and children), it did seem to affect carers’ satisfaction with how their children got along with one another. This is consistent with research showing the negative impact of caring for a person with a disability on non-disabled siblings, perhaps because of the reduction in attention they receive (see Higgins, Bailey, & Pearce, 2005).

Conflict is the aspect of family functioning that carers most frequently see as problematic (one in three identified this aspect as a problem). Carers of someone with a psychiatric disability are the most likely to report two or more problems in family functioning, with carers of someone with a physical disability the least likely. Poor family functioning is associated with greater care needs of the person with a disability, suggesting that the level of impairment is a good proxy measure of the likely impact of caring for someone with a disability on broader family relationships.

The report also provides new data on the timing and risk of increased arguments and relationship breakdown between carers and their partners since caring began. When a partner is being cared for and there is a relationship separation, the carer will usually cease being a carer, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, when examining separations and arguments, we restricted the sample to carers of a person with a disability who was not a partner. The results showed a heightened risk of arguments between carers and their partners shortly after commencement of caring, but an even distribution of the risk of relationship separation over time (after accounting for the number of carers still caring in each subsequent year). Almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring. These data suggest that support services that focus on addressing relationship conflict in the first year of caring and target carers under the age of 50 may reduce separations and arguments between spouses.

**Hours of care**

Sixty per cent of carers reported that they cared for the person with a disability for more than 100 hours per week. The 100 or more hours of care per week was likely to include the time associated with direct care as well as the time associated with monitoring the person with a disability (being “on call”). While the number of hours of caring may not always represent direct care, even being on call has implications for the lives of the carer and their families. Carers may not feel that they can leave the person in their care by themselves, which has implications for engaging in a social life outside of the house, independent of the carer, and also in employment.

**Multiple care responsibilities**

Thirteen per cent of primary carers cared for two or three people with a disability. In addition, almost one in three cared for at least one child along with the person with a disability (who could also be a child). Caring for more than one person with a disability and/or caring for a person or child with a disability while caring for other children were associated with carers having significantly worse mental health and vitality and higher rates of depression. Moreover, carers aged 18 to 50—the age when they would most likely be caring for children—had the worst mental health and vitality and the highest rates of depression. These data suggest that carers raising children (both with and without a disability) or those caring for multiple family members with a disability are under significant stress.

**Support services**

The use of support services by families was also explored. Although the focus of the survey was not on the support needs of carers, we asked one general question on the types of services carers
and their families used. Almost half of carers’ families did not use any support services, with the most commonly used services being respite care (13%) or a general practitioner (11%). The general nature of the question may have led to some underestimation of the number of services used by families. However, underestimation of service use was unlikely to be large, as several services, including respite, were specifically mentioned by interviewers. Few families reported using respite care—three out of five used respite for less than 20 hours per month, although close to one in five used it for more than 50 hours per month.

Summary

This report has documented the significant emotional costs for all family members—the primary carer, the person with a disability and other family members—associated with caring. Carers raising children (both children who have a disability and those who do not) or caring for multiple family members with a disability were at particular risk of worse mental health outcomes. The evidence in this report also suggests that aspects of the family environment (such as good family functioning and adequate support to the carer) are critical to the good mental health of family members and the physical health of carers. However, there are relationship costs for some groups; for example, one in three carers under the age of 50 years had separated from their partner since they started caring. The economic costs to the carer and their families were also considerable. Many carers gave up work to care for the person with a disability, and three-quarters of those who were not employed expressed a desire to work. Also, compared to families from the general population, a greater proportion of carers’ families suffered from greater financial hardship.

This report documents the substantial social, emotional and economic costs of caring for a person with a disability, not only for the primary carer but also for the family. The challenge for policy makers and the Australian community is to develop policies and an environment that minimise these costs so that families can care for their relatives with a disability.

3. Interviewers asked the following question: “Could you please tell me whether you or [the person with a disability] (or anyone else in your household) use any disability services like respite, counselling, disability employment services or carer support services”.

4. When a partner is being cared for and there is a relationship separation, the carer will usually cease being a carer, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, we restricted the sample to carers of a person with a disability who was not a partner.
SECTION A
“When you’re a carer, you need to realize that you’ve got to take care of yourself, because, not only are you going to have to rise to the occasion and help someone else, but you have to model for the next generation.” Naomi Judd (2004)

A measure of the success of a society is the extent to which those requiring care because of disability or old age receive the care they need in a dignified way. In Australia, a great deal of care is provided informally, often by family members. More than one in ten adults (13%) provide some assistance to someone who needs help because of disability or age. Of these carers, about one in five is the primary carer (Australian Bureau of Statistics [ABS], 2004). This means that around 2.4% of Australian adults (that is, approximately 474,600 primary carers in Australia) provide primary ongoing help or supervision to someone who needs help because of disability or age.

It is widely recognised that those who provide unpaid care make a major contribution to society, and the efforts of carers are widely applauded. There is an increasing recognition of the economic significance of informal care. Access Economics (2005) estimated the annual value of informal care in Australia ranged from $4.9 billion to $30.5 billion (in 2005 dollars), depending upon the method used to estimate the economic value of caring.

Caring can have an impact upon the carer. While we know quite a lot about the impact of caregiving upon the physical, mental or emotional health of carers (Pinquart & Sorensen, 2003), little is known about how the caring role affects family relationships. Understanding the impact of long-term caring upon carers and their families is particularly important given the growth in recent years in the number of people requiring care (and hence the increase in demand for carers), coupled with projections of the continued growth in demand for carers (e.g., NATSEM, 2004). The increasing demand for carers is in part a consequence of the structural ageing of the population (NATSEM, 2004). It is also a consequence of the shift from institutional care to community care for adults with a disability. There is some evidence that this shift has increased the burden on carers (Tolhurst, 2001).

The limited Australian research available suggests that caring for a person with a disability can limit the social networks of the carer (Schofield et al., 1998) and may have a negative effect on family cohesion and flexibility and marital happiness (Higgins et al., 2005). Moreover, poorer family relationships have also been associated with greater carer burden (Schofield et al., 1998) and depression and anxiety (Edwards & Clarke, 2004). While the employment rates of carers have been documented as being lower than those of non-carers, there is little Australian research that examines the causal impact of caring on paid employment (Bittman, Hill, & Thomson, 2003).

5. The 2003 Australian Bureau of Statistics Survey of Disability, Ageing and Caring (ABS, 2004) defines a “carer” as “a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to ‘everyday types of activities’, without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: cognition or emotion; communication; health care; housework; meal preparation; mobility; paperwork; property maintenance; self care; and transport” (p. 71). A “primary carer” is defined by the ABS as “a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care)” (p. 77).

6. NATSEM, the National Centre for Social and Economic Modelling, (2004) projected that the number of older Australians needing assistance because of severe or profound disability will rise by 160% from 2001 to 2031.
2007; de Vaus, 2004; Lee & Gramotnev 2007). Much of the research to date is based upon small and unrepresentative samples and therefore cannot be generalised. Another limitation of the Australian and international research is that it has focused on the primary carer and, as a consequence, much less is known about the effect that caring for a person with a disability has on other family members and the nature of family functioning (family dynamics) (see Chapter 5).

Who provides care for people with a disability?

The Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC) estimated that there were 474,600 people who were the primary carers of a person because of disability or age. Seventy-one per cent of these primary carers were women and the largest age group among primary carers were 45 to 54 years old (ABS, 2004). The main disabling conditions for younger people being cared for were intellectual and developmental disorders, whereas for older people physical conditions predominated (Australian Institute of Health and Welfare [AIHW], 2004).

The proportion of primary carers in the Australian population increases with age. One per cent of 18- to 24-year-olds are primary carers and this increases with age until 5% of 55- to 64-year-olds are primary carers (and stays around 5% for older age groups) (ABS, 2004).

The SDAC 2003 data and other studies confirm that the burden of care falls unequally on women. Gender differences have been found in relation to: (a) who provides care; (b) the patterns of care provided (consistent with the generally gendered nature of the division of labour in most household tasks); and (c) carer burden or distress. For example, Essex and Hong (2005) found evidence of a traditional division of labour for most tasks among older married parents caring for adult children with an intellectual disability—with women shouldering most of the caregiving tasks. While the majority of carers are not employed, even when carers are employed there is still an imbalance in the amount of care provided by men and women. For instance, Neal, Ingersoll-Dayton, and Starrels (1997) noted the differential impact of the gender imbalance in the provision of care:

Among employed caregivers of elders, nearly all studies have revealed a more profoundly negative effect on work–family conflict and work-role strain for women than men. (p. 805)

Increased labour force participation of women, combined with these gender differences, raises concerns about the availability of carers.

Our understanding of the impact of caring on a broad range of measures of wellbeing of carers, family members and family relationships has been limited to date by a lack of representative surveys with a large enough sample of carers that combine measures of health, family relationships and economic outcomes. In order to begin to fill this gap, the Families Caring for a Person with a Disability Study (FCPDS) was conducted in 2006. The sample for the FCPDS consisted of 1,002 primary carers receiving Carer Payment or Carer Allowance (see Chapter 2 for a description of these payments).

The FCPDS investigates the impact on carers who received Carer Payment and/or Carer Allowance, and their families, of caring for a person with a disability. The aims of this report are to:

- examine the effect of caring on family and social relationships;
- document the social, emotional, physical and financial impact on families of caring for a person with a disability;
- examine the effect of caring on labour force status.

In this study, we focus on primary carers who are adults. However, we are aware that there are unique issues faced by children and young adults who have care responsibilities for adults or other family members (Williams, 1996). A study specifically focusing on children who have caring responsibilities would be better placed to address these unique issues.
Outline of the report

Chapter 2 provides a description of Carer Payment and Carer Allowance, as well as the policy background of these government payments for caring for a person with a disability. It also details the growth in recent years in the cost of Carer Payment and Carer Allowance and the number of carers receiving them, and describes the characteristics of people receiving these payments.

Section B incorporates two chapters that describe the methodology of the FCPDS and the demographic characteristics of the participating carers and their families. Specifically, Chapter 3 details the methodology of the current study, including the procedure, non-response analysis, representativeness of the survey, information about the measures and statistical analyses. Chapter 4 describes the demographic characteristics of the sample of carers, the people with a disability that they care for and other family members in the carers’ households. The chapter also documents the financial situation of carers’ families and the use of services by carers, people with a disability and other members of the family.

Section C focuses on family relationships and support networks. Chapter 5 reviews studies examining the impact that caring for a person with a disability has on the primary carer (and, where information is available, on family members), with respect to family relationships and support networks. In the literature review chapters in the report, we are selective in the papers we review as that we focus on large-scale representative studies (where available) to ensure that the evidence reviewed was based on representative data. Chapter 6 presents empirical results of the FCPDS with respect to the relationships, family functioning and support networks of carers and their families, and factors associated with these variables.

The mental and physical health of families caring for a person with a disability is the focus of Section D. Chapter 7 reviews studies examining the emotional and physical impact of caring for a person with a disability on the primary carer (and, where information is available, on family members). The empirical results are described in Chapters 8 through 10. Chapter 8 compares the mental health of carers to the general population, as well as identifying variables that were associated with mental health. Chapter 9 focuses on the mental health of other family members and the factors associated with their mental health. Carers’ physical health and correlates of poor physical health are also the focus of Chapter 10.

Section E comprises Chapter 11, which reviews the literature and presents empirical data on the employment status of carers and family labour force status.

In the final section, Chapter 12 provides a summary of the main findings of the report, a comparison of findings to prior research and a discussion of some policy implications of these findings. Future research directions are also explored in this chapter.

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7. A literature review of employment issues and labour force status for carers is incorporated into the employment empirical chapter (Chapter 11).
8. Appendix A documents the literature search process in detail.
Carer Payment and Carer Allowance policy background

Marcia Kingston

The Australian Government provides financial assistance to carers through the income support system. The main payments available to carers are Carer Payment and Carer Allowance. The details of these payments and the policy background are described in this chapter. There are also government initiatives that aim to improve access to respite care as well as initiatives aimed at improving the quality and accessibility of information available to carers.

Carer Payment

Carer Payment is an income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. Like other income support payments, Carer Payment is targeted at those most in need. It is subject to income and assets tests and is paid at the same rate as other social security pensions. At 20 March 2008, the maximum single rate of Carer Payment was $546.80 and the maximum partnered rate was $456.80 per fortnight. Income testing arrangements mean that carers who participate in the workforce may have their Carer Payment reduced when their income level reaches a prescribed level, and the payment can stop altogether if the carer earns more than the upper level of the income test.

Where the person being cared for is aged 16 years or over, it is a requirement that the care receiver’s level of care needs are assessed using the Adult Disability Assessment Tool (ADAT). It is designed to provide access to Carer Payment for carers of people with similar levels of disability, even where the cause and type of disability differ. The ADAT measures the amount of help required to undertake activities of daily living, such as mobility, communication, hygiene, eating and a range of cognitive and behavioural areas. This may include supervising and prompting the care receiver to undertake these daily activities.

In the case of children under 16 years of age, Carer Payment is available to carers of children who have a profound disability, or two or more children who, together, require a level of care that is at least equivalent to the level of care required by a child with a profound disability. The eligibility criteria are stringent and focus on the high level of care required by the child. The criteria are not targeted at particular medical conditions, and the payment is not extended to carers of children with moderate disabilities.

Table 2.1 documents the history of the major changes to Carer Payment legislation and policy over the years.

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9. Both Carer Payment and Carer Allowance are the responsibility of the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs and are delivered to the community by Centrelink, the Commonwealth agency responsible for delivering a range of social welfare payments and services.
10. Carer Payment is also available to carers who are of Age Pension age.
Carer Allowance is a supplementary payment available to people who provide daily care and attention in a private home to a person who has a disability, severe medical condition or who is frail aged. Carer Allowance is not taxable or subject to an income and assets test. It can be paid in addition to Carer Payment or other social security income support payment. At 20 March 2008, the rate of payment was $100.60 per fortnight.

There are adult and child streams of Carer Allowance, with different assessment methods used to assess the care receiver. Up until 1998, the adult and child streams of Carer Allowance had quite different histories. Table 2.2 provides a history of the major changes made to Carer Allowance legislation and policy. Like Carer Payment, where the care receiver is an adult aged 16 years or over, eligibility includes an assessment of the care needs of the person requiring care, using the ADAT.
Where the care receiver is a dependent child under 16 years of age, the child is firstly assessed against the Lists of Recognised Disabilities (LORD). The LORD contain certain disabilities and medical conditions that are consistently severe enough to qualify the parent or carer for the allowance. If a child’s medical condition or disability is not on the LORD, they are assessed using the Child Disability Assessment Tool (CDAT). The tool measures the severity of disability by assessing whether the child functions according to standards appropriate to their age. The child’s ability is measured in a series of functional categories: language skills, self-care skills, social and community skills, and fine and gross motor skills. Additionally, behaviour is taken into account where it is significantly affected by the disability, along with special care needs.

Carer Allowance can only be paid to the same carer in relation to the care they provide for up to two adults with disabilities. However, there is no limit on the number of dependent children in relation to whom a parent can be paid Carer Allowance.

Growth in the payments

There has been large growth in the number of people accessing Carer Payment and Carer Allowance (see Figure 2.1), especially over the last several years. Consequently, expenditure on these programs has increased dramatically (see Figure 2.2). Since 1999–2000, the number of people receiving Carer Payment grew by 145% and expenditure increased by 283%. During the same period, the number of people receiving Carer Allowance increased by 102% and annual expenditure rose by 223%. These increases reflect:

- demographic changes, such as the ageing of the population, and the associated increase in the incidence of people suffering from disability;
- greater public awareness of the two payments;

**Table 2.2 Major changes to Carer Allowance legislation and policy, 1974–2006**

<table>
<thead>
<tr>
<th>Date</th>
<th>Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>1974</td>
<td>Handicapped Child Allowance was introduced. Distinction made as to degree of disability, and income test applied in some cases.</td>
</tr>
<tr>
<td>1978</td>
<td>Became payable in respect of students aged 16 to 24 years.</td>
</tr>
<tr>
<td>1987</td>
<td>Replaced by Child Disability Allowance (CDA); eligibility was based on the requirement that the child required more care and attention. No income test applied.</td>
</tr>
<tr>
<td>1993</td>
<td>Temporary cessation of care that is allowable increased from 28 to 42 days per calendar year.</td>
</tr>
<tr>
<td>1998</td>
<td>Introduction of the Lists of Recognised Disabilities (LORD) and the Child Disability Assessment Tool (CDAT) to assess eligibility. Temporary cessation of care that is allowable increased from 42 to 63 days per calendar year. Health Care Card eligibility was extended to carers who did not qualify for the fortnightly payment but had a child who required substantially more care and attention than a person of the same age without disability.</td>
</tr>
<tr>
<td>1999</td>
<td>Carer Allowance was introduced. It combined CDA and the Domiciliary Nursing Care Benefit, which was administered by the Department of Health and Aged Care, and was paid to carers of adults who required a nursing home level of care. Introduction of Adult Disability Assessment Tool (ADAT) to assess eligibility for carers of people 16 years and over. Introduction of provision to enable carers to continue to receive Carer Payment for up to 63 days a year when the person they care for is hospitalised and they participate in their care.</td>
</tr>
<tr>
<td>2002</td>
<td>Four special care needs were added and a number of minor amendments were made to refine the operation of the CDAT.</td>
</tr>
<tr>
<td>2004</td>
<td>Eligibility extended to carers of adults who do not live with the person to whom they provide substantial levels (20 hours per week) of personal care on a daily basis.</td>
</tr>
<tr>
<td>2005</td>
<td>Some disabilities and medical conditions were added or modified on the LORD.</td>
</tr>
<tr>
<td>2006</td>
<td>Backdating provisions set at 12 weeks for carers of adults and children. Diabetess mellitus type 1 added to the LORD.</td>
</tr>
<tr>
<td>2007</td>
<td>A Health Care Card (HCC) was extended to all 16–25 year old full-time students who held a Carer Allowance (Child) HCC on the day before their 16th birthday. The card is a claimable card, valid for 12 months at a time. An annual $1,000 supplement (Child Disability Assistance Payment (CDAP)) was introduced for each child with disability for whom the carer was receiving Carer Allowance (Child) on 1 July, to help purchase assistance for that child.</td>
</tr>
<tr>
<td>2004–07</td>
<td>One-off carer bonuses of $600 were paid to eligible Carer Allowance recipients for each care receiver.</td>
</tr>
</tbody>
</table>

Source: FaHCSIA
an increase in the number of people with disability and medical conditions being cared for at home; and
changes to qualification criteria that have extended eligibility of these payments to a wider group.

Characteristics of people receiving Carer Payment

As at June 2007, there were 116,614 people who were receiving Carer Payment. The majority of these people cared for adults, and two-thirds of payment recipients were female (the proportion

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**Figure 2.1** Number of recipients of Carer Payment and Carer Allowance, 1999–2000 to 2006–07

**Figure 2.2** Expenditure on Carer Payment and Carer Allowance, 1999–2000 to 2006–07
of females has been increasing every year). More than a third of people receiving Carer Payment were aged between 50 and 59 years and nearly 65% were partnered. Most Carer Payment recipients were on the maximum rate of pension, with only 13% having income from employment that was sufficient to reduce the amount of Carer Payment received. While less than 1% of recipients had been on the payment for more than 15 years, nearly 75% had been receiving the payment for less than 5 years.

**Characteristics of people receiving Carer Allowance**

As at June 2007, there were 393,263 recipients of Carer Allowance. Of these people, 278,602 were caring for adults, 109,118 were caring for children under 16 years of age and also 4,902 recipients were caring for both adults and children. Of those caring for adults, 32% were male and 68% were female; 94% of those caring for children were female.

There is a wide range in age of Carer Allowance recipients, and the age structure differed between those receiving Carer Allowance for caring for an adult and those who are caring for a child. Carers of children tended to be younger than carers of adults, with over half of the former being under 40 years of age, while over 40% of carers of adults were aged between 60 and 79 years.

Over half of Carer Allowance recipients also received an income support payment such as Carer Payment, Age Pension, Parenting Payment or Disability Support Pension. Just under half of Carer Allowance recipients had only been on the payment for less than 3 years, but just over 20% had been receiving the payment for 6 years or more.

At June 2007, 393,263 carers provided care for 292,491 adults and 129,298 children under 16 years of age. Additionally, there were 19,030 children for whom a Health Care Card was received.

There were some differences between the primary medical condition of adult and child care-receivers. The main types of medical conditions for adult care-receivers were musculo-skeletal disorders (22%), circulatory conditions (21%) and disorders of the nervous system (17%). For child care-receivers, the largest group had a learning disability (17%), followed by attention deficit hyperactivity disorder (ADHD) or attention deficit disorder (15%), and autism (14%).

While the history and purpose of Carer Payment and Carer Allowance are quite different, in recent times both have been characterised by a large growth in the number of people receiving these payments and the expenditure on these programs. By June 2007, over half a million people were receiving Carer Payment and Carer Allowance. With the ageing of the population, it is likely that the number of recipients of Carer Payment and Carer Allowance will continue to grow and issues to do with this group of people will continue to be a policy focus.
SECTION B
THE FAMILIES CARING FOR A PERSON WITH A DISABILITY STUDY
Ben Edwards

This chapter describes the process by which the sampling and fieldwork for the Families Caring for a Person with a Disability Study (FCPDS) were conducted. The major steps involved in the process of designing the interview schedule and the recruitment and interviewing of the participants are outlined. Response rates are presented and the demographic characteristics of the sample are then compared with the population.

Overview of the sampling procedure and fieldwork

The sample was obtained through random selection from the Centrelink administrative database of carers over 18 years of age who were at the time receiving the Australian Government Carer Allowance or Carer Payment. As discussed in Chapter 2, those receiving Carer Payment may also be eligible for Carer Allowance. The interviews were conducted using computer-assisted telephone interviewing.

The sample selection and recruitment involved the following steps:

1. A random sample of 5,000 people receiving Carer Payment and/or Carer Allowance in June 2006 was selected from the Centrelink administrative database.12
2. Selected Centrelink customers were sent a brochure advising them that they had been selected to be potentially contacted to participate in the survey and that if they did not want their contact details released to the fieldwork company, they needed to contact FaHCSIA to opt out of the study. The brochure also detailed the nature of the study and its aims (see Appendix B). Sixty-five carers opted out of the survey at this point, leaving a total of 4,935 potential respondents available for the survey.
3. Contact details and the type of payment received for the potential respondents were then provided to the fieldwork agency.13
4. The fieldwork agency contacted potential respondents by telephone. A total of 10,856 calls were placed to 2,126 sample people to achieve 1,00314 completed interviews. This equates to one completed interview for every 10.8 calls. The most commonly occurring call outcomes were: no answer (26.8%), “soft” appointment15 (26.5%) and answering machine (15.4%).

The survey collected information from primary carers about how their families cared for a person with a disability and the impact of this on their family.16 The average interview length was 34 minutes. The final sample size achieved was 1,002 carers.17

12. The Centrelink administrative list of 5,000 people did not include recipients whose telephone numbers were silent. Otherwise, all carers who were receiving Carers Payment and/or Carer Allowance were included.
13. The interviews were conducted by the Social Research Centre, Melbourne, in October and November 2006.
14. Participation in the survey was voluntary.
15. A “soft” appointment was when someone indicated they wanted to participate, but advised the interviewer to call back later at an unspecified time.
17. In this study, we focused on primary carers who were adults. However, we are aware that there are unique issues faced by children and young adults who have care responsibilities for adults or other family members (Williams, 1996).
As with all surveys, there was a level of non-response. Almost three-quarters (72.7%) of the carers with whom contact was made and who were eligible to be interviewed agreed to participate and completed the interview. This is a relatively high response rate for a telephone survey, particularly given that the interview was quite long.

Figure 3.1 provides detailed information about the CATI interview process. Of the 4,935 names provided to the fieldwork company, only 2,126 were used. In order to reduce the possibility of participation bias, batches of new numbers were progressively released to the telephone interviewers only after maximum effort had been put into attempting to contact the original set of carers. Of these, 261 had unusable telephone numbers, most commonly because the number had been disconnected (n = 196). Other reasons for numbers being unusable included them being wrong numbers, being a fax or modem number, not being a residential number, or the selected person not being known at the number. A further 201 carers had a valid telephone number, but it was not possible to contact the carer on that number. This occurred for a variety of reasons, including that the number was engaged at all attempts, there was an answering machine and calls were not returned, there was no answer, or because the carer was contacted and an appointment was made to conduct the interview at a later date, but that appointment was not kept because the period allocated for conducting the CATI interviews had expired. Of the 1,664 people who were contacted, 284 were out of scope, mainly because they said they were not carers or they were away for the duration of the interviewing period. Of the 1,380 in-scope carers with whom contact was made, 1,003 (72.7%) completed an interview. The response rate was not significantly different between those receiving only Carer Allowance (72.3%) and those receiving Carer Payment and/or Carer Allowance (74.0%).

Of the remaining 377 carers who were contacted, 240 personally refused to participate, while a further 39 household members refused on the carers’ behalf. There were a further 98 instances where it was not clear who refused—the carer or another household member.

Carers who declined to participate in the survey were asked their reasons for not wanting to participate. While not all of those who declined to participate gave reasons, many did. For carers, the most common reasons for refusal to participate were: not interested (39%), too busy (22%), or the survey was too long (8%) (Table 3.1). In some instances, the carer made no comment or just hung up (9%); this was the second most prevalent response from another household member who answered the phone (41%). A further 46% of members of the remaining carers’ households said that the carer was not interested.

<table>
<thead>
<tr>
<th>Table 3.1 Reasons for refusal to participate in the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondent</td>
</tr>
<tr>
<td>%</td>
</tr>
<tr>
<td>Not interested</td>
</tr>
<tr>
<td>Too busy</td>
</tr>
<tr>
<td>No comment or just hung up</td>
</tr>
<tr>
<td>25 minutes is too long</td>
</tr>
<tr>
<td>Too personal or intrusive</td>
</tr>
<tr>
<td>Don’t believe surveys are confidential or privacy concerns</td>
</tr>
<tr>
<td>Never do surveys</td>
</tr>
<tr>
<td>Don’t like subject matter</td>
</tr>
<tr>
<td>Don’t trust surveys or government</td>
</tr>
<tr>
<td>Get too many calls for surveys or telemarketing</td>
</tr>
<tr>
<td>Asked to be taken off list (add to Do Not Call Register)</td>
</tr>
<tr>
<td>Other reason</td>
</tr>
<tr>
<td>Total</td>
</tr>
<tr>
<td>Number of observations</td>
</tr>
</tbody>
</table>

Note: Percentages may not total 100% due to rounding.
Source: FCPDS 2006

18. $\chi^2 (1) = 0.60, p > .05$
Representativeness of the sample

One of the advantages of obtaining the sample from an administrative database is that it is possible to compare the characteristics of those who responded to the survey with those of the population from which the sample was obtained (that is, the total number of payment recipients in Australia). Table 3.2 presents data on the characteristics of the respondents and the population. The characteristics that can be examined are obviously limited to those contained in the administrative database. As can be seen from the percentages in Table 3.2, the characteristics of the respondents to the survey were very similar to the total population of carers who receive government assistance.\(^\text{19}\) Statistical tests also indicated that there were no significant differences for gender, state/territory and payment type considered; however, there were differences for the age of the carer. There were more carers aged 35 to 44 and 65 or more, and fewer carers aged

\(^{19}\) People who receive Carer Payment may also be entitled to and often receive Carer Allowance. Therefore, the Carer Payment demographic data in Table 3.2 includes some carers who also received Carer Allowance.
18 to 24 in the sample than in the population of payment recipients. In summary, with the exception of the age distribution of carers, the sample is representative of carers who receive Carer Allowance or Carer Payment for the characteristics examined.

Table 3.2 Characteristics of survey respondents and total population receiving Carer Allowance or Carer Payment

<table>
<thead>
<tr>
<th></th>
<th>FCPDS sample</th>
<th>Population of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22.5</td>
<td>26.2</td>
</tr>
<tr>
<td>Female</td>
<td>77.5</td>
<td>73.8</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–24 years</td>
<td>1.0</td>
<td>2.1</td>
</tr>
<tr>
<td>25–34 years</td>
<td>8.2</td>
<td>9.9</td>
</tr>
<tr>
<td>35–44 years</td>
<td>25.3</td>
<td>21.9</td>
</tr>
<tr>
<td>45–54 years</td>
<td>20.9</td>
<td>22.1</td>
</tr>
<tr>
<td>55–64 years</td>
<td>20.8</td>
<td>23.6</td>
</tr>
<tr>
<td>65 years or more</td>
<td>23.7</td>
<td>20.4</td>
</tr>
<tr>
<td>State</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACT</td>
<td>1.2</td>
<td>0.9</td>
</tr>
<tr>
<td>NSW</td>
<td>32.4</td>
<td>34.3</td>
</tr>
<tr>
<td>NT</td>
<td>0.5</td>
<td>0.5</td>
</tr>
<tr>
<td>QLD</td>
<td>21.5</td>
<td>19.5</td>
</tr>
<tr>
<td>SA</td>
<td>9.2</td>
<td>8.2</td>
</tr>
<tr>
<td>TAS</td>
<td>3.7</td>
<td>3.0</td>
</tr>
<tr>
<td>VIC</td>
<td>24.0</td>
<td>26.0</td>
</tr>
<tr>
<td>WA</td>
<td>7.6</td>
<td>7.7</td>
</tr>
<tr>
<td>Payment type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only Carer Allowance</td>
<td>74.8</td>
<td>77.8</td>
</tr>
<tr>
<td>Carer Payment (including those on both payment types)</td>
<td>25.2</td>
<td>22.2</td>
</tr>
<tr>
<td>Number of observations</td>
<td>1,002</td>
<td>471,815</td>
</tr>
</tbody>
</table>

Notes: Statistical tests showed that carers’ age was different (χ² (5) = 23.01, p < .01), but not the proportion of male and female carers (χ² (1) = 0.09, p > .01), their state/territory of origin (χ² (7) = 8.70, p > .01), or the proportion in each payment type (χ² (1) = 5.12, p > .01). Percentages may not total 100% due to rounding.

Sources: FCPDS 2006; population figures provided by Centrelink

The interview schedule

The survey\(^{20}\) comprised several modules focusing on a number of themes, including:

- Disabling condition and caring role;
- Care of person with disability;
- Household composition and demographic characteristics;
- Service use;
- Support networks;
- Family life events;
- Family relationships;
- Caregiver’s general health and wellbeing;

\(^{20}\) A copy of the survey, showing the specific questions asked, can be found on the Institute’s website at: www.aifs.gov.au/institute/pubs/resreport16/main.html
About your social life;
About education;
About work; and
Financial issues.

Wherever possible, the questions were sourced from valid and reliable measures or from widely used surveys, such as the ABS 2003 Survey of Disability, Ageing and Carers or the Household Income and Labour Dynamics in Australia (HILDA) survey. The use of standardised measures ensured that the information gathered was valid and reliable. In addition, these measures have also been used in other large-scale surveys of the general population, such as the HILDA survey, thus enabling data collected in the FCPDS to be compared to the general population who do not have caring responsibilities. There are several instances in the empirical chapters of this report where data from carers in the FCPDS are compared with data from the general population from the HILDA survey.

This section provides a summary of the standardised measures used in the survey.

**Mental health**

The five-item Mental Health Inventory from the Medical Outcomes Study Short Form 36 (SF-36), a widely used measure of health-related quality of life (Ware, Kosinski, & Gandek, 2002), was used to assess the mental health status of carers. Scores range from 0 to 100, with higher scores indicating better mental health status. People who score less than 52 have been found to satisfy the clinical diagnostic criteria for depression and related disorders. The sensitivity and specificity of this cut-off has been found to be high (Berwick et al., 1991). We used this cut-off as an indicator of carers with clinical levels of depression and a continuous score as an indicator of the carers’ mental health. The internal consistency of the scale was very good ($\alpha = .84$).21

Carers were asked whether they or other household members had been depressed or sad (even if they felt OK sometimes) for 6 months or more. The question was adapted from one of the items from the Kemper three-item screening measure for depression, which has been found to be a valid indicator of clinical levels of depression in nationally representative samples (Kemper & Babonis, 1992; Lanzi, Pascoe, Keltner, & Ramey, 1999). Carers were also asked in what year the depressive episode occurred and for how long (one year, a period of consecutive years, or multiple non-consecutive years). The format of these questions enabled the timing of depressive episodes since the family started caring to be estimated.22

There are several issues that need to be taken into account when interpreting data collected from this set of questions. First, although the questions used can be seen as being indicative of prolonged depressive symptoms, it was not a standardised diagnostic interview, which is the gold standard in terms of measuring clinical levels of depression. There is only one Australian national epidemiological study that we are aware of that has employed standardised diagnostic interviews—the 1997 National Survey of Mental Health and Wellbeing (Andrews, Hall, Teesson, & Henderson, 1999)—largely because of the time and costs associated with conducting such interviews. Consequently, for the purposes of this study, carers or family members who have reported experiencing depression for 6 months or more should be considered to have been at risk of having (i.e., highly likely to have) suffered clinical levels of depression over this time period.

Second, inaccuracies can be introduced when people are asked to retrospectively recall their mental health status. However, studies that have examined recall bias indicate that it is more likely that people fail to recall previous depressive episodes rather than provide overestimates (Patten, 2003).

21. Cronbach’s alpha is the average of all the correlations between items in a measure and, because it increases as the correlation between items increases, it is often used as a measure of the internal consistency of a scale.

22. In some instances where the person with a disability had a gradually deteriorating condition, it may have been difficult for the carer to recall when caring began.
Third, carers were asked to indicate whether other family members had experienced a prolonged period of depression. Research examining the validity of proxy reports of the mental health of people with a disability, and more generally, have found that mental health problems tend to be under-reported by proxies because feelings are not directly observable (Ball, Russell, Seymour, Primrose, & Garrett, 2000; McPherson & Addington-Hall, 2003; Todorov & Kirchner, 2000). It is less likely for there to be under-reporting of depression in the current study, as family members’ depressive symptoms needed to occur for 6 months or more for carers to report them. Previous research examining proxy reports of mental health problems has typically examined mental health problems in the last 4 weeks, so it may be that mental health problems that occur for a longer period of time would be less likely to go unnoticed by the proxy reporter. Nevertheless, there is still a possibility that carers may have under-reported family members’ experiences. Consequently, the estimates of depression of family members in this report should be considered to be lower-bound estimates.

**Vitality**

The vitality or energy levels of carers was assessed using the Vitality subscale of the Medical Outcomes Study Short Form 36 (SF-36). Scores range from 0 to 100, with higher scores indicating more vitality or energy. A four-item measure, the Vitality subscale has been found to be a valid and reliable measure in the general population as well as in other populations (Ware et al., 2002). The internal consistency was .83 in the current sample.

**General health**

General health was measured by the question: “In general, would you say your health is excellent, very good, good, fair or poor?” The question was drawn from the Medical Outcomes Study Short Form 36 (SF-36). Self-rated health has been found to be highly predictive of subsequent morbidity and mortality, independent of other factors (e.g., Jenkinson & McGee, 1998). Research examining this measure has found that this question reflects the presence of acute and chronic physical health problems (Idler & Benyamini, 1997).

**Relationship satisfaction**

Relationship satisfaction of the carer with other members of their family was also assessed, using a series of items that have been used in the HILDA survey. The carers’ satisfaction with their relationship with their partner, the person (or persons) with a disability, their children (not including the person with a disability), and their parents; the carers’ partner’s relationship with their children; and how the children got along with each other were all assessed. The relationship items have been widely used and have established validity. For example, low levels of relationship satisfaction with partners were associated with later marital separation (Heady, Warren, & Harding, 2006).

**Increased arguments with partner**

Carers were also asked: “Since you began caring for [name of person with disability], was there a period or periods in your life when the number of arguments with your spouse or partner increased significantly?” This item has been frequently used in standardised measures of stressful life events (Lin, Dean, & Ensel, 1986).

**Separation**

Carers were asked whether they had separated from their spouse or long-term partner since caring began.

**Family functioning**

Family functioning was assessed using a five-item scale. Three of these items were derived from the Family Relationship Inventory. Each of the three items used were developed to assess

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23. Proxy reports occur when one survey respondent provides information about the experiences of another. In this case, the carer is reporting on the mental health of other members of their family.
different dimensions of family functioning: family cohesion (the commitment, help and support family members provide for one another), expressiveness (acting openly and expressing feelings directly) and conflict (the open expression of anger and aggression) (Edwards & Clarke, 2005). To assess an additional dimension of family functioning—flexibility (the degree of flexibility within the family in dealing with new challenges)—an item from the Adaptability subscale of the Family Adaptability and Cohesion Scale IV was used (Olson, 1993). We developed a final item—“Our family copes with and recovers from times of hardship”—to assess family resilience. Carers were asked whether they strongly agreed, agreed, disagreed or strongly disagreed with each of the five items. For example, disagreeing with the statement: “There is a feeling of togetherness in our family” suggested low family cohesion, while agreeing with: “There is a lot of tension in our family” indicated family conflict. Previous studies of family functioning have indicated that problems in just one dimension of family functioning can have implications for mental health (Edwards & Clarke, 2005). For this study, we considered “family problems” to be where carers indicated they “disagreed” or “strongly disagreed” with that item (except for the conflict item, which was negatively worded, so we looked at where carers “agreed” or “strongly agreed” in that case). We also summed the number of family problems to indicate on how many of the five different dimensions of family functioning problems occurred.

Support needs

Support needs of the carer were assessed by the question: “Now thinking about the support you receive in providing care for [name of person with a disability] overall, do you feel that you need: a lot more support, a little more support or is the support you are getting now about right?” The question was adapted from a valid and reliable measure of social support—the Arizona Social Support Interview Schedule (Barrera, 1981).

Supportive behaviours

Supportive behaviours of family members and friends were assessed in some detail for the support they provided to carers and to the person with a disability. The support questions assessed the main areas of social support recognised in the wider social support literature—informational, emotional and practical assistance to the carer and the person with a disability (Barrera, 1981). With the assistance and comments from experts in social network measurement and analysis, Associate Professor Garry Robins and Dr Dean Lusher, the questions were tailored to be appropriate for measuring the social networks of carers and people with a disability (see also Robins, Pattison, Kalish & Lusher, 2007). Carers were asked whether there was someone they could turn to for informational support (advice about caring for the person with a disability), emotional support (availability to talk to about worries and fears in general and related to caring), practical support (help with everyday duties other than caring for the person with a disability, like going to the shops or doing housework), and financial support (extra money to assist in the caring role). Carers were also asked whether there was anyone other than them who provided the person with a disability with assistance with self-care, mobility or communication and, when appropriate, whether anyone else assisted the person with household management tasks like preparing meals, doing housework and shopping. The emotional support provided to the person with a disability by people other than the carer was also assessed.

Care needs

Care needs of the person with the disability were assessed through a series of age-specific questions that were used in the ABS Survey of Disability, Ageing and Carers and the 2006 Census. Carers were asked two sets of three questions about the care needs of the person with a disability. The first set of questions asked whether the adult person with the disability ever needed someone to help with or be with them for self-care activities (e.g., eating, showering, dressing or toileting), body movement activities (e.g., getting out of bed, or moving around at home or at places away from home), and communication activities (e.g., understanding or being understood by others).

24. The validity of proxy reports of tangible assistance from family and friends and social interaction with others has been supported by Conner, Conwell, and Duberstein (2001). However, proxies tended to under-report the level of emotional support provided.
The second set of questions asked whether the adult person with a disability needed someone to help with making friendships, interacting with others or maintaining relationships, coping with feelings or emotions, and making decisions or thinking through problems.

If the carer was caring for a child with a disability under the age of 7, then carers were asked whether the child needed assistance with self-care, body movement and communication activities more than other children his/her own age. For carers of children under the age of 15 (including children with a disability under the age of 6), instead of the second set of questions, carers were asked whether the child needed more care or help than other children his/her own age to interact or play with others, cope with feelings or emotions, and to manage his/her behaviour. Carers were given the following response options to the six care needs questions: “yes, always” (= 2); “yes, sometimes” (= 1); or “no” (= 0). The responses to the six questions were summed to form a scale score, with a possible range from 0 to 12. The internal consistency of the care needs scale was acceptable, with Cronbach’s alpha ranging from .63 to .78.\(^{25}\) depending on whether the person cared for was a child aged 7–14 years or a child under the age of 7 years.

For each of the 120 carers who were caring for either two (\(n = 114\)) or three or more people (\(n = 12\)) with a disability, the data for the person with a disability who had the highest care needs were used in the statistical analyses. To ease interpretation in the statistical analyses, the scores on care needs were divided into three groups: low (a score of 0 to 4), medium (5 to 8) and high (9 to 12).

**Type of disability**

Type of disability was derived from a question to the carer about the primary medical diagnosis or disability of the person being cared for. Carers’ responses to this question were categorised to form the five major categories used by the Australian Institute of Health and Welfare, using version 4 of the National Community Services Data Dictionary (National Community Services Data Committee, 2006). Two additional categories were also created. Consultations with experts in the field of disability indicated that often the person with the disability suffers from two or more medical or disabling conditions. Consequently, these were categorised as “multiple medical conditions”. In some instances, the carers’ responses did not provide sufficient information to categorise using the ABS definitions; in these cases we created an “unassigned” category. In this category, carers frequently said “old age” was the disabling condition and therefore it was unclear as to which area or areas the person with the disability had the impairment.

**Other caregiving characteristics**

Other caregiving characteristics included the number of people with a disability (one, two or three) who were cared for, hours of caring per week, years of caring, and caring for other people who were not disabled (e.g., children or ageing parents). As 120 carers were caring for either two (\(n = 114\)) or three or more people (\(n = 12\)) with a disability, the highest level of hours of caring per week and years of caring reported for any one of the people with a disability were used in the statistical analyses.

**Financial hardship**

Financial hardship was measured by asking participants whether their household had experienced four events. Respondents were asked: “Since January of this year, did any of the following happen to your family because of a shortage of money: could not pay electricity or the telephone bills on time; could not pay the mortgage or rent on time; pawned or sold something; asked for financial help from friends or family?” Originally included in the ABS 1998–1999 Household Expenditure Survey, these events were also included in the HILDA survey, along with three other events (the three other events were: “went without meals; unable to heat home; and asked for help from community organisations”). “Unable to heat home” was excluded as it was felt that this event was not an indicator of financial hardship in some of the warmer climates in Australia. “Asked for help from community organisations” was addressed in other areas of the survey and it was considered repetitive to include this event. “Went without meals” was the event with the lowest

\(^{25}\) See footnote 21 for an explanation of Cronbach’s alpha.
incidence of the remaining events in other surveys of income support recipients (after “unable to heat home” and “asked for help from community organisations” were excluded) and due to concerns about the length of the survey, this event was also excluded. Despite the reduction in the number of events, the four-item financial hardship scale had acceptable levels of internal consistency ($\alpha = .73$).

**Other socio-demographic variables**

Other socio-demographic variables included the carer’s gender, age and labour force status (employed, unemployed, not in the labour force); household income; and whether the individual was partnered. The number of adults and children in the household was taken into account when calculating household income. This is referred to as “equivalised household income”, which is a method of adjusting household income by household size to give a more valid measure of material standard of living. We used the OECD equivalence scale, where one adult is given a score of 1.0, then other adults are given a score of .5 and children are given a score of .3. Household income is then divided by the sum of the individual scores. For example, a household of two adults and two children would have an equivalence score of 2.1 and its equivalised income would be total income (e.g., $100,000) divided by 2.1 ($47,619).

**Statistical analyses for the report**

When comparing groups of individuals (e.g., males and females) on average scores, tests of statistical significance were calculated using a 95% level of confidence ($p < .05$). The confidence intervals are displayed on the relevant graphs by means of vertical confidence interval bars. Non-overlapping confidence intervals on two columns in a graph suggest that we can be 95% confident that the two values represented in the columns are significantly different.

When comparing percentages across groups of individuals, we employed a statistical test referred to as a chi-square test ($\chi^2$). In the context of this report, the chi-square test tells us whether the distribution of frequencies in two or more groups are different. For example, we tested whether there was a difference in the percentage of males and females that had been depressed. In cases when the chi-square test is statistically significant, we indicate the confidence level at which they are significant at the 95% level ($p < .05$), 99% level ($p < .01$) or 99.9% level ($p < .001$).
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-
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.
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

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

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 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

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

Note: Percentages may not total 100% due to rounding.
Source: FCPDS 2006

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

Source: FCPDS 2006
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, a psychiatrist or a psychologist.

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

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

Number of observations 1,002

Source: FCPDS 2006

Carers who used respite (n = 124) 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

<table>
<thead>
<tr>
<th>Hours of respite per month</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–10 hours</td>
<td>37.1</td>
</tr>
<tr>
<td>11–20 hours</td>
<td>21.0</td>
</tr>
<tr>
<td>21–30 hours</td>
<td>12.1</td>
</tr>
<tr>
<td>31–40 hours</td>
<td>5.6</td>
</tr>
<tr>
<td>41–50 hours</td>
<td>7.3</td>
</tr>
<tr>
<td>51 hours or more</td>
<td>16.9</td>
</tr>
</tbody>
</table>

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.
SECTION C
FAMILY RELATIONSHIPS AND SUPPORT NETWORKS
According to Pakenham (1998), “illnesses disrupt family dynamics, which then require a reorganization of effort” (p. 269). To understand the experiences of carers of people with disability, the broader context of the family and social environment in which the care takes place needs to be considered. These contextual factors include family relationships, marital relationships and support networks. The first section of this chapter focuses on family relationship issues, family coping, positive aspects of caring for family relationships and specific family relationship issues for families caring for people with particular types of disabling conditions. The literature on relationship separation in the context of caring for a person with a disability is then reviewed. Finally, the support networks of families caring for a person with a disability are examined.

The dimensions of family functioning

In the context of caring for a person with a disability, family functioning is of relevance because: (a) it influences the availability of emotional support for the person with a disability by buffering the stresses that families experience; and (b) it is related to the availability of direct care for the person with a disability (Mitrani et al., 2006). It is also dynamic, and changes over time in response to new demands. As Highet, McNair, Davenport, and Hickie (2004) noted:

the quality of such an environment may change progressively in response to illness-related factors, which include the chronicity of illness and its impact on social, economic and interpersonal functioning, as well as other adverse interactions with healthcare, social welfare services, and the employment and insurance industries. (p. 56)

Many dimensions of family functioning have been studied, and the research indicates that caring for a family member who has or develops a disability can have an impact. Table 5.1 documents the dimensions of family functioning that have been examined and provides a brief summary of findings from a selection of research studies.

The time and emotional energy involved in caring can significantly influence the dynamics of interactions within the family, often through the reduced availability of the primary carer to spend time with others. Hales (2007) presented Australian data showing that 17% of those providing care to a person with a disability other than their spouse stated that caring had placed a strain on the relationship. An even greater number of carers indicated that their relationships with other co-resident family members were negatively affected (22%). Some of the ways in which caring for a person with a disability influences family functioning are now addressed.

Family functioning in the face of stress

The research evidence seems to suggest a bi-directional relationship between family functioning and stress. For example, Mitrani et al. (2006) found that, as well as contributing directly to stress, family functioning was an important intervening variable that helped explain the relationship between distress (anxiety, depression and perceived health) and the objective burden of care. Higher levels of the objective burden of care were associated with lower levels of family functioning,
Table 5.1 Dimensions of family functioning and the impact of caring for a person with a disability

<table>
<thead>
<tr>
<th>Dimension of family functioning</th>
<th>Definition</th>
<th>Selected research on the impact of caring for a person with a disability</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adaptability</strong></td>
<td>The family’s ability to change its rules, roles and power structure in response to situational and developmental stress (Olson, Sprenkle, &amp; Russell, 1979). High levels of adaptability represent “flexibility”, and low levels represent “rigidity”.</td>
<td>Families where a member has a disability are more rigid (Martin &amp; Cole, 1993). Poor family adaptability was the most powerful predictor of carer depression (Deimling, Smeriglia, &amp; Schaefer, 2001). Parents of a child with an autism spectrum disorder had lower adaptability than population norms (Higgins et al., 2005).</td>
</tr>
<tr>
<td><strong>Cohesion</strong></td>
<td>The emotional bonding that exists between family members (sense of “togetherness” and interconnection); provision of help and support (Olson &amp; Tiesel, 1991). Low cohesion is seen as dysfunctional.</td>
<td>Parents of a child with an autism spectrum disorder had lower cohesion than population norms (Higgins et al., 2005). Parents of children with ADHD reported more problems with expressiveness (Pressman et al., 2006).</td>
</tr>
<tr>
<td><strong>Parent–child relationship satisfaction</strong></td>
<td>The degree of closeness or the quality of the relationship between children and parents. Often measured on a continuum from warmth through to hostility.</td>
<td>Primary care providers of children with autism spectrum disorder reported lower marital satisfaction than population norms (Higgins et al., 2005). Parents caring for a child with a disability have an increased risk of separation/divorce (Risdal &amp; Singer, 2004).</td>
</tr>
<tr>
<td><strong>Conflict</strong></td>
<td>Openly expressed anger and aggression (Moos &amp; Moos, 1986)</td>
<td>Bull (1998) found a range of dementia-related family loss and grief experienced by carers (e.g., loss of the “person”, sharing, contact, family unit, way of life, family role) that were related to change of roles. Role reversal in women caring for an elderly parent leads to conflict and role confusion (Murphy, 2000).</td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td>Verbal exchanges of information within the family; the ability to speak and listen to each other (Olson, 1993). Includes elements such as openness, sharing feelings, expressiveness, affective responsiveness and involvement, one-sided communication. Dysfunctional communication is masked or indirect (Epstein, Bishop, Ryan, Miller, &amp; Keitner, 1993).</td>
<td>Poorer family communication is associated with higher levels of distress in breast cancer patients (Hilton, 1994). Direct communication is associated with lower levels of anxiety in families of recently diagnosed cancer patients (Edwards &amp; Clarke, 2004). Parents of children with ADHD reported more problems with expressiveness (Pressman et al., 2006).</td>
</tr>
<tr>
<td><strong>Problem-solving and decision-making</strong></td>
<td>Instrumental problem-solving (e.g., about basic family tasks such as provision of food). Affective problem-solving (e.g., about emotional issues).</td>
<td>Wade, Carey, &amp; Wolfe (2006) showed that “family problem-solving interventions” are beneficial for families of children with acquired brain injury. This is a particularly salient aspect of family functioning in relation to illness or disabilities where families need to respond to new information and concerns, and make decisions about the current and future care of the person with a disability (Wade et al., 2006).</td>
</tr>
</tbody>
</table>
which in turn were associated with higher levels of anxiety, depression and perceptions of poorer health. Beach et al. (2005) reported that carers with poorer mental and physical health were more likely to provide lower quality care. They also found that having a carer with poor physical and mental health was a significant predictor of elder abuse—most commonly psychological abuse.

The increased time and energy spent caring for a family member with a disability (particularly by a mother, who often assumes the extra care responsibilities) reduces the physical and emotional time (and energy) available to other members of the family, particularly non-disabled siblings (Martin & Cole, 1993). Brothers and sisters of a child with a disability may also be affected in other ways. In addition to reduced care for non-disabled siblings from their parents, children of primary carers may also provide emotional support to the person with a disability and the primary carer. For example, Pruchno, Patrick, and Burant (1996) reported that non-disabled siblings have strong, close emotional ties to their siblings with chronic disabilities, but provide little functional support. Some studies report negative psychosocial consequences for these siblings, but these are usually dependent on the severity of the disabling conditions experienced (siblings of children with autism experience more negative psychosocial outcomes when compared with siblings of children with Down Syndrome) (Cuskelly & Hayes, 2004).

Given the increase in life expectancy of many people with chronic disabilities due to advances in medical care, many siblings also may in the future become the primary carer. In fact, a recent review suggested that the majority of siblings would take or are preparing to take responsibility for the care of their brother or sister with a disability (Cuskelly & Hayes, 2004).

Although there have been studies looking at the impact of caring on carers (e.g., ABS, 2004), currently, no large-scale or population-based studies exist on the impact more broadly on families of caring for a person with a disability (child or adult) in Australia. In order to improve our understanding of this growing part of the Australian community, a large-scale national study of carers and the impact of caring on families is needed.

Coping with a disability

Given that caring for a person with a disability can be stressful, it is important to examine factors that promote family resilience. However, it is first important to consider what is meant by the concept of family resilience. Hawley and De Haan (1996) defined “resilience”—in the context of families—as follows:

Family resilience describes the path a family follows as it adapts and prospers in the face of stress, both in the present and over time. Resilient families positively respond to these conditions in unique ways, depending on the context, developmental level, the interactive combination of risk and protective factors, and the family’s shared outlook. (p. 293)

The construct of “adaptability” is particularly relevant to understanding the ways in which a family member having a disability affects families. The birth of a child with a physical disability—or the discovery later on that a child is failing to meet normal developmental milestones—is a recognised stressor for families (Cuskelly & Hayes, 2004). Similar issues are likely to emerge for families who are faced with care responsibilities for adults (e.g., a sibling, an adult child, or a parent who develops a disability, mental illness or other physical condition requiring care). Part of the stress of caring is due to changes in roles, and the need to adapt to the new roles. Therefore, it is important to understand more about how the family adapts (particularly the ability to be flexible in the way individuals perform roles and tasks).

Based on transactional stress and coping theory, when faced with stressors (such as coping with care responsibilities for a family member with a disability), mental health outcomes are influenced by the coping strategies employed. According to Lazarus and Folkman (1984)—the classic theorists in this area—there are two major styles of coping that people employ in response to a stressful event (such as taking on the care responsibility for a family member with a disability): (a) problem-focused coping (that is, actively doing something to reduce the stressor, such as seeking social support, information or services); and/or (b) emotion-focused coping strategies (that is, regulating the emotional consequences of the event, such as “avoidance”). In general,
emotion-focused coping strategies are associated with more negative outcomes than problem-focused coping strategies.

**Differences in family members’ coping styles**

At the collective level, the more adaptive coping strategies match those found at the individual level—namely, that problem-focused coping (active behaviours to deal with the problem) are more beneficial than emotion-focused coping (mental and behavioural avoidance strategies) (Pakenham, 1998).

As will be discussed in Chapter 7, the levels of distress reported by care receivers and their partners are correlated. This raises the question of whether there are common coping strategies for couples, reinforcing the need to explore both individual and dyadic coping strategies. Pakenham (1998) found that “greater couple problem-focused coping was related to lower collective global distress” (p. 273). However, what was also important was the match between the coping strategies of each member of the couple. He found that “greater discrepancy between partners’ reliance on problem-focused coping was related to lower collective depression” (p. 273). Pakenham’s findings suggest that “both coping congruence and average level of couple coping are related to collective and individual adjustment” (p. 275). These findings highlight the complex set of interdependencies that develop between family members in the context of caring for a person with a disability.

**Positive effects of caring on family relationships**

Many carers also derive positive benefits from their care role (see Hughes, 2007). Parents often talk about the closeness of their relationship to the child with a disability as a positive outcome of caring (Hughes, 2007). For example, analysis of the ABS 2003 SDAC survey showed that 35% of carers stated that caring brought them close together, compared with 18% who said it placed a strain on the relationship, and 42% who identified no change (Hales, 2007). Siblings also develop good relationships with the child with a disability. Cuskelly and Gunn (2002) reported that siblings of a child with a disability reported more positive relationships in these families than in comparison families where there was no sibling with a disabling condition. Similarly, parents of children with an intellectual disability focused on the positive aspects of their lifelong caregiving role, and the positive impact on the quality of their family life (Jokinen & Brown, 2005).

**Chronic illness/disability and caring**

To highlight the family relationship issues, we draw on research looking at the experiences of those caring for family members with four different groups of families: families caring for a person with cancer or acquired brain injury, and children with a disability or attention deficit hyperactivity disorder.

**Cancer**

Edwards and Clarke (2004) examined a variety of dimensions of family functioning in relatives and newly diagnosed cancer patients, and their role in influencing depression and anxiety of both patients and family members. It was found, in particular, that poor expressiveness and problem-solving were related to elevated levels of depression. They concluded that “a diagnosis of cancer affects the whole family” (p. 570). As family members are likely to be providing care for the patient, family functioning in providing care for a family member with an illness or disability affects the wellbeing not just of the “patient” or person with a disability, but the broader family, including the carer.

**Acquired brain injury**

Similarly, Perlez, Kinsella, and Crowe (2000) showed the broad impact on families of caring for a patient with acquired brain injury. They found that, while primary carers (particularly wives) were at greatest risk for poor psychosocial outcomes, other family members who played a care role also displayed high levels of distress. Mean scores on the measure of dissatisfaction for various aspects of family life were above the mid-point for the person with the brain injury,
their primary carer and other carers in the family. In particular, they noted the high level of dissatisfaction reported by other family members (mainly siblings).

**Children with a disability**

Particular developmental issues are relevant when discussing the impact that caring for a child with a disability has on families. There is general agreement in the literature that parenting a child with a disability is associated with higher levels of stress (Cuskelly & Hayes, 2004). In turn, this stress is likely to impact on relationships and family functioning. For example, researchers have found higher levels of maternal stress, family strain, lower social support, and greater use of avoidant coping strategies associated with parenting a child with autism spectrum disorder (Higgins et al., 2005; Montes & Halterman, 2007). Parents of a child with an autism spectrum disorder also had lower adaptability and cohesion and more problems with expressiveness than population norms (Higgins et al., 2005; Pressman et al., 2006). Summers (2003) noted that the stress of caring for a child with an intellectual disability also appears “to vary with the characteristics of the child, with parents who have children with problem behaviours reporting higher levels of stress” (p. 778). Despite the stressful nature of caring for a child with a disability, Cuskelly and Hayes noted that many parents were remarkably resilient. Factors involved in this resilience were reported to be improved coping strategies of parents over time and improvement in services.

**Attention deficit with hyperactivity disorder**

In a sample of sibling pairs where one child has ADHD, Pressman et al. (2006) found that “family conflict is significantly associated with sibling similarity in functional impairment associated with ADHD” (p. 349), accounting for 40% of similarity between ADHD-affected sibling pairs. Pressman et al. noted that:

> these data underscore the strong links between impairment in children with ADHD and family environment as well as the fact that different processes and mechanisms may contribute to impairment in different children within the same family. (p. 353)

Family functioning in the context of a developmental disability affects not only the person with a disability, but other family members. It is difficult to disentangle, however, whether the disability causes poor overall family functioning, which then leads to individual maladjustment of a sibling—or whether a child’s maladjustment to having a sibling with a disability itself leads to the overall poor family functioning. Familial factors are an important environmental influence on children who are at risk of negative outcomes, including children with a disability.

**Relationship separation and caring for a person with a disability**

A meta-analysis of six studies investigating the incidence rates of separation or divorce in families of children with and without disabilities showed that caring for a child with a disability was associated with a higher rate of separation or divorce (Risdal & Singer, 2004). In large-scale epidemiological studies, researchers have also reported higher rates of divorce or separation in families caring for a child with a disability than in other families. For example, data from the 1994 and 1995 disability supplements of the National Health Interview Surveys (NHIS) in the US (n = 3,362) indicated that there were higher percentages of families with school age children with a disability who experienced divorce (14.3% versus 11.4%) and separation (8.2% versus 5.4%) (Witt, Riley & Coiro, 2003). Other analyses of the 1981 disability supplement of the NHIS have also shown that white women were about 3% more likely to divorce if their child aged between 3 and 15 had a physical health condition (Corman & Kaestner, 1992).

A recent study of data from the 2000 US Census also suggested that divorce and separation rates are higher for families with a child aged 5 to 15 years with a disability (Cohen & Petrescu-Prahova, 2006). Children with a disability were 1.64 times more likely to live with a single parent

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28. Meta-analysis is a statistical method of synthesising the results of several quantitative empirical studies. As this technique accounts for the size of the samples and aggregates results across studies, it enables more precise estimates than analyses of any single study might yield.
than both parents. A more recent analysis of 3,920 families from US cities also suggested that having a child with poor health decreased the probability of parents living together 12 to 18 months after the child’s birth by 10%\(^{29}\) (Reichman, Corman, & Noonan, 2004).

It is important to note that other studies, with smaller samples of families with children with a disability, have not reported significantly higher rates of divorce and separation than found in the general population (e.g., Graefe & Lichter, 1999). In fact, some early studies of families with a child with Down syndrome found the rate of divorce was half the rate of the general population (Gath & Gumley, 1986). A very recent large-scale study found divorce rates among families with Down syndrome to be lower than families with a child with no identified disability and a child with a birth defect (Urbano & Hodapp, 2007).\(^{30}\)

In sum, the literature is dominated by US studies and we were unable to identify any Australian studies that have compared divorce or separation rates of families caring for a person with a disability. Moreover, all of the studies we reviewed examined divorce or separation rates in families caring for a child or adolescent with a disability, even though many families care for adult children, or partners who have a disability.

Support networks in families caring for a person with a disability

**Perceptions of support**

Much of the literature examining social support has focused on carers’ perceptions of support from friends or relatives (Magliano et al., 2006; Schofield et al., 1998). Perceptions of support have robust associations with carers’ mental health, but only small associations with physical health. A meta-analysis of correlates of carers’ depression showed that carers who perceived that they had more social support had lower levels of depression (Pinquart & Sorensen, 2007). Of all the variables examined, social support had the second strongest association with carers’ depression. The same pattern of association between carers’ perceptions of social support and physical health was also observed; however, the size of the association was only small. In the large-scale, longitudinal, population-based Victorian Carers study, Schofield et al. (1998) also reported that female carers had lower levels of social support than females who did not have caring responsibilities. People caring for someone with a physical disability reported that they had more support than those caring for a person with dementia or undiagnosed memory loss.

The Victorian Carers study confirmed that the level of perceived support by carers depended on the actual number of support people in their support network (Schofield et al., 1998). Larger support networks were also associated with greater life satisfaction and less resentment and anger about caring for the person with a disability (however, carers’ anxiety, depression, feelings of overload and physical health were not associated with the size of their support networks).

Although it is difficult to address directly the perceptions that carers have of support, public policies can be used to address the availability of support, through such things as encouraging family-friendly, flexible work practices to enable a broader group of people to assist with the care of the person with a disability and/or to support the primary carer. Given that the perception of the available support has a positive impact on the level of carers’ wellbeing, it is important that carers are aware of the availability of these services and know how to obtain them. In this respect, services that disseminate relevant information to carers about such supports play a significant role.

**Social networks**

Less is known about carers’ actual social contacts and social networks than perceptions of social support. The available evidence does seem to suggest that carers’ social lives are affected by caring. One Italian study of 709 carers of people with schizophrenia, 646 carers of patients with physical diseases (e.g., heart, brain, renal and lung diseases, or diabetes) and 714 people from the general population reported that relatives of people with schizophrenia and physical diseases had

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29. In this study, approximately three-quarters of the parents were unmarried when the child was born.
30. There were 647 families with a child with Down syndrome, 10,823 with birth defects and 361,154 with no disability (Urbano & Hodapp, 2007).
significantly lower levels of social contacts than the general public, even when controlling for a range of socio-demographic variables (Magliano et al., 2006). Similar analyses also revealed that carers of a person with schizophrenia also had significantly lower levels of practical support (e.g., someone to help with housework or run errands) and emotional support (e.g., someone to talk to or be reassured by) than carers of a person with a physical illness and people from the general public. The same paper also reported that 15% of relatives of people with schizophrenia and 17% of relatives with physical diseases said that their social relationships had worsened in the last year compared to 6% of the general public. Another study in Sweden that compared 783 carers and 4,278 non-carers who were aged 75 years or over reported that carers had smaller social networks than people who did not have caring responsibilities (Ekwall, Sivberg, & Hallberg, 2005).

In Australia, the 2003 ABS Survey of Disability, Ageing and Carers (2004) provides some insight into how the social networks of carers are affected by caring for a person with a disability. Just over half of the carers indicated that their circle of friends was unaffected (55%), and even a small minority (3.3%) indicated that their circle of friends had increased as a result of caring of the person with the disability. However, almost a quarter (23.9%) of carers indicated that they had lost or were losing touch with existing friends since they had started caring. A limitation of the ABS data is that carers were asked to report retrospectively on changes in their social network. For example, some carers may have been caring for the person with a disability for many years and it may have been difficult for them to remember what their social network was like prior to caring. Moreover, the influence of caring on carers’ social network may have changed over time as the care needs of the person(s) with a disability had increased or decreased. It is important to note that the 2003 ABS Survey of Disability, Ageing and Carers asked carers to give a global judgement of the effect that caring had had on their social network, without reference to any particular time period, or the frequency of social interactions.

The Victorian Carers study, the other large-scale Australian study, focused on carers’ support networks and provided detailed information on how carers’ social networks were affected (Schofield et al., 1998). Eighty-four per cent of carers reported that they received help from two other people. Larger support networks were evident when carers were female, a parent or offspring of the person with a disability and worked part-time (compared to non-workers). More support people were also evident when the person with a disability was female and under 21 years of age.31

Very few studies have documented the demographic characteristics of people in carers’ social networks; however, the Victorian Carers study collected some demographic information about the 1,770 people who supported the 976 carers (Schofield et al., 1998). One in four were the carers’ offspring (26%), with carers’ siblings (19%) and spouses (18%) the next most prevalent groups of supporters. As the sample of carers in that study was older (65% were 45 years of age or more), 7% of support people were parents, with other relatives also playing a role (14%). Fifteen per cent of support people were not relatives of the carer.

Filial relationships between people who provided support to the carer and the person with a disability were important determinants of the types of relatives who provided support (Schofield et al., 1998). For example, for carers looking after their parent, 75% of those providing assistance to the carers were the carers’ siblings. Children of carers mainly provided support when the carer was caring for their spouse (that is, the child’s other parent) or their parent (that is, the child’s grandparent). Carers’ parents-in-law typically provided support when the person with a disability was the parents-in-law’s child or grandchild.

**Types of support**

Often a distinction is made between different types of support provided by social network members, as they can be associated with different outcomes for the individuals being supported. Schofield and colleagues (1998) reported that higher levels of emotional support provided by network members were associated with higher levels of negative mood and resentment of carers.

31. The size of the support network was not associated with the type or severity of the condition or the amount of help the person with a disability required with everyday activities, nor was it related to the amount of help the carer required or the years of care provided by the carer.
Although Schofield and colleagues did not comment on this finding it may be that carers who displayed more signs of negativity and resentment elicited higher levels of emotional support from network members. More direct help (e.g., personal care, visiting, or taking the person on an outing) provided by network members was associated with greater life satisfaction and a positive mood and lower levels of negative mood and resentment.

The frequency of providing different types of support was also dependent on the filial relationship; this time the relationship of the support provider to the carer (Schofield et al., 1998). Spouses and siblings of the carer provided the most direct help, while spouses and the carers’ parents were more likely to provide indirect help by doing things like housework, home repairs, childminding and providing financial support. Spouses were more likely to provide emotional support than siblings and other relatives.

In conclusion, perceptions of social support had robust associations with carers’ depression, but only small associations with carers’ physical health (Pinquart & Sorensen, 2007). Australian data suggested that, compared to the general population, carers had lower levels of perceived social support (Schofield et al., 1998). Carers with larger social networks had higher levels of perceived social support; however, international studies suggested that carers have smaller social networks than the general population (Ekwall et al., 2005; Magliano et al., 2006). ABS data from the 2003 Survey of Disability, Ageing and Carers (2004) suggested that not all carers’ social networks were affected; 23.9% indicated that they had lost or were losing touch with friends since they started caring. The size of social networks also varied with the demographic characteristics of Australian carers, with female carers, parents or offspring of the person with a disability, and part-time workers having larger social networks than other carers (Schofield et al., 1998). Filial relationships between the support providers and the person with a disability were determinants of the types of relatives who provided support to the carer, while filial relationships between the support provider and the carer were related to the type of support provided (Schofield et al., 1998).

**Conclusion**

In summary, this brief literature review has identified the following ways in which family functioning is related to the task of caring for a family member with a disability:

- Caring can impact on a wide range of dimensions of family functioning and family wellbeing, including adaptability, cohesion, relationship satisfaction, role change, conflict, communication, and problem-solving and decision-making.
- A “stress and coping” framework is useful for understanding the relationship between caring, the burden experienced by carers, coping strategies that carers employ, and the risk of stress or negative outcomes not only for carers, but for other family members.
- Although the literature reports some negative impacts, many carers emphasise the positive reasons for caring, the benefits they receive, and how good family functioning in the context of caring for a family member with a disability can play a protective role in assisting the carer to cope with their role and promote positive outcomes for the person with a disability and other household members.
- Families with care responsibilities for a person with a disability may have higher rates of separation or divorce.
- Most support for carers is provided by their family, and this varies according to how the support providers are related to the carer and the person with a disability.
- Perceptions of the availability of social support are associated with positive mental health outcomes for carers.
- Carers generally have smaller social networks than other people, but carers with larger social networks generally have greater satisfaction with the support available to them in their caring role.
Empirical findings on relationships, family functioning and supports for carers

Daryl Higgins and Ben Edwards

As outlined in Chapter 5, previous research has identified how caring for a family member with a disability can impact on a wide range of dimensions of family functioning and family wellbeing. Good family functioning is an important factor in supporting carers and achieving positive outcomes for the person with a disability and other household members.

Supports for the person with a disability and their carer

Carers were asked a number of questions about the support they or the person with a disability received or could seek from other members of the family and other people. A separate question was asked about their use of services. The main purpose of these questions was to explore the availability of a support network and its impact on caring activities and carers’ wellbeing. Previous research has identified the important aspects of carer networks to be the size, composition and activities of its members (Penrod, Kane, Kane, & Finch, 1995). The availability of supports for carers varies, and yet is an important aspect in understanding carer stress and wellbeing, and may influence the ability of the carer to engage in paid employment, or their use of formal care to supplement the informal care they provide.

Supports for the person with a disability

In Figure 6.1, we show the number of people who provided support to the person with a disability in addition to the support provided by the carer, according to the type of task. This support would benefit not only a person with disability but also their carer. Across all four tasks—talking about worries and fears; providing advice; assisting with self-care, mobility and communication; assisting with household tasks—the majority of people with a disability had no person or one person other than the primary carer to assist them. For example, 23.7% had no other person and 43.3% had one other person to talk to about their worries and fears. Similarly, for providing advice, 27.9% had no-one, and 43.2% one person other than the primary carer. Besides the primary carer, 31.9% of the people with a disability had no other person and 40.3% had one other person to assist them with self-care, mobility and communication. Finally, 50.1% had no other person and 36.3% had one person other than the primary carer to assist with household tasks. These data suggest that assistance with household tasks is the area where people with a disability rely to the greatest extent on their primary carer. Therefore, approximately one in two carers were taking sole responsibility for household tasks.

Supports for carers

In Figure 6.2, we show the percentage of carers who received support from none, one, two, three, or more than three people in relation to each task. Carers most commonly received support from one other person (varying between 35.5% and 39.8% across the four tasks). “Advice about caring for the person with a disability” and “talking about worries and fears” were the tasks for which more carers had assistance. Only 14.3% of carers had no-one to assist them with advice; 39.2% had one person, and 46.0% had more than two people to rely on for advice. The task for which carers were most often left with no support was “help with everyday duties”, such as going to the shops or doing housework (32.8% had no assistance).
Advice about caring
Talking about worries and fears about caring
Talking about worries and fears in general
Help with everyday duties

Type of support provided to carers

Percentage of carers

No supporter
1 supporter
2 supporters
3 supporters
4+ supporters

Note: There were 5 questions that carers were asked concerning different tasks or domains with which the carer and/or the person with a disability may require help. Four are represented in this figure. The final domain was financial support. As nearly all carers (95.6%) did not receive financial assistance (excluding government support) from any other person, including this in the figure would have made it visually hard to decipher.

Source: FCPDS 2006

Figure 6.2 People receiving support from others, by type of support and number of supporters
Although not shown in Figure 6.2, very few carers had financial support from other people in their network: 95.6% of carers did not receive any financial assistance for caring from other people. Looking at both Figures 7.1 and 7.2, the data show that, on average, the level of support that is provided directly to a person with disability (from people other than the primary carer) is higher than the level of support available to carers. However, carers may still benefit from the support provided directly to a person with disability. When another person cares for a person with a disability or assists with tasks, the primary carer may be able to enjoy some “respite”, or feel that the responsibility for caring is shared. However, sometimes assistance from others can bring conflict or disagreements about caring; this is addressed later on in this report (see Figure 6.4).

Figure 6.3 provides a comparison of data from the ABS 2003 Survey of Disability, Ageing and Carers (2004) with data from the FCPDS. Respondents were asked to think about the support they received in providing care for the person(s) with a disability, whether they required more support, or whether the level of support was about right. The two responses (“a lot more support” and “a little more support”) were combined to indicate carers who needed more support than they were receiving at the time. These data show that, compared to the ABS survey, carers in the current FCPDS were more likely to indicate that they needed more support. In total, 46.1% of FCPDS carers (compared to 37.2% in the ABS SDAC) needed more support, whereas 53.8% of FCPDS carers (52.4% in the ABS SDAC) indicated they did not need more support. In both studies, more than half of the carers indicated that they did not need more support, it is still a very sizeable group of carers who need either a little or a lot more support, particularly in the FCPDS sample of carers.

FCPDS data were not standardised by age or gender, whereas ABS 2003 SDAC were weighted to reflect the population.

As discussed in Chapter 5 and will be discussed in Chapter 7 (where we review previous research concerning mental health, physical health and family functioning), providing care for a family member with a disability can increase the levels of stress and conflict both for the individual primary carer and within the family. One of the ways in which this occurs is when conflict or disagreements arise about specific care issues. Most primary carers did not have disagreements with supporters or other family members: 81.0% of carers had no disagreements with any other

![Figure 6.3](image-url)

Note: Percentages do not add to 100% for the ABS 2003 SDAC, as some carers did not answer the question.
Sources: FCPDS 2006; ABS, 2004

**Figure 6.3** Support needs of carers, by estimates from ABS 2003 SDAC and 2006 FCPDS
person about caring for the person with a disability (see Figure 6.4). Twelve per cent of carers had disagreements with one other supporter or family member, and another 6.7% were having disagreements with two or more other supporters or family members.

Cooperation between people providing support to the primary carer is an important issue. Around 60% of carers reported that all of the people who provided support for the carer or the person with a disability cooperated with each other. Nearly one in five carers (19.5%) had no-one else with whom to cooperate, while 11.1% reported that none of their support people cooperated. Some level of cooperation was reported by 6.8%. As discussed in Chapter 5, lack of cooperation between primary carers and other family members or supporters is a significant contributor to stress, poor health and wellbeing outcomes for primary carers. This study provides unique data on this issue, highlighting the importance of cooperation and the broader networks of supports for carers.

Primary carers were asked to identify who supports them as carers, as well as who else assists them with provision of care for the person with a disability. The majority of primary carers (83.7%) indicated that they (and the person with a disability) had no support or assistance from social groups such as work colleagues or craft groups. The remainder had support from either one (12.6%) or two different sources (3.7%).

In terms of support from people living in the same household, in 54.3% of cases, carers received no support from others within the household, with 31.7% of carers having one supporter, and 10.0% having two supporters. In very few cases (4%), there were more than two other people within the household to support the carer.

Almost one in five carers (16.5%) had no support people outside of the household (see Figure 6.6). Over half (54.5%) of carers had between one and three people to assist them with caring, while 29.0% of carers had four or more people from outside the household to assist them.

![Disagreements about caring for the person with a disability, by number of supporters](image)

Note: This analysis included carers that had no support on any of the tasks identified in Figure 6.2.
Source: FCPDS 2006

**Figure 6.4** Disagreements about caring for the person with a disability, by number of supporters

32. When examining the characteristics of the person with a disability receiving care, where carers are providing care to more than one person, the analyses we report here relate only to the first person with a disability identified in the interview (PWD1) for whom the carer provides care. In our study, 11.4% of carers were caring for two people with a disability, and 1.2% were providing care for three or more people with a disability.
Note: The responses to this question were limited by the knowledge that the primary carer had about other members of the care network, and the degree to which she or he believed that they cooperated with one another. Given that primary carers have significant time commitments to caring, and are interacting personally with the person with a disability, they would be well-placed to have a view on the levels of cooperation; however, the person with a disability may have a different perspective. It is also possible that primary carers might not be aware of other carers/supporters or the role they play in the provision of assistance to the person with a disability (or may not consider their contribution as “support”).

Source: FCPDS 2006

Figure 6.5  Support provided to the carer and person with a disability, by level of cooperation

Source: FCPDS 2006

Figure 6.6  Support people to the carer from outside the household
In order to examine the total level of support available to carers, Figure 6.7 provides a breakdown of the percentage of carers who have different numbers of supporters for themselves and the person with a disability (ranging from none through to 11). As the shape of the distribution in Figure 6.7 shows, the largest group of carers was those who had three supporters (18.5%), followed by 17.6% with two supporters, and 15.3% with four supporters. Although in absolute numbers the group is relatively small, the 6.4% of carers for whom there were no supporters for themselves or the person for whom they are caring is of concern.

Given the gender imbalance in care tasks reported in the literature, we have analysed the available data on supporters according to the gender of the carer. We found a similar pattern in the FCPDS, with 77.5% of carers being female and 22.5% male. As shown in Figure 6.8, the difference in the distribution of supporters for male and female carers is statistically significant. Overall, male carers had fewer supporters than female carers. In particular, a significantly higher proportion of males (12.0%) had no supporters (cf. 4.8% of females). There were also higher proportions of male carers than female carers with one (16.9% cf. 12.6%) or two supporters (20.0% cf. 16.9%). For all categories above two supporters, there were more female carers than males (see Figure 6.8).

One possible explanation for why male carers have fewer supporters than female carers is that the men may be more likely to be the partner of the person with a disability for whom they are the primary carer. In the FCPDS, male carers are older than female carers (41.8% of males are over 65; cf. 16.1% of female carers; see Chapter 4), and may have no-one in the house on whom to rely. Another possible explanation, based on gender-role socialisation, is that although not traditionally socialised into caring roles, when men do take on this role (perhaps out of necessity, e.g., to care for their ageing and infirm partner), they may lack the skills to seek out emotional or practical supports, and may present a stoic, self-reliant image.

Of all the occupants of the household, the most common groups providing support for the carer or assisting with care for the person with a disability were the carer’s husband/wife, son/daughter and partner/de facto (see Table 6.1). Although the largest group of people living in the carers’ households were sons and daughters of the primary carer \( n = 640 \), less than half of these (39.7%) assisted with care/support. This was likely to be due to many still being children or adolescents, and having other responsibilities (e.g., school), as well as the care tasks being developmentally
inappropriate for a minor. In contrast, nearly all of the carers’ co-resident partners also provided support or care: 92.3% of husbands/wives and 93.9% of de facto partners.

To examine more closely where supports for carers are coming from, the data presented earlier in Figure 6.8 are now examined separately according to whether the support comes from within or outside the household, or whether it comes from the carer’s participation in a social group. As shown in Table 6.2, there were more males who had no household supporters (78.7%) compared to females (47.2%). The gender difference for supporters from within the household and social

### Table 6.1 Assistance provided by household members, by relationship to carer

<table>
<thead>
<tr>
<th>Relationship to carer</th>
<th>Number in household</th>
<th>% who assist with care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband or wife</td>
<td>313</td>
<td>92.3</td>
</tr>
<tr>
<td>Partner or de facto</td>
<td>33</td>
<td>93.9</td>
</tr>
<tr>
<td>Son or daughter</td>
<td>640</td>
<td>39.7</td>
</tr>
<tr>
<td>Stepson or stepdaughter</td>
<td>17</td>
<td>47.1</td>
</tr>
<tr>
<td>Partner’s son or daughter</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>Parent</td>
<td>25</td>
<td>96.0</td>
</tr>
<tr>
<td>Parent-in-law</td>
<td>5</td>
<td>33.3</td>
</tr>
<tr>
<td>Grandparent</td>
<td>1</td>
<td>0.0</td>
</tr>
<tr>
<td>Grandchild</td>
<td>26</td>
<td>11.5</td>
</tr>
<tr>
<td>Sibling</td>
<td>18</td>
<td>94.4</td>
</tr>
<tr>
<td>Uncle or aunt</td>
<td>1</td>
<td>100.0</td>
</tr>
<tr>
<td>Friend</td>
<td>13</td>
<td>69.2</td>
</tr>
<tr>
<td>Flatmate or boarder</td>
<td>4</td>
<td>25.0</td>
</tr>
<tr>
<td>Other relative</td>
<td>35</td>
<td>25.7</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>1,133</strong></td>
<td><strong>57.3</strong></td>
</tr>
</tbody>
</table>

Note: Tests of statistical significance were not conducted due to very small numbers in some cells. Caution should be taken when interpreting the proportion of particular groups of household members, where the numbers are small (i.e., less than 50). This table excludes the person(s) with a disability—it only refers to other household members.

Source: FCPDS 2006

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**Figure 6.8** Number of supporters, by carers’ gender

Note: Using chi-square, the difference between male and female carers was statistically significant ($\chi^2 (11) = 28.97, p < .01$).

Source: FCPDS 2006
groups were both statistically significant, with male carers having fewer supporters than female carers. However, males and female carers had similar numbers of outside supporters.

Table 6.2

<table>
<thead>
<tr>
<th>Number of supporters</th>
<th>Individual supporters from within the household</th>
<th>Individual supporters from outside the household</th>
<th>Support from social groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male carers</td>
<td>Female carers</td>
<td>Male carers</td>
</tr>
<tr>
<td>----------------------</td>
<td>-------------</td>
<td>--------------</td>
<td>-------------</td>
</tr>
<tr>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>0</td>
<td>78.7</td>
<td>47.2</td>
<td>20.0</td>
</tr>
<tr>
<td>1</td>
<td>16.9</td>
<td>36.0</td>
<td>16.4</td>
</tr>
<tr>
<td>2</td>
<td>2.2</td>
<td>12.2</td>
<td>18.2</td>
</tr>
<tr>
<td>3</td>
<td>1.8</td>
<td>3.6</td>
<td>16.4</td>
</tr>
<tr>
<td>4</td>
<td>0.4</td>
<td>0.6</td>
<td>10.2</td>
</tr>
<tr>
<td>5</td>
<td>0.0</td>
<td>0.1</td>
<td>7.1</td>
</tr>
<tr>
<td>6</td>
<td>0.0</td>
<td>0.1</td>
<td>4.9</td>
</tr>
<tr>
<td>7</td>
<td>0.0</td>
<td>0.0</td>
<td>6.7</td>
</tr>
<tr>
<td>Total</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Number of observations

225 777 225 777 225 777

Note: Percentages may not total 100% due to rounding. A greater proportion of female carers had more supporters who came from within the household ($\chi^2 (6) = 71.52, p < .001$) and social groups ($\chi^2 (2) = 6.92, p < .05$) than male carers. The number of supporters from outside the household was not statistically different between male and female carers ($\chi^2 (7) = 5.09, p > .05$).

Source: FCPDS 2006

In addition to the data presented in Tables 7.1 and 7.2, we analysed separately the number of supporters from within the household, outside the household, and from a social group. Looking at all supporters from within the household ($n = 1,133$), we investigated who was more likely to provide support to the primary carer. Sons and daughters of the primary carer were the largest group (56.5%), followed by husbands or wives (27.6%). Grandchildren and parents comprised 3% or less of the support people. In terms of the number of supporters from outside the household ($n = 2,455$), friends were the largest group (comprising 33.5% of supporters from outside the household), followed by sons and daughters (25.7%), other outside people (14.6%), parents (11.2%), parents-in-law (4.5%), and friends of the person with a disability (3.8%). Many of the supporters were not residing within the household, including the carers’ children, parents and friends. Of the total number of supporters both within and outside the household ($n = 3,588$), sons and daughters were the largest group (35.4%), followed by friends (23.2%) and other outside persons (10.0%). Husbands and wives accounted for 8.7% of total supporters, parents comprised 8.4%, and 3.2% were parents-in-law. Other groups (stepson or stepdaughter, grandchild, neighbour, other relative, partner or de facto, uncle or aunt, sibling, other provider of support services, partners’ son or daughter, grandparent, flatmate or boarder, general practitioner) each comprised less than 2% of supporters from within and outside the household and, in total, amounted to 8.4% of all supporters (resident and non-resident combined).

One limitation of these analyses is that we do not distinguish between support provided to the carer (e.g., emotional support) and the assistance with care that is provided directly to the person with a disability. In addition, the number of supporters may not equate to the total amount of support provided. Different supporters may provide different amounts of support (e.g., 1 hour per month cf. 2 days per week). We have collected data on this issue in FCPDS, which will be explored further in the future. Also, the provision of support may not equate to the perceived value of the supportive behaviour to the carer (that is, their satisfaction with the type and level of support), which is an issue that needs to be addressed in order to understand the complexity of supports available to carers and their impact.

Carers’ relationships

In the Families Caring for a Person with a Disability Study, we asked two sets of questions about family relationships. First, carers were asked about their satisfaction with their relationship
with: their partner, the person(s) with a disability, and their children. They were also asked to rate how satisfied they were with their partner’s relationship with their children, and how well children in the household get along with each other. Each item was rated on a scale from 0 (completely dissatisfied) through to 10 (completely satisfied). Second, carers were asked to what extent they agreed at the time with five statements used to describe the family dynamics of the whole family.

In Figure 6.9, we present data on a measure of relationship satisfaction. Data were compared for three groups: carers’ relationship satisfaction with people when that person is not the person with a disability, relationship satisfaction with people who have a disability (and for whom they provide care), and comparative data from non-carers from the general population. Estimates of statistically significant results were calculated with a 95% level of confidence. The confidence intervals are displayed in Figure 6.9 by means of vertical confidence interval bars. Non-overlapping confidence intervals on two columns in a figure suggest that we can be 95% confident that the two values represented in the columns are significantly different. Carers in the FCPDS tended to be older and the ratio of females to males was higher than in the general population in the HILDA survey. In order that differences are not attributable to these characteristics, responses for FCPDS carers were weighted by age and gender to reflect the general population.

Different trends emerge depending on the type of relationship under examination. In relation to partners, respondents in the FCPDS reported significantly higher satisfaction than adults in the HILDA survey. There was no statistically significant difference between FCPDS carers’ satisfaction with partners who were the person with a disability for whom they were caring and those partners that did not have a disability. However, one of the limitations with conducting a cross-sectional survey and examining relationship satisfaction with partners with a disability is that estimates are based on surviving relationships only. When a partner is being cared for and there is

Note: Both HILDA general population data and FCPDS data on carers have been weighted by gender and age. Carers’ relationship satisfaction is presented separately for relationships with family members when that person is the person with a disability, and for family members who are not the person with a disability.

Sources: FCPDS 2006; HILDA Wave 4.1

Figure 6.9  Satisfaction with relationship with and between family members, by relationship and caring status

33. Where comparisons are made with data from the general population (HILDA Wave 4.1), any respondents in HILDA who identified that they were providing care for a person with a disability were excluded, so that comparisons could be made with “non-carers” only.
a relationship separation, the carer will usually cease to provide care, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, the relationship satisfaction of partners with a disability measured in this study is an overestimate of the level of relationship satisfaction with partners with a disability.

Regarding satisfaction with relationships with their children, carers in the FCPDS study whose child was the person with a disability for whom they are the primary carer reported significantly greater satisfaction than non-carer parents from the general population. However, carers reported even greater satisfaction with their relationship with children who were not the person with a disability for whom they are the primary carer. So although carers’ satisfaction with their relationships with children was better overall than comparative data with non-carers, the task of caring for a child with a disability is associated with poorer relationship satisfaction with children (see Figure 6.9).

Carers were also asked to report on the degree to which they were satisfied with the quality of the relationship between their partner and their children. Carers in FCPDS reported significantly better relationships between partners and children than comparable non-carers (HILDA), and there was no significant difference in relationship satisfaction between carers’ partners and children with a disability and children who are not. A different pattern of results emerged for sibling relationships. Carers reported significantly lower satisfaction with relationships between siblings (“children getting on”) when the child is the person with a disability, compared to when the child is not the person with a disability, or compared to the general population (see Figure 6.9).

**Family functioning**

Figure 6.10 shows the percentage of FCPDS carers endorsing each of the four response categories (strongly agree, agree, disagree, strongly disagree) for the five items measuring different dimensions of family functioning that have been identified in the literature as being relevant to the impact on families of caring for a person with a disability: cohesion, communication, resilience, adaptability and conflict.

In relation to the first item, measuring family cohesion (togetherness), most carers either agreed or strongly agreed (87.1%), with most strongly agreeing (54.4%), that there was a feeling of togetherness in the family. Most carers agreed or strongly agreed that they talked about their personal problems and helped each other deal with them. Similarly, most carers also strongly agreed or agreed that their family coped with and recovered from times of hardship. The pattern was a little weaker for the item measuring adaptability (trying new ways of solving problems), with 79.9% agreeing or strongly agreeing. For the item measuring conflict, 63.8% disagreed or strongly disagreed that there was a lot of tension in the family. This still left a substantial minority of carers who either agreed (22.3%) or strongly agreed (10.6%) that there was tension in their families. This suggests that, of all the aspects of family functioning, providing ways to strengthen the abilities of families caring for a person with a disability to cope with—and indeed lower—the level of conflict and tension would be one of the most important aspects to address.

The relationship between family problems and the type of disability and level of care needs was also examined. For these analyses, we considered “family problems” to be where carers indicated they “disagreed” or “strongly disagreed” with that item (except for the conflict item, which is negatively worded, so we looked at where carers “agreed” or “strongly agreed” in that case). In both cases, where carers were caring for more than one person with a disability, we only examined the type of disability and level of care needs for the first person they identified in the interview.

There were more problems in family functioning for families that cared for a person with a psychiatric disability than the other families caring for a person with another disabling condition ($\chi^2 (6) = 20.61, p < .01$).

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34. In the relationship breakdown section, we reported rates of separation for carers of partners and non-partners with a disability that suggest that there is a selection bias present.
Figure 6.11 provides a description of the number of family problems that carers reported, according to the type of disability of the person for whom they are providing care. Carers of someone with a physical disability were the most likely to report no family problems, followed by carers of someone with an intellectual/learning disability or multiple disabilities. Finally, those caring for someone with a psychiatric disability were the least likely to have reported no family functioning problems, and were the most likely to have one problem. Interestingly, there were no differences between the groups in the proportion reporting two or more problems. It seems that the type of disability of the person being cared for is associated with whether the family either has no or one family problem, but is not significantly related to whether or not they have two or more problems.

In Figure 6.12, we considered the number of family problems as a function of the level of care needs. Using the carers’ responses to a range of questions about the types of tasks with which the person requires assistance, their level of care was categorised as low, medium or high. We found a statistically significant association between the level of care needs and the number of family problems. Those who were caring for a person with a disability who had the lowest level of care needs had the fewest family problems, while high care needs were more likely to have one, two or more family problems. This shows a statistically significant relationship between the level of care needs that the person with a disability has (and, consequently, the burden on the carer), and the problems experienced by the broader family, not just by the carer.

**Relationship breakdown**

We asked carers about their current relationship status, as well as their relationship experiences since they started caring. One of the limitations with conducting a cross-sectional survey and examining relationship experiences such as separation is that our estimates are open to a selection bias for carers of a partner with a disability. More specifically, when a partner is being cared for and there is a relationship separation, the carer will usually cease to provide care, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, it is possible that
Notes: Where carers were providing care for more than one person with a disability, responses were coded according to the type of disability of the first person that carers identified. The particular dimension of family functioning was coded as a “problem” when carers either “disagreed” or “strongly disagreed” with positive items (and vice versa for the negative item: “a lot of tension in the family”).

Source: FCPDS 2006

Figure 6.11 Families with problems of family functioning, by type of disability and number of problems

Note: Where carers were providing care for more than one person with a disability, responses were coded according to the type of disability of the first person that carers identified. The particular dimension was coded as problematic when carers either “disagreed” or “strongly disagreed” with positive items (and vice versa for the negative item). Based on the level of care needs of the person for whom they were caring, differences between carers in the number of family dimensions that were problematic were statistically significant ($\chi^2 (4) = 40.85$, $p < .001$).

Source: FCPDS 2006

Figure 6.12 Families with problems of family functioning, by level of care needs and number of problems
by including carers of partners we have underestimated the rate of relationship separation. An examination of the rates of separation in the FCPDS confirms the selection bias, with a 1.2% separation rate for carers of partners, compared to a separation rate of 28.0% for carers of a person with a disability who was not their partner.

To overcome this selection bias, we restricted the sample to carers of a person with a disability who was not a partner. We acknowledge that our examination of relationship experiences is limited by such an approach; however, it would be inappropriate to draw any inferences about the relationship separation of carers whose partner is the person with disability with the FCPDS data. As stated previously, we found that 28.0% of carers had separated from their partners since they started caring for the family member that was not a partner. Including those who were partnered and separated before and since caring, 18.1% of carers had reconciled with their partner since they commenced caring. Of carers who had a partner at any time since they started caring, 57.6% reported a significant increase in arguments.

As shown in Figure 6.13, 30% or more female carers aged 31 to 40 and 41 to 50 years had separated since they started caring. In contrast, less than 15% of carers 51 years of age or older had separated since they began caring. For younger carers, the progression into a caregiving role may be abrupt or unexpected and may place additional stress on the carer—including the risk of relationship difficulties and separation. Due to their smaller numbers when divided by age categories, male carers were excluded from this analysis.

As shown in Table 6.3, approximately three-quarters of those who had separated since commencing care reported a significant increase in arguments. However, even for those who were partnered and did not separate, 51.6% reported at least one or more periods in their relationship when there was a significantly higher level of arguments.

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Figure 6.13 Relationship separation of female carers, by age group

Note: Female carers of a person with a disability who was not their partner ($n = 396$). Although there was a very high rate of separation for carers aged 18 to 30 (55.6%), this should be regarded with caution, due to the small sample size ($n = 18$); however, the other rates were robust.

Source: FCPDS 2006

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35. Of 414 carers whose partner was a person with a disability, 5 had separated.
36. Of 435 carers of a person with a disability who was not their partner, 122 had separated.
37. The majority of carers of partners in the FCPDS sample were also aged fifty or more (84.8%), suggesting differential selection into the FCPDS sample.
This suggests that conflict within relationships—as well as relationship breakdowns—commonly occur in families with care responsibilities for a person with a disability.

### Relationship separation

Figure 6.14 displays the likelihood of a relationship separation occurring in each year since caring commenced for carers who were not caring for a partner with a disability (taking into account the fewer carers in each subsequent year, and those who had separated in a previous year). With a few minor variations, the risk of relationship separation is fairly evenly distributed across the years since caring commenced. The risk of separation in each year of the first 10 years since the start of care varies between 1.5% and 4.0%, with the average over the first ten years of care being 3.0%.

Figure 6.15 displays the percentage of relationships that were intact at each year since caring began. Eighty-five per cent of carers’ relationships had endured for five years and almost 78% for ten years.

### Increases in arguments

In Figure 6.16, we looked at timing in relation to another aspect of relationships: when there were periods of significant increases in arguments. We took into account the greater number of...
Note: The data presented are based on 431 carers who (a) were not caring for a partner with a disability; and (b) had at any stage had a spouse/partner.

Source: FCPDS 2006

**Figure 6.15** Intact partner relationships of carers not caring for a partner, by years since starting caring

Note: The data presented are based on 431 carers who (a) were not caring for a partner with a disability; and (b) had at any stage had a spouse/partner.

Source: FCPDS 2006

**Figure 6.16** Reports by carers not caring for a partner of significant increase in arguments, by years since starting caring
carers who had cared for the person with a disability for fewer years by calculating the percentage of carers reporting a first period of significantly increased arguments since commencement of care, after accounting for the total number of carers at each year. The risk of a significant increase in arguments was highest in the first year (18.4%) and then declined. The pattern of decline after the first year of caring was fairly consistent; however, there was an increase in the rate of arguments at years two (7.9%) and three (9.3%).

Figure 6.17 indicates the percentage of carers who were partnered who did not have a significant increase in arguments since caring began. At five years, only 61.0% of partnered carers did not have a significant increase in arguments with their partner and by 10 years 54.8% of partnered carers had at least one significant increase in arguments with their partner. In summary, there was a substantial number of carers who experienced a significant increase in arguments with their partner, particularly in the first year of caring.

Conclusion

Carers’ support needs

Results from the FCPDS suggest that one in five carers does not have assistance with caring for the person(s) with a disability. One in five has disagreements with others about caring, and of those who have support, one in five has other support people for the person with a disability with whom there were some problems with cooperating about the care provided. Almost half of carers indicated they needed more support, suggesting that the typical carer in Australia believes they need more support than is currently available to them.

Carers’ relationships

Carers are satisfied with their relationships with their partners—or at least they are as satisfied as non-carers from the general population—even when their partner is the person with a disability.
Although provision of care for a person with a disability is not associated with dissatisfaction with relationships (between carers and their partners, children and parents, and the relationship between carers’ partners and children), it does seem to affect carers’ satisfaction with their children’s relationships. This is consistent with research showing the negative impact of caring for a person with a disability on non-disabled siblings, perhaps because of the reduction in attention they receive (see Higgins et al., 2005).

**Family functioning**

Conflict is the aspect of family functioning that carers most frequently see as problematic. Carers of someone with a psychiatric disability are the most likely to report two or more problems in family functioning, with carers of someone with a physical disability the least likely. Poor family functioning is associated with greater care needs of the person with a disability, suggesting level of impairment is a good proxy measure of the likely impact of caring for someone with a disability on the broader family.

**Relationship breakdown**

The FCPDS provides unique data on the timing and risk of increased arguments and relationship breakdown between carers and their partners. The data show a heightened risk of arguments early on, but a fairly even distribution of the risk of relationship separation.
SECTION D
THE MENTAL AND PHYSICAL HEALTH OF FAMILIES CARING FOR A PERSON WITH A DISABILITY
Caring for a person with a disability can have considerable psychological and physical impacts upon those providing care; it can also have an impact upon the health of other family members. This chapter provides a review of the literature, examining how caring influences various emotional responses (depression, anxiety and anger, as well as positive responses), and highlighting gaps in our understanding of families’ psychological response to caregiving. We then address the physical health of carers. We were unable to identify any studies that have examined the physical health impact of caring for any family member other than the primary carer and this is a major limitation of the research to date.

Mental health

*Multiple family members*

Very few researchers have examined the mental health of the primary carer and other family members caring for a person with a disability. The few studies that have focused on carers reported significant rates of depression. Edwards and Clarke (2005) reported that the incidence of clinical levels of depression among relatives of cancer patients was 20.8% within three months of diagnosis; six weeks later it was 18.6%, dropping to 10.0% at 6 months post-diagnosis. Families of patients with cancer in the palliation phase had even higher rates of depression (Kissane et al., 1994): 35.0% of spouses and 28.0% of children had clinical levels of depression, and 15.5% of spouses and 14.5% of children had severe distress levels.

Studies of families caring for a person recently diagnosed with cancer suggest that there was a significant correlation between family members’ depression and anxiety (Edwards & Clarke, 2004). Over the course of 6 months, the correlations between family members’ depression and anxiety reduced, but were still significant (Edwards & Clarke, 2005). The correlation between family members’ depression and anxiety was lower for families caring for a person with cancer who was in palliative care than for families with a person recently diagnosed with cancer (Kissane et al., 2003).

A study of 251 families in which the mother and father cared for their adult children who had either a developmental disability or schizophrenia also showed that mothers’ and fathers’ psychological distress was very similar. In this study, Pruchno and Patrick (1999) found mothers’ and fathers’ depression and life satisfaction were not significantly different from one another and the correlation between the couples’ levels of depression and life satisfaction were also significant. This suggests that families may experience similar levels of mental health problems in response to caring for a sick or disabled relative.

The mental health of family members of a person with a disability also seems to be affected by the amount of responsibility taken for caring (Perlesz et al., 2000). An Australian study of

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38. The Beck Depression Inventory—Fastscreen (Beck, Steer, Ball, Ciervo, & Kabat, 1997) was used to measure depression.
39. Kissane et al. (1994) used the cognitive items from the Beck Depression Inventory to measure depression.
40. Depression was measured using the Centre for Epidemiological Studies—Depression scale (CES-D; Radloff, 1977) and life satisfaction was assessed using the Life Satisfaction Index (Neugarten, Havighurst, & Tobin, 1961).
79 families in which a person suffered acquired brain injury (ABI) showed that primary carers had significantly higher mean levels of depression, anxiety and anger than secondary and tertiary carers within the same family, as well as when the different types of carers were compared as independent groups (Perlesz et al., 2000). Primary carers also had greater levels of clinical levels of depression (37.7%) and anxiety (44.1%) than both secondary carers, who had a depression rate of 18.6% and anxiety rate of 15%, and tertiary carers, who had a depression rate of 27.3% and anxiety of 31.8%. These data suggest that, although other family members who have care responsibilities were affected by caring, primary carers are the most susceptible to mental health problems.

In summary, the few studies we were able to identify that focused on the mental health of the carer and of other family members who did not have a disability were limited, as they were based on convenience samples of carers for a specific type of disabling condition (Edwards & Clarke, 2004; Kissane et al., 2003; Perlesz et al., 2000; Pruchno & Patrick, 1999). Representative, population-based studies of families who care for a person with a disability do not appear to have been conducted. The available evidence does suggest that the mental health of carers and other family members were associated with one another, although primary carers’ mental health was worse than secondary or tertiary carers.

**Primary carers**

The primary carer has been the focus of the majority of studies investigating the influence of caring for a person with a disability on carers’ mental health. A series of meta-analyses of the mental health of carers provides some of the more accurate estimates of the emotional impact of providing care.

**Differences between carers and non-carers**

A meta-analysis examining the differences between carers and non-carers in terms of their psychological health was provided by Pinquart and Sorenson (2003). Their meta-analysis of 84 studies indicated that carers had significantly higher levels of depression and lower levels of general subjective wellbeing than non-carers. Spousal caregiving was particularly stressful, as there were large differences in the levels of depression and stress of carers who were spouses compared to non-carers. There were small but consistent and statistically significant differences in the levels of depression and stress between adult carers who were the children of the people with a disability and non-carers. Caring for a person with dementia was particularly challenging. When the differences between carers and non-carers were compared, studies of carers of people with dementia reported the highest levels of stress and greatest impairment in psychological wellbeing. Pinquart and Sorenson also noted that differences between carers’ and non-carers’ levels of depression and subjective wellbeing were less pronounced in population-based studies with representative samples of carers than those with non-representative samples. This finding underscores the importance of taking a representative sample of the general population in obtaining accurate estimates of the impact of caring for a person with a disability on mental health.

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41. Primary carers were considered by the family or the researcher to bear the most responsibility for caring for the person with acquired brain injury. Using the same criteria, secondary carers bore the next most responsibility and tertiary carers the next most responsibility.

42. Depression was measured using the Beck Depression Inventory, anxiety using the State Anxiety scale of the State–Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983) and anger from the Profile of Mood States (McNair, Lorr, & Droppleman, 1971).

43. Depression was mainly assessed with the Hamilton Depression Rating Scale (Hamilton, 1967; 15 studies), the Center for Epidemiological Studies—Depression scale (CES–D; Radloff, 1977; 13 studies), the Beck Depression Inventory (Beck et al., 1997; 11 studies), clinical interviews (4 studies), and other scales (13 studies).

44. Stress was most often assessed with the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983; 6 studies), single-item indicators (2 studies), and other scales (14 studies).

45. Carers’ subjective wellbeing was mainly assessed with life satisfaction scales (e.g., Life Satisfaction Index; Neugarten et al., 1961; 11 studies), positive affect scales (e.g., Positive and Negative Affect Schedule; Watson, Clark, & Tellegen, 1988; 9 studies), single-item indicators on happiness (5 studies), and other scales (9 studies).

46. The other groups studied were carers of people who did not have dementia or mixed disability groups.
Gender differences in the mental health of carers

A meta-analysis of gender differences in the mental health of carers suggested that female carers had higher levels of depression and lower levels of wellbeing than male carers (Pinquart & Sorensen, 2006). Although these differences were significant, gender differences were only small in nature (explaining only 2.9% of the variation in scores on depression, carer burden and subjective wellbeing).

Are gender differences in carer mental health caregiving specific?

In the general population, women report higher levels of mental health problems than do men. Pinquart and Sorensen (2006) also investigated whether gender differences in mental health outcomes for carers simply reflected this population difference. A meta-analysis of gender differences in the general population indicated that there was a greater difference between female and male carers with respect to depression than there were between males and females who did not care for a person with a disability. However, gender differences in subjective wellbeing for carers was similar to the general population. Consequently, caregiving seems to have a particular effect on women’s depression levels.

Population-based studies of the impact of caregiving on distress

Several epidemiological studies have investigated the impact of caring on primary carers’ emotional distress, although none has focused on other family members. Using a representative sample of close to 10,000 people in England, Scotland and Wales, Hirst (2003) concluded that, for the period 1991–2000, male and female carers had higher rates of psychological distress than those who were not in a caregiving role. When a diagnostic interview has been employed to detect the prevalence of psychiatric conditions in epidemiological studies, similar findings have also been reported. In a population-based survey of 9,953 people in Ontario, Canada, that used a diagnostic interview, carers had higher rates of affective disorders (6.3% versus 4.2%) and anxiety disorders (17.5% versus 10.9%) than non-carers (Cochrane, Goering, & Rogers, 1997).

Some epidemiological studies have also been longitudinal and consequently enable an assessment of the psychological impact of transitioning into and out of the caring role. Longitudinal analysis of a nationally representative sample of 8,826 US adults followed for five years (1987 to 1992) indicated that transitioning into caring for primary kin was associated with increased levels of depression (Marks, Lambert, & Choi, 2002).

Transitioning to caregiving also led to an increase in the level of negative and positive psychological wellbeing, depending on the gender of the carer and whether the carer was providing support to a child, spouse, another family member or a friend (Marks et al., 2002). For example, the transition to providing care for a child with a disability was associated with higher levels of depression and hostility, but was also marked by a greater sense of autonomy for female carers than other women not in a caring role. Men who started caring for a child also had higher levels of depression than non-carers, were less happy and had a lower sense of mastery than other males who were not providing care for a child with a disability. There are several types of caring that were associated with positive outcomes for the carer, although they did vary between men and women. For instance, men who provided care for their parents-in-law reported more

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47. Details of the measures of depression and subjective wellbeing are provided in footnotes 43, 44 and 45. Also, subsequent analyses that controlled for caring stressors, such as hours of caring and social resources (e.g., informal support) accounted for much of these differences.

48. Mental health was assessed using the 12-item General Health Questionnaire (GHQ; Goldberg & Williams, 1991).

49. Diagnoses from the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition, revised, were generated on the basis of a structured diagnostic interview.

50. “Primary kin” was defined as a child, spouse or biological parent in need of assistance because of a physical or mental condition, illness or disability.

51. As measured by a 12-item version of the CES-D (Radloff, 1977).

52. Hostility was measured by 3 items: “On how many days of the past week did you feel irritable, or likely to fight or argue?”

53. Autonomy, personal growth, purpose in life, and self-acceptance were measured by three-item versions of Ryff and Keyes’ (1995) psychological wellness scales.

54. Mastery was measured by a five-item version of the Pearlin Mastery Scale (Pearlin, Lieberman, Menaghan, Menaghan, & Mullan, 1981).
positive relations with others and having a greater purpose in life than men not providing care. Providing care to a friend was particularly positive for women. The transition to this type of care was associated with more autonomy, personal growth, purpose in life and self-acceptance than when not providing care.

One of the limitations of the study by Mark and colleagues (2002) was that it did not take into account the amount of caregiving provided by the carer. Other large-scale longitudinal community studies have addressed this issue and reported that higher levels of care were associated with higher levels of psychological distress. For instance, one US community-based population study that had information on 428 individuals showed that people who transitioned into heavy caregiving had significantly higher levels of depression and lower levels of mastery over a five-year period than people who were not carers or who had transitioned into a moderate caregiving role (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Another longitudinal population-based study, using data from the British Household Panel Survey, reported that, compared to non-carers, the risk for onset of high distress increased with the amount of time devoted to caring each week (Hirst, 2005). For instance, compared to non-carers, women who provided care for 10 to 19 hours per week were 1.7 times more likely to have high distress, while the odds of high distress were 2.9 times more likely for women caring 20 hours or more per week. Hirst also noted that ongoing care increased carers’ vulnerability to recurring high distress. The increased risk of the onset and recurrence of high distress remained, even after caregiving ceased. For example, when caring for 20 hours or more a week, women had twice the risk for the onset and recurrence of high distress than women who had no caring responsibilities. Another epidemiological study of women also noted that excessive numbers of hours providing care (in this case, 36 or more per week) increased the odds of depressive or anxious symptoms 5.6 times, even after controlling for a range of other factors, including previous depressive or anxious symptoms (Cannuscio et al., 2002).

**The Australian evidence**

In the last decade, there have been three major large-scale community-based epidemiological studies of the emotional impact of caring for a relative with a disability: the Victorian Carers study; the 2003 Australian Bureau of Statistics Survey of Disability, Ageing and Carers; and the Carer Health and Wellbeing Survey.

The Victorian Carers study was a large-scale, longitudinal, population-based survey of 976 carers and 219 non-carers who formed a comparison group (Schofield et al., 1998). Female carers reported significantly lower levels of life satisfaction and positive affect, as well as higher levels of negative mood, compared to female non-carers. Over the course of 15 months, the life satisfaction of both female carers who continued to care and non-carers decreased, but at the same rate for carers and non-carers alike. However, at both measurement periods, female carers had lower levels of life satisfaction than their non-caring counterparts. The Victorian Carers study also examined differences in life satisfaction and positive and negative mood between

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55. People were considered to be providing heavy caregiving if they helped another person with one of the following: eating, dressing, bathing, transferring, toileting and walking. Moderate caregiving referred to the provision of help to someone with one or more of the following: using the telephone, preparing meals, doing light or heavy housekeeping, shopping or managing money.

56. Depression was measured using a 10-item version of the CES–D (Radloff, 1977) and mastery was assessed using a seven-item version of the Pearlin Mastery Scale (Pearlin et al., 1981).

57. As measured by the General Health Questionnaire (GHQ; Goldberg & Williams, 1991).

58. The Mental Health Inventory of the SF-36 (Ware et al., 2002) was used to assess depressive or anxious symptoms.

59. Carers were identified by asking the following question: “Do you or does anyone in your household take the main responsibility in caring for someone who is aged or has a long-term illness, disability or other problem?”

60. This group were all adult females.

61. Female carers comprised 78% of the 976 carers.

62. Schofield et al. (1998) provided details of the 6 items used to measure life satisfaction. Positive and negative mood was measured using the Positive and Negative Affect Scales (PANAS; Watson et al., 1988).

63. Comparisons with carers and non-carers were not possible for negative and positive affect because non-carers’ negative and positive affect were not assessed.
continuing carers and those who were no longer caring. Between the first and third interview (30 months later), life satisfaction had decreased for those still caring, but had increased for those no longer doing so. For positive or negative mood, the rate of change over time was the same for continuing carers and those who were no longer caring. There were some subtle demographic differences in positive mood, with spouses who were no longer caring having significantly lower levels of positive mood than spouses who were continuing caring at both follow-up interviews.

Several differences in the emotional outcomes of carers at the first interview period were also noted for selected demographic characteristics, such as the type of disabling condition of the care recipient and the carer's gender. When care recipients were divided into those with physical impairment, undiagnosed memory loss, and Alzheimer's disease or dementia, and the carers' emotional outcomes compared based on these groups, carers of people with a physical impairment had significantly higher levels of life satisfaction and lower levels of negative affect than carers in the other two groups. Although there were no gender differences in levels of life satisfaction or positive affect, Schofield and colleagues did report that female carers had significantly higher levels of negative affect and a greater sense of role overload than male carers (Schofield et al., 1998).

The second major Australian study was the 2003 Survey of Disability, Ageing and Carers (SDAC; ABS, 2004). Carers were asked: “What physical or emotional effects have you experienced as a result of your caring role?” They could say yes or no to the following options: “Your physical or emotional wellbeing has changed”, “You feel satisfied”, “You feel weary or lack energy”, “You frequently feel worried or depressed”, “You frequently feel angry or resentful”, and “You have been diagnosed as having a stress-related illness”. These questions were not standardised measures of emotional wellbeing, which limits the validity of the findings. Carers’ views of the emotional effects of caring will be the focus of discussion in this instance and further examination of carers’ views of the physical effects of caring will be discussed in Chapter 10. As can be seen from Figure 7.1, approximately 1 in 3 carers frequently felt worried or depressed, while 1 in 7 frequently felt angry or resentful. One in 10 carers had also been diagnosed as having a stress-related illness. Despite these results, about 1 in 4 carers reported a sense of satisfaction from their caring role.

The final and most recent large-scale Australian study has been the Carers’ Health and Wellbeing study, a survey conducted by Carers Australia, Australian Unity and Deakin University (Cummins et al., 2007). The survey consisted of 4,107 carers who were members of each of the state/territory Carers Associations, and they were compared with data from about 30,000 adults from the general population who had completed the bi-annual Australian Unity Wellbeing Index survey. Cummins and colleagues reported that carers had the lowest levels of personal wellbeing—a measure of life satisfaction—of any of the demographic groups that had been studied previously (e.g., people living alone and unemployed; people earning less than $15,000 and unemployed; people unemployed). When depression was considered, 19% of carers had extremely severe levels of depression, with a further 18% exhibiting severe levels and 19% moderate levels of depression, according to the clinical cut-offs developed for the Depression subscale of the Depression, Anxiety and Stress Scale (Lovibond & Lovibond, 1995).

There were also gender differences in relation to carers’ personal wellbeing, depression and stress. Male carers had higher levels of personal wellbeing than female carers—the reverse of findings in

64. Carers who were no longer caring because the person whom they were caring for had died were excluded from this analysis, as information about their emotional wellbeing was not gathered in follow-up interviews. It should be noted that there were two follow-up interviews: at 15 months and 30 months after the first interview.
65. The physical impairment group included 186 carers reporting their relatives as being moderately or severely physically impaired, but with no intellectual impairment. The undiagnosed memory loss group consisted of 182 carers who described their relative as having memory loss, but did not mention Alzheimer's disease or dementia. The Alzheimer's disease or dementia group described their relative as having Alzheimer's disease, dementia or senile dementia. Most care recipients in the last two groups also had some physical impairment.
66. Questionnaires were sent to 11,200 members of the state/territory Carers Associations, so the response rate to the survey was 37%.
67. The Stress subscale of the Depression, Anxiety and Stress Scale was used to measure stress (Lovibond & Lovibond, 1995). The Personal Wellbeing Index (International Wellbeing Group, 2006) was used to measure personal wellbeing.
the general population, where females had higher levels of personal wellbeing than males. Both male and female carers had significantly lower levels of personal wellbeing than their non-caring counterparts. Female carers also had significantly higher levels of depression and stress than male carers. Another notable finding was that the gap in personal wellbeing between carers and the general population was smaller when carers were older. Depression and stress followed a similar pattern to personal wellbeing, with carers’ depression and stress significantly lower when carers were aged 55 years or older, compared to carers at younger ages.

Examination of differences in carers’ mental health and wellbeing by household composition suggested that caring and having children was particularly stressful (Cummins et al., 2007). Carers with children (either sole parents or those with partners) had lower levels of wellbeing than carers without children. Sole parents had the highest levels of depression and partnered parents with a child had the highest levels of stress.

Factors associated with carers’ mental health

There is a wealth of literature on factors associated with carers’ mental health and psychological wellbeing. The reader is referred to several excellent reviews that focus on this topic (Cummins, 2001; Savage & Bailey, 2004). Rather than conduct yet another selective review of the factors associated with the mental health of carers, we focus here on meta-analyses of factors associated with carers’ depression. Of the carer stressors that Pinquart and Sorenson (2004) examined in their meta-analysis, behavioural problems of the person with a disability had the strongest association with carers’ depression. More hours of care per week had the next strongest association with carers’ depression, followed by the person with a disability having cognitive impairments, the person with a disability having physical impairments, and the number of caregiving tasks. The years spent caring for the person with a disability had the weakest association with carers’ depression in all of the studies analysed. When carers’ resources were considered, informal support provided by friends or relatives had the strongest association with carers’ depression, followed by carers’ level of education, formal supports from professionals, and income (Pinquart & Sorensen, 2007). Behavioural problems also had the strongest association with carers’ psychological wellbeing, followed by the person with a disability having physical impairments or cognitive impairments, and the hours of care provided. There was no statistically significant association between the

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**Figure 7.1 Carer’s reports of emotional and physical effects of caring**

number of years spent caring for the person with a disability and the carers’ psychological wellbeing (Pinquart & Sorensen, 2007).

**Limitations and future directions**

Despite evidence suggesting that other family members are affected by caring for a person with a disability, most studies have focused on primary carers. Consequently, we were unable to locate any large-scale epidemiological studies that focused on the primary carer and other family carers. One suspects that this neglect has not been as a result of the view that other family members are not important, but rather that the additional resources to interview other family members may be too prohibitive. One method to obtain some data on this may be to ask the primary carer a series of questions about the influence that caring has on family members’ mental health. Although there are some limitations to such an approach, the use of proxy reports of the mental health and wellbeing of people with a disability (Pierre, Wood-Dauphinee, Korner-Bitensky, Gayton, & Hanley, 1998) and the general population (Ellis et al., 2003) have been used in previous studies. The main limitation to such an approach is that proxy reporters (such as a relative) tend to under-report mental health problems, so in this context we would expect that a proxy report of the mental health impact of caring to be an underestimate.

The Victorian Carers study and Carers’ Health and Wellbeing study have been the only Australian large-scale epidemiological studies to assess the mental health of carers using standardised measures (Cummins et al., 2007; Schofield et al., 1998). Both have limitations. The Victorian Carers study was a sample of carers residing in Victoria and the data collection was conducted in 1993. While more recent, the Carer Health and Wellbeing study only surveyed carers who were members of the state/territory Carers Associations, and only 37% of these members completed the survey. Representative recent national estimates of the mental health problems of carers would be important for policy-makers.

**Physical health**

As stated at the beginning of the chapter, we were unable to identify any studies of the physical health impact of caring for a family member with a disability for people other than the primary carer. Therefore, the focus of this review is on primary carers’ physical health.

**Primary carers**

**Differences between carers and non-carers**

Meta-analyses have indicated that carers have poorer self-reported health than non-carers (Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003). In addition to self-reported health, Vitaliano and colleagues’ meta-analysis of the health consequences of caring for a family member with dementia indicated that carers also had a 23% higher level of stress hormones and a 15% lower level of antibody responses than did non-carers.

**Gender differences in the physical health of carers**

Meta-analyses of gender differences in the physical health of carers have suggested that female carers report worse physical health than male carers (Pinquart & Sorensen, 2006; Vitaliano et al., 2003). Moreover, the gender difference in self-reported physical health was greater than that observed in the general population (Pinquart & Sorensen, 2006). Although female carers had worse levels of physical health than male carers, Vitaliano et al. reported that male carers had slightly (but not significantly) higher levels of stress hormones and worse cardiovascular and metabolic outcomes than female carers. They speculated that these contrary findings may be explained by a tendency for women to be more aware of their health problems, or by the fact that self-reported health is related to distress and distress is higher in female carers than their male counterparts.
As was the case with mental health, there are several epidemiological studies of the physical health of primary carers. Perhaps the most well-known and influential epidemiological study of these is the US Carer Health Effects Study (CHES; Schulz & Beach, 1999). The Carer Health Effects Study was an ancillary study of the Cardiovascular Health Study, a large population-based study of the elderly. The CHES consisted of 392 carers, and 427 non-carers who served as a comparison group. Analysis of mortality risks after four years indicated that, after controlling for confounding factors, carers who were providing care and experiencing caregiving strain were 63% more likely to die than non-carers in the comparison group. Longitudinal analyses from the CHES also indicated that those who had transitioned directly into heavy caregiving had poorer self-reported health and health behaviours—such as missing doctors appointments, forgetting to take medications or not getting enough exercise—than non-carers (Burton et al., 2003). Data from 1,219 informal carers (15% of the total sample) in the Ontario Health Survey also suggested that physical health was affected in those providing care. Carers were 30% more likely than non-carers to have at least one physical health problem, even when controlling for participants’ age, gender, employment status and economic disadvantage (Cochrane et al., 1997).

The Australian evidence

The Victorian Carers study, the 2003 Australian Bureau of Statistics Survey of Disability, Ageing and Carers, and the Carers’ Health and Wellbeing study have been the three major epidemiological studies that have examined carers’ physical health in Australia.

In the Victorian Carers study, female carers (n = 757) were compared to a group of 219 females who did not have caring responsibilities. Female carers were 43% more likely to have a major health problem, 33% more likely to use medication and 39% more likely to have poor health than females with no caring responsibilities. Longitudinal comparisons of carers and non-carers over 15 months indicated that carers were 33% more likely to have a continuing health problem, but not to continue to take medication. Although carers’ and non-carers’ self-rated physical health changed at the same rate over the course of 15 months, carers rated their self-rated physical health as significantly poorer than non-carers (Schofield et al., 1998).

The Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers collected some information about the physical health of carers; however, these were combined with emotional wellbeing measures (ABS, 2004). Almost 30% of carers indicated that their physical or emotional wellbeing had been affected by caring, while one in three carers felt weary or lacked energy because of caring (see Figure 7.1).

The Carers’ Health and Wellbeing study (Cummins et al., 2007) focused on carers’ pain, injury caused by caring, and the medical or psychological conditions of the carer. Only 13.5% of carers did not experience any physical pain, compared to 36.0% of the general population. Almost two-thirds of carers (65.7%) reported they never carried an injury caused by their caring; of these carers, 21.3% reported they were more likely than not to be carrying an injury. Sixty-nine per cent of carers reported that they had a medical or psychological condition that warranted visiting a doctor; however, only 76% of these carers were receiving treatment for their condition. Many who were not receiving medical treatment said that this was because they had no time (27%) or for “multiple reasons” (23%). The majority of carers with a medical condition reported that they had had it for less than one year.

68. We were unable to identify any epidemiological study that focused on the physical health of multiple family members.
69. Age, gender, race (white cf. other), years of education, stressful life events, and prior physical health were controlled for.
70. “Caregiving strain” was defined as the carer reporting physical or emotional strain in providing help with one or more activities of daily living to the person with a disability.
71. Self-reported health was rated “excellent”, “very good”, “good”, “fair” and “poor”.
72. Information on carers’ body mass index was also collected; however, the data was not presented, so the percentage of overweight or obese carers was not able to be determined by the authors, nor could comparisons be made with the general population.
73. In addition to “not enough time”, the multiple reasons included: “appropriate treatment unavailable where I live”, “difficulty with transport”, “cannot afford treatment” and “other.”
Limitations and future directions

With the exception of the Victorian Carers study, very little information has been collected on the self-reported physical health of carers in Australia; the Carers’ Health and Wellbeing study was the only large-scale Australian study to focus on carers’ pain, injuries and medical conditions. Moreover, even less information is available from large-scale epidemiological studies on other aspects of physical health, such as health behaviours, stress hormones or antibody responses. While the cost of collection of physiological information (such as stress hormones or antibody responses) is prohibitive for population-based studies, information about self-reported physical health, pain, injuries, medical conditions and health behaviours can easily be obtained through interview. Future studies could easily collect self-reported health information from carers; however, significant funds would be required to collect physiological information from a large group of carers.

Another major limitation of the research to date is that data have not been collected on the physical health of other family members, either in Australia or internationally. Again, the costs associated with a thorough examination of the physical health of family members in a family caring for a person with a disability may have prohibited such studies.

Conclusion

In summary, very few studies have examined the mental health of the carer and other family members who did not have a disability and we did not find any studies on the physical health of carers and other family members. The available evidence does suggest that the mental health of carers and other family members are correlated with one another; however, the studies were limited, as they were based on convenience samples of carers for a specific type of disabling condition (Edwards & Clarke, 2004; Kissane et al., 2003; Perlesz et al., 2000; Pruchno & Patrick, 1999).

International and Australian large-scale studies that focused on the mental health of primary carers suggest that:

- carers have higher levels of depression and stress, and lower levels of subjective wellbeing than people with no caring responsibilities;
- female carers have higher levels of depression and stress, and lower levels of wellbeing than male carers;
- greater care needs (e.g., behavioural problems, cognitive and physical impairments of the person with a disability, and number of caregiving tasks) and more hours of care are associated with higher levels of carer depression; and
- lower levels of depression are associated with informal support from friends or relatives, formal supports from professionals, and income.

The literature on primary carers’ physical health suggest that:

- carers have poorer self-reported physical health, higher levels of stress hormones and lower levels of antibody responses than non-carers; and
- carers are more likely to have a major health problem, use medication and experience physical pain than non-carers.
As outlined in Chapter 7, previous research has suggested that caregivers have significantly greater mental health problems, depression and anxiety. In the Families Caring for a Person with a Disability study, we asked two sets of questions about mental health. Firstly, carers were asked a set of standardised questions about their mental health and their vitality in the last 4 weeks. People who had scores below 56 on the mental health scale have been found to satisfy the clinical diagnostic criteria for depression and related disorders (Berwick et al., 1991). We used this cut-off as an indicator of clinical levels of depression over the 4-week period, as we did not employ a standardised diagnostic interview (see Chapter 3 for details). The same questions were also asked in the Household, Income and Labour Dynamics in Australia survey. Consequently, comparisons of mental health and vitality can be made between carers in the FCPDS and those in the general population who do not have caring responsibilities for a person with a disability. These comparisons enable an understanding of how carers are faring compared to the rest of the population.

The second set of questions asked whether the carer or other household members had ever been depressed or sad (even if they felt OK sometimes) for 6 months or more (a "depressive episode"). Carers were also asked in what year(s) the depressive episode occurred and for how long (one year, a period of consecutive years, or multiple non-consecutive years). The format of these questions enabled the timing of depressive episodes since the family started caring to be estimated. Again, we did not employ a standard diagnostic interview. However, if respondents answered “yes” to whether they had ever been depressed or sad (even if they felt OK sometimes) for 6 months or more, it provided an indication of clinical levels of depression—a key criteria for major depressive disorder is a depressed mood for most of the day for more than a 2-week period. The question is also derived from the Kemper three-item screening measure for depression, which has been found to be a valid indicator of clinical levels of depression in nationally representative samples (Kemper & Babonis, 1992; Lanzi et al., 1999).

Compared with the general population, carers had significantly worse mental health and vitality (see Figure 8.1). Based on normative information on mental health scores in other populations, carers in the FCPDS had, on average, greater mental health problems (that is, lower mental health scores) than patients with hypertension, congestive heart failure, type II diabetes and a recent acute myocardial infarction (Ware et al., 2002). Carers also had lower levels of vitality (that is, higher vitality scores) than patients with these same physical illnesses, except when compared to patients with congestive heart failure.74

Figure 8.2 indicates that male and female carers had significantly worse mental health than males from the general population and female carers also had significantly worse mental health than females from the general population. In the FCPDS, female carers also had significantly lower levels of mental health compared to male carers. Although this finding mirrored the gender difference in the general population, where females had worse mental health than males, the

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74. Comparisons were based on calculating 95% confidence intervals from standard errors provided in Ware et al. (2002).
Figure 8.1  Average levels of mental health and vitality, by caring status

Figure 8.2  Average levels of mental health, by gender and caring status
gender difference in mental health scores was greater for carers (4.9) than it was for the general population (2.5). The size of the gender difference in mental health scores for carers was twice that of the general population, suggesting that caring affects females’ mental health more than males, even after accounting for the size of the gender difference in the general population. These results are consistent with previous research. For instance, a meta-analysis of gender differences in the normal population indicated that there was a greater difference between female and male caregivers with respect to depression than there were with males and females who did not care for a person with a disability (Pinquart & Sorenson, 2006).

Figure 8.3 displays the incidence of clinical levels of depression in the last 4 weeks for male and female carers compared to the general population. The incidence of clinical levels of depression in the last 4 weeks was also significantly higher for male and female carers than male and females with no caring responsibilities. Thirteen per cent of male carers and 18.8% of female carers were at risk of having clinical levels of depression in the last 4 weeks.

Figure 8.3 Clinical levels of depression over last 4 weeks, by gender and caring status

As described at the beginning of this chapter, we also asked carers whether they had been depressed for 6 months or more since they started caring for a person with a disability. Figure 8.4 indicates that 50.7% of female carers and 30.7% of male carers reported that they had been depressed for 6 months or more since they started caring. We used information on the 12-month and lifetime estimates of the prevalence of depression in the Australian population from the 1997 National Survey of Mental Health and Wellbeing as a reference point for the incidence rates of depression illustrated in Figure 8.4. The 1997 National Survey of Mental Health and Wellbeing asked people about their depression in the last 4 weeks and these results were extrapolated to create 12-month and lifetime estimates of depression. Figure 8.4 suggests that the 12-month incidence of depression that was reported by both male and female carers is greater than the lifetime prevalence of depression in Australia. Moreover, the incidence of carers’ depression (again, for both sexes) is seven times higher than the 12-month prevalence rate in the general population.

75. The 1997 National Survey of Mental Health and Wellbeing collected information on the 12-month prevalence of depression in the Australian population and synthetic estimates were calculated for the lifetime prevalence of depression (Andrews et al., 1999; Kruijshaar et al., 2005).
There are several caveats that one should be aware of when making comparisons between incidence of depression among carers and national incidence rates of depression. Firstly, the question that was asked of carers about their level of depression in the last 6 months was not equivalent to the series of questions in the 1997 National Survey of Mental Health and Wellbeing. The 1997 National Survey of Mental Health and Wellbeing employed a diagnostic interview that complied with standardised diagnostic criteria used to diagnose someone with a major depressive disorder. Second, when people are asked to retrospectively recall their mental health status, inaccuracies can be introduced. However, studies that have examined recall biases have found that it is likely that people tend to fail to recall previous depressive episodes rather than provide overestimates (Patten, 2003). Moreover, 74% of carers in our sample have been caring for 10 years or less, making their estimates less likely to be open to recall bias. The much higher incidence rates of carers’ depression over a 4-week period, when compared to a large general population sample obtained using the Mental Health Inventory, also support the high rates of depression over the longer 6-month period. Consequently, we believe that high rates of depressive episodes experienced over the 6-month period are not artefacts of the study design, but are fairly good estimates of carers’ experience of depression.

Figure 8.4  Comparison of depression of carers with prevalence rates among the general population, by gender

Timing of carers’ first depressive episode

Figure 8.5 illustrates the risk of a first depressive episode, taking into account the fewer carers in each subsequent year, and those who had separated in a previous year.76 The most striking feature of Figure 8.5 is that the greatest risk appears to be at year 0, the first year of caring. After year 0, the risk of a first depressive episode is fairly constant, ranging between 2.0% to 5.0% for much of the next 20 years. The average risk over this 20-year period is around 3.0%. The most obvious implication of the findings in Figure 8.5 is that the first year of caring (year 0) is the time that any early intervention or support services that address mental health issues should be targeted.77

76. This is often referred to as a “hazard rate”. The hazard rate is expressed as the percentage of carers who have experienced a first depressive episode at a particular time point, divided by all the carers who have not previously experienced a depressive episode and are still caring at that time point. For example, at Year 1, 48 carers experienced their first depressive episode and 843 did not, creating a hazard rate of 5.4%.

77. It may be that part of the increased risk for a depressive episode in year 0 is due to a selection effect. In other words, carers who experienced a depressive episode in their first year of caring may not have continued caring and therefore would not have been part of the FCPDS sample. However, the evidence from the FCPDS sample does not support such an argument.
Thereafter, a less intensive but easily accessible intervention would be more appropriate. Although the average risk of a depressive episode over the next 20 years is only around 3.0% per annum, the cumulative effect of this risk is significant.

![Graph showing percentage risk of depression](image)

Source: FCPDS 2006

**Figure 8.5** Reports of carers’ first depressive episode, by years since starting caring

### Demographic and caring characteristics and carers’ mental health

In this chapter, we have already illustrated that female carers are at greater risk of depression and worse mental health than male carers. In this section, we focus on a few key demographic and caregiving variables and see how they relate to the mental health and vitality of carers.

#### Carers’ age

It has been projected that Australia’s population will grow over the next 40 years, but with a higher proportion of older people (Treasury, 2007). Consequently, a policy concern is that a greater proportion of carers will also be older (AIHW, 2004). Male carers were not included in these analyses because the number of male carers in some age categories was too small to provide reliable comparisons. Figures 8.6 compares the average mental health scores of female carers of different ages with females from the general population for each age group. Female carers had better mental health in each successive age group, and a similar trend can be seen for females from the general population. The mental health gap closed with increasing age; the largest differences were observed between female carers and females from the general population aged 18 to 35 years, but there was no significant difference in levels of mental health for those aged 65 years old or greater. A similar pattern could be observed when comparing the vitality of female carers to females in the general population. Female carers in the two younger age cohorts (18–35 and 36–50 years) had significantly worse vitality scores than females in the general population (see Figure 8.7). The gap between carers and the general population is smaller in the next age cohort (51–65 years), with female carers having very similar vitality scores to females in the general population and, interestingly, in the oldest group (65 years or more), carers actually had better vitality.
Figure 8.6 Mental health of females, by age and caring status

Figure 8.7 Vitality of females, by age and caring status

Figure 8.8 compares the incidence of clinical levels of depression for female carers and females from the general population who do not care for a person with a disability. The general pattern is the same as for Figures 8.6 and 8.7. The first point to note is that the incidence of clinical levels of depression declines as female carers and females from the general population age. More importantly, Figure 8.8 suggests that the difference in the incidence of clinical levels of depression is highest when carers are younger (26.9% of carers aged 18–35 years are at risk of clinical levels of depression, compared to 12.8% of 18–35 year old female non-carers), and declines markedly from the age of 50 onwards.
Caring for a child with a disability

Caring for a child with a disability may be particularly challenging (see Chapter 5). Almost one in three carers in the FCPDS (34.7%) cared for a person with a disability who was under 18 years of age. We investigated whether caring for a child with a disability was more stressful than caring for an adult. Figure 8.9 suggests that carers who cared for at least one child with a disability had significantly lower levels of mental health and vitality than carers who did not. Carers who cared for a child with a disability also had a significantly higher incidence of depression in the last 4 weeks and reported higher rates of depression when asked whether they had experienced depression for 6 months or more since they started caring (Figure 8.10). As can be seen from the figure, the difference in the incidence of depression between carers of adults with a disability and carers of children with a disability was not as marked when depression was measured for the last 4 weeks (15.2% versus 22.7%), compared to when carers had experienced depression for 6 months or more since caring started (39.5% versus 61.4%). The reasons for these results may be myriad, and a more detailed study is required to fully understand the factors behind the higher rates of mental health problems in carers of children with a disability. However, they do underscore that caring for a child with a disability is particularly stressful.

Care needs of the person with a disability

A variety of studies have suggested that high care needs of the person with a disability is associated with lower energy levels and worse mental health for carers (Pinquart & Sorensen, 2004). The influence of the care needs of the person with a disability78 on carers’ mental health and vitality are illustrated in Figure 8.11. Carers of people with low care needs have significantly better mental health and more vitality than carers of people who have medium or high care needs. Moreover, carers of people with medium care needs also have significantly better mental health and vitality than carers of people with high care needs.

A similar pattern was evident with respect to the incidence of carers’ depression in the last 4 weeks and for 6 months or more since they started caring (Figure 8.12). Carers who cared for people with more care needs had significantly higher incidences of depression when assessed for

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78. As 120 carers were caring for two or three people with a disability, the highest level of care needs reported for any one of the people of the disability is used.
the last 4 weeks and for 6 months or more since caring started. For example, carers of a person with a disability with high care needs had three times the rate of clinical levels of depression (30.9% compared to 10.5%) when measured over the last 4 weeks and almost twice the rate for 6 months or more since caring started than those caring for a person with low care needs (68.9% compared to 34.8%).

Source: FCPDS 2006

**Figure 8.9** Mental health and vitality of carers, by whether they care for a child

Notes: Carers who cared for a child with a disability also had significantly higher incidences of depression in the last 4 weeks ($\chi^2 (1) = 8.12, p < .01$) and reported higher rates of depression when asked whether they had experienced depression for 6 months or more since they started caring ($\chi^2 (1) = 40.15, p < .001$).

Source: FCPDS 2006

**Figure 8.10** Incidence of carers’ depression, by whether they care for a child
**Caring for more than one person with a disability**

One hundred and twenty-six carers (12.6% of the sample) cared for two or more people with a disability. Caring for multiple persons with a disability has particular challenges, including the potential for an increased amount of care being required, as well as needing to cater to a broader variety of care needs. With these issues in mind, we investigated differences in mental health and vitality for those who were caring for a single person or multiple people with a disability. As there were too few carers who cared for three or more people with a disability to derive reliable

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**Figure 8.11** Carers' mental health and vitality, by care needs

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**Figure 8.12** Carers' depression, by care needs

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Notes: Carers who cared for people with more care needs had significantly higher incidences of depression at 4 weeks ($\chi^2 (2) = 36.79, p < .001$) and for 6 months or more since caring started ($\chi^2 (2) = 59.84, p < .001$).

Source: FCPDS 2006
results ($n = 12$; 1.2% of the sample), our analysis focused on differences between carers of one person or two people with a disability. Figure 8.13 suggests that carers who cared for two people with a disability had significantly worse mental health and vitality than carers who cared for one person. The incidence of carers’ depression in the last 4 weeks and for 6 months or more since they started caring was also greater for carers of two people with a disability than for carers of one person (see Figure 8.14).

**Figure 8.13** Mental health and vitality of carers, by number of people cared for

**Figure 8.14** Incidence of carers’ depression, by number of people cared for
Other care roles

In addition to the role they play in caring for a person with a disability, carers also may have other care roles. In the FCPDS, 31.9% of carers were caring for at least one child without a disability and 2.5% were caring for parents who did not have a disabling condition. Role overload is one factor that has been associated with carers' mental health (Murphy, 2000). Figure 8.15 displays the average mental health and vitality scores of carers who have no additional care roles, care for a child without a disability or care for a parent without a disability. Carers who care for a child (or children) have significantly worse mental health than carers who care for a parent or have no additional care roles. The vitality of carers who care for a child (or children) was also significantly worse than carers who had no additional care roles (but not significantly different from the vitality of those caring for an adult with a disability). The incidence of depression in the last 4 weeks, as well as for 6 months or more since carers started caring was also highest for carers who cared for a child (or children), compared to both carers who cared for a parent and carers with no additional care roles (see Figure 8.16). These results are consistent with Cummins and colleagues (2007), who reported that carers with children had the highest levels of stress and greater levels of depression than carers who were living alone or with their partner. These results, when taken together with the increased rates of mental health problems of carers caring for a child with a disability, suggest that carers who have dependent children are at particular risk of mental health problems.

Family functioning

Family functioning has been associated with carers' and their families' mental health (e.g., Edwards & Clarke, 2004, 2005). Less is known about the influence of family functioning on carers' vitality or energy levels. Based on the literature and conceptual models reviewed in Chapter 5, it was expected that families with better family functioning would provide more support for the carer, and hence carers would be expected to have more vitality in families with higher levels of family functioning. As described in more detail in Chapter 3, carers were asked to indicate whether they agreed or disagreed with five questions assessing family functioning. These questions assessed family cohesion, tension, communication, flexibility and resilience. We defined having a problem in family functioning as being when carers indicated that their family
had an issue in one of the dimensions of family functioning. For instance, if the carer disagreed or strongly disagreed with the statement “We talk about our personal problems and help each other deal with them”, this was considered to indicate a problem with communication.

Figure 8.17 displays the average scores on mental health and vitality for carers who indicated that there were no problems on any of the five dimensions of family functioning compared to carers who have indicated they had one, or two or more problems. Carers who indicated their family had no problems in family functioning had significantly better mental health and vitality than the other two groups. Carers who indicated that their families had two or more problems in the dimensions of family functioning in turn had significantly worse mental health and vitality than carers who indicated that their family had only one problem in family functioning. Although carers scores on vitality were worse than for mental health overall, the same pattern was evident for both outcome measures: a greater number of family problems were associated with poorer wellbeing.

The incidence of carers’ depression was also higher when carers indicated that their families had problems in one, or two or more dimensions of family functioning. Figure 8.18 suggests that carers who indicated they had one problem in a dimension of family functioning had four times the incidence of depression in the last 4 weeks than carers with no problems in family functioning (29.3% versus 7.0%). Carers who had two or more problems in family functioning had five times the incidence of depression than carers who had no problems in family functioning (38.5% versus 7.0%). A similar pattern can be observed when carers reported being depressed for 6 months or more since they started caring (see Figure 8.18). These results underscore the robust association that has been observed in other Australian and international studies between mental health and family functioning (e.g., Edwards & Clarke, 2004).

The availability of support people

As has been documented in Chapter 5, extensive information was collected about the types of support received by the carer and by the person with a disability. The availability of support people has been found to be associated with carers’ mental health and energy levels in other
studies (Pinquart & Sorensen, 2007). Figure 8.19 shows the average mental health scores for carers by the number of support people engaged in four types of supportive behaviours. Carers who had no support people to help with everyday duties had significantly lower levels of mental health than carers who had one, two, or three or more support people. Carers who had three or more people to help with everyday duties also had significantly higher levels of mental health than carers in each of the other three groups. When the person with a disability had three or more people (excluding the carer) to assist with self-care, mobility and communication, their primary carers' mental health was significantly better than when there were 0 to 2 support people. Carers
had significantly better mental health when three or more support people (in addition to the carer) could provide assistance to the person with a disability with household tasks than when there were 0 to 2 people providing assistance in this area. When two people were providing assistance to the person with a disability with household tasks, carers’ mental health levels were significantly higher than when there were no support people in this area.

![Figure 8.19](image)

Source: FCPDS 2006

**Figure 8.19** Carers’ mental health, by type of support and number of people providing support

Fewer differences in carers’ levels of vitality were evident when the numbers of people providing various supportive behaviours were considered (see Figure 8.20). Carers with no people or one person to assist with everyday household tasks had significantly worse vitality than when there were three or more people providing this type of assistance. Moreover, when carers had no person to help with everyday duties, the carers had significantly lower vitality than those who had the assistance of one or more people in this area. As with mental health, the number of people available to talk about worries and fears, and assist the person with a disability with self-care, mobility and communication was not associated with carers’ vitality.

The incidence of clinical levels of depression in the last 4 weeks had some associations with the number of people providing particular types of support (Figure 8.21). There was an association between the number of people providing help with everyday duties and the incidence of clinical levels of depression in the last 4 weeks. For example, 22.0% of carers who had no people providing help with everyday duties had clinical levels of depression, compared to 12.1% of carers who had the support of three or more people in this area. There was an even stronger association between the number of people providing assistance to the person with a disability with household tasks, and the incidence of carer depression; when no-one else assisted the person with a disability with household tasks, 18.8% of carers had clinical levels of depression, compared to 3.0% when three or more people assisted the person with a disability in this area. It appears from this data that lack of availability of supports for carers and the person with a disability is associated with a 6-fold increase in the risk of developing clinical levels of depression.

**Unmet support needs**

Perceptions of support have been found to have even stronger associations with carers’ mental health and vitality than the number of support people (e.g. Roth, Mittelman, Clay, Madan, & Haley, 2005). In the FCPDS, we asked carers whether they received the support they needed.
Talk about worries and fears in general
Help with everyday duties
Assist with selfcare, mobility, communication
Assist with household tasks

Type of support provided by carer

Average vitality score

Source: FCPDS 2006

Figure 8.20  Carers’ vitality, by type of support and number of people providing support

Notes: There was an association between the number of people providing help with everyday duties and the incidence of clinical levels of depression in the last 4 weeks ($\chi^2 (3) = 9.00, p < .05$). There was an even stronger association between the number of people providing assistance to the person with a disability with household tasks and the incidence of carer depression ($\chi^2 (3) = 11.15, p < .05$).

Source: FCPDS 2006

Figure 8.21  Carers’ depression, by type of support and number of people providing support
The association between carers’ mental health and vitality and the need for more support is demonstrated in Figure 8.22. There is a clear and consistent pattern, with carers who indicated that the support they received was “about right” having significantly better mental health and vitality than carers who needed a lot or a little more support. Carers who said they needed a lot more support also had worse mental health and vitality than carers who indicated they needed a little more support (although the difference was small, it was still statistically significant).

Source: FCPDS 2006

Figure 8.22 Carers mental health and vitality, by level of need for support

Carers’ perceptions of support were also associated with the incidence of depression in the last 4 weeks and the frequency of reporting they had been depressed or sad for 6 months or more since they had started caring. Compared to carers who thought the support they received was about right (9.4%), carers who needed a little more support had twice the rate of depression in the last 4 weeks (21.9%), and carers who needed a lot more support had three times the rate (31.1%; see Figure 8.23). A similar pattern can be observed with carers reporting they had been depressed for 6 months or more since they started caring. Carers who needed a little more support had an incidence rate 1.58 times that of carers who said the support they received was about right (54.6% versus 34.5%). Moreover, carers who needed a lot more support had an incidence rate 1.88 times that of carers who indicated the support they received was about right (65.0% versus 34.5%).

The mental health of other family members

Mental health problems in a household are often not isolated to one family member, as multiple family members may experience mental health problems (Edwards & Clarke, 2004). There are several possible explanations that have been proposed for this phenomenon, including a shared genetic susceptibility or the experience of similar environmental stressors. In the context of caring for a person with a disability, several characteristics of caring were associated with carers’ mental health, and exposure to these factors is shared by household members. The experience of depression or mental health problems in one individual family member has previously been associated with other family members’ depression and anxiety, and could be a risk factor for carers. The influence of other household members’ mental health problems on the mental health of the carer is illustrated in Figure 8.24. When there are other household members who have experienced depression for a period of 6 months or more, the incidence rate of carers experiencing depression in the last 4 weeks as well as for 6 months or more is higher. For example, when two
household members had been depressed for 6 months or more, 32.4% of carers reported they had been depressed in the last 4 weeks, whereas only 14.5% of carers were depressed in the last 4 weeks when no other household members had been depressed. Similar patterns were also evident for carers’ experience of depression for 6 months or more since caring, with 35.4% of carers reporting depression for 6 months or more when no other family member had the same

Notes: Carers’ perceptions of support were also associated with the incidence of their depression in the last 4 weeks ($\chi^2 (2) = 51.69, p < .001$) and the frequency of reporting that they had been depressed or sad for 6 months or more since they had started caring ($\chi^2 (2) = 64.90, p < .001$).

Source: FCPDS 2006

Figure 8.23 Carers’ depression, by level need for support

Notes: The associations do not account for the number of household members in the household, nor do they provide information about whether the depression of a particular family member in the household has a particular impact on carers’ depression. Future analyses will be able to explore this issue in more detail.

Source: FCPDS 2006

Figure 8.24 Carers’ depression, by number of household members with depression
experience and 88.2% of carers reporting depression when two family members had also reported depression for 6 months or more since they started caring.

**Conclusion**

The data from this chapter suggest that carers have significantly worse mental health, worse vitality and higher rates of depression than the general population. Differences on these variables were evident for carers of all age groups, except when carers were 65 years or older.

Fifty-one percent of female carers and 30.7% of male carers reported that they had been depressed for 6 months or more since they started caring. The 12-month incidence of depression reported by carers of both sexes was greater than the lifetime prevalence of depression in Australia.

The risk of carers experiencing a first depressive episode of at least a 6-month duration was greatest in the first year of caring (over 13% of carers), and over the next 20 years was fairly stable at about 3%. In this context, early intensive interventions and supports are important in the first year of caring and thereafter a less intensive, but easily accessible, intervention would be more appropriate.

Carers had more mental health problems, worse vitality and higher rates of depression when:

- caring for a child with a disability;
- caring for a person with a disability with high care needs;
- caring for more than one person with a disability;
- one of their other care roles was to look after children who did not have a disabling condition;
- there were one or more problems in family functioning;
- they indicated that they needed a little or a lot more support than they were receiving; and
- other family members had experienced a period of 6 months or more of depression.
Mental health of other family members, including the person with a disability

Ben Edwards

We are not aware of any large-scale population studies in Australia or internationally that have focused on the mental health of family members of the primary carer other than the person with a disability. In this section, we focus on one aspect of mental health: the experience of a depressive episode by family members with and without a disability. The Families Caring for a Person with a Disability study collected information about the mental health of other family members, not just the primary carer. Carers were asked whether any family members had been depressed or sad (even if they felt OK sometimes) for 6 months or more since caring began. This question was adapted from the Kemper three-item screening measure for depression, which has been found to be a valid indicator of clinical levels of depression (Kemper & Babonis, 1992; Lanzi et al., 1999) and can be considered an indicator of clinical levels of depression—a key criteria for a major depressive disorder is a depressed mood for most of the day for more than a 2-week period. Consequently, when a family member had experienced a period of 6 months or more where they reported being depressed or sad (a “depressive episode”), carers were also asked in what year(s) the depressive episode had occurred.79 The timing of depressive episodes relative to when the carer started caring could also be calculated.

Family members who have a disabling condition had a very similar number of depressive episodes (17.2%) compared to family members who did not have a disability (16.7%).80 Instead of the disabling condition, the experience of a depressive episode was related to the person’s relationship to the carer. Figure 9.1 indicates partners of the primary carer81 were much more likely to have experienced a depressive episode of 6 months or more (27.3%) than were carer’s parents (12.1%) and carer’s children (10.6%).

Table 9.1 provides the percentage of family members experiencing a depressive episode of 6 months or more, depending on whether the family member had a disability or not, and according to their relationship with the primary carer (partners, children and parents of carers). Slightly more partners who were not disabled (28.5%) than partners who were disabled (26.4%) had been depressed for 6 months or more since the carer started caring, but this was not statistically significant. Children’s rates of depressive episodes were very similar, irrespective of whether the child had a disability or not; in both cases, approximately 10% experienced a depressive episode of 6 months or longer. Parents who had a disability had higher rates of depressive episodes (12.9%) than parents who did not have a disability (7.4%); however, given the small numbers of parents without a disability living in the same household as the carer, this was not statistically significant.

Gender and family members’ experience of depression

As was noted in the previous section addressing carers’ mental health, females in the general population tend to show higher rates of depression than males. We compared the experience of depression for male and female partners, and children and parents of carers. Female partners with a disability had higher rates of depression than male partners (see Figure 9.2). The reverse

79. A discussion of the validity of proxy reports of mental health can be found in Chapter 3.
80. These differences were not statistically significant ($\chi^2 (1) = 0.44, p > .05$).
81. In this section, when we talk about “partner with a disability”, we mean that the person with a disability for whom the carer is providing care is that carer’s partner.
trend was evident for partners with no disability: a higher percentage of male partners than female partners had experienced a depressive episode of 6 months or longer. However, it should be noted that there were only 14 female partners of carers and, consequently, these differences may simply be due to sampling error; moreover, they were certainly not statistically significant. The small number of female partners of carers reflects the well-documented gendered nature of caring, as females are most likely to be the primary carer (see Chapter 1).

As has been noted, far fewer offspring of carers experienced a depressive episode than partners of carers. There were no differences in the rates of experiencing a depressive episode for offspring with and without a disability (see Figure 9.3). There was also no statistically significant gender difference for offspring with a disability and without a disability.

Very similar percentages of men and women with a disability who were cared for by their adult children experienced a depressive episode (see Figure 9.4 on p. 86). Slightly more mothers (13.7%) than fathers (10.5%) with a disability had experienced a depressive episode of 6 months or more since their child began caring for them; however, this was not statistically significant. As can be noted from Table 9.1, there were only 27 parents with no disability residing in the carers’ household. As a consequence, it is not possible to draw any firm conclusions from an examination of gender differences in the depressive episodes of these parents. No fathers and
Notes: Female partners with a disability had significantly higher rates of depression than male partners with a disability ($\chi^2 (1) = 7.53, p < .01$). For carers’ partners who did not have a disability, there was no statistically significant difference in the rate of depression ($\chi^2 (1) = 0.36, p > .05$) between male and female partners.

Source: FCPDS 2006

**Figure 9.2** Carers’ partners’ experience of depression, by disability status and gender

Notes: There was no statistically significant gender difference for offspring with a disability ($\chi^2 (1) = 0.01, p > .05$) and without a disability ($\chi^2 (1) = 0.50, p > .05$).

Source: FCPDS 2006

**Figure 9.3** Carers’ offsprings’ experience of depression, by disability status and gender
12.5% of mothers without a disability experienced a depressive episode of 6 months or more. However, the gender differences in parents with no disability for the rates of depressive episodes may be simply an artefact of measurement error due to the small sample size.

In summary, a greater percentage of female partners who had a disability experienced a depressive episode of 6 months or longer when compared to male partners with a disability. However, there were no gender differences in the experience of depressive episodes of 6 months or more for parents and offspring of carers. The lower rates of depressive episodes experienced by offspring and parents of carers may offer some explanation for the lack of gender differences in these groups. The results from this section do suggest female partners with a disability were at particular risk of a depressive episode and could be the focus of more targeted support.

**Timing of family members’ first depressive episode**

When carers were asked whether their family members had been depressed for 6 months or more, they were also asked in what year the depression occurred. As the FCPDS also collected information on when carers first started caring, we were able to determine the number of years from when carers started caring to when family members had their first depressive episode. Figure 9.5 details the timing of first depressive episodes for family members with and without a disabling condition. Similar to the timing of first depressive episodes of carers (see Figure 8.5), the most obvious feature of Figure 9.5 is that the greatest number of depressive episodes for both people with a disability and other family members occurred in the first year of caring. Sixty-two people with a disability and 34 other household members experienced their first depressive episode in the first year of caring (year 0). This first year of caring accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members. The rate of first depressive episodes dropped off markedly after the first year for people with a disability—a further 44 people with a disability (29.5%) experienced a first depressive episode over the next four years following the first year. The rate of first depressive episodes for family members was a little more evenly spread over the years since
care commenced, with 78 family members experiencing their first depressive episode over the next four years (41.1% of all depressive episodes experienced).

![Graph showing the number of people with and without a disability experiencing their first depressive episode over the years since started caring.]

Although greater numbers of people (both those with a disability and other family members) experienced a first depressive episode in the early years since the carer commenced caring, the length of time that individuals were “at risk” may have inflated the numbers experiencing a first depressive episode in the early years. Unlike carers, however, it is not straightforward to assess the risk period for people with a disability and other family members from our data. For people with a disability and other family members to have been “at risk”, they needed to be residing in the household for the duration of the caring period and be of an age when depression could be assessed (4 years or older) (Sawyer et al., 2000). Any attempt to calculate the risk of experiencing a depressive episode over time needs to take these issues into account. We did not conduct such an analysis, given the inherent complexity and the number of assumptions needed. Consequently, the data we have presented can be considered indicative, but not definitive, data on the timing of first depressive episodes of people with a disability and family members.

The implications of the timing of the depressive episodes of people with a disability and other family members are similar to those for carers. Early intervention may be particularly important given that 28.9% of people with a disability and 41.0% of family members experienced a first depressive episode in the first four years of caring.

Demographic and caring characteristics and family members’ mental health

In this section, we focus on a few demographic, caregiving and family variables and see how they relate to the experience of depression of family members.

Age and disability status

In the general population, the peak age period when people experience depression is in late adolescence and early adulthood. We examined age differences for partners and offspring of carers (but not for parents of carers, as the number of parents in the household was too small to
derive reliable estimates from any statistical analysis). The analyses also compared partners and offspring of carers who had a disability and those who did not.

**Partners**

For partners with a disability, there was a decrease in the percentage that experienced a depressive episode as they got older (Figure 9.6). This trend approached, but did not reach, statistical significance and was consistent with the experience of depression in the general population—namely, a decline in the rate of depression as people age. The experience of depressive episodes for partners without a disabling condition was very different. Overall, fewer partners without disabling conditions were experiencing a depressive episode, but a much greater percentage of partners aged 51 to 65 years of age experienced a depressive episode than the other age categories. A greater percentage of partners aged 51 to 65 years of age with no disabling condition had experienced a depressive episode than partners with a disabling condition (however, this difference was not statistically significant). It should also be noted that, although a greater percentage of partners with a disabling condition experienced a depressive episode in the other three age categories, these were not statistically significant differences.

![Graph showing percentage experiencing depression by age and disability status](image)

Notes: A smaller percentage of partners with a disability experienced a depressive episode in each successive age group; however, this trend was not statistically significant ($\chi^2 (3) = 7.01, p < .10$). The statistical test suggested that a greater percentage of partners with no disabling condition aged 51 to 65 years of age experienced a depressive episode than the other age categories ($\chi^2 (3) = 38.84, p < .001$). Although it appears that a greater percentage of partners aged 51 to 65 years of age with no disabling condition had experienced a depressive episode than partners with a disabling condition, this difference was not statistically significant ($\chi^2 (1) = 1.36, p > .05$). There were also no statistically significant differences between partners with a disabling condition in the other three age categories who experienced a depressive episode than partners with no disability ($\chi^2 (1) = 0.53$ to $2.23, p > .05$).

Source: FCPDS 2006

**Figure 9.6**  Carers’ partners’ experience of depression, by partners’ age and disability status

**Offspring of carers**

The percentage of carers’ offspring who experienced a depressive episode varied depending on the age of the son or daughter and whether they had a disabling condition (Figure 9.7). When offspring had a disability, those aged 31 years or more had the highest rates of depressive episodes (although only 39 offspring were in this category; therefore this result may not be accurate, given the sample size). Secondary–school aged children (13 to 18 years of age) had the next highest rate of experiencing a depressive episode (13.9%). Primary–school aged children had a lower rate of depressive episodes (10.0%). These rates should be interpreted in the context of population estimates of depressive disorders for primary– and secondary–school aged children. Australian estimates of depression in primary–school aged children are 3.7% for males and 2.1% for females;
and in secondary-school aged children, 4.8% for males and 4.9% for females (Sawyer et al., 2000). In this context, rates of depressive episodes among children with a disability in primary and secondary school are twice to three times that of the general population.

Among carers’ offspring without a disability, young adults were the ones with the highest rates of depressive episodes. Eighteen per cent of carers’ offspring who were aged 18 to 31 experienced a depressive episode of 6 months or more since the carer started caring. Secondary-school aged children of carers were the group with the second highest rates of depressive episodes at 14.8%. While there were some differences in the pattern of depressive episodes across the age categories for offspring with and without a disability, these were not significantly different from one another for each of the five age groups.

Family members’ experience of depression and carers’ depression

In the chapter on carers’ mental health, an association between the number of family members who had experienced a depressive episode and carers’ mental health was noted (see Figure 8.24). In this section, we explore this issue further by examining the association between different types of family members’ experience of a depressive episode and the primary carers’ mental health. We first examined the association between carers experiencing depression in the last 4 weeks and family members’ experience of a depressive episode of 6 months or more since caring began. Figure 9.8 suggests that carers’ experience of depression in the last 4 weeks was associated with higher rates of depressive episodes for partners of carers who did not have a disability, but not for partners with a disability. Higher rates of depressive episodes among offspring were evident when the carer had been depressed in the last 4 weeks (regardless of whether the offspring had a disability), but not among parents with a disability. It should be noted that there were too few parents without a disability (n = 27) living in the household to test the association between carers’ depression and parents’ experience of a depression episode.

There were stronger associations between carers’ experience of a depressive episode since they started caring and the experience of depression in carers’ parents and offspring (Figure 9.9). Therefore, there were higher rates of depressive episodes for partners (both with and without
Notes: Carers’ experience of depression in the last 4 weeks was associated with higher rates of depressive episodes for partners of carers who did not have a disability ($\chi^2 (1) = 7.63, p < .01$), but not for partners with a disability ($\chi^2 (1) = 0.28, p > .05$). Higher rates of depressive episodes were evident when carers were depressed in the last 4 weeks for children with a disability ($\chi^2 (1) = 6.58, p < .05$) and without ($\chi^2 (1) = 6.20, p < .05$), but not for parents with a disability ($\chi^2 (1) = 0.08, p > .05$).

Source: FCPDS 2006

Figure 9.8  Family members’ experience of depression, by disability status and whether carer was depressed in the last 4 weeks

Notes: When carers experienced a period of depression for 6 months or more, family members had higher rates of depressive episodes that were statistically significant when the family member was: a partner with a disability ($\chi^2 (1) = 20.85, p < .001$) and without ($\chi^2 (1) = 48.61, p < .001$); and children with a disability ($\chi^2 (1) = 5.66, p < .05$) and without ($\chi^2 (1) = 22.47, p < .001$). Parents with a disability did not have significantly higher rates of depression when carers had experienced a period of depression for 6 months or more ($\chi^2 (1) = 2.15, p > .05$).

Source: FCPDS 2006

Figure 9.9  Family members’ experience of depression, by disability status and whether carer has been depressed for 6 months since starting caring
a disability) when carers also experienced a period of 6 months or more of depression since caring began. Forty-three per cent of carers’ partners who did not have a disability experienced a depressive episode when the carer experienced a depressive episode, compared to 8.9% of partners of carers who had not experienced depression in the care period. This represents almost a five-fold increased risk. When partners of carers had a disability, they were twice as likely to have experienced a period of depression when the carer had also had a depressive episode of 6 months or more since caring began (39.2% versus 18.9%).

Offspring of carers who had experienced a depressive episode since caring began were also at a greater risk of experiencing depression. Carers’ offspring with a disability were twice as likely to experience depression when carers had also been depressed since caring began (13.1% versus 6.4%). Offspring who did not have a disability were at even greater risk of depression when carers had experienced depression, with these offspring being four times more likely to have experienced depression in the caring period when the carer had been depressed (15.7% versus 3.8%).

Parents with a disability were the only group who did not have significantly elevated rates of depression when the carer had experienced a depressive episode of 6 months or more. Although exploration of the mechanisms by which other family members were at higher risk of experiencing depression when the carer experienced a depressive episode are beyond the scope of the current report, it is likely that being older may have been a protective factor for carers’ parents.

In summary, partners and offspring of carers were twice to five times more likely to experience a depressive episode of 6 months or more when the carer also had experienced a depressive episode of 6 months or more since caring began. When carers had been depressed in the last 4 weeks, their offspring (both with and without a disability) and partners without a disability were also at an increased risk of depression; however, partners with a disability did not have an increased risk of depression. The differences between results when the carer had been depressed in the last 4 weeks compared with a depressive episode of 6 months or more highlight the stressful nature of a prolonged experience of depression for family members.

**Family functioning**

As has been noted in Chapter 5, family relationships can become strained as a result of caring for a person with a disability, although good family functioning can be an important protective factor for the mental health of family members (see Chapter 7). Figure 9.10 highlights the influence that family functioning has on family members’ experience of depressive episodes. There was a significant association between family functioning and the experience of a depressive episode of partners who did not have a disability (but not for depression in partners with a disability). Where there were two or more problems in family functioning, partners with no disabling condition had over twice the rate of depressive episodes than partners with no disability who lived in households with no family functioning problems (46.3% versus 21.7%). Family functioning was also associated with the experience of depressive episodes by children with and without a disability. For example, children (both with and without a disability) who lived in a family with two or more problems in family functioning had over 2.5 times the rate of depressive episodes than children with no problems in family functioning. Although there was not a significant association between the experience of depressive episodes and family functioning for parents with a disability, there was a trend for a greater proportion of parents with a disability to experience more depressive episodes in families with more problems with family functioning. These results underscore the important role that strong family relationships play in protecting against mental illness (Edwards & Clarke, 2004) and suggest that interventions aimed at improving the mental health of those caring for a person with a disability need to address family relationships (for an example of this approach, see Kissane & Bloch, 2002).

**Conclusion**

Results from carers’ reports of family members’ experience of depression found that 27.3% of partners, 12.1% of parents and 10.6% of offspring had experienced a depressive episode of
6 months or more since caring began. The only gender difference that we found was that female partners with a disability experienced more depression (34.2%) than male partners with disability (27.0%).

The risk of family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring. This first year of caring accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members.

Partners and offspring of carers (both with and without a disability) were twice to five times more likely to experience a depressive episode when the carer had also experienced a depressive episode of 6 months or more since they had started caring. Higher rates of depressive episodes for partners with no disabling condition and children (with and without a disability) were also evident when there were problems in dimensions of family functioning.

Notes: There was a significant association between family functioning and the experience of a depressive episode by partners who did not have a disability (χ² (2) = 9.15, p < .05), but not with the depression of partners with a disability (χ² (2) = 1.00, p > .05). Family functioning was also associated with the experience of depressive episodes of children with a disability (χ² (2) = 9.15, p < .05) and without (χ² (2) = 11.11, p < .01).

Source: FCPDS 2006

Figure 9.10 Family members’ experience of depression and family functioning problems, by disability status and number of problems
The empirical literature suggests that the self-rated physical health of carers for a person with a disability is worse than the physical health of the general population (Pinquart & Sorensen, 2003; Vitaliano et al., 2003). This chapter addresses the physical health of carers.

The Families Caring for a Person with a Disability study measured carers’ physical health, using the question: “In general, would you say your health is excellent, very good, good, fair or poor?” Self-rated health has been found to be highly predictive of subsequent morbidity and mortality, independent of other factors (e.g., Jenkinson & McGee, 1998). Also, research examining this measure has found that this question reflects the presence of acute and chronic physical health problems (Ware et al., 2002).

Caring status and gender

Carers from the FCPDS had significantly worse physical health than the general population (see Figure 10.1). A higher percentage of carers indicated that they had fair or poor health than did the general population, although about the same proportion of carers (35.3%) and people from the general population (35.6%) stated they were in good health. People who say that they are in fair or poor health are commonly considered to have poor health, and this outcome has been widely used as an indicator of poor health in other surveys (Kim, Subramanian, & Kawachi, 2005).
Combining these responses, 29.0% of carers were in poor health compared to 17.2% of the general population.82

The rates of poor health were much higher for female carers (28.5%) compared with females from the general population (18.3%). The same pattern was also evident for poor health in male carers (31.7%) compared to the general population of males (15.9%). Details are displayed in Figure 10.2.

**Age**

Differences between carers’ self-rated physical health and the general population were also evident across most age groups. As there were too few male carers for valid comparisons to be made across age groups, our analysis focused on female carers. Compared to females in the general population, a greater percentage of female carers had poor physical health when aged 18 to 35 years, 36 to 50 years and 51 to 65 years. The percentage of poor physical health in female carers and the general female population was only comparable when people were aged 65 years or older. The differences across the younger age categories suggest that the lower levels of physical health reported by carers is not a function of carers being an older group of people, but rather reflects the physical toll that caring can place on the body. Our results for older people could be interpreted to mean that caring does not have an impact on physical health for carers aged 65 years or older. It is likely however, that these results reflect a selection effect, where people who are capable of providing care when aged 65 years or older continue to care when they are physically robust, while frailer older carers give up providing care and make other caring arrangements for their relative. It also evident from Figure 10.3 that, in the general population, the percentage of people reporting poor physical health increases with age. In contrast, the percentage of carers reporting poor physical health is similar for the carers aged 35 years or over. This further indicates that the prevalence of poor physical health among carers may not relate directly to ageing processes, but rather to physical and other strains induced by caring.

**Notes:**

- A greater proportion of female carers were in poor physical health than females from the general population ($\chi^2 (1) = 45.30, p < .001$).
- A greater proportion of male carers were in poor physical health than males from the general population ($\chi^2 (1) = 38.66, p < .001$).

Sources: FCPDS 2006; HILDA Wave 4.1

**Figure 10.2** Incidence of poor physical health, by gender and caring status

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82. A greater percentage of carers were in poor health than the general population ($\chi^2 (1) = 89.04, p < .001$).
Care needs of the person with a disability

Caring for a person with a disability may exact a physical toll, either directly through physical wear and tear or indirectly by restricting the time and energy available for health care behaviours, such as seeing a doctor for regular health check-ups or by engaging in regular physical exercise. People with a disability who have higher care needs may require more physical care by the carer and more time to be devoted to their care, and consequently leave less time for the carer to engage in health care behaviours. Figure 10.4 suggests that higher care needs of the person with a disability were associated with a higher rate of poor physical health. For example, 24.4% of carers who were caring for a person with a disability with low care needs had poor physical health, while 37.6% of carers had poor physical health when they cared for a person with a disability with high care needs.

Caring for more than one person with a disability

Caring for more than one person with a disability may necessitate an increased amount of care, as well as needing to meet a broader variety of care needs. The likelihood of carers needing to engage in direct physical care may be increased and the time available for health care behaviours decreased. Figure 10.5 shows that, as would be expected, carers who cared for two people with a disability had significantly higher rates of poor physical health than those who cared for one.

Unmet support needs

The level of unmet support needs may have an indirect influence on carers’ physical health. The stress of caring for a person with a disability has been found to be buffered by perceptions of support and, consequently, for carers who felt supported, their physical health symptoms were affected less by caregiver stress (Goode, Haley, Roth, & Ford, 1998). While such complex analyses are beyond the purview of this report, we did examine the direct association between carers’ physical health and their perceptions of support. We found that there was an association
Note: Higher care needs of the person with a disability were associated with a higher rate of poor physical health ($\chi^2 (2) = 11.32, p < .01$).
Source: FCPDS 2006

Figure 10.4 Incidence of poor physical health of carers, by care needs

Note: Carers who cared for two people with a disability had higher rates of poor health than carers who cared for one person ($\chi^2 (1) = 6.88, p < .01$).
Source: FCPDS 2006

Figure 10.5 Incidence of poor physical health of carers, by number of people with a disability cared for
between carers’ perceptions of support and their physical health. Carers who said they felt they needed a lot more support were 1.8 times more likely to have poor physical health than carers who indicated that the support they received was about right (39.9% versus 22.2%). Whether the mechanism by which support operates directly or indirectly (e.g., by reducing the physical care undertaken by the caregiver or moderating psychological stress) is unclear from these data. More detailed analyses of these data could shed light on these mechanisms.

**Family functioning**

Very few studies have examined how family relationships may influence the physical health of the carer in the context of caring for a person with a disability. Effective family functioning may enable families to coordinate and distribute support in a more equitable fashion throughout the family, thereby reducing the caring load on the primary carer. Moreover, good family relationships have been found to ameliorate carers’ stress (Edwards & Clarke, 2004; Higgins et al., 2005), and carer mental health problems have been associated with physical health problems such as coronary heart disease (Vitaliano et al., 2002). In the FCPDS, we used a five-item measure of family functioning (see Chapter 3). We tallied carers’ responses to the five items to indicate when a problem in a family functioning dimension occurred. The data presented in Figure 10.7 suggests that there was a statistically significant association between carers’ physical health and problems in family functioning. For example, when there were no problems in any of the dimensions of family functioning, 20.8% of carers had poor physical health, compared to the 48.3% of carers who indicated there were two or more dimensions of family functioning in which there were problems. These results suggest that family functioning was associated with carers’ poor physical health. Further research investigating mechanisms of risk are required, as well as further analyses controlling for confounding variables such as education and household income. Longitudinal studies will enable the temporal direction of the association to be tested; it could be that having poor physical health means that people evaluate their families more negatively.

**Figure 10.6 Incidence of poor physical health of carers, by perceptions of support needed**

Notes: $\chi^2 (2) = 26.39, p < .001$

Source: FCPDS 2006

![Chart showing incidence of poor physical health of carers, by perceptions of support needed](chart.png)
In summary, almost twice as many carers were in poor physical health (29.0%) than the general population (17.2%). These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories except when carers and the general population were aged 65 years or more.

Several factors were associated with higher rates of poor physical health for carers. Higher rates of poor physical health were associated with caring for a person with a disability with high care needs and more than one person with a disability. One or more problems in family functioning was also associated with higher rates of carers’ poor physical health. Carers who indicated that they needed more support (a little or a lot) also had higher rates of poor physical health than carers who said the support they received was “about right”.

Note: More problems in family functioning were associated with higher rates of poor physical health in carers ($\chi^2$ (1) = 48.72, $p < .001$).
Source: FCPDS 2006

**Figure 10.7** Incidence of poor physical health of carers, by number of family functioning problems

**Conclusion**

In summary, almost twice as many carers were in poor physical health (29.0%) than the general population (17.2%). These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories except when carers and the general population were aged 65 years or more.

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Source: FCPDS 2006

**Figure 10.7** Incidence of poor physical health of carers, by number of family functioning problems

**Conclusion**

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Source: FCPDS 2006

**Figure 10.7** Incidence of poor physical health of carers, by number of family functioning problems
SECTION E
LABOUR FORCE PARTICIPATION
Matthew Gray, Ben Edwards and Norbert Zmijewski

Introduction

Understanding the impact of long-term caring on participation in the labour market is of crucial importance to social policy in coming decades, given projected increases in the demand for informal care providers. It is important, not only for the economic wellbeing of carers, but also from a national economic perspective, given projected labour shortages associated with an ageing population and increasing dependency ratios.

Primary carers of an adult or a disabled child have lower rates of employment and labour force participation than those without caring responsibilities of this nature. It is estimated, after taking into account age and gender differences, that the employment rate of Australian primary carers in 2003 was 42.8%, which is lower than the Australia-wide average of 59.2% (Access Economics, 2005).83 The main reason for the lower employment rates of carers is a much lower full-time employment rate (19.2% for carers and 42.0% for the Australia-wide average). The part-time employment rates are slightly higher for carers (22.8%) than the Australia-wide average (17.2%).

To date, there has been relatively little Australian research into the impact of caring responsibilities on the labour force status of carers. There has been even less research specifically on the labour force status of carers who receive Carer Payment and/or Carer Allowance, a group of particular policy interest. Two recent Australian studies have used longitudinal data to analyse the impact of caring responsibilities on labour market participation (Bittman et al., 2007; Lee & Gramotnev, 2007).84

Understanding the impact of long-term caring upon labour market participation is particularly important, given the growth in recent years in the number of people requiring care, and projections that the demand will continue to grow in coming decades (e.g. NATSEM, 2004).85 The increasing demand for carers is in part a consequence of the structural ageing of the population (e.g., NATSEM, 2004). It is also a consequence of the shift from institutional to community care for adults with a disability. There is some evidence that this shift has increased the burden on carers (Tolhurst, 2001).

In this chapter, we use the FCPDS data to analyse a number of labour market issues for people of working age who provide ongoing care to persons with disabilities, long-term health conditions or older persons and who receive an Australian government payment that is directed towards carers (Carer Allowance and Carer Payment).

There are a number of reasons for expecting significant caring responsibilities to reduce the likelihood of carers being in paid employment or, if employed, working less hours. The time taken to provide care may be incompatible with paid employment. The jobs available to the carer...
may require particular working hours, or may have insufficient flexibility to allow the carer to provide care as well as sustain paid employment.

Although the employment rate of primary carers is much lower than the Australia-wide average, these differences cannot necessarily be interpreted as being a consequence of caring. There are a number of other possible explanations. First, carers may have, on average, different human capital and demographic characteristics than non-carers, which could explain part or all of the differences in employment rates. Second, the decision as to who cares within a family may be related to labour market opportunities, with family members who have fewer labour market opportunities being more likely to take on the primary carer role.\(^86\) Third, potential carers who have a good labour market earnings capacity may decide to purchase formal care rather than provide care themselves in order to allow participation in the labour market. Economic models suggest that people whose hourly labour market earnings exceed the hourly costs of formal care will purchase formal care. Of course, beliefs about what is the right thing to do, sense of loyalty and the intrinsic rewards of caring will also be important in decisions as to whether to provide informal care or purchase formal care (see Hales, 2007, for a discussion of these issues).

Although there is some Australian evidence on the labour market outcomes of carers and how they compare to non-carers, there is relatively little Australian research that models the impact of providing care on the labour market participation of the carer. In particular, it would appear that appropriate models of the effects of caring responsibilities on labour force status have not been estimated for Australia. Models should take account of differences in the characteristics of carers and non-carers and the potential selection effect of those with more limited labour market opportunities on taking on caring.\(^87\)

There has also been relatively little research into the types of employment conditions that can best assist caregivers to combine caring with paid employment. Exceptions include Glezer and Wolcott (2000), Gray and Hughes (2005), and Jenson and Jacobzone (2000).

As discussed in the methodology chapter (Chapter 3), the sample for the FCPDS was selected from the Centrelink administrative database of those receiving Carer Payment and/or Carer Allowance. Carer Payment is an income support payment for those who are unable to participate in the workforce full-time as a result of their caring responsibilities. As outlined in Chapter 2, Carer Payment is means tested (income and asset tests) and eligibility is also dependent on the level of impairment of the care receiver. Carer Allowance is provided to people who provide daily care and attention at home to a person who has a disability or severe medical condition. A more detailed description of the Australian Government payments available to carers is provided in Chapter 2.

Although there is information available on the labour market outcomes for carers from the ABS 2003 SDAC, there is relatively little information available on the labour market outcomes and aspiration of carers who specifically receive Carer Payment or Carer Allowance. As discussed in Chapter 2, eligibility conditions for Carer Allowance and Carer Payment mean that the sample used in the FCPD survey will differ in some important respects from the general population of carers in Australia.

This chapter makes several contributions to the literature. First, it provides a detailed description of the labour force status of carers in receipt of the Australian Government payments: Carer Allowance or Carer Payment; in particular, the extent to which non-employed carers want to be in paid employment. Second, some information on labour market experience since starting to provide care is outlined. Third, information on job changes that employed carers have made as a

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86. The foregone earnings costs of providing care would be minimised if the family member with the lowest labour market earning potential takes on the primary caring role. The empirical evidence on this question is mixed. Pavalko and Artis (1997) and Spiess and Schneider (2002), using longitudinal data from the US and the European Community respectively, found that the decision as to who in the family provides care was not related to pre-care employment status. Dautzenberg et. al. (2000), using Dutch data, found the reverse result.

87. There are relatively few studies that have used longitudinal data to analyse the effects of caring on labour force participation. Henz (2004), in a study based on longitudinal data from the United Kingdom, found that providing informal care is associated with movements out of employment and with a reduction in working hours for those who remained employed.
The relatively small sample of employed carers means that some caution needs to be exercised when interpreting some of the data presented in this chapter. There are significant differences in patterns of labour force participation between males and females, so any analysis of labour force status needs to be conducted separately for males and females. The relatively small number of male carers of working age in the sample precludes an analysis of labour market outcomes according to payment type for men. The analysis in this chapter is therefore restricted to female carers.

**Data issues and definitions**

Given that eligibility for Carer Payment is restricted to carers who are unable to participate in the workforce full-time as a result of their caring responsibilities (an eligibility condition that does not apply to Carer Allowance), when analysing labour market issues, it is essential to conduct the analysis separately for those receiving Carer Payment and those receiving only Carer Allowance. This is a departure from much of the analysis in earlier chapters. Analysis of how labour force status varies according to the level of impairment of the care receiver has not been undertaken because whether or not the carer receives Carer Payment is likely to be correlated with the level of impairment.

The categories of labour force status used are fairly conventional. They are: (a) employed full-time (usually works 35 or more hours per week in all jobs), (b) employed part-time (usually works 1 to 34 hours per week), (c) unemployed, (d) marginally attached (not employed and wants to work, but is not currently looking for work), and (e) not in the labour force and does not want to work.

The analysis in this section is restricted to those of working age, who are defined as being in the age range 18–64 years.

**The labour force status of carers**

**Current labour force status**

Table 11.1 shows labour force status for female carers of working age according to the type of payments received—only Carer Allowance or Carer Payment (including those who also received Carer Allowance).

The full-time employment rate of female carers who receive only Carer Allowance is 11.4% and the part-time employment rate is 35.7%. This gives a total employment rate of 47.1%. As expected, given the eligibility requirements for Carer Payment, just 0.8% of women in receipt of Carer Payment are employed full-time. However, 25.2% are employed part-time, giving a total employment rate of 26.0%.

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88. There were 116 male carers of working age and 109 male carers of non-working age (over 64 years of age or had indicated they were retired). Forty-seven male carers of working age received Carer Allowance only, while 69 male carers of working age received Carer Payment.

89. Included paid and unpaid overtime. If working hours were irregular, respondents were asked to average the last four weeks.

90. The definition of unemployment we used differs from the standard ABS definition in several ways. The most important difference is that the definition of unemployment used in this report does not have the requirement that the job seeker is available to start work.

91. The definition of marginal attachment differs from the standard ABS definition in the following ways. The ABS definition includes as marginally attached those who are not employed, are actively looking for work and want to work but are not available to start work within four weeks (and are hence not classified as being unemployed). In this paper, we included as being marginally attached those who were not employed, wanted to work, were not actively looking for work and were not available to start work. The ABS would classify this group as being not in the labour force (NILF).

92. A number of carers (81) aged 64 years or younger who said that they were not working at the time of the interview because they were retired were excluded.
The unemployment to population rate was 6.6% for those receiving only Carer Allowance and 4.6% for those receiving Carer Payment. The unemployment rate is conventionally defined as the proportion of those in the labour force (that is employed or unemployed) who are unemployed. The unemployment rate was 12.3% for females receiving only Carer Allowance and 15.0% for those receiving Carer Payment.

The proportion of carers who were not in the labour force was quite high; it was 46.3% for those receiving only Carer Allowance and 69.5% for those receiving Carer Payment.

Table 11.2 provides information on the extent to which carers who were not in the labour force wanted to work (marginally attached). The proportion of female carers who were marginally attached (that is not employed, wanted to work, but were not actively looking for work and hence not classified as being unemployed) was very high. Almost one-third (30.2%) of those receiving only Carer Allowance and 35.1% of those receiving Carer Payment were marginally attached to the labour force.93

The proportion of working-age female carers who did not work at all was quite low, being 16.1% of those who received only Carer Allowance and 34.4% of those receiving Carer Payment (including those who also received Carer Allowance).

**Table 11.1 Labour force status of female carers, by payment type**

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment to population rate</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Full-time</td>
<td>11.4</td>
<td>0.8</td>
</tr>
<tr>
<td>Part-time</td>
<td>35.7</td>
<td>25.2</td>
</tr>
<tr>
<td>Total employed</td>
<td>47.1</td>
<td>26.0</td>
</tr>
<tr>
<td>Unemployment to population rate</td>
<td>6.6</td>
<td>4.6</td>
</tr>
<tr>
<td>Not in the labour force to population rate</td>
<td>46.3</td>
<td>69.5</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Unemployment rate</td>
<td>12.3</td>
<td>15.0</td>
</tr>
<tr>
<td>Labour force participation rate</td>
<td>53.7</td>
<td>30.6</td>
</tr>
<tr>
<td>Number of observations</td>
<td>454</td>
<td>131</td>
</tr>
</tbody>
</table>

Notes: The unemployment rate is defined as the number unemployed divided by the number in the labour force (employed plus the unemployed). The labour force participation rate is the proportion of the population either employed or unemployed. Excludes those aged 65 years or older. Percentages may not total 100% due to rounding.

Source: FCPDS 2006

**Table 11.2 Detailed labour force status for female carers not in the labour force, by payment type**

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>%</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Marginally attached (wanted to work but not actively looking for work)</td>
<td>30.2</td>
<td>35.1</td>
</tr>
<tr>
<td>Not in the labour force and did not want to work</td>
<td>16.1</td>
<td>34.4</td>
</tr>
<tr>
<td>Total not in the labour force</td>
<td>46.3</td>
<td>69.5</td>
</tr>
<tr>
<td>Number of observations</td>
<td>454</td>
<td>131</td>
</tr>
</tbody>
</table>

Notes: Excludes those aged 65 years or older.

Source: FCPDS 2006

93. Bittman et al. (2007), using HILDA data, found that between 10% and 15% of carers with intensive caring responsibility were marginally attached to the labour force. This is much lower than the rate estimated from the FCPD survey. Possible explanations for this include differences in the definition of caring and Bittman et al.’s (2007) estimates are for male and female carers combined and for different time periods.
**Labour market experience since commencing providing care**

The FCPDS collected information on the employment experience of the carer since they started providing care. Among female carers who received only Carer Allowance, 39.7% had not worked since they started caring, 13.2% were not employed at the time of the interview, but had worked since starting to provide care and 47.1% were employed at the time of the interview (Table 11.3). Overall, 60.3% had been employed at some point since starting to provide care. A higher proportion of female carers who were receiving Carer Payment than those receiving only Carer Allowance had not worked at all since starting caring (57.7% and 39.7% respectively).

### Table 11.3 Female carers employment status since commencing caring, by type of payment

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently working</td>
<td>47.1</td>
<td>26.0</td>
</tr>
<tr>
<td>Not currently working but has worked since started caring</td>
<td>13.2</td>
<td>16.8</td>
</tr>
<tr>
<td>Not currently working and has not worked since started caring</td>
<td>39.7</td>
<td>57.3</td>
</tr>
<tr>
<td>Number of observations</td>
<td>454</td>
<td>131</td>
</tr>
</tbody>
</table>

Notes: Excludes those aged 65 years or older. Percentages may not total 100% due to rounding. Source: FCPDS 2006

**Impact of caring on paid employment**

As discussed above, differences in the employment rates of carers and non-carers cannot simply be interpreted as the effects of caring on employment rates. While the effects of caring on employment may vary depending upon the stage of the caring, there is evidence that there can be a change in labour force status about the time of starting caring (Spiess & Schneider, 2002).

**Changes in employment status since starting caring**

### Non-employed carers

The FCPDS asked respondents who were not employed at the time of the interview whether they were employed just prior to commencing caring and, if they were employed, whether starting care was the main reason they gave up work.

Almost half of female carers who were not employed (unemployed and not in the labour force) at the time of the interview were employed just prior to commencing caring (Table 11.4). Interestingly, for female carers there was little difference in the pre-caring labour force status according to which payment type they received—45.4% of those receiving only Carer Allowance and 47.4% of those receiving Carer Payment were employed just prior to commencing care.

For female carers who were not employed at the time of the interview, but employed just prior to commencing caring, 83.0% of those receiving only Carer Allowance at the time of the interview said that providing care was the main reason they left their job. A similar proportion (78.3%) of those receiving Carer Payment at the time of the interview also said that providing care was the main reason they left their job.

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94. For carers who are providing care to more than one disabled adult or child the question refers to the person they had been caring for the longest.

95. Of course, it is possible that a carer who was employed at the time of the interview may have had to withdraw from the labour force for a period. The FCPDS did ask employed carers whether they had stopped work at any stage because of their caring responsibilities and these data are described in this section under “Employed carers”, in Table 11.5.
Table 11.4  Employment history since commencing caring of currently non-employed female carers, by type of payment

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed just prior to commencing caring</td>
<td>45.4</td>
<td>47.4</td>
</tr>
<tr>
<td>Not employed just prior to commencing caring</td>
<td>54.6</td>
<td>52.6</td>
</tr>
</tbody>
</table>

Number of observations 238 97

Notes: Two female carers receiving only Carer Allowance answered “don’t know” to the question: “Were you employed just before you began to care for the person with a disability?” and are excluded from this table. It also excludes those aged 65 years or older.

Source: FCPDS 2006

Employed carers

Employed carers were asked whether they had considered leaving their current job to care for the person with a disability. It appears that the majority had not—14.2% of females receiving only Carer Allowance and 26.5% of female carers receiving Carer Payment reported that they had considered leaving their current job to care.

Carers who were employed at the time of the interview were asked whether they had ever had to stop working in order to provide care for the person with a disability. A substantial number of employed female carers reported that they had at some time given up work to provide care for the person with a disability. Among those receiving only Carer Allowance, 39.3% had at some stage had to give up work (Table 11.5). Over half (58.8%) of currently employed women who received Carer Payment left paid employment at some stage to provide care. The small number of currently employed women receiving Carer Payment means that the results for this group need to be treated with some caution.

Table 11.5  Changes to employment made as a consequence of caring responsibilities by female carers, by type of payment

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had to give up work to provide care for the person with a disability</td>
<td>39.3</td>
<td>58.8</td>
</tr>
<tr>
<td>Changed jobs or working arrangements in order to provide care for the person with a disability</td>
<td>72.4</td>
<td>79.4</td>
</tr>
<tr>
<td>Taken periods of leave to provide care</td>
<td>66.7</td>
<td>58.8</td>
</tr>
</tbody>
</table>

Number of observations 214 34

Note: Excludes those aged 65 years or older.

Source: FCPDS 2006

The majority of employed carers reported having changed jobs or working arrangements in order to provide care for the person with a disability. About three-quarters of employed female carers said that they had changed jobs or working arrangements (72.4% of those receiving only Carer Allowance and 79.4% of those receiving Carer Payment). Changing jobs or working arrangements included reducing hours, adopting flexible hours, quitting a job or taking up another position that provided shorter or more flexible hours.

Over half of employed female carers had to take periods of leave to provide care to the person with a disability. The percentage of carers who had taken periods of leave to provide care to the person with a disability was similar for carers receiving only Carer Allowance (66.7%) and those receiving Carer Payment (58.8%).

Barriers to employment for non-employed carers

Carers who were not employed, but wanted to work, were asked what they saw as their main barrier to finding employment. Although what non-working respondents saw as barriers to them being

96. Several response options were provided to respondents, which are detailed in Table 11.6.
employed needs to be treated with caution, it can provide some useful information. The most common barrier reported by female carers who received only Carer Allowance was “difficulty in arranging working hours” (23.0%), followed by “no alternative disability care arrangements available” (22.4%) (Table 11.6). The next most common reason given was that it “would be too disruptive to the person with the disability” (12.7%). Perhaps somewhat surprisingly, the costs of paying for care while at work was not commonly cited as a reason.

The number of female carers receiving Carer Payment who wanted to be in paid employment was relatively small (51 respondents, that is, 5% of the total sample) and so the results for this group should be treated with caution. Overall, the main barriers to employment cited by those receiving Carer Payment was similar to those receiving only Carer Allowance. The main difference was that their age was much more commonly given as a barrier for Carer Payment recipients (17.6%) than those receiving only Carer Allowance (6.7%).

Table 11.6 Main barriers to employment identified by female carers who were not in the labour force but would like to work, by payment type

<table>
<thead>
<tr>
<th>Payment type</th>
<th>Carer Allowance only</th>
<th>Carer Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>No alternative disability care arrangements available</td>
<td>22.4</td>
<td>21.6</td>
</tr>
<tr>
<td>Would be too disruptive to the person with the disability</td>
<td>12.7</td>
<td>17.6</td>
</tr>
<tr>
<td>Difficult to arrange working hours</td>
<td>23.0</td>
<td>15.7</td>
</tr>
<tr>
<td>Loss of skills from being out of the workforce</td>
<td>3.0</td>
<td>2.0</td>
</tr>
<tr>
<td>Age</td>
<td>6.7</td>
<td>17.6</td>
</tr>
<tr>
<td>Cost of paying for disability care while at work</td>
<td>2.4</td>
<td>2.0</td>
</tr>
<tr>
<td>Other</td>
<td>27.3</td>
<td>23.5</td>
</tr>
<tr>
<td>No difficulties expected</td>
<td>2.4</td>
<td>0.0</td>
</tr>
<tr>
<td>Number of observations</td>
<td>165</td>
<td>51</td>
</tr>
</tbody>
</table>

Notes: Excludes those aged 65 years or older. Of the 84 carers who indicated that there was an “other” barrier to employment, 27 (32.1%) indicated that their own health was a factor.

Source: FCPDS 2006

Caring and living in jobless households

The financial impact of not being employed depends, in part, upon the employment participation of other members of the household. This section presents information on the extent to which carers live in jobless households or households in which other adults are employed.

Almost one-quarter (23.8%) of female carers who receive only Carer Allowance live in a household in which no adult is employed. In comparison, more than twice the proportion of female carers receiving Carer Payment live in households in which no adult is employed (50.4%).

It is important to distinguish between households in which the carer is the only able-bodied working-age adult in the household and those in which there are other able-bodied working-age adults.

If the analysis is restricted to households in which the carer is the only able-bodied working-age adult, the proportion in jobless households is much higher; over half (59.1%) of female carers who receive only Carer Allowance and 72.5% of those receiving Carer Payment live in a jobless household (see Table 11.7). In contrast, for female carers living in a household with other able-bodied working-age adults, just 8.5% of those receiving only Carer Allowance and 25.8% of those receiving Carer Payment are in a jobless household. The proportion of females living in households with at least one other able-bodied adult and in which two or more adults

97. Responses to this type of question can generate answers that are heavily influenced by social desirability, or what the interviewee thinks the interviewer wants or expects to hear.
98. An able-bodied working-age adult refers to a person with no disability who is aged 18 to 64 years.
are employed is much higher for those receiving only Carer Allowance (50.8%) than those who receive Carer Payment (24.2%).

Table 11.7 Proportion of female carers living in households in which no adult is employed, by type of payment

<table>
<thead>
<tr>
<th>Carer is only able-bodied working age adult in the household</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No adult employed</td>
<td>59.1%</td>
<td>72.5%</td>
</tr>
<tr>
<td>Number of observations</td>
<td>137</td>
<td>69</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Household contains more than one able-bodied adult of working age</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No adult employed</td>
<td>8.5%</td>
<td>25.8%</td>
</tr>
<tr>
<td>Carer not employed and at least one other adult employed</td>
<td>40.7%</td>
<td>50%</td>
</tr>
<tr>
<td>Carer employed and at least one other adult employed</td>
<td>50.8%</td>
<td>24.2%</td>
</tr>
<tr>
<td>Number of observations</td>
<td>317</td>
<td>62</td>
</tr>
</tbody>
</table>

Notes: The labour force status of the person being cared for was not asked in the survey. This means that the estimates in this table may overstate the extent to which carers are living in jobless households. However, any overstatement is likely to be small, given that the level of care required in order for the carer to qualify for Carer Allowance or Carer Payment is likely to preclude the care recipient from being able to work. Excludes those aged 65 years or older.

Concluding comments

This chapter has provided an overview of the labour force status and selected labour market issues for female carers who received an Australian Government payment directed towards carers (Carer Allowance and/or Carer Payment).

In relation to labour force status, there were a number of key findings:

- Consistent with the findings of other research, carers receiving Carer Allowance or Carer Payment had relatively low rates of employment and labour force participation.
- Employed carers were relatively more likely to be employed part-time.
- Those receiving Carer Payment had a lower employment rate than those receiving only Carer Allowance.
- Many carers who were not in the labour force wanted to work, particularly those receiving only Carer Allowance. Almost one-third of carers were marginally attached to the labour force (that is, they wanted to work but were not actively looking for work).
- A substantial proportion of carers had not worked since starting caring (39.7% of those receiving only Carer Allowance and 57.4% of those receiving Carer Payment).
- Almost half of the carers of working age at the time of the interview were not employed at the time of the interview. There was little difference in employment rates prior to commencing caring between those receiving only Carer Allowance (45.4%) and those receiving Carer Payment (47.4%).
- Of female carers who were not employed at the time of the interview, but who had been employed just prior to commencing caring, a very high proportion said that providing care was the main reason for leaving that job (83.0% of those receiving only Carer Allowance and 78.3% of those receiving Carer Payment).
- Many carers who were employed at the time of the interview had to temporarily give up work to provide care for the person with a disability since they starting caring, particularly those receiving Carer Payment (58.8%).
- The majority of employed carers had changed jobs or their working arrangements in order to provide care for the person with a disability.
- Where carers had another adult living in the household who was of working age and who did not have a disability, it was more likely that someone in the household was employed than where the carer was the only working-age adult without a disability.
The data illustrated the very substantial impact that caring had on carers’ participation in the labour market and, if employed, their patterns of work hours and the types of jobs in which they were employed.

The data described in this chapter provides direct evidence on the changes in labour force status of carers since starting caring. It is clear that many carers had stopped working since commencing caring (either temporarily or permanently) and, when asked why, a large majority said that it was because of their caring responsibilities. Interestingly, at least among non-employed carers, there was little difference in the employment rates prior to commencing caring between those who received only Carer Allowance and those who received Carer Payment.

The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment suggests that policies that support carers who want to be in paid employment may be worthwhile. This is particularly important given that many carers, particularly those of working age, will not remain carers all their life. Caring status can change for a number or reasons, including the death of the person being cared for, the requirement for institutional care, partial or full recovery of the person requiring care, and a change of primary carer. There is strong evidence that long periods out of the labour force can make it difficult to re-enter the labour market. It is therefore important for their long-term economic outcomes that carers who want to work and whose caring responsibilities do allow participation in the labour market are assisted in achieving this.
Family care giving is usually generous and provided with love and compassion. It also frequently brings to the caregiver a personal sense of satisfaction and achievement. The pleasure of seeing a person with a disability responding to care, growing in capacity and developing their relationships and experiences is very powerful. While there are these personal benefits flowing to a caregiver, it nevertheless comes at significant emotional, social and economic cost to the family. The challenge for a community is to seek out ways in which the impact of these costs can be reduced so that families have the opportunity to experience a positive outcome from the caring role both for themselves and for the person with the disability. (Spicer, 2007, p. 30)

It has been estimated that in 2003 there were 474,600 primary carers of a person due to disability or age. As the Australian population ages, the number of carers is projected to increase in coming decades. Despite the large number of carers in Australia and the projected increase in their numbers, relatively little is known about the impact of providing care upon the caregiver and their families. This report has provided an analysis of the impact on carers and their families of caring for a person with a disability.

The analysis in this report was based on data from a nationally representative survey conducted in 2006 of carers who were receiving an Australian Government payment directed towards carers (Carer Payment and/or Carer Allowance). The Families Caring for a Person with a Disability Study (FCPDS) involved interviews with 1,002 of these carers. The aims of this report are to:

- examine the effect of caring on family and social relationships;
- document the social, emotional, physical and financial impact on families of caring for a person with a disability;
- examine the effect of caring on labour force status.

**Key findings**

**Mental health**

One of the key issues to emerge from this research is that carers and their families experienced very high rates of mental health problems. The data from Chapter 8 suggest that carers had significantly worse mental health and vitality and higher rates of depression than the general population. The differences between carers and the general population observed in the FCPDS were consistent with evidence on this issue from international reviews and population-based studies from overseas (e.g., Cochrane et al., 1997; Hirst, 2003; Pinquart & Sorenson, 2003), and major large-scale Australian studies (Cummins et al., 2007; Schofield et al., 1998). Moreover, carers in the FCPDS had, on average, greater mental health problems (that is, lower mental health scores) than patients with hypertension, congestive heart failure, type II diabetes and a recent acute myocardial infarction, when compared to normative information on mental health scores in other populations (Ware et al., 2002). Carers also had lower levels of vitality (that is, higher vitality scores) than patients with these same physical illnesses, except when compared to patients with congestive heart failure.99

99. Comparisons were based on calculating 95% confidence intervals from standard errors provided in Ware et al. (2002).
Differences between carers and the general population on mental health, vitality and rates of depression were evident for female carers of all age groups, except when carers were 65 years or older. There were not sufficient numbers of male carers in some age categories to make a comparison with males in the general population. Cummins and colleagues (2007) also reported that the gap between carers and the general population in personal wellbeing, depression and stress was less when people were 55 years or older.

When we used the mental health scale as an indicator of clinical levels of depression, we found that the rates of clinical levels of depression in the last 4 weeks were 19% for female carers and 13% for male carers, while for females and males in the general population, they were 11% and 8% respectively. Fifty-one per cent of female carers and 30.7% of males also reported that they had been depressed for 6 months or more since they started caring. While these estimates of clinical levels of depression may appear high, in the Carer Health and Wellbeing study, Cummins et al. (2007) reported that 56% of carers had clinical levels of depression (19% extremely severe, 18% severe, 19% moderate) when carers reported on how they had been feeling over the past week. We attribute the lower estimates in the rates of depression in the FCPDS compared to the Carer Health and Wellbeing study to differences in the sampling frames. The FCPDS had a 73% response rate from a representative sample of carers receiving government payments, while in the Carer Health and Wellbeing study, members of the state Carers Associations were invited to participate (37% took part). In any case, the rates of depression in both studies were very high and the mental health of carers is clearly a concern.

Female carers also had higher clinical levels of depression than male carers (19% versus 13% in the last 4 weeks, and 51% versus 31% for 6 months since they started caring). These results were consistent with previous international research (e.g., Pinquart & Sorenson, 2006) and the Australian Carer Health and Wellbeing study (Cummins et al., 2007).

Family members also experienced periods of depression, with 27.3% of partners, 12.1% of parents and 10.6% of offspring of carers experiencing a depressive episode of 6 months or more since caring began (a “depressive episode”). Moreover, the carer’s experience of depression was associated with other family members’ experiences of depression, a finding consistent with other studies that have examined this issue (see Edwards & Clarke, 2004; Kissane et al., 2003; Pruchno & Patrick, 1999). For instance, carers’ partners and children (with and without a disability) were twice to five times more likely to experience a depressive episode when the carer had also experienced a depressive episode of 6 months or more since they had started caring. Higher rates of depressive episodes for partners with no disabling condition and children (with and without a disability) were also evident when there were problems in dimensions of family functioning. Family functioning has also been reported to be a critical correlate of mental health in Australian studies of carers of cancer patients and their families (Edwards & Clarke, 2004; Kissane et al., 2003).

It should be noted that our study of family members’ experience of depression had some limitations. First, although the question we asked about family members’ experience of depression can be seen as being indicative of prolonged depressive symptoms, it was not a standardised diagnostic interview. Second, we relied on carers to report on other family members’ depression; but mental health problems tend to be under-reported by proxies because feelings are not directly observable (Ball et al., 2000; McPherson & Addington-Hall, 2003; Todorov & Kirchner, 2000). Although it is less likely for there to be under-reporting of depression in the current study, as family members’ depressive symptoms needed to occur for 6 months or more for carers to report them, there is still a possibility that carers may under-report family members’ depression.

The risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring. The risk of carers experiencing a first depressive episode of at least a 6-month duration was greatest in the first year of caring (over 13% of carers), but over the next 20 years the risk was fairly stable at about 3%. For other family members, the first year of caring accounted for 41.6% of all the first depressive episodes experienced by people with a disability and 17.9% of first depressive episodes of other household members. Although based on retrospective reports from carers and hence open to inaccuracies, previous research on this issue suggests that people tend to fail to recall previous depressive episodes rather than provide.
overestimates (Patten, 2003). In any case, these data highlight that the period of greatest risk for mental health problems for both carers and other family members is in the first year of caring. We are not aware of any comparable longitudinal data on self-reports of depression of carers and their relatives in any other study.

Several factors were associated with carers having more mental health problems, worse vitality and higher rates of depression than people from the general population. These included: caring for a child (rather than an adult) with a disability; caring for a person with a disability with high care needs; caring for more than one person with a disability; carers’ having another care role of looking after children who did not have a disabling condition; having one or more problems in family functioning; and carers indicating that they needed a little or a lot more support.

In the context of the data from the FCPDS, early intervention is important in the first year of caring and thereafter, a less intensive, but easily accessible intervention may be more appropriate. The early intervention may need to be intensive, given our data on the interconnections between carers and other family members’ mental health. It probably would need to address relationship issues such as poor family functioning, for instance, as this variable was associated with higher rates of depression within the family.

**Physical health**

We also examined the physical health of carers (Chapter 10). Almost twice as many carers were in poor physical health than the general population. These elevated rates of poor physical health were not the result of carers being older than the general population, as female carers had poorer physical health than females in the general population for all age categories except when aged 65 years or more. Moreover, they are consistent with the international empirical reviews of the differences in self-reported physical health between carers and the general population (Pinquart & Sorensen, 2003; Vitaliano et al., 2003).

Several factors were associated with higher rates of poor physical health for carers. Higher rates of poor physical health were associated with caring for a person with a disability who has high care needs, or with caring for more than one person with a disability. Schulz and Beach (1999) also reported that more intensive caring was associated with poorer self-reported physical health and even higher rates of mortality. Having one or more problems in family functioning was also associated with carers’ self-rating of poor physical health, a finding that, to our knowledge, has not previously been reported in the research literature. Carers who indicated that they needed more support also had higher rates of poor physical health than carers who said the support they received was “about right”. Pinquart and Sorensen (2007) also reported small but consistent associations between social support and self-reported physical health in a meta-analysis of correlates of carers’ physical health. As many of the risk factors for poor physical health were the same for poor mental health of carers, a coordinated bio-psychosocial intervention may best meet the needs of carers and their families.

**Employment**

The analysis in Chapter 11 provided direct evidence on changes in labour force status of carers since starting caring. It is clear that many carers had stopped working since commencing caring and when asked why, a large majority said that it was because of their caring responsibilities. Interestingly, at least among non-employed carers, there is little difference in the employment rates prior to commencing caring between those who received only Carer Allowance and those who received Carer Payment.

The fact that a large number of non-employed carers of working age expressed a desire to be in paid employment suggests that policies that support carers who want to maintain some form of paid employment may be worthwhile. This is particularly important given that many carers will not remain carers all their life. There is strong evidence that long periods out of the labour force can make it difficult to re-enter the workforce. It is therefore important for their long-term economic outcomes that carers who want to work and whose caring responsibilities do

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100. There were not sufficient numbers of male carers in the different age categories to conduct analyses for male carers.
allow participation in the labour market are assisted in achieving this. Further analysis of the FCPDS data will enable a more detailed understanding of the barriers to employment for primary carers, including factors such as availability of other carers and the employment of other family members.

Financial hardship

Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship. Irrespective of which payment carers’ families received, families that cared for a person with a disability experienced a higher level of financial hardship than the general population. For example, 30% of families with a carer receiving Carer Allowance and 29.2% of families with a carer receiving Carer Payment had experienced difficulty in paying electricity, gas or telephone bills on time. Only 14.6% of the general population indicated that they experienced financial hardship in this area. The high levels of financial hardship found in the FCPDS are consistent with other recent work on the costs of caring for a person with a disability in Australia. For example, using data from the 1998-99 Household Expenditure Survey, Saunders (2006) showed that, where there is someone in the household with a disability, financial hardship is more prevalent.

Relationships and support networks

We investigated carers’ support networks, relationships, relationship breakdown and family functioning in Chapter 6. Although most carers had supportive people around them, there was a substantial minority of carers (one in five) who had no assistance from other people in caring for the person or people with a disability. For the majority of carers who did have support, the support provided was not without some issues attached. Even when carers had people to support them and the person with a disability, one in five carers had disagreements with others about caring. Of those carers who had support people, one in five had support people who had some problems with cooperating with other supporters about the care for the person with a disability. Disagreements about caring and problems with cooperating in the care of the person with a disability are issues that we do not believe have been investigated in other studies. These novel findings highlight that coordination, disagreement and conflict about care tasks can ensue from caring for a person with a disability and these can be barriers to the effective provision of informal care.

Subsequent analysis of these data suggest that, for carers who have people providing some support, only 49.8% had both no disagreements with the supporters and everyone cooperating with one another. Almost half of the carers indicated they needed more support, a finding that is not so surprising in light of the data on the lack of people available to provide support, problems with cooperation, and level of disagreements. The fact that one in two families do not use formal support services (as detailed in Chapter 4) may also explain the large proportion of carers who indicated they needed more support. Further analysis of the FCPDS data would provide more detailed information on the types of situations in which primary carers have no support people for themselves or the person with a disability. Further examination is also needed regarding primary carers who have support people that have difficulty cooperating or have disagreements about the care of the person with a disability. This analysis would inform policy development in this area.

Carers are satisfied with their relationships with their partners, or at least they are as satisfied as non-carers from the general population—even when their partner is the person with a disability. Although provision of care for a person with a disability is not associated with dissatisfaction with relationships between carers and their partners, children and parents, and the relationship between carers’ partners and children, it does seem to affect carers’ satisfaction with the relationships of their children with each other. This is consistent with research showing the negative impact of caring for a person with a disability on non-disabled siblings, perhaps because of the reduction in attention they receive (see Higgins et al., 2005).

Conflict is the aspect of family functioning that carers most frequently see as being problematic (one in three identified this aspect as a problem). Carers of someone with a psychiatric disability
are the most likely to report two or more problems in family functioning, with carers of someone with a physical disability the least likely to report problems in family functioning. Poor family functioning is associated with greater care needs of the person with a disability, suggesting that the level of impairment is a good proxy measure of the likely impact of caring for someone with a disability on broader family relationships.

The FCPDS provides novel data on the timing and risk of increased arguments and relationship breakdown between carers and their partners since caring began. When a partner is being cared for and there is a relationship separation, the carer will usually cease to provide care, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, we restricted the sample to carers of a person with a disability who was not a partner. The results showed a heightened risk of arguments early on, but an even distribution of the risk of relationship separation over time (after accounting for the number of carers still caring in each subsequent year). Our analyses of the FCPDS data also suggested that almost one in three female carers aged 50 or less had separated or divorced since they started caring, while one in seven over the age of 50 had separated or divorced since they started caring. These results suggest that carers who are of the age where care responsibilities for children are most prevalent are under greater risk of separation. This finding is consistent with US studies that have showed that caring for a child with a disability was associated with a higher rate of separation or divorce (e.g., Graefe & Lichter, 1999; Reichman et al., 2004; Risdal & Singer, 2004). The data from the FCPDS also suggest that support services that focus on addressing relationship conflict in the first year of caring and that target carers under the age of 50 would minimise separations and arguments between spouses. Future analyses could identify variables that are associated with the timing of arguments and separations so that support services could be targeted to achieve maximum effect to families most in need.

**Hours of care**

Sixty per cent of carers reported that they cared for the person with a disability for more than 100 hours per week. The large number of carers who stated that they provided more than 100 hours of care per week is 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”. However, even monitoring the person with a disability or being on call has implications for the lives of the carer and their families. Carers may not feel that they can leave the person in their care by themselves, which has implications for engaging in a social life outside of the house independent of the person with a disability, and also involvement in employment. Further research using detailed diaries tailored to the caring experience could be used to investigate the type and amount of care provided to people with a disability by their family carer.

**Multiple care responsibilities**

Thirteen per cent of primary carers cared for two or three people with a disability. In addition, almost one in three cared for at least one child as well as the person with a disability (who could also be a child). Caring for more than one person with a disability, caring for a child with a disability and caring for other children without a disability was associated with carers having significantly worse mental health and vitality and higher rates of depression. Moreover, carers aged 18 to 50—the age when they would most likely to be caring for children—had worse mental health and vitality, and higher rates of depression and separation. These data suggest that carers raising children with or without a disability or those caring for multiple family members with a disability are under significant stress. More needs to be done to support these groups.

**Support services**

The use of support services by families was described in Chapter 4. Although the focus of the survey was not on the needs of carers, we asked one general question on the types of services carers and their families used. Of concern was that almost half of carers’ families did not use any support services, with the most commonly used services being respite care (13%) or a general practitioner (11%). The general nature of the question may have led to some underestimation of the number of services used by families. However, underestimation of service use was unlikely
to be large as several services, including respite, were specifically mentioned by interviewers. Even though respite services were included in the question stem on service use, very few families used this type of service. Three out of five used respite for less than 20 hours per month and one in five used it for more than 50 hours per month. As the focus of the study was not service use, we did not explore the barriers to using respite, or service use more generally. Knowledge of the support services available to families caring for a person with a disability and the accessibility and affordability of these services may also be important factors in service use. Moreover, carers’ ability to acknowledge their need for help may be a necessary precursor to access services. Our findings in this area highlight that there is a role for further research on service use.

**Conclusion**

As Spicer (2007) argued in the quote at the beginning of this chapter, the challenge for the Australian community is to give families an opportunity to care for a person with a disability, while minimising the social, emotional and economic costs associated with caring. This report has documented the significant emotional costs associated with caring for all family members—the primary carer, the person with a disability and other family members. Carers raising children (both with and without a disability) or those caring for multiple family members with a disability were at particular risk of worse mental health outcomes. The evidence in this report also suggests that aspects of the family environment are critical to the good mental health of family members and the physical health of carers (such as good family functioning and adequate support to the carer). However, there are relationship costs for some groups—for example, one in three carers under the age of 50 years had separated from their partner since they had started caring. The economic costs to the carers and their families were also considerable. Many carers gave up work to care for the person with a disability and three-quarters of those who were not employed expressed a desire to work. Also, compared to families from the general population, a greater proportion of carers’ families suffered from greater financial hardship.

This report has documented the substantial economic, social and emotional costs, not only for the primary carer but also for the family. The challenge for policy makers and the Australian community is to develop policies to create an environment that minimises these costs so that families can be best supported as they care for a person with a disability.

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101. Interviewers asked the following question: “Could you please tell me whether you [or the person with a disability] (or another member of your household) use any disability services like respite, counselling, disability employment services or carer support services”.

102. When a partner is being cared for and there is a relationship separation, the carer will usually cease to provide care, and therefore no longer be eligible for Carer Payment and/or Carer Allowance. Consequently, we restricted the sample to carers of a person with a disability who was not a partner.
References


Appendices

Appendix A: Literature search strategy

The literature search strategy initially identified 124 relevant references. Databases were searched for the period 1995–2006. Table A.1 outlines the databases searched and the search terms used. Additional literature was identified through searching the reference lists of the articles that were identified in the initial search.

Table A.1 Databases search strategy

<table>
<thead>
<tr>
<th>Title of database</th>
<th>Search terms used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Family and Society Abstracts (AFSA)</td>
<td>Carers and effects</td>
</tr>
<tr>
<td></td>
<td>Disabled and social support networks</td>
</tr>
<tr>
<td>Australian Public Affairs Information Service (APAIS)</td>
<td>Carers</td>
</tr>
<tr>
<td>Education Resources Information Centre (ERIC)</td>
<td>Caregiver attitudes</td>
</tr>
<tr>
<td>Psychinfo</td>
<td>Disabled and carers</td>
</tr>
<tr>
<td>(searched 2000 onwards because of amount of references)</td>
<td>Carers and wellbeing</td>
</tr>
<tr>
<td>Sociological index</td>
<td>Carers and wellbeing</td>
</tr>
<tr>
<td>Social Services Abstracts and Sociological Abstracts</td>
<td>Carers (and caregivers) and disabled</td>
</tr>
<tr>
<td></td>
<td>Family relations and caregivers</td>
</tr>
<tr>
<td>PubMed</td>
<td>Carers and disabled</td>
</tr>
</tbody>
</table>
Is your participation voluntary?

Your participation in this study is voluntary. Even if you agree now, you can withdraw later if you wish.

Your name and contact details will only be passed on to the interviewers after you have had a chance to consider if you would like to take part.

If you would like further information, need to update your contact details, or do not wish to participate in this study, please call the Department of Families, Community Services and Indigenous Affairs (FaCSIA) on 1800 337 176 (a free call except from mobile and pay phones) by 15 September.

When and how?

If you want to be involved in this valuable study you do not have to do anything now. The next step will be if you receive a telephone call to invite you to participate. An interview can be conducted at the time of the telephone call or an appointment will be made to call you back at a more convenient time.

If it is difficult for you to take part in a telephone survey, due to language differences, disability or any other reason, please contact the fieldwork agency that has been contracted to conduct the interviews, the Social Research Centre, on 1800 023 040 by 15 September to make other arrangements.

Australian Institute of Family Studies
300 Queen Street, Melbourne
Victoria 3000 Australia
Telephone: (03) 921 47888
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What is the Families Caring for a Person with a Disability Study?

The Families Caring for a Person with a Disability Study is an important new study of Australian families funded by the Australian Government Department of Families, Community Services and Indigenous Affairs. The aim of the study is to get a better understanding of how families care for a person with a disability and how it affects family life.

The study will interview 1,000 primary caregivers of a person with a disability about how families support one another, family relationships, service use, and the impact of caring on the carer’s physical and mental health.

The Families Caring for a Person with a Disability Study is being conducted by the Australian Institute of Family Studies.

Australian Institute of Family Studies

The Australian Institute of Family Studies is an Australian Government statutory authority that was established in 1980. Funded by the Australian Government, the Institute conducts research that aims to promote the understanding of social and economic factors influencing family wellbeing.

Why is this study important?

The results of the Families Caring for a Person with a Disability Study will provide a picture of the lives of families caring for a person with a disability in Australia today and a description of the services you use for support. The information will be used to better understand how families care for a person with a disability and how caring for the person with a disability affects family relationships and the physical, emotional and economic well-being of family members.

Your views are really important, and will help us to ensure that we get an accurate picture of what life is like for families caring for a person with a disability.

Why should I help?

For survey results to be accurate, it is important that each person selected takes part in the survey. Otherwise, the survey will not provide a true indication of the circumstances of all families.

What does the study involve?

The study will involve a telephone interview that will take about 25 minutes to complete. At the time of the initial telephone call, you can make an appointment for the most convenient time for you to be interviewed.

You will be asked about things such as who cares for the person with the disability, how family members support each other, the impact that caring has on family relationships, work, finances, and health.

How was your family selected?

Your family was selected as part of a large sample randomly chosen from Centrelink computer records of families with caring responsibilities.

What about my privacy?

It is natural for you to be concerned about how your privacy will be protected. All information collected will be kept strictly confidential as required by law.

The ethics committee of the Australian Institute of Family Studies has approved the study. All researchers involved must comply with the Privacy Act 1988.

Personal details that could identify you or your family will be removed prior to use by researchers. Personal details that could identify you will not be provided to any government agency or the Australian Institute of Family Studies.

Will my caring payments be affected?

The financial assistance you receive (e.g. Carer Payment or Carer Allowance) on both of these payments for caring for your relative with a disability will not be affected whether you choose to participate in the study or not.