

# Executive summary

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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.<sup>1</sup>

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.<sup>2</sup>

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

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.<sup>3</sup> 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.<sup>4</sup> 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.

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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.