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(Inq into better support for carers)



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Australian Institute of Family Studies

House of Representatives Standing Committee
on Family, Community, Housing & Youth

Inquiry into Better Support for Carers

Submission from the
Australian Institute of Family Studies

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House of Representatives Standing Committee on Family, Community, Housing & Youth

Inquiry into Better Support for Carers

The Australian Institute of Family Studies is pleased to have the opportunity to make a submission to the House of Representatives Standing Committee on Family, Community, Housing & Youth Inquiry into Better Support for Carers.

The Institute has undertaken research into the impact of caring for a person with a disability or who requires care because of old age. It has conducted a large-scale research study into issues affecting carers, as well as bringing together a collection of research and policy analysis published in a special issue of the Institute's journal, *Family Matters*. Our submission mainly addresses the role and contribution of carers in society and the barriers to social and economic participation for carers.

The Families Caring for a Person with a Disability Study

While a great deal is known about the impact and contribution of carers in society, much less is known about how the carer and other family members work together to care for a relative with a disability.

The AIFS Research Report 16, *The Nature and Impact of Caring for Family Members with a Disability in Australia* (Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008), was the output from a collaborative project between the Australian Institute of Family Studies and the Carers Branch of the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. The Families Caring for a Person with a Disability Study (FCPDS) investigated the impact of caring for a person with a disability on carers who received government payments to care and on their families.

In late 2006, we conducted a telephone survey on a representative sample of 1,002 carers from the total population of Australia's 474,600 primary carers receiving Federal Government payments. This is the first detailed, nationally representative analysis looking into the lives of families providing care. The study has several important features that make the findings robust and reliable:

- A high percentage of carers participated in the interviews (73%), leading to reliable results.
- Participating carers were no different on key demographic variables than other carers who received government payments.
- It was a very large survey of primary carers. We believe it is the largest survey of primary carers receiving government payments in Australia.¹
- We asked carers about how caring impacted on other members of their household.

It is a study specifically aimed at carers receiving Carer Allowance and Carer Payment and results from these groups may not be able to be generalised to carers not receiving these payments.

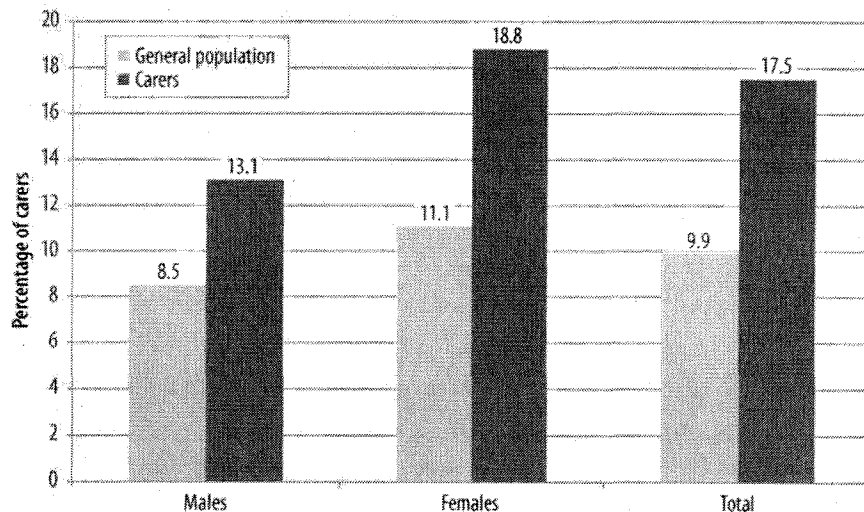
Emotional, physical, relational and economic costs of caring

The major findings from the study suggest that while caring for a person with a disability is very important, there are significant emotional, physical, social and economic costs to carers and their families. Some key findings from the study are highlighted below.

¹ By comparison, the 2003 Survey of Disability, Ageing and Carers had 870 primary carers, with a further 3,877 other carers also surveyed.

1. Carers had significantly worse mental health and vitality and higher rates of depression than the general population.

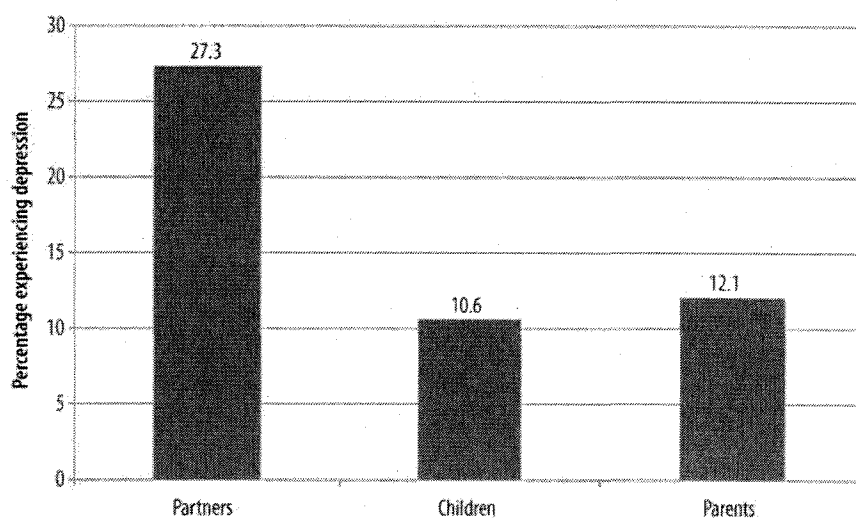
Differences between carers and the general population on these variables were evident for carers of all age groups, except when carers were 65 years or older. The rates of clinical levels of depression were 19% for female carers and 13% for male carers, while for females and males in the general population they were 11% and 8% respectively (see Figure 1). 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. 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 (see Figure 2).



Notes: The incidence of clinical levels of depression in the past 4 weeks was also significantly higher for male and female carers than males and females with no caring responsibilities (males: $\chi^2(1) = 5.84, p < .05$; females: $\chi^2(1) = 39.18, p < .001$).

Source: FCPDS 2006; Household, Income and Labour Dynamics in Australia (HILDA) survey Wave 4.1

Figure 1: Clinical levels of depression over last 4 weeks, by gender and caring status



Note: More partners experienced a depressive episode than children and parents of the primary carer ($\chi^2(2) = 93.67, p < .001$).

Source: FCPDS 2006

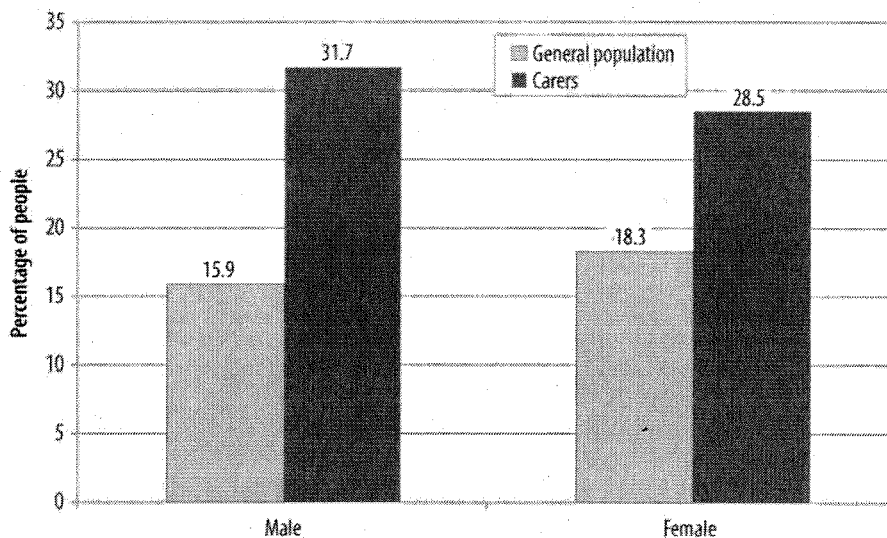
Figure 2: Family members' experience of depression

2. 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. In this context, 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.

3. Almost twice as many carers were in poor physical health than the general population (see Figure 3).

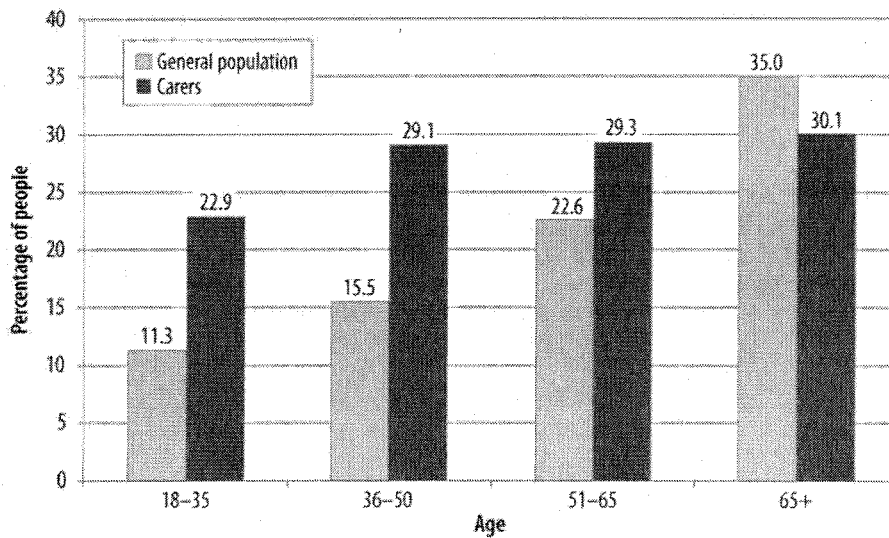
This was not the result of carers being older than the general population (see Figure 4). As many of the risk factors for poor physical health were the same as for poor mental health of carers, a coordinated bio-psychosocial intervention may best meet the needs of carers and their families.



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 3: Incidence of poor physical health, by gender and caring status



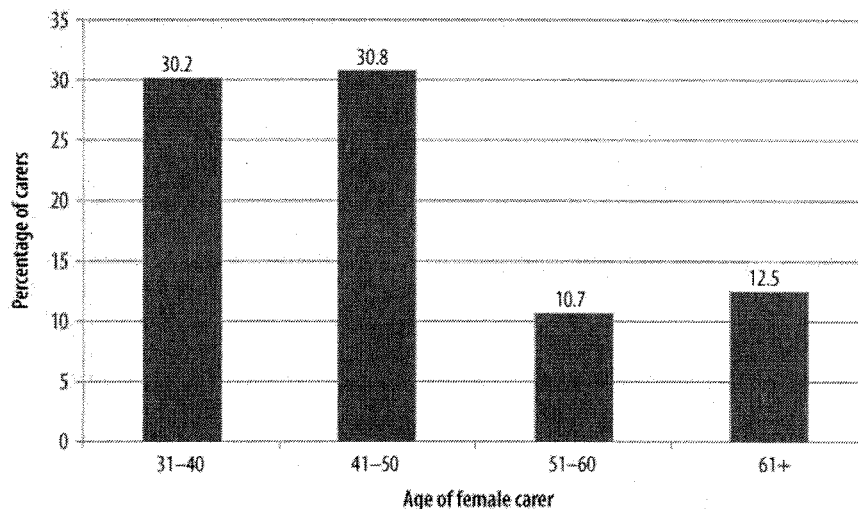
Notes: Compared to females in the general population, a greater percentage of female carers had poor physical health when aged 18 to 35 years ($\chi^2(1) = 13.25, p < .001$), 36 to 50 years ($\chi^2(1) = 33.68, p < .001$) and 51 to 65 years of age ($\chi^2(1) = 4.68, p < .05$). There were not statistically significant differences for people aged 65 years or older ($\chi^2(1) = 1.16, p > .05$)

Sources: FCPDS 2006; HILDA Wave 4.1

Figure 4: Incidence of poor physical health, by age and caring status

4. 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 (see Figure 5).

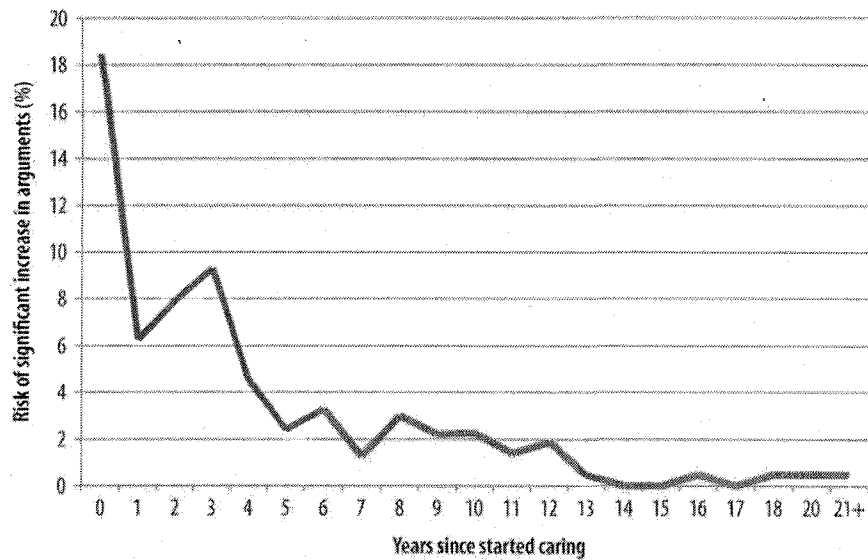
The report also provides new information on the timing and risk of increased arguments and relationship breakdown between carers and their partners since caring began. There was heightened risk of arguments between carers and their partners shortly after commencement of caring (see Figure 6), but an even distribution of the risk of relationship separation over time. The first year of caring seems to be the critical period when additional support may reduce arguments between spouses. The provision of care for a person with a disability did not affect carers' satisfaction with their relationships with other family members. However, carers' children did not get along as well with one another when compared to the general population.



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

Figure 5: Relationship separation of female carers, by age group



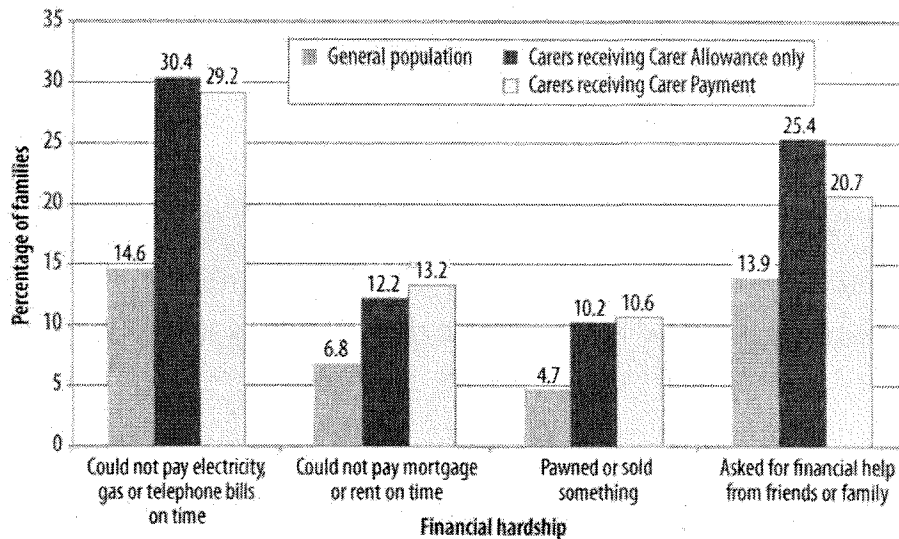
Note: The data presented are based on 431 carers who (a) were not caring for a partner with a disability; and (b) had at any stage had a spouse/partner.

Source: FCPDS 2006

Figure 6: Reports by carers not caring for a partner of significant increase in arguments, by years since started caring

5. Compared to families from the general population, a higher proportion of families of carers suffered from greater financial hardship (see Figure 7).

Irrespective of which payment carers received (Carer Payment or Carer Allowance only), families who cared for a person with a disability experienced a higher level of financial hardship than the general population. Higher levels of financial hardship are a key factor in the higher rates of depression and lower levels of face-to-face social contacts that carers experience (see Edwards & Higgins, 2008; Edwards, Higgins & Zmijewski, 2007).



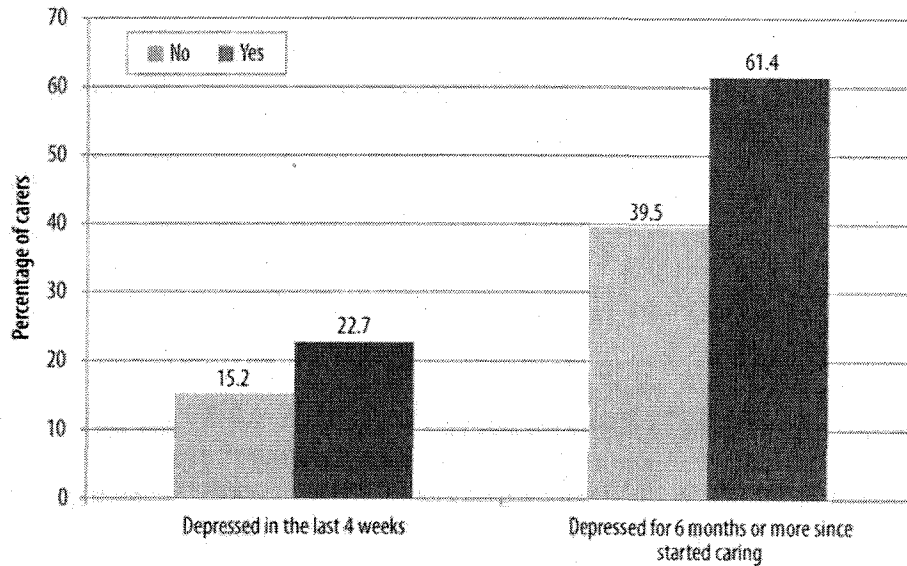
Notes: In this instance, the data for carers from the FCPDS have been weighted by gender and age to match the gender and age characteristics of the general population in HILDA Wave 4.1. Statistical tests suggested that, compared to the general population, significantly higher percentages of households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

Sources: FCPDS 2006; HILDA Wave 4.1

Figure 7: Financial hardships in carers' families, by type of hardship and caring responsibilities

6. Carers who had multiple care responsibilities or who were caring for children had worse mental health outcomes.

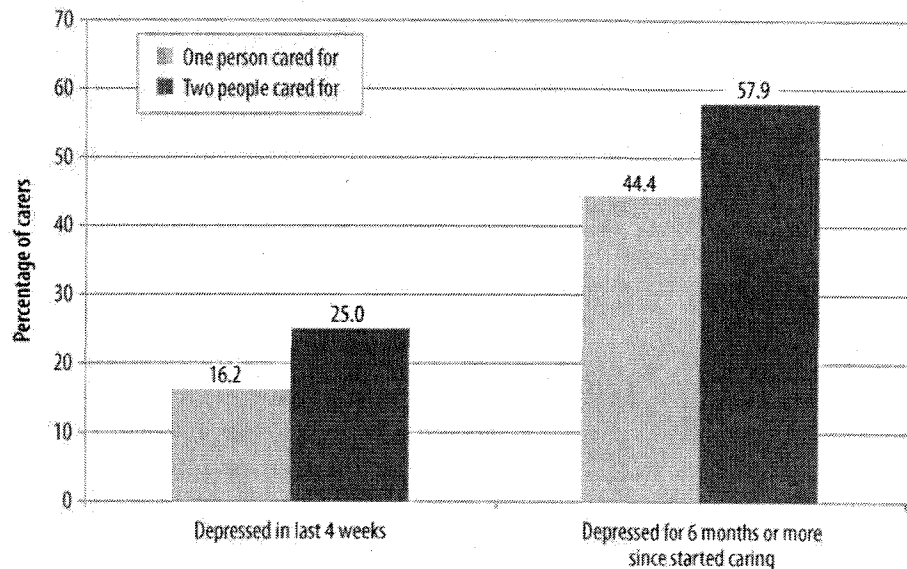
Thirteen per cent of primary carers cared for two or three people with a disability. In addition, one in three (34.7%) cared for at least one child along with the person with a disability (who could also be a child) (see Figure 8). Caring for more than one person with a disability and/or caring for a person or child with a disability while caring for other children were associated with carers having significantly worse mental health outcomes (see Figures 9 and 10).



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 ($\chi^2(1) = 40.15, p < .001$).

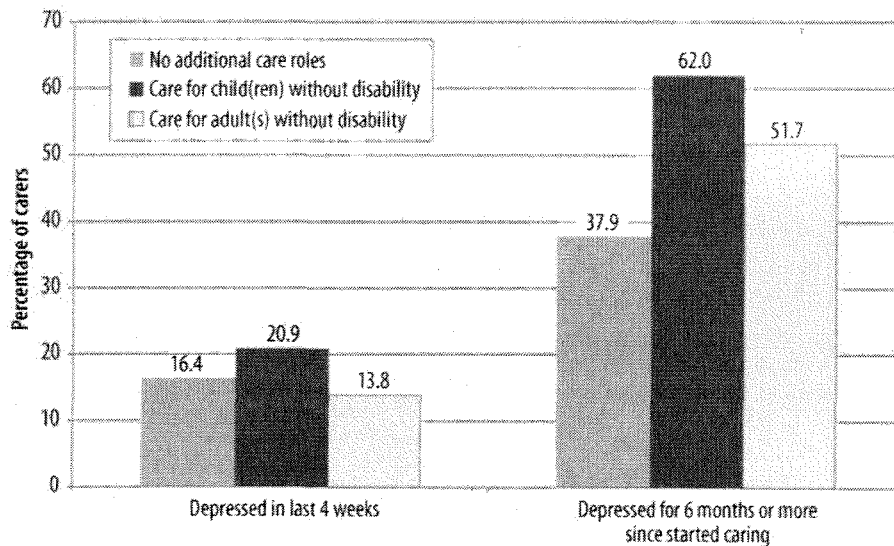
Source: FCPDS 2006

Figure 8: Incidence of carers' depression, by whether they care for a child



Source: FCPDS 2006

Figure 9: Incidence of carers' depression, by number of people cared for



Source: FCPDS 2006

Figure 10: Carers' depression, by additional care roles

Caring and women's labour market participation

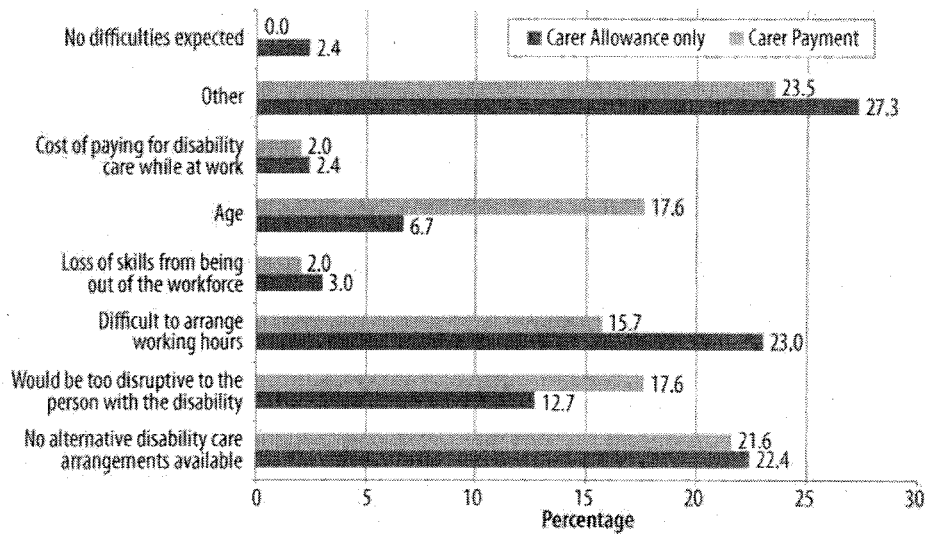
This section provides a description of the labour force status of carers, based on data from the FCPDS survey (see Gray, Edwards, & Zmijewski, 2008). In particular, the following issues were explored:

- the extent to which non-employed carers want to be in paid employment, which has important implications for the design of income support payments to carers and the extent to which resources should be expended attempting to help carers find employment;
- the extent to which having caring responsibilities has a causal impact upon labour force participation;
- job changes that employed carers have made as a consequence of their caring responsibilities; and
- the implications of paid work for the income of carers.

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 ($n = 116$) in the sample precluded an analysis of labour market outcomes according to payment type for men. The analysis was therefore restricted to female carers.

1. Results suggested that more than half of the carers who were not in paid employment would have liked to work.

Among those receiving only Carer Allowance who were not employed, 69.6% said they wanted to work, and of those receiving Carer Payment, 53.6% said they wanted to work. The main barriers to finding employment were difficulties in arranging working hours and the lack of alternative disability care arrangements (see Figure 11). Percentages reported for Carer Payment recipients should be treated with caution as only small number of female carers were in this category (51); however, they are broadly consistent with findings from recipients of Carer Allowance only.



Source: FCPDS 2006

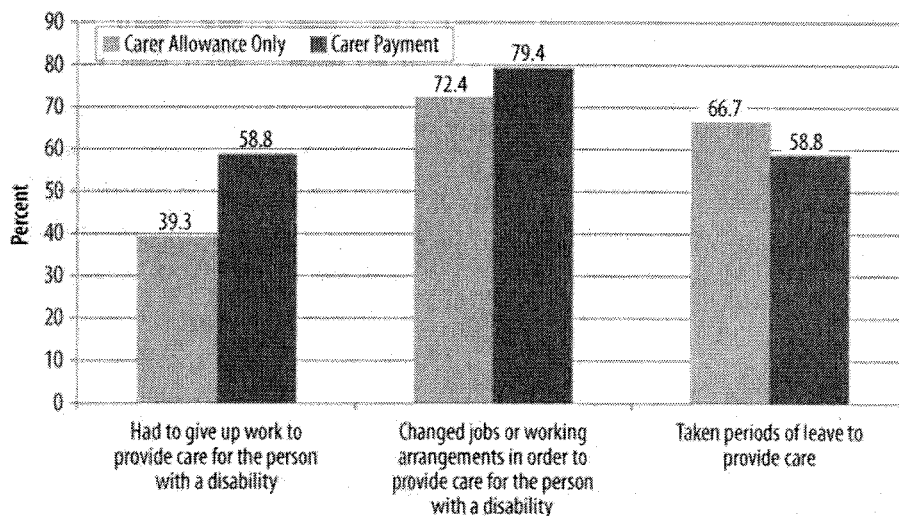
Figure 11: Barriers to finding employment

2. Almost half of the carers who were not employed at the time of the interview were employed just prior to commencing caring.

Of those who had stopped employment after commencing caring, the majority said that providing care was the main reason for leaving that job (83.0% of those receiving Carer Allowance only and 78.3 % of those receiving Carer Payment).

3. Of those receiving Carer Payment who were employed at the time of the interview, 58.8% had temporarily given up work since they started caring in order to provide care for the person with a disability.

A sizable percentage of those receiving Carer Allowance (39%) had also temporarily given up work to care. The majority of employed carers (irrespective of the payment they received) had changed jobs or their working arrangements in order to provide care for the person with a disability. Over half of the female carers had also taken periods of leave to provide care (see Figure 12).

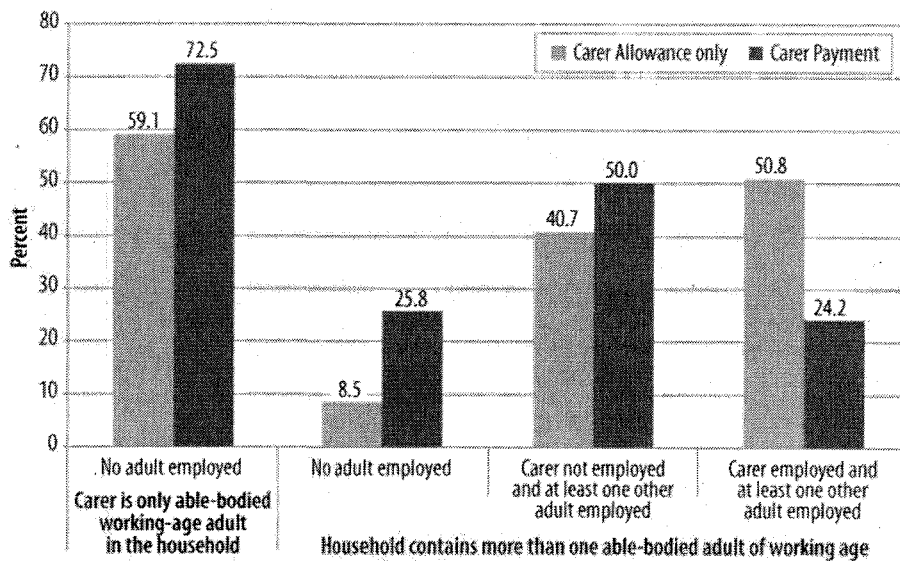


Source: FCPDS 2006

Figure 12: Changes to employment of employed female carers made as a consequence of caring responsibilities, by type of payment, 2006

4. The financial impact of not being employed depends, in part, upon the employment participation of other members of the household.

Almost one-quarter (23.8%) of female carers who received only Carer Allowance lived in a household in which no adult was employed. In comparison, more than twice the proportion of female carers receiving Carer Payment lived in households in which no adult was employed (50.4%). It was important to distinguish between households in which the carer was the only able-bodied working-age adult in the household and those in which there were other able-bodied working-age adults. When the analysis was restricted to households in which the carer was the only able-bodied working age adult, the proportion in jobless households was much higher; over half (59.1%) of female carers who received only Carer Allowance and 72.5% of those receiving Carer Payment lived in a jobless household (see Figure 13). 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 were 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 were employed was much higher for those receiving only Carer Allowance (50.8%) than those who received Carer Payment (24.2%).

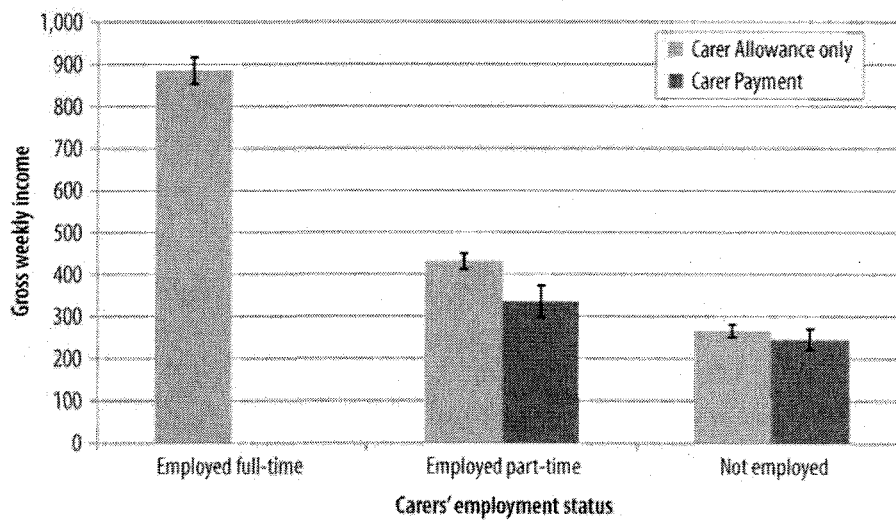


Source: FCPDS 2006

Figure 13: Proportion of female carers living in households in which no adult is employed, by type of payment

5. One of the benefits of employment is the additional income it brings.

As would be expected, carers who are employed have higher incomes than those who are not employed, and those who are employed full-time have higher incomes than those who are employed part-time (Figure 14). In the FCPDS not-employed carers receiving only Carer Allowance had an average gross personal income of \$265 per week. Part- and full-time employed carers receiving Carer Allowance had average personal incomes of \$431 and \$885 per week respectively. For those receiving Carer Payment, the not-employed had an average income of \$245 per week. The part-time employed had an average income of \$335. The increase in income from part-time employment for those receiving Carer Payment was substantially less than for those receiving Carer Allowance only. This is probably a consequence of both the lower education levels of the Carer Payment population compared to the Carer Allowance population; and the income testing of Carer Payment, which results in a reduction in benefits received as the free-area threshold is crossed.



Note: Excludes those aged 65 years or older.
 Source: FCPDS 2006

Figure 14: Gross weekly income of female carers by payment status and labour force status

The fact that a large number of not-employed carers of working age expressed a desire to be in paid employment suggests that supporting such carers may be worthwhile and result in higher levels of social inclusion. Given that carers cited workplace flexibility as one of the barriers to paid employment, encouraging increased workplace flexibility may provide opportunities for carers to be involved in the workforce. The lack of suitable alternative care arrangements, the other major barrier to employment cited by carers in our study, implies that appropriate and routinely available care arrangements would also help facilitate increased employment rates among carers.

Maintaining paid employment and attachment to the workforce are 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 of 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.

Caring and social participation

In this section we report on the social lives of carers and the barriers to face-to-face social contact (see Edwards, Higgins, & Zmijewski, 2007 for details). The key findings are outlined below.

1. Eighteen per cent of carers have face-to-face social contact with friends or relatives outside of the household once or twice every 3 months, or less often than this.

In the general population, significantly fewer people (10.2%) have similarly low levels of face-to-face social contact with friends or relatives not living with them. One of the limitations of making this comparison is that carers may be systematically different to the general population on a range of other variables, which may, in turn, be associated with their level of face-to-face social contacts. However, even after controlling for many demographic variables, carers from the FCPDS were still 1.46 times more likely than the general population to have low face-to-face social contact with friends or relatives outside of the household.

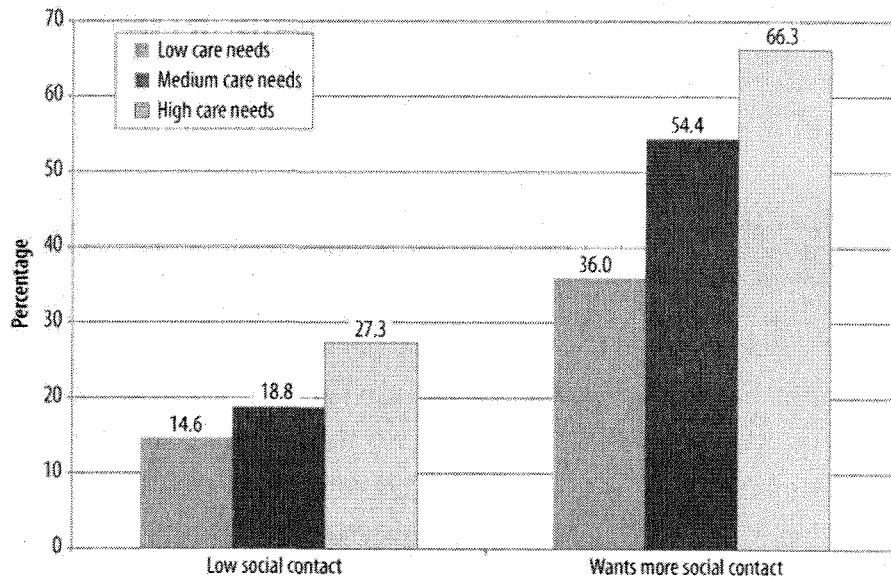
2. Almost half of interviewed carers wanted more face-to-face social contact (47.9% of all carers) when asked whether they would like to get together.

Half were satisfied with the level of face-to-face social contact, while only 2% wanted to get together less often.

3. There were two main factors associated with carers who had low levels of face-to-face social contact and those who wanted more face-to-face social contact: the care needs of the person with the disability and financial hardship.

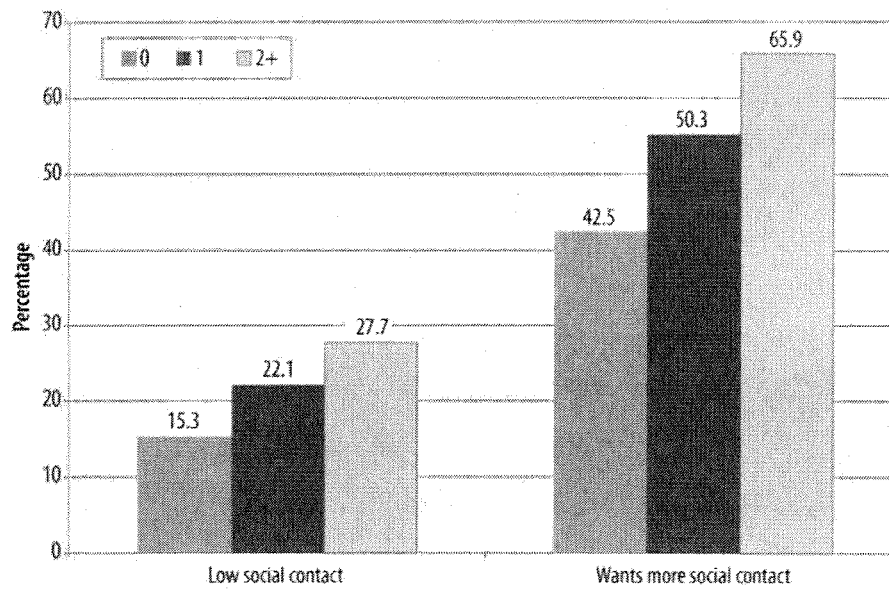
Carers who were caring for a person with a disability with high care needs were 1.9 times more likely to have low face-to-face social contact and 2.7 times more likely to want more face-to-face social contact than carers of a person with low care needs (see Figure 15). Compared to carers who did not experience any financial hardship events, carers who experienced two or more financial hardship events were 2.5 times more likely to have low face-to-face social contact and 1.9 times more likely to want more face-to-face social contact (see Figure 16).

These findings suggest that carers who provide care for people with more complex and difficult disabilities struggle to find suitable alternative care arrangements to allow them to get out and socialise. On the basis of these results, it also seems reasonable to suggest that the experience of financial hardship may limit the ability of carers to see friends or relatives outside of the household, as socialising may require carers to be able to meet the costs of either catering for visitors or the costs of going out (transport, a meal or other social activity and the potential costs of providing alternative care in their absence). Saunders (2006) has documented the higher levels of financial hardship experienced by Australian households in which there is a person with a disability, and one interpretation of our results suggests that carers could be responding to such financial hardship by limiting social outings in order to reduce costs.



Source: FCPDS 2006

Figure 15: Carers' face-to-face social contact with friends and relatives outside of the household and the care needs of the person with the disability



Source: FCPDS 2006

Figure 16: Carers' face-to-face social contact and the experience of financial hardship

Broader issues

In 2007, the Institute published a special issue of our flagship journal, *Family Matters*, with the theme "Families caring: Juggling a complex matter". The authors highlighted the different ways in which families engage in "care work", and addressed a number of issues that affect the nature of care, the ability of family and parental substitutes to provide this care, and the impact that it has on them. Caring is used widely to refer to a range of care-giving behaviours and relationships.

Across all of the data and perspectives covered in the special issue, a strong theme that emerged was that carers need recognition and support. The range of support required includes financial, respite and emotional support and opportunities for work-related and caring skills development. The authors raised other important issues, such as:

- an ageing "care force";
- caring beyond the nuclear family;
- multiple care roles, and the "sandwich" generation (including care needs of the individuals themselves, their partners, their parents and their children);
- the interaction between informal care work and paid employment (while work is an additional time burden, it has also been shown to have positive impacts on carers—financially, as well as in the provision of social connections and opportunities for external interactions; see Lewis, Kagan, Heaton, & Cranshaw, 1999);
- the personal impact of caring (both the emotional burden of caring and the health impact);
- the broader impact of care work on families; and
- the appropriate response from a healthy and "caring" community to these issues.

Providing informal care for family members can be intrinsically rewarding, and often carers cited personal satisfaction as a motivation for caring—and one of its key rewards—along with a belief about the quality of care they provide. However, data from the ABS Survey of Disability, Ageing and Carers, as well as the Australian Institute of Family Studies' FCPDS demonstrate a range of ways in which carers experience difficulties in the areas of mental and physical health, finance, workforce participation, family wellbeing and social connections due to the demands of their care work.

Conclusion

In this submission, we have drawn attention to research that shows the important role that family members play in caring for people with a disability. In recognising the substantial role and contribution that carers play, it is important to consider the personal cost to carers, as well as the broader impact on their family wellbeing. In particular, our research highlights some of the impacts of caring on the physical and mental health, social contacts, financial wellbeing and labour participation of carers. Carers emphasise the importance to them of social supports, respite and economic supports to help them cope with their roles. Understanding the extent and impact of caring and how families structure themselves around the care needs of individuals provides an important insight into the future needs of families and how policies can continue to address these issues to improve the wellbeing for all families and individuals who are giving care, and those who are needing care.

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- Edwards, B., Higgins, D. J., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia* (AIFS Research Report No. 16). Melbourne: Australian Institute of Family Studies. Retrieved 1 July 2008, from <http://www.aifs.gov.au/institute/pubs/resreport16/main.html>
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- Saunders, P. (2006). *The costs of disability and the incidence of poverty* (Social Policy Research Centre Discussion Paper No. 147). Sydney: Social Policy Research Centre, University of New South Wales.

List of attachments

There are four electronic attachments to this submission:

1. Edwards, B., Higgins, D. J., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia* (AIFS Research Report No. 16). Melbourne: Australian Institute of Family Studies. Retrieved 1 July 2008, from <http://www.aifs.gov.au/institute/pubs/resreport16/main.html>
2. Edwards, B., Higgins, D. J., & Zmijewski, N. (2007). The Families Caring for a Person with a Disability Study and the social lives of carers. *Family Matters*, 76, 8–17.
3. Gray, M., Edwards, B., & Zmijewski, N. (2008). Caring and women's labour market participation. *Family Matters*, 78, 28–35.
4. Edwards, B., & Higgins, D. (2008). *Is caring a health hazard? The mental health and vitality of carers of a person with a disability in Australia*. Manuscript submitted for publication.