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# **The costs of caring and the living standards of carers**

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# Executive summary

This report presents the findings of a study undertaken by the Social Policy Research Centre (SPRC) for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

Informal carers are people who provide unpaid help, support or assistance to family members or friends with disability, chronic illness, mental illness, other illness, or alcohol or other drug problems. Recent estimates suggest that around 16 per cent of the adult population in Australia provide informal care (ABS 2008) and that the majority of people who require help or assistance receive support from family or friends. Demographic and policy changes have increased the demand for informal care over recent decades and projections suggest that the need for informal carers is likely to increase with an ageing population. Women, who are often the main providers of informal care, are entering the labour force in increasing numbers. Thus it is likely that many will encounter the challenges of negotiating the competing demands of caring and paid employment. The evidence suggests that, given limited alternative care arrangements, many carers adapt to their caring role by reducing or leaving employment. This outcome has implications for their short-term and long-term financial security and retirement incomes.

The economic value of the contribution of informal carers to the Australian economy has been estimated at over \$40 billion a year, if all the care was to be replaced by formal services (Access Economics 2010). The social value of informal care is immense, because care provided by family or friends enables others to remain in their home, connected to their family and community. Yet the available evidence suggests that, under the current policy settings, the contribution of informal carers may significantly affect the lives of the individual carers. The impact of caring may be conceptualised as costs. In the literature, such costs may be interpreted as both indirect and direct costs. The indirect costs of care are the opportunity costs of reducing employment, leisure and other activities to provide care, the time devoted to caring, and the impact caring has on the informal carer's physical and mental health. International and Australian research suggests that the indirect costs of caring are significant. To understand direct costs requires a conceptual distinction to be made between the direct costs of disability and the direct costs of caring. The direct costs of disability are expenses arising from the needs associated with disability, which may be borne by the person with disability, the carer or a range of other agencies, for example, government, non-government organisations (NGOs) or insurance companies. The direct costs of care refer to the additional monetary expenses incurred by carers as a result of taking on the caring role, which may include home modifications or transport, or health costs for carers to mitigate the stresses associated with caring. The size of the direct costs of disability and direct costs of caring for carers depends on the type of needs of the person with disability and the support provided by formal services and other sources. Little is known about the size of the direct costs incurred by taking on informal care in the Australian context and the most appropriate ways to estimate the extent of such costs.

This project addressed this issue by investigating three research questions:

- What is known about the direct costs incurred in informal caring as distinct from the indirect costs of care?
- What are the most robust methods to investigate the direct costs of care and what data are available in Australia to do so?
- What are the living standards of different subgroups of carers in Australia and what might this imply about the direct costs of care?

The first component of this study reviewed the Australian and international literature on the direct and indirect costs of care. The second component examined and evaluated methods for estimating the direct costs of disability that may provide the basis for disaggregating the direct costs of disability from the direct costs of care. However, this study did not produce estimates of the direct costs of care. This section of the research also scoped existing national datasets to describe the data that are available and the data that would be needed for an analysis of the direct costs of care. The final component of the project consisted of an empirical analysis of the living standards of carers, using four indicators. These indicators included before-housing income poverty, after-housing income poverty, subjective poverty and financial stress.

## Summary of the main findings

### *Indirect costs of care*

Overall the research shows that the costs of care are likely to be considerable. A substantial body of research has examined the indirect costs of care. Indirect costs of care encompass opportunity costs, time costs and impacts on health.

International and Australian research has shown that informal care has a negative impact on participation in the labour market, hours worked and income. Carers providing intensive levels of informal assistance can incur the greatest opportunity costs. These costs are not just immediate, but can continue into the future even when caring has ceased.

Estimating the time costs of informal care is difficult because carers may not distinguish between activities related to care and other household tasks. However, the development of a 'time signature' (distinct profile of time allocation) provides evidence of significant time costs for carers: estimates suggest that most carers undertake the equivalent of a part-time job providing informal care a week.

Another indirect cost of care is the effect on carers' physical and mental health of providing informal support. Research indicates that the provision of informal care may adversely affect carers' physical and emotional health, particularly with respect to those providing the most informal care. An Australian study found that carers had the lowest collective wellbeing of any population group examined by the researchers.

### *Direct costs of care*

Overall, the limited available research on the direct costs of care shows that:

- Carers may incur substantial costs associated with their caring role.
- The extra costs of care referred to in the literature included additional heating and cleaning expenses, and costs associated with travel, communication and services.
- Within households, carers reported pooling resources with other household members.
- Carers reported helping the person with disability to pay their own expenses.
- Carers reduced spending on items such as holidays and leisure activities.

Generally, the extant research provides some basic data on the additional costs of care but fails to examine the complex nature of the relationship between the extra costs of disability and those related to care. As noted above, to disaggregate the costs of care from the costs of disability requires a conceptual distinction between needs and costs that arise due to the disability and those that occur due to taking on the caring role.

### *Methods of estimating the direct costs of care*

Research on estimating the direct costs of disability provides a potentially useful theoretical framework for investigating the direct costs of care and attempting to disaggregate these from those associated with disability.

Four main approaches to estimating the extra costs of disability are outlined in the literature. These include:

- the subjective approach—asking people how much they need to spend to meet their needs
- the budget standards approach—estimating what people need to achieve a particular standard of living
- the comparative approach—using expenditure data to compare the consumption of households
- the standard of living approach—estimating the difference in income required by different types of household to achieve a similar standard of living.

Each method differs in how needs, and therefore costs, are measured and the information on expenditure and the allocation of resources used in analysis. Despite the obvious link between disability and the provision of informal care, the studies do not take into consideration the presence of a carer, perhaps for both theoretical and empirical reasons.

Each of these methods could be applied to estimating the costs of care. However, as yet, only the subjective method has been used to investigate the direct costs of care. Extant studies based on this method have focused on the items on which carers spend, and not on the amount they would be required to spend to meet all their needs. The budget standards approach could be applied to the investigation of the direct costs of care; however, it would require substantial resources to collect the necessary data.

Both the comparative approach and the standard of living approach are based on analysis of large scale surveys containing expenditure and standard of living data. A number of nationally representative household surveys contain some of the variables required for each of these approaches. These include the Household Expenditure Survey (HES), the Survey of Disability, Ageing and Carers (SDAC), and the Household, Income and Labour Dynamics in Australia (HILDA) survey. However, the data scoping revealed several gaps, including:

- HES—very limited information on disability or informal care
- SDAC—limited information on expenditure and no information on financial stress
- HILDA—limited information on financial stress at the household level.

At this time, the most promising datasets include HES (comparative approach), although information on informal care and disability would be required; and HILDA (standard of living approach), which contains good information on informal care and disability but limited data on standard of living at the household level, which raises an issue with respect to replicating previous analyses but may also be a strength of a modified approach. These additional variables would be required to maximise the potential of these existing data sources to produce a more robust analysis of the extra costs of care.

### *The living standards of carers*

Four different approaches to assessing the living standards of carers and non-carers were used: before-housing income poverty, after-housing income poverty, subjective poverty and financial stress. The analysis identifies carers who are poor with respect to different dimensions of economic disadvantage: low income, high housing costs, perceiving oneself to be poor, and having difficulties managing financially. The analysis used two waves of the HILDA survey (2005 and 2006).

The key findings are as follows:

- Overall, at the aggregate level, carers had higher rates of poverty than non-carers on all measures.
- Carers who had been caring for two years had higher poverty rates than non-carers and were more likely to be in persistent poverty.
- Overall, multivariate analysis showed that caring did not increase the risk of income poverty or subjective poverty, but did increase the risk of financial stress, even when controlling for income and wealth. This finding may indicate that carers have higher costs than their non-carer counterparts.
- Carers caring for their spouse were disadvantaged on the before-housing income poverty and after-housing income poverty measures, while carers caring for a parent were at increased risk of financial stress.

### *Before-housing income poverty*

- Carers who had higher rates of before-housing income poverty were: aged 65 years and over, Indigenous carers, carers from culturally and linguistically diverse (CALD) backgrounds, public renters, those highly reliant on government transfers, and on the Disability Support Pension, Age Pensions, or allowances. Carers not in employment and carers living alone also had relatively high rates of before-housing income poverty.
- Multivariate analysis of the carer sample showed that factors that increased the risk of before-housing income poverty were: CALD status, disability, lower education, a lower proportion of time spent in employment since leaving school and low wealth.

### *After-housing income poverty*

- Carers who had higher rates of after-housing income poverty—or high housing costs—were: aged 25 to 44 years, CALD and Indigenous carers, renters, carers highly reliant on government transfers, those receiving Disability Support Pension, unemployed carers, and carers in lone-parent and lone-person households.
- Multivariate analysis of the carer sample showed that the factors associated with an increased risk of high housing costs were: CALD status, disability, proportionally less time in employment in the past and low levels of wealth.

### *Subjective poverty*

- Carers with higher levels of subjective poverty were: aged 25 to 44 years, renters and those in receipt of Disability Support Pension.
- Multivariate analysis showed that factors increasing the likelihood of a carer perceiving themselves to be poor were: having a disability, having spent more years unemployed and having lower levels of wealth.

### *Financial stress*

- Carers with higher rates of financial stress, and potentially higher costs associated with caring were: aged 15 to 44 years, Indigenous carers, renters, highly reliant on government transfers, in receipt of Disability Support Pension or allowances, or unemployed.
- Multivariate analysis showed that carers with a higher risk of financial stress were: males, younger, without a partner, with more children and in receipt of lower levels of income.

Extant research on carers provides extensive evidence on the indirect costs of care, which may have long-term effects on informal carers' financial security, social participation and health. The effects are greater for those carers providing intensive support. Less is known about the direct costs of caring, although surveys of carers themselves reveal additional expenses in some domains, while carers cut back on other aspects of spending. Further research is required to identify the specific costs that carers encounter and how policy could assist in defraying the expenses associated with these needs. The scoping of available datasets indicates that future research could develop robust and comprehensive estimates of the direct costs of caring, if additional variables were added to the datasets. The evidence on living standards in Australia highlights carers' economic disadvantage using a number of indicators. The evidence of increased financial stress for carers is compelling and is likely to be an indicator of substantial costs associated with caring. This research has identified groups that may be more vulnerable on different dimensions of poverty. The evidence presented in this report raises issues that might inform the policy agenda when the circumstances of carers are being considered.

# 1 Introduction

The Department of Families, Housing, Communities Services and Indigenous Affairs (FaHCSIA) commissioned the Social Policy Research Centre, at the University of New South Wales (UNSW), to conduct this project to investigate the costs associated with informal caring and examine carers' standard of living.

This project explored three research questions:

- What is known about the direct costs incurred in informal caring as distinct from the indirect costs of care?
- What are the most robust methods to investigate the direct costs of care and what data are available in Australia to do so?
- What are the living standards of different subgroups of carers in Australia and what might this imply about the direct costs of care?

## 1.1 Background

Demographic and policy changes have significantly impacted on the demand and supply of informal care. The ageing of the population has resulted in an increased demand for informal support, while women's increased labour-market participation and the smaller size of families have effectively reduced the pool of available informal carers. Nevertheless, despite the well documented constraints on labour force participation that informal care provision imposes, a considerable amount of Australian and international evidence shows that a significant proportion of informal carers of labour-force age are combining care with employment, often with part-time employment. This indicates that rather than there being an attrition of informal carers, it is more likely that new combinations of care and employment are being, and will be, forged, as women's labour force participation rates increase (ABS 2008; Hill et al. 2008; House of Commons Work and Pensions Committee 2008). However, as will be discussed below, these combinations of participation in informal care giving and in the labour force do not negate the probability that increased costs of care giving will be incurred.

A consequence of population ageing is that increasing numbers of employees will retire over the next 20 years. Therefore more people will need to be recruited into the workforce to pay taxes to fund welfare, medical and social care programs if living standards of elderly people are to be maintained now and into the future. A potential source of additional employees is women who left employment after having children. However, these women are increasingly likely to have informal care responsibilities as well. It is predicted that over the next 25 years the number of people with a disability aged 65 years and over will grow by 150 per cent and there will be an increase of 200 per cent in the number of people aged 85 years and older. Also, over the next 50 years the ratio of carers to people with severe or profound disability is estimated to fall from 2.5 to less than one (AMP.NATSEM 2006).

In Australia, in 2003 the ABS estimated that around 16 per cent of the Australian adult population (over 15 years), or 2.5 million adults, provided informal care to a person with a disability, chronic illness or frailty due to old age (ABS 2008). Support provided by informal carers is crucial to enable frail older people and people with disability to remain at home until it is no longer possible. Over 90 per cent of people aged under 65 years in need of ongoing assistance with self care, mobility or communication received support from family or friends, compared with 26 per cent who received assistance from formal care providers (AIHW 2005, Table 5.21, p. 249). In 2010, it is estimated that carers in Australia provide approximately 1.32 billion hours of care, and that it would cost approximately \$40 billion to purchase formal services to replace this informal support if these carers were unavailable (Access Economics 2010).

A considerable body of research documents the additional physical and emotional demands of caring and the negative impact this can have on carers' quality of life (Bittman, Hill & Thomson 2007; Brodaty & Berman 2008; Brodaty et al. 2005; Brodaty, Griffin & Hadzi-Pavlovic 1990; eds Schofield et al. 1998). Formal services such as respite and support programs can help support carers and reduce some of the detrimental effects of caring. However, relatively few carers access these services and programs (Brodaty et al. 2005; Hill et al. 2007; Parker 2000; eds Schofield et al. 1998).

Without access to effective formal support, carers undertaking significant caring responsibilities are often unable to combine care with paid employment, and therefore leave the labour force or reduce the hours of their employment (Hill et al. 2008; Thomson et al. 2008). These carers may be eligible for Carer Payment and/or Carer Allowance. Carer Payment is an income support payment for people whose caring responsibilities prevent them from undertaking substantial workforce participation. Carer Payment is subject to income and assets tests. Carer Allowance is an income supplement available to people who provide daily care and attention at home to a person with disability or a severe medical condition. Carer Allowance is neither taxable nor income and assets tested. It can be paid in addition to a social security income support payment.

The impact of caring may be interpreted as having 'direct' or 'indirect' costs. The indirect costs of care are the opportunity costs of reducing employment, leisure and other activities to provide care, the time devoted to caring, and the impact caring has on the informal carer's physical and mental health. International and Australian research suggests that the indirect costs of caring are significant. Reducing or leaving paid employment to provide informal care has been shown to have immediate and long-term indirect costs for the carer, with respect to reduction of participation in paid employment and reduced access to market incomes, with implications for carers' superannuation and retirement incomes (AMP.NATSEM 2006; Buckner & Yeandle 2007; Hill et al. 2008). Providing support for a person with a disability, chronic illness or a frail aged parent may also involve additional expenditures or **direct** monetary costs.

To understand direct costs requires a conceptual distinction to be made between the direct costs of disability and the direct costs of caring. The direct costs of disability are expenses arising from the needs associated with disability, which may be borne by the person with disability, the carer or a range of other sources (for example, government, non-government organisations (NGOs), insurance companies). The direct costs of care refer to the additional monetary expenses incurred by carers as a result of taking on the caring role, which may include home modifications or transport, costs of medication or treatment for carers to mitigate the stresses associated with caring. The size of the direct costs of disability and direct costs of caring for carers depends on the type of needs of the person with disability and the support provided by formal services and other sources. Little is known about the size of the direct costs incurred by taking on informal care in the Australian context and the most appropriate ways to estimate the extent of such costs.

The full range of direct and indirect costs of care and their impact on carers' living standards has yet to be comprehensively documented in Australia. This information may inform policy regarding the financial security of groups such as carers who have been identified as vulnerable by the Senate Committee on Community Affairs. They have found that the 'maximum rate of pension may be insufficient to maintain a basic, decent standard of living' (Harmer 2008, p. v).

This project reviews the Australian and international literature on the direct and indirect costs of care; undertakes a scoping of the data sources and methods that would aim to disaggregate the direct costs of disability and caring; and conducts an empirical analysis examining four alternative indicators of the living standards of carers. The research describes what is known about the costs of care, assesses the relative merits and analytical possibilities of four methods for estimating the direct costs of care, and provides new evidence on different components of the living standards of carers in Australia.

## 1.2 Overview of the project

The project comprises three components:

- ▶ A literature review of the Australian and international research on the direct and indirect costs of informal care. The literature review primarily focuses on what is known about the direct costs of care and approaches to identifying 'need' and 'costs' in relation to disability and care. The literature also examines recent key studies on the indirect costs for carers in terms of opportunity costs, including non-participation in paid employment and time costs.
- ▶ A scoping of data sources and methods, which examines the robustness of available data sources and of analytical methodologies in order to estimate the direct costs of care. Four methods for estimating the direct costs of disability and care are considered: the subjective method; the budget standards approach; the comparative approach; and the standard of living approach.

- ▶ An empirical analysis of de-identified data examines four alternative indicators of the living standards of different subgroups of carers. The analysis uses two waves of the HILDA survey data (2005 and 2006). The purpose of the study is to explore different aspects of economic disadvantage: low income; high housing costs; the carer's own perception of their situation; and the extent to which the carer is coping financially.

### 1.3 Outline of report

This report begins by providing a background to the issues facing carers. Section 2 summarises the main findings from the Australian and international research on the direct and indirect costs of informal care. In Section 3, methods for estimating the direct costs of care are considered together with the appropriateness of available data sources for this type of analysis. Section 4 reports the findings from the empirical analysis of the living standards of different subgroups of carers. The final section of the report (Section 5) summarises the main findings from the project and outlines the implications for future research on the direct and indirect costs of care.



## 2 Costs of care: direct and indirect

This section of the report summarises research on the direct and indirect costs of informal caring. It begins by reviewing Australian and international literature on the direct costs of care. This review is followed by recent key studies on the indirect opportunity costs of carers, including forgone earnings, impact on health and wellbeing and time costs. An emerging area of research in relation to the costs of care focusing on economic evaluation of care is then discussed.

### 2.1 Conceptualising needs, costs and care

The development and growth of the welfare and social support system is based on recognition that certain groups have needs that may be met through social supports and services. One of the principles of the Australian social security system is that ‘it is equitable’ and that ‘it treats people in similar circumstances similarly’ (Harmer 2008, p. 4). To this extent, the Australian system is able to recognise that different individuals may need additional support ‘to help them to achieve a similar standard of living’ (Harmer 2008, p. 4). However, defining ‘needs’ that will be supported by social welfare systems is not straightforward. For example, according to Bradshaw (1972), four approaches to defining needs that can be met by social services or ‘social need’ are commonly used. These include:

- **normative need**—when a person or group falls below a certain standard of living that is determined by experts or professionals
- **felt need**—when a need for a particular service is felt but not requested or demanded
- **expressed need or demand**—when someone demands a service
- **comparative need**—when a person, not in receipt of a service, has a similar characteristic to service users.

These methods for recognising or defining need rely on diverse criteria and judgements made by individuals and experts. Determining whether needs are intrinsic to the individual (that is, something they cannot influence through choice) may be regarded as another criteria in the process of defining what constitutes a need to be met by a social welfare system. For some groups, for example, people with disability, it is clear that their needs are intrinsic because they have limited choices or options to change the effect of their disability. For other groups, such as carers, the question of the degree of choice they have to determine the additional needs that may arise from their caring role may be more ambiguous. On the one hand, it can be argued that assuming the role of informal care is a choice. However, taking on caring responsibilities over the short term and long term is influenced by a number of factors outside of the carer’s control. The factors include familial relationships, other personal relationships, social obligations, lack of other family members to provide care and limited access to formal services. To the extent that carers in a particular policy context may have little choice over the amount of care they provide, and that informal caring is regarded as a valuable social contribution, the needs and associated costs generated as a result of taking on a caring role may be recognised and subsidised within the social welfare system.

The current policy framework, emphasising community care policies and ‘ageing in place’ for the frail aged, relies heavily on the additional and complementary provision of informal care to enable older people and those with disability or chronic illness to remain at home rather than enter residential care facilities. Daly and Lewis’s (2000) conceptualisation of social care as a multi-dimensional concept focuses on three aspects:

1. **Care as labour**—care involves work, either unpaid or paid and the conditions under which it is conducted and government’s role in the provision of formal care services should be considered.
2. **Care is located within a normative framework of obligation and responsibility**—care is provided within interconnected relationships, obligations and reciprocity.
3. **Care is an activity with financial and emotional costs**—these costs, indirect and direct, are incurred by individuals, families and society.

To date, research on the costs of care has predominantly focused on the indirect or opportunity costs. Estimating the direct costs of caring presents theoretical and empirical challenges due to the complex nature of the relationship between the carer and the person with disability and the diverse contexts in which care takes place. Conceptually, to separate the costs of disability from the costs of care requires a framework to distinguish between needs that arise from the presence of disability and needs associated with the caring role, while recognising the overlapping and interlinked nature of costs and needs within households and care relationships.

The following section outlines the conceptual frameworks used with the existing literature to understand the additional needs generated by disability and the direct costs incurred. However, disability and the associated costs are inextricably linked to the provision of care and, as yet, this link has not been addressed within these frameworks. Also considered is the appropriateness of this framework and how it could be applied to understand the needs of carers and, in turn, estimate the direct costs of informal care.

## 2.2 Direct costs

Conceptually, the costs of caring involve indirect and direct costs to individuals and the community more broadly. In the United Kingdom House of Commons Work and Pensions Committee Fourth Report it is stated that:

DWP [Department of Work and Pensions] acknowledges that there is not enough research evidence on the extra costs incurred by caring. In particular, the Department suggests, it is not easy to distinguish between the costs of caring and the costs of disability. The Department states that it continues to review available evidence on whether there are separate extra costs for caring, what they are and what their impact is. (House of Commons Work and Pensions Committee 2008, p. 34)

The report goes on to state that some examples of direct costs of care put forward in evidence to the Inquiry included: costs for heating, particularly when caring for a child or elderly person who is at home all day; washing clothes and bed clothes (a particular problem when caring for someone who is incontinent); special food that people with certain conditions need; and transport and parking costs. Many carers also pay for dressings and other medical equipment, which is not provided by health services. Families often struggle to get adaptations to their homes and can end up paying for them themselves rather than waiting months for subsidised support for home adaptations (House of Commons Work and Pensions Committee 2008).

It could be argued that some of these direct costs are derived from the costs of disability. However, given the paucity of evidence on the interconnection of the costs of disability and the costs of care, the authors of this current report take the view that more evidence is required to shed light on the direct costs of care and note, where possible, where and how they might be distinguished from the costs of disability. We further take the view that to attribute all the direct costs to disability and to dismiss the possibility of the direct costs of care, and as a consequence cease to attempt to identify and assess those costs, overlooks the complexities of the relationship between the carer and the person with disability, the diversity of households and the relationship between income and expenditure. This is especially pertinent where households and individual incomes are low and very often it is the carer who must undertake the efforts to meet the direct everyday costs of both disability and care.

To investigate the question, ‘What are the direct costs of care?’, it is necessary to first define the types of costs to which we are referring, and then examine methods of estimating these extra costs.

### Types of costs

Carers require certain goods (food, housing, electricity) and services (health, support services) to meet their needs, as do non-carers, but carers may have additional costs associated with providing informal care. Berthoud (1991) outlined various types of additional costs associated with disability. The provision of informal care is obviously linked to disability and the associated extra costs. Extra costs arise from the extra needs of a person with disability (Tibble 2005). These extra costs and how they affect carers may include the following:

- **One-off costs**—expenditure on capital items required only once, such as modifications to a home or vehicle. Carers may need to modify their vehicle to accommodate the person with disability.
- **Recurrent costs**—expenditure on goods such as food, clothing or electricity required on a regular basis. For carers, these costs could involve the cost of petrol for travel to the place of care.

- ▶ **Intermittent recurrent costs**—durable goods, for example, washing machines or wheelchairs, that involve costs sporadically if they have to be replaced. Carers could incur these costs if they have to purchase a washing machine or dryer to cope with additional laundry.
- ▶ **Special costs**—people with disability, compared to people without disability, may have to purchase special items due to their disability, such as medication, or personal care services. For carers, whose own health could be affected by the caring role, these costs could include medication and respite services.
- ▶ **Additional costs**—all people require some items such as food, telephone and transport but people with disability may require more. However, it is difficult to estimate exactly how much more is required. Carers may be required to make additional phone calls to manage their care situation.
- ▶ **Reduced costs**—expenditure on some goods and services may be reduced due to disability, for example, reduced expenditure on social activities (Berthoud 1991; Tibble 2005). For carers, these costs could involve reductions in spending on holidays or leisure activities.

Other costs as described by Tibble (2005) in relation to disability include:

- ▶ **direct costs**—spending on items to meet needs related to the disability (for example, medications)
- ▶ **indirect costs**—a reduction in income or wellbeing (compared to a person without disability) resulting from the disability (for example, reducing work hours or leaving employment)
- ▶ **potential costs**—costs that may be incurred if income were not constrained in terms of meeting all disability-related needs
- ▶ **realised costs**—actual expenditure by individuals (or households) to meet their disability-related needs.

### Identifying costs through changes in expenditure

One of the main problems associated with research attempting to estimate the extra costs associated with disability is identifying additional spending on needs created by the disability, given that spending is constrained by available income. One definition of a need is the goods and services that people buy despite having limited income, for example, food, housing and fuel, for which expenditure remains relatively constant with respect to increases in the level of income (that is, it is inelastic). Households and individuals with relatively low resources thus might spend a higher proportion of their income on such items compared with higher income households. Items that are needs are contrasted with luxuries, which are things people buy only if they have a high income (Berthoud 1991). Expenditure on these items tends to increase as household income increases.

In relation to carers, if their income is limited, increased expenditure on a particular item will mean they have less to spend on other items, thus expenditure is displaced. This displacement of expenditure can result in a lower standard of living compared to others who do not have these additional needs but have the same income level. It could be argued that the extra costs of care are not additional spending on, for example, transport but reduced consumption on social activities outside the household, as outlined by Berthoud (1991) in relation to the extra costs of disability.

The approaches to identifying the direct costs of disability (or care) thus focus on identifying the magnitude of 'displaced' expenditures (Zaidi & Burchardt 2005). In relation to caring for the person with the disability, displaced expenditures include additional expenditure on regular items, such as laundry and heating, and other expenditures associated with the specific disability, for example, home and car modifications, medications and support services (Zaidi & Burchardt 2005). To disaggregate the costs of disability from the costs of caring, a conceptual distinction needs to be made between displaced expenditure due to the disability and that due to the caring role. As discussed below, survey and focus group data on the expenses of carers reveal that displaced expenditures associated with caring include additional expenses on transport, communication and even accommodation, if caring for a person living outside the household (Carers UK 2005; Evercare 2007; Thomson et al. 2008). For all carers, there may be additional expenses required to maintain the carer's own health and social and economic participation, given the additional stresses and responsibilities of providing informal care. Evidence on displaced expenditure or changes in consumption patterns is also provided by

reports of ‘cutting back’ on expenditure on items such as going out, holidays, own clothing and leisure activities. The size of direct costs experienced by a person with disability or a carer will depend upon the severity of restrictions imposed by the disability or chronic illness, the type of disability, and the degree to which the specific goods and services required to support the person with the disability and the carer are subsidised (Zaidi & Burchardt 2005).

### **Methods of estimating extra costs of disability**

Before reviewing the limited research on the direct costs of care, the existing literature on the extra needs and additional costs of disability is discussed (Saunders 2007; Tibble 2005; Zaidi & Burchardt 2005). The conceptual difficulties associated with identifying what constitutes the extra costs associated with disability are acknowledged within the literature but, overall, the research findings concur that there are extra costs (Tibble 2005).

Four main methods are used in the literature to estimate the extra costs associated with disability. The costs to carers are referred to incidentally in this literature. However, it is apparent that disability and care costs are confounded even in these methods. These approaches and their potential relevance to carers are:

- ▶ **the subjective method**—asking respondents themselves how much they are required to spend to meet their needs (Berthoud 1991; Tibble 2005)
- ▶ **the budget standards approach**—where experts define the additional basket of goods/services and costs required to meet the additional needs (Saunders 2007; Tibble 2005)
- ▶ **the comparative approach**—where expenditure data is used to compare the consumption of households (for specific items) of different composition (Berthoud 1991; Frisch 2001; Matthews & Truscott 1990; Tibble 2005)
- ▶ **the standard of living approach**—where models are used to estimate the level of incomes required by different types of households to achieve the same standard of living (Saunders 2007; Tibble 2005; Zaidi & Burchardt 2005).

However, extant research on the costs of disability does not take into account the presence of an informal carer, possibly due to lack of information about carers in the available data. Nor has it investigated the additional costs or needs associated with providing informal care separate from the needs and costs of a person with a disability. Nevertheless, the theoretical and analytical framework of this body of research provides a useful foundation to supplement and extend the existing research on the direct costs of care outlined below. Further details of key studies using each of these methods, and their appropriateness for estimating the direct costs of care using existing datasets, are outlined in Section 3. The next subsection looks at available research on the direct costs of care.

## **2.3 Research on the direct costs of care**

A limited number of international and Australian studies have examined the direct costs of care and provided some preliminary evidence of the magnitude of these costs. However, on the whole, these studies have relied on subjective measures or asking carers about the direct costs of care.

### **International research**

Carers UK has conducted a number of studies investigating the direct and indirect costs of care. One study involved a questionnaire distributed by branches and associated members of Carers UK through its website. A total of 848 carers responded to the survey. Most carers, 88 per cent of the sample, were currently providing informal support. All survey respondents were over 60 years old. Over 90 per cent of the sample provided more than 20 hours of care a week. The survey contained open-ended questions about other issues that affected them financially. One hundred and fifteen respondents indicated increased costs, such as extra heating or cleaning associated with disability. Other additional costs included transport (particularly for getting prescriptions, or taking the care recipient to appointments or hospital), food (due to buying from more expensive shops that were close by, and not having time to travel to less expensive shops), and respite and other support services.

Some carers, due to the ill health of their spouse, now had to pay for gardeners or tradesmen to do odd jobs around their homes (Carers UK 2005).

Another Carers UK study showed that providing support resulted in carers being unable to take up opportunities that may improve their quality of life. These findings were based on a survey conducted between December 2006 and January 2007. The survey questions were based on those in a survey conducted in 1999. The survey was distributed via the *Caring Magazine*, Carers UK mailing list, local carers and other organisations, National Black Carers Network and London Black Carers Network and key contacts, and promoted on their website. A total of 2,950 written responses were received with a further 1,597 collected online. The majority of carers were providing support full-time for more than 50 hours a week. Two-thirds of respondents were female (Carers UK 2007a).

This study also showed that the direct costs of care include 'displaced' expenditures on supporting the person with the disability or undertaking the caring role. Carers in this study reported cutting back on expenses such as food purchases (19 per cent) and heating (25 per cent). Caring also affected carers' finances, in particular debt, as 33 per cent were currently or had been in debt and 61 per cent of the carers on income support were in debt. In the first year of caring, 36 per cent struggled to pay household bills such as electricity, gas or telephone, compared with 30 per cent of all carers. In addition, 35 per cent indicated they were spending their income or savings to pay for care. Forty-four per cent of the sample had no savings and almost one-third of the carers indicated that the costs of services were too high. Carers also indicated that they met gaps in costs for the person with disability. For example, if the person with disability could not afford to pay expenses, carers often helped by paying the difference or gap. Some carers pooled income to cover the costs of disability. Carers also reduced expenditure on items such as holidays, leisure and going out with friends (Carers UK 2007a). This survey was conducted again in 2008 by Carers UK. The results enable comparisons of carers' current financial situation to that of the previous year (Carers UK 2008).

A qualitative study of 30 working age carers in the United Kingdom, conducted by Glendinning (1989), found a number of different types of costs associated with disability and care such as one-off capital costs (modification to homes or equipment), recurrent extra costs (additional heating and food costs) and costs related to payment for formal services (Glendinning 1989).

A study conducted by the Metropolitan Life Insurance Company, based on a national survey by the National Alliance for Caregiving and the American Association of Retired Persons, investigated the direct and indirect costs of care in the United States. The sample consisted of 1,509 people aged over 18 years who provided unpaid care to a relative or friend aged 50 years or over. In addition, 55 carers completed an in-depth telephone interview focusing on the short and long-term consequences of balancing work and care commitments (Metlife 1999).

All respondents in the study indicated that they had helped the care recipient financially by paying for one or more expenses, most commonly for food, transport and medications. The highest amount paid by a carer a month was for rent (US\$364), and home care professionals (US\$322). On average, carers estimated they had spent US\$19,525 on expenses to help the care recipient. On average, carers had helped the care recipient with expenses for two to six years. About one-quarter of the sample could estimate the amount of money they would have devoted to savings or investment if they did not have to cover the costs of care. The average total amount of reductions to savings due to caring was US\$25,028 (Metlife 1999).

A US study in 2007 explored the direct and indirect costs of caring in detail. The study involved a national telephone survey to examine the costs of care of 1,000 carers. In addition, a sub-sample of respondents (41) took part in a 30-day study of direct and indirect costs of care. These participants completed expense diaries. The sample consisted of carers providing unpaid help to someone over the age of 50 years in activities of daily living or instrumental activities of daily living during the past month. The findings suggest that there are significant financial implications associated with providing unpaid care. Also, the amount of out-of-pocket expenses was correlated with levels of reported stress, health and wellbeing. Annual out-of-pocket expenses for survey participants were estimated to be US\$5,531, calculated by multiplying the sum of all monthly expense by 12, plus annual expenses. This constituted around 10 per cent of their median income (US\$43,026). For over 40 per cent of the sample, the most common expenses included household goods, food and meals, followed by

travel and transport costs (40 per cent) and medical care and medications (31 per cent). In order to manage these expenses, respondents cut back on leisure activities (49 per cent), holidays (47 per cent), cut down or stopped saving (38 per cent), and put off buying large scale items or home renovations (34 per cent). Similar to studies in the United Kingdom, over one-third of the sample had used savings to pay for expenses (Evercare 2007).

The study also found that one in five respondents had reduced spending on their own health and dental care needs. Carers who did not live with the care recipient and had to travel long distances to provide support had the highest annual expenses (US\$8,728) compared to ex-residential carers living close to the care recipient (US\$4,570) and co-residential carers (US\$5,885). In terms of the diarists, the average expenses for the 30-day period were US\$1,029. In contrast to the survey respondents, co-residential carers had the highest average costs a year (US\$14,823) compared to long distance ex-residential carers (US\$14,064) and ex-residential carers living less than an hour away (US\$8,496). The types of costs reported by diarists were similar to those reported by survey participants. However, a higher percentage of diarists reported costs in all categories for example, 70 per cent were paying for groceries and 60 per cent were paying for medical expenses, household items and transport. This could indicate that the diary method of reporting expenses is a more accurate method of collecting information on expenditure. The study also found that although carers had additional financial costs associated with care, the most significant cost was time (Evercare 2007).

### **Australian research**

Few studies in Australia have investigated the direct costs of care. One of the first to investigate this issue, to a certain extent, was conducted by the Taskforce on Care Costs (TOCC). The study, based on a telephone survey of 512 employed carers, predominantly focused on the costs of care for children (without disability). The study found that those who paid for care services for older people and those with disability spent on average \$162 a week (\$8,400 a year) on support for older people, and \$118 a week (\$6,100 a year) on support of people with disability (TOCC 2005).

Another Australian study examining the impact of caring on employment and economic disadvantage found what could be regarded as evidence of the additional costs of care, although it did not attempt to estimate these costs. This study was based on analysis of data from the 2001 HILDA survey, and examined income poverty rates and financial stress (defined as two or more indicators). Multivariate analysis using HILDA confirmed that caring does not appear to increase the likelihood of being in income poverty (Thomson et al. 2008). However, to further investigate the financial impacts of caring, indicators of financial stress were analysed. The multivariate analysis showed that there was an increased risk of financial stress among carers compared to non-carers even after controlling for household income levels. This suggests that carers may have additional costs associated with caring for a person with disability, not captured in an income poverty measure (Thomson et al. 2008). This study is discussed in greater detail in Section 4.

This project (Thomson et al. 2008) also involved a number of focus groups. A common issue raised in the focus groups were the costs of care, both indirect and direct. Focus groups were conducted with employed and non-employed carers living in metropolitan and non-metropolitan locations. The direct costs associated with providing care were a major concern for participants in the non-metropolitan location. Carers noted additional expenditure, particularly on travel and overnight accommodation, often required for medical treatment. Other direct costs included specialised medications, clothing, equipment and modifications to vehicles and homes. In one case, the family sold their house and built a new home that was suitable for a wheelchair.

## **2.4 Indirect costs**

The indirect costs of care encompass opportunity costs, time costs and impacts on health. There is substantial international and Australian literature on such costs in relation to informal caring.

An opportunity cost in economic theory is the value of what you give up in order to undertake a particular activity. It is a key component of economic decision making theory and social cost–benefit analysis. Time and effort spent in care may involve reductions in time spent in other activities such as employment, education, accumulation of human capital (leading to lower lifetime earnings and superannuation contributions), and time

spent in other unpaid work, personal care or leisure. Ettner (1996) has argued that the opportunity costs of the carer should be taken into account along with direct expenses for formal care when governments are considering which costs of caring to offset or subsidise.

The opportunity cost framework perceives time spent in informal caring to be the outcome of a 'choice' in an individualised decision-making framework (Carmichael & Charles 1998, 2003). As Carmichael and Charles point out, theoretically, due to a number of competing influences, it is not independently clear what the impact of informal caring on participation in other activities, such as employment, is likely to be. Carmichael and Charles note that on the one hand it is argued that carers may 'choose' to substitute time for caring rather than time spent in other activities on the basis of a personal preference to provide the care themselves, or due to the limited availability of other informal or formal supports. Alternatively, the increased costs of providing support and care to a person with disability may require that the carers earn more income in the labour market and thus they may need to increase their hours in employment. However, for carers there are also the additional considerations of the utility gained from social activities and employment as a 'respite' from caring and a means to maintain social contacts that may decrease the hours of informal care provided. Finally the degree of 'choice' about jobs may be particularly restricted for carers, due to the constraints imposed by informal care on the types of jobs and locations of work that the carer may engage in: thus, jobs in organisations that have long work hours cultures and jobs far away from the home of the care recipient may not be available to an informal carer. Further, juggling the responsibilities of employment and care giving may result in negative impacts on physical and mental health, which also have cost implications.

Empirically, international research has identified negative effects of informal caring responsibilities on hours worked and participation in the labour market, even when controlling for the possible endogeneity of informal care (Carmichael & Charles 1998, 2003; Evandrou & Glaser 2004; Heitmueller 2007; Heitmueller & Inglis 2007; Heitmueller & Michaud 2006; Hutton & Hirst 2000; Lilly, Laporte & Coyte 2007). Studies find that carers with substantial care responsibilities are less likely to be employed than non-carers or carers with lighter responsibilities (Lilly, Laporte & Coyte 2007; Thomson et al. 2008), and they are also more likely to work fewer hours and experience wage penalties (Carmichael & Charles 1998; Heitmueller & Inglis 2007; Thomson et al. 2008). Longitudinal research has also suggested that there are 'after effects' of caring on employment; carers who have ceased caring are less likely than non-employed non-carers to re-enter the labour market (Evandrou & Glaser 2004; Hutton & Hirst 2000; Lee & Gramotnev 2007; Parvalko & Artis 1997; Speiss & Schnieder 2003).

An analysis of a nationally representative longitudinal data source in Australia, the HILDA survey, reiterated the international findings about a negative effect of caring on employment (Bittman, Hill & Thompson 2007; Thomson et al. 2008). Carers had lower employment rates than non-carers overall. After commencing care, carers were more likely to reduce or leave employment than non-carers. Another nationally representative survey, the ABS Survey of Disability, Ageing and Carers (SDAC), was also analysed, and identified the lack of available alternative care arrangements, disruption for the care recipient, inflexible hours of work, age and loss of skills as barriers to employment (Thomson et al. 2008). Factors that might reduce such opportunity costs or provide the basis for a more genuine 'choice' between time spent in paid work and time spent in care were also examined in this study. Workplace arrangements, such as part-time hours and special leave for caring, and job security were key factors associated with carers remaining in employment (Hill et al. 2008) and the use of formal services to support the care recipient was also associated with higher employment rates (Thomson et al. 2008).

Australian research on the disincentives to paid employment posed by the financial costs of formal care implies that there are significant substitution effects in the current Australian policy environment. The Taskforce on Care Costs (2005) survey found that around one-third of the employees caring for a person with a disability and two-fifths of employees caring for an older relative had contemplated leaving paid work as a result of the costs of formal care. Over one-quarter of employees with care responsibilities had reduced their hours of work, and two-fifths indicated that they would increase their hours of employment if the cost of formal care was lower.

Research on young carers in Australia has demonstrated the negative impact of informal caring on completion of Year 12 education, particularly for young carers in regional areas (Hill et al. 2009). Young male carers had higher rates of non-completion of Year 12 than young female carers, yet young female carers appeared to be more disadvantaged than young male carers compared to their non-carer peers. Leaving education early has a major impact on lifetime opportunities and earnings.

A recent study undertaken by Carers UK (2007b) confirmed previous research demonstrating the significant opportunity costs associated with providing care. The results were based on a survey of nearly 3,000 carers carried out during January 2007. The findings indicated that carers in their late-50s and early-60s faced the biggest loss of earnings, as well as early retirement and reduced pensions. The main reasons carers gave up work or reduced work hours was due to a lack of appropriate support services, as well as a lack of flexibility at work or unsupportive colleagues. The cost of replacement care, lack of tax incentives, and an inflexible benefits system may result in carers being financially worse off by working and therefore trapped on benefits. Another reason for service non-use was a refusal by the person they care for to accept formal care services (Carers UK 2007b).

The UK study also found that, of the 1,000 carers who completed a question on how much they had lost in earnings in the last year by either giving up work, reducing hours or taking a more junior position, the average loss was 11,050 pounds. The research also showed that nearly three-quarters of respondents reported they were worse off since becoming a carer and over half reported that their health had suffered because of worry about their finances. Carers providing the highest number of hours of support were most affected by lost earnings. Evidence of other aspects of the financial impact of caring was found in the difficulty carers faced trying to save. Forty-four per cent of survey respondents indicated they had no savings, and an additional 32 per cent had savings of less than 1,500 pounds. Those approaching retirement faced a bigger loss of earnings; those aged 60 to 64 years lost 13,220 pounds, followed by those aged 55 to 59 years who lost 12,247 pounds (Carers UK 2007b).

Another survey conducted in the United States (Metlife 1999) also measured long-term effects from wage reductions, lost retirement benefits, lost opportunities for training/promotion and stress-related problems. The key findings from the study of the 55 carers who had made some type of work adjustment due to caring responsibilities indicated that caring had impacted on their ability to apply for promotion and attend training. Forty per cent reported caring impacted on their ability to advance in their job and over 60 per cent reported that caring had impacted on their earnings. Carers reported that retirement income was also affected. Due to caring responsibilities, carers estimated that Social Security benefits decreased on average by US\$2,160 a year. The average loss in total wealth, estimated by aggregating lost wages, Social Security and lost pension benefits over a lifetime was US\$659,139 (Metlife 1999).

Two recent studies in Australia have investigated the opportunity costs of care. The first, commissioned by Carers Australia with funding provided by Commonwealth Financial Planning, aimed to examine the impact of care on the health and economic wellbeing of women in Australia over their work life. In the study, two scenarios were identified representing women carers who pay the highest price, in terms of health and financial wellbeing. The main data sources used in the study are the HILDA survey Wave 6 (2006) and the 2003 SDAC. Health impact was assessed in terms of self-reported health status and the number of healthy years they expected to live over the remaining working life, up to 65 years. Financial stress was assessed in terms of prospective income accumulated over the remaining working life. Income indicators examined include individual and family income from wages and salaries, government benefits and superannuation. Overall, the study showed that the impact of being a primary carer extends to the rest of the primary carer's life; they experience reduced periods of good health over their working years; are less able to participate in paid employment; receive lower income during their working years; and are less able to invest towards retirement (NATSEM 2008).

Another Australian report by AMP.NATSEM (2006) also highlights the costs of care. It is estimated that if a single person, on an average weekly wage from employment, provided care, their weekly income would drop by \$481 if they relied on Carer Payment. This figure is based on an after-tax income of \$775 in December 2005. Other evidence of the financial impact of care provided in the report relates to carers' lower levels of income and living standards. For example, carers' median gross personal weekly income of \$300 is around 25 per cent less than non-carers. Primary carers' median gross personal weekly income is even less (\$237). Even after controlling for age, the reduction in annual earnings is estimated to be \$9,300 for a primary carer and \$2,600 for other carers. These findings have implications for carers' superannuation and retirement incomes (AMP.NATSEM 2006).

The time costs of informal care are estimates of the amount of time spent engaged in caring. The time commitment required for informal care depends on a variety of factors, including the type and severity of disability and the level of need for assistance with activities of daily living. Australian research has explored this issue using time-diaries, focus groups, and secondary analysis of both diary and recall data in national surveys (Bittman & Thomson 2000; Bittman, Hill et al. 2004; Bittman et al. 2005). As this research notes, time use studies of informal care provide important insights for policy makers into the experiences and contexts for activities of informal carers. However, conceptualising the effect of care on activities and time use, and the ensuing time costs, is not straightforward (Bittman & Thomson 2000; Bittman, Hill et al. 2004; Bittman et al. 2005).

A key issue that arises in the time diary records of informal care is that they are ‘designed to capture activities, not responsibilities or constraints’ (Bittman, Fast et al. 2004). In addition, as Bittman, Fast and colleagues (2004) note, individuals caring for a person within the household also undertake simultaneous activities and engage in joint production, which means that disentangling ‘care’ activities for a particular person from other domestic tasks undertaken for the household is difficult. The focus groups conducted by Bittman and Thomson (2000) showed that many carers did not conceptualise the activities they did for the care recipient as ‘care’. The analysis of time-diaries also found that time recorded explicitly as ‘care’ in dairies is generally fairly low. Nevertheless, further analysis of time-diaries provides evidence of a distinct profile of time allocation—or a time signature—for carers, which provides evidence of significant time costs (Bittman & Thomson 2000). The research on time signatures showed that carers spent twice as much time on laundry and domestic activities, 60 per cent more time in food preparation, clean-up and housework, and 40 per cent more time on gardening and lawn care than the general population. Carers also spent less time in leisure.

Estimates of weekly time spent in informal care suggest that most carers undertake the equivalent of a part-time job in providing informal care to a relative or friend and that over one-quarter of households providing care allocated the equivalent of a full-time job and another quarter provide between 20 and 39 hours a week (Bittman et al. 2005). Australian Institute of Health and Welfare (AIHW) (2004) estimated that the aggregate time spent in informal care in Australia in 2004 was the equivalent of one million full-time jobs. The time costs of care have been a major focus of economic evaluations that attempt to account for the cost of informal care. Details of the approach used to value the time spent caring are outlined in the next section.

Another indirect cost of care is the effect on carers’ physical and mental health of providing informal support. Research indicates that carers have poorer health when compared to those without caring responsibilities (Edwards et al. 2008; Lee 2004; Lee & Gramotnev 2007; Rosenman et al. 1993). This is particularly the case for carers providing intensive levels of support (Hutton & Hirst 2000; Young, Grundy & Jitlal 2006).

Carers’ mental health appears to be vulnerable to the physical and emotional demands of care. An Australian study of the subjective wellbeing of informal carers found that they have the lowest collective wellbeing of any population group examined by the researchers (Cummins et al. 2007). These findings were reiterated in Edwards et al. (2008) who found that carers experience higher rates of mental ill health compared to the general population.

Transitions into care can be accompanied by the onset of a major illness or serious accident. Carers often have to make adjustment to other facets of their lives, such as paid employment, when assuming caring responsibilities. Research suggests that transitions into care are associated with increased use of health services (Hutton & Hirst 2000; Lee 2004; Lee & Gramotnev 2007), which result in additional expenses and increased absenteeism (Metlife 1999). Poor health also appears to be related to financial stress (Carers UK 2007a; Nepal et al. 2008).

The relationship between poor health outcomes, the provision of care and the direction of causality has been debated (van den Berg, Brouwer & Koopmanschap 2004; Young, Grundy & Jitlal 2006). However, it is argued that taking account of the health impacts of informal care is an important consideration in economic evaluations. A number of different methods for measuring health-related quality of life have been developed; for example, the CarerQoL-VAS, which combines seven burden dimensions and a happiness index. The inclusion of carers’ health in economic evaluations, although difficult, will further extend our understanding of the costs of care. The economic evaluation approach is discussed in the next subsection.

## 2.5 Economic evaluation of care

Another emerging body of research related to the costs of care is economic evaluations. Some key issues and methods relating to the incorporation of care into these evaluations are outlined below.

Economic evaluations are increasingly used to inform policy decisions about the effectiveness of programs in terms of outcomes and costs. However, various methods are employed, which in turn influences the elements used in the models and how these are valued (van den Berg & Spauwen 2006). Some argue that economic evaluations should take a societal perspective and include all who are affected by an intervention in the evaluation of outcomes and costs, thereby preventing cost shifting from one sector to another, such as the informal economy. If a societal perspective is used, then the impact of informal care should be included in the analysis, although currently this is not usual practice. Also, the methods available do not adequately measure and value the input from informal care (van den Berg, Brouwer & Koopmanschap 2004).

If informal care is to be accurately measured and valued in economic evaluations, a clear definition is required. However, due to variations in the relationships between carers and care recipients, and the duration, intensity and types of assistance provided, this is not an easy task. Also, more than one informal carer can provide assistance. Another source of variation is where the carer resides, either with the care recipient or in a separate residence, which has implications for time allocated to care tasks and time spent travelling (van den Berg, Brouwer & Koopmanschap 2004). In addition, carers, particularly co-residential carers, often find it difficult to disaggregate time spent in care tasks versus other household duties (Fast et al. 2004). One definition of informal care is ‘a non-market composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of care demands of the care recipient’ (van den Berg, Brouwer & Koopmanschap 2004, p. 38). This definition allows for the possibility that the informal carer may receive some type of payment but still remain an informal care rather than a formal care provider (van den Berg, Brouwer & Koopmanschap 2004, p. 38). The way in which time devoted to caring activities is measured is another significant variable to be considered in the economic evaluation of care (McDaid 2001; van den Berg, Brouwer & Koopmanschap 2004; van den Berg & Spauwen 2006). The recall method and time-diaries are the two main methods used to measure time devoted to informal care. Time-diaries are regarded as the gold standard for measuring time; however, further research is required to assess the validity of the recall method (van den Berg & Spauwen 2006).

A number of methods for valuing care are considered in the economic evaluation literature. These include the following:

- **Opportunity cost method**—benefits to the carers forgone due to time spent providing informal care. Forgone benefits are estimated using the individual’s market wage.
- **Proxy good/market cost method**—values time spent on informal care at the market price/wage rate of a service that is equivalent.
- **Contingent valuation**—provides a monetary value for caring; a societal and individual valuation of providing care to offset against costs of providing care.
- **Conjoint analysis**—or choice experiment, is based on care givers expressing preferences between specific scenarios involving differing amounts of time spent caring and access to formal care services.
- **Objective burden**—involves assessing the time devoted to caring activities, the severity of care recipient’s illness and the types of care tasks performed.
- **Subjective burden**—relates to assessing the strain or burden experienced by the carer.
- **Health-related quality of life**—quality of life instruments are used to assess the impact of providing care on the carer.
- **Wellbeing**—assessing the value of caring by changes in wellbeing of the carer.

Research using different methods produces variations in results (van den Berg et al. 2006). Further research is needed to assess the merits of each method or a combination of methods to capture the full value of care in economic evaluations (McDaid 2001; van den Berg, Brouwer & Koopmanschap 2004).

## 2.6 Summary

Overall, the research shows that the costs of care are likely to be considerable. A substantial body of research has examined the indirect costs of care in terms of opportunity costs, time costs and health costs. The findings all concur that the provision of informal care negatively impacts on employment, income, financial stress, time pressure and health. Research on the direct costs of care shows that carers may have substantial expenses associated with the provision of informal care, including additional heating and cleaning expenses and costs associated with travel, communication and services. Some carers reported pooling resources and helping the person with disability to cover expenses. Carers also often reduced spending on items such as holidays and leisure activities. This research predominantly relies on subjective methods to investigate the direct costs of care and does not address the issue of how to disaggregate the costs of care from those of disability. The following section examines possible methods to address this issue.



## 3 Estimating the direct costs of care

The primary focus of the literature review and data scoping component of this project is the direct costs of care. As outlined in Section 2, very little research internationally or in Australia has investigated these costs. The research summarised in Section 2 provides some constructive information about particular expenses borne by carers as a result of providing informal care and rough estimates of the direct costs incurred by carers. However, it does not investigate the different types of costs or the complexity of the relationship between the costs of disability and the costs of care. It also does not attempt to disaggregate these costs.

The literature on estimating the direct costs of disability is further developed than literature on the costs of care, and provides a useful theoretical framework for investigating the direct costs of care. The literature refers to four methods for estimating the direct costs of disability, which have implications for identifying and estimating the separate costs of care. As outlined in Section 2 these are: the subjective method—asking people with disability how much they are required to spend; the budget standards approach—where experts define the additional basket of goods/services and costs required to meet the needs of a person with a disability; the comparative approach—where expenditure data is used to compare the consumption of households (for specific items) of different composition; and the standard of living approach—where models are used to estimate the level of incomes required by different types of households to achieve the same standard of living (Saunders 2007; Zaidi & Burchardt 2005).

The following section discusses each method and reviews key studies to consider the appropriateness of each method for estimating the direct costs of care.

### 3.1 Methods to estimate the direct costs of disability

The four main approaches to estimating the extra costs of disability differ in how they measure needs, the extra costs associated with meeting these needs, data required to estimate expenditure and the allocation of resources (Tibble 2005). Despite the link between disability and the provision of informal care the studies do not take into consideration the presence of a carer. This is perhaps for both theoretical and empirical reasons.

#### Subjective approach

The subjective approach is based on asking people with disability how much they are required to spend on particular items associated with their disability (for example, pharmaceuticals, disability equipment, hospital-related expenses, home services/treatment) and, also, how much extra they need to spend on items everyone needs (for example, fuel, food, clothing, laundry, travel). This method also asks people with disability to speculate on how they would spend their money under different circumstances, that is, if they did not have a disability. Estimates of the extra costs are derived from these answers. The advantage of this approach is that people with disability are asked about how much income they require to meet their needs. This is an important difference from other approaches, where estimates are based solely on the level of income of people with disability, which tends to be lower than people without disability (Berthoud 1991; Tibble 2005). The disadvantages of this approach include difficulty in recalling specific costs over a long period of time, differentiating between the extra expenditure associated with disability and items that all household members require, and distinguishing these from different preferences between households and the manner in which households manage their resources (Berthoud 1991; Matthews & Truscott 1990; Tibble 2005).

In summary, this approach could be applied to estimating the extra costs of care. The studies available on the costs of care outlined in Section 2 are loosely based on this approach (Carers UK 2005; Carers UK 2007a; Metlife 1999; TOCC 2005). However, they focus on just one component of this method, which is asking carers what they actually spend, and do not investigate what they require to satisfy their needs. The application of this approach to fully investigate the costs of care requires both components to be investigated.

## Budget standards approach

The budget standards approach asks people to estimate how much they should spend on particular items to meet their needs to achieve an acceptable standard of living (Tibble 2005). An alternative approach is to develop budgets based on normative standards defined by experts. To estimate the costs of disability, budgets are developed for households with and without disability and the differences between these budgets indicates the magnitude of the extra costs.

A budget standard estimates what is needed, in terms of material goods and services, by a particular type of family in order to achieve a particular standard of living in a particular place at a particular time. (Saunders 1998, p. 2)

The Budget Standards Unit (BSU) at the SPRC developed budget standards for different household types at two levels: a modest but adequate standard and a low cost standard. These budgets were based on normative standards and behavioural factors. In some cases, normative standards have official guidelines, for example, nutritional guidelines developed and approved by national authorities. Where no normative data existed, the budgets were based on expert recommendations. However, normative standards also had to reflect population behavioural patterns. The budgets were modified according to behavioural data in order to reflect the day-to-day experiences of people. However, it was noted that behaviour patterns are also influenced by resource constraints. A Steering Committee of experts reviewed the budgets at various stages. Preliminary estimates were also reviewed by focus groups representing different types of households. Finally, the estimates were compared with expenditure data from the 1993–94 HES (Saunders 1998).

The budgets were divided into nine main areas: housing, energy, food, clothing and footwear, household goods and services, health, transport, leisure, and personal care. For items such as food, clothing and footwear, health and personal care, separate budgets for individuals were developed and then aggregated to the household level. For areas such as housing, energy and transport, needs were specified, and items to address those needs were identified at the household level. Decisions about which goods, services and activities to include in the budget were based on the percentage of households in Australia who either owned these items, used the services or undertook the activities (75 per cent for the low cost budget and 50 per cent for the modest but adequate budget). A total of 46 budgets were developed (Saunders 1998).

A deductive (or difference) model was used to estimate the costs of a child in the BSU budget standards. This involved subtracting the budget standard for a couple with no children from that of a couple with a child. Only the extra costs associated with the child, such as the difference between rent for a dwelling for a couple compared to the rent for a dwelling with an extra bedroom, or additional transport costs associated with travelling to child care, were allocated to the child's costs (McHugh 2007).

An alternative approach to estimating the costs of children used in the BSU is the itemised variant model (IVM) or normative approach.

This method separates out all individual and shared items that can be ascribed to a child. Individual child costs (for example, food, and clothing and footwear) are calculated and set aside. Costs are derived for goods and services jointly consumed by all family members, by way of a series of processes: *a capita* estimates, differential calculations, and normative (or subjective) judgements on what items relate to children. (Oldfield 1992, 1993, 1997 as cited in McHugh 2007, p. 69)

In the United Kingdom, Smith et al. (2004), investigated the additional needs and associated costs for a person with a disability using the budget standards approach. The budgets were developed through focus groups discussing a series of case studies. The study found that the major costs associated with disability were equipment required for independent living and higher ongoing expenses for food, clothing, household bills and recreation.

The advantages of the budget standards approach according to Frisch (2001) are:

- It is based on needs rather than expenditure patterns that are influenced by income.
- The overreporting and underreporting issues are minimised.
- Assumptions about need are transparent and can be adjusted to individual circumstances.

- Costs can be accurately evaluated and verified.
- Supports can be tailored to individual needs based on the results.

The disadvantages of the budget standards approach are as follows:

- Budgets for comparison between different households with and without disability have not been adequately developed (Tibble 2005).
- Budgets have to be developed for specific definitions of disability, which limits the ability of the results to be applied more broadly, and budgets for both households with disability and those without should correspond to the same standard of living, otherwise differences will partly reflect differences in the standard of living rather than differences in costs needed to achieve the same standard of living (Saunders 2007).
- This method does not adequately take account of services that are subsidised or provided free of charge (Tibble 2005).

In summary, this approach could be applied to estimating the costs of care, and warrants further investigation. The deductive model and the IVM used in estimating the costs of a child provides another possible method to disaggregate the costs of care from the costs of disability. However, developing individual budget standards for comparable households with persons with disability and situations of informal care provision requires a substantial commitment of time and resources. Variations in the types and levels of care situations and the provision of free or subsidised services would make this difficult.

### **Comparative approach**

The comparative approach compares the expenditure patterns of a sample of people with disability with the spending patterns of people without disability, while controlling for other factors such as income. This approach is based on expenditure diaries, which record expenditure on particular goods and services.

A study in the United Kingdom by Matthews and Truscott (1990) used the comparative approach to estimate the costs of disability. The analysis was based on the Family Expenditure Survey (FES) in the United Kingdom, which contains detailed information on the expenditure of households. A sub-sample of households containing a person with disability was followed up for a year to gain more detailed information on expenditure related to disability. Out of 7,000 households, 63 people with severe restrictions and 150 in moderate restrictions were included in the sub-sample.

The analysis found that households with a person with disability had lower total gross income compared to other households. This difference was greater for those under retirement age. This lower total gross income was due to lower income from earnings, as people with disability tended to work fewer hours. Households with a person with disability had a greater likelihood of receiving a pension. Equivalised net household income was also lower in households with a person with disability than other households (Matthews & Truscott 1990).

The analysis also showed that in households with a person with disability, total spending was lower compared to other households. However, measuring extra costs is not the same as measuring extra spending when income is insufficient to meet the extra costs of disability (Matthews & Truscott 1990). Other factors such as where people live, access to free or subsidised services and preferences also affect expenditure and should be taken into account (Matthews & Truscott 1990).

The results comparing household members with and without disability matched for income and household composition showed that people with disability had additional expenditure on fuel, durables, tobacco and services. Those households that included people with disability tended to spend less than expected on clothing and transport compared with households without a person with disability (Matthews & Truscott 1990).

Another British study by Baldwin (1985) using the comparative approach was based on interviews with 480 families with a child with disability receiving the attendance allowance. These families were compared to a matched sub-sample from the FES. The analysis showed that the extra costs associated with disability were transport, food, durables, tobacco and clothing (Baldwin 1985, cited in Berthoud 1991). Berthoud (1991) notes that additional expenditure on tobacco suggests carers bear some of the additional costs.

The advantages of this approach are that it is more accurate than the subjective or budget standard approaches, because it relies on actual spending rather than speculation about how people with disability would spend if income were not constrained (Matthews & Truscott 1990). This method also provides a mechanism to examine the extra costs, because it is possible to examine differences in the expenditure patterns of households with and without disability and to show where household resources are diverted (Berthoud 1991). However, a major criticism of the comparative approach is that extra expenditure on particular items is compensated for by reduced expenditure on other items, because income is limited (Berthoud 1991; Frisch 2001; Matthews & Truscott 1990; Tibble 2005). Also, it is difficult to determine whether differences in expenditure are a result of difference in needs, available resources, or the way in which the household distribute resources (Saunders 2007).

Frisch (2001) notes that interpretation of the extra costs associated with disability from expenditure surveys is problematic because of the following:

- ▶ The context of infrastructure, social security arrangements, financial supports and preferences of survey respondents influence expenditure patterns.
- ▶ The analysis reflects the income of the respondents rather than their needs.
- ▶ The potential for overreporting and underreporting of expenditure.
- ▶ It ignores time costs and income loss costs, even though these are attributable to disability.

Other difficulties with this approach, outlined by Berthoud (1991) include:

- ▶ Expenditure is measured at the household level rather than the individual level. Increased costs for people with disability may be averaged out by reductions in consumption by other household members.
- ▶ Expenditure is only a reliable indicator of consumption if the purchase price of goods and services is the same for people with and without disability.
- ▶ Income levels and household composition affect expenditure patterns. Large sample sizes are required because goods and services are coded into detailed categories and summarised, which may result in extra spending in one category being averaged out with reduced spending in another (Berthoud 1991).

In summary, the comparative approach could be applied to estimating the direct costs of care. However, time costs and the impact on carers' ability to purchase goods at cheaper rates and reduced income levels as a result of care noted in the literature have to be taken into account (Bittman, Hill & Thomson 2007; Carers UK 2005; Fast et al. 2004; Thomson et al. 2008). A number of existing datasets in Australia could be analysed using this approach. Details of the datasets and the variables required for the analysis are described in Section 3.2.

### **Standard of living approach**

The standard of living approach assumes that people with disability have additional needs and must redirect income to goods and services to meet these needs. As a result, the standard of living of a person with disability on a given income is lower than a person without disability on the same income. This difference in living standards results from the additional costs associated with meeting these needs. In this approach, indicators of the standard of living are used to compare the standard of living of households with and without a person with disability. It is then possible to estimate the extra costs of disability by comparing the incomes of both groups to achieve a given standard of living. The difference between these levels of income is the extra cost of the disability (Berthoud 1991; Tibble 2005).

Previous research has used this method in relation to the additional costs of disability (Saunders 2007; Zaidi & Burchardt 2005). The theory underpinning this method assumes that a household's standard of living is a function of income and needs. It focuses on material wellbeing rather than a broader definition of 'welfare' or 'utility' (Saunders 2007; Zaidi & Burchardt 2005). These studies used responses to questions about the household's standard of living and household income to estimate the additional costs of disability. The standard of living indicator used in this framework must be sensitive to the 'displaced' consumption patterns of people with disability and carers.

Zaidi and Burchardt (2005) based their analysis on data from two UK household surveys. The first was the Disability Follow-Up component of the Family Resources Survey (FRS) conducted in 1996–97. The second data source was Wave 9 of the British Household Panel Survey (BHPS). This survey is conducted annually and contains a nationally representative sample of 25,000 households. The analysis aimed to quantify how income was related to standard of living and how disability reduced standard of living. The indicators of standard of living used in the analysis were chosen so that they rose with overall standard of living and were not just related to income. A range of items were chosen for the analysis so that if a relationship between need and preferences for a particular item for a certain group existed it was less likely to be repeated across all items. The indicators for the analysis were: whether a household had any savings, an index of ownership of consumer durables (including video player, tumble dryer, dishwasher, CD player, access to a motor vehicle, microwave, mobile telephone, washing machine, home computer, satellite TV, central heating, fridge/freezer, telephone), and an assessment of how well the household was managing financially. These indicators were also chosen because they responded to changes in income. The income measure used in the analysis was net of direct taxes and social insurance contributions at the household level. Analysis of before and after-housing costs was also conducted (Zaidi & Burchardt 2005).

The empirical method involves multiple regression analysis estimating the relationship between standard of living, income and disability. Controls for other factors known to cause living standards to vary are also included in the model. The analysis of Zaidi and Burchardt found there were significant costs associated with disability and these increased with the severity of disability (Zaidi & Burchardt 2005).

A study by Saunders (2007), based on the standard of living approach developed by Zaidi and Burchardt (2005) and applied to Australia, used the 1998–99 HES to estimate the costs of disability. The 1998–99 HES survey contains information on whether household members have a disability or long-term health condition and the severity of the associated restriction. In the analysis, household income was adjusted for need using the modified Organisation for Economic Co-Operation and Development (OECD) equivalence scale. As outlined above, Zaidi and Burchardt (2005) used three variables to measure standard of living. The only comparable variable available in the HES was the subjective assessment of the household's financial situation. Ordered logit regression models were used in the analysis. Explanatory variables included in the model were: equivalised income, presence of disability, and a range of other variables that controlled for differences in household characteristic (Saunders 2007). In addition, the severity of the restriction was also examined because the inclusion of people with low levels of disability may lead to an overestimation of the costs of disability for people with low levels of disability if they were to be allocated the average cost (Saunders 2007).

The advantage of the standard of living approach is that it uses a measure of standard of living to estimate the costs of disability that is not based solely on income, because households with a person with a disability generally have lower incomes than households without disability, and spending and costs are influenced by income. However, the disadvantages of this approach are that: the degree to which disability-related needs are met or left unmet are not calculated (Tibble 2005); and, if a household with a disability is given the additional income needed to achieve a certain standard of living, their disability-related needs may still not be met because income may be diverted to other needs (Tibble 2005).

It is possible to apply this method to estimating the direct costs of care; however, a number of issues need to be addressed. Theoretically, the effect of the presence of an informal carer on changes in consumption and the household's living standard is not clear. On the one hand, the presence of the informal carer may substitute for formal care provision, and hence, lower the direct formal costs of disability and permit members of the household to spend money on usual consumption items and perceive that it is better off financially. However, if the carer would have otherwise been in paid employment, and the aggregate household income is lower due to the time spent in informal caring, the household may perceive itself to be worse off. These contradictory effects imply that the 'cost of caring' estimated by this method could be ambiguous.

Nevertheless, the method deployed in the above studies on the cost of disability could possibly be extended to attempt to disaggregate the relative share of additional costs attributable to disability and to providing care itself. As with the comparative approach, several existing databases in Australia contain some of the necessary variables for this analysis. The following section provides an assessment of the usefulness of, and gaps in, existing data sources for the analysis of the costs borne by carers as a result of their informal caring.

## 3.2 Data scoping

The subjective and budget standards methods outlined in the previous section require specialised surveys or studies to gather the appropriate data to estimate the costs of care. However, it may be feasible to employ the comparative approach and the standard of living approach to estimate the costs of care with datasets that are currently available. The following section outlines the data required for these latter approaches and the variables available to conduct such analyses in national datasets in Australia.

### Comparative approach

The comparative approach compares the expenditures of people with and without disability on a range of items. Assuming that the provision of subsidised goods and services is fixed, it estimates differences in the way that people spend their current income. The approach estimates separate OLS (Ordinary Least Squares) regression models predicting the amount spent on each item of household expenditure. The unit of analysis in this method is households. One approach to disaggregating the costs of care from the costs of disability would be to estimate a model that could compare households, without a person with disability or carer, with households with a person with a disability and no carer, with households with a carer but not a person with a disability (ex-resident carers) and households with a carer and a disability (co-resident carer).

A large sample size is required for the comparative approach in order to identify what may be small changes in expenditure patterns. The key variables needed are:

- detailed expenditure diaries and total household expenditure
- equivalised household income (income and household composition)
- source of income
- employment status
- disability (different models for severity of disability and type of disability)
- carer (co-resident or ex-resident, main carer or other carer).

The main data source available in Australia to estimate the costs of disability and care is the HES, in which respondents fill in a detailed diary about expenditure over a period of two weeks for some expenditure items, and then other information is based on recall. The most recent HES (2003–04) does not have any variables indicating the presence of disability or carer in a household, except for whether the person is a recipient of carer payment and disability payment. Thus, costs could be estimated for this subpopulation, but no data on severity or type of disability would be present. The sample size of households containing this group would also be fairly small. A comparative analysis would be possible if future HES surveys contained detailed carer and disability data.

The HILDA survey collects information on disability in every wave, and has collected information on caring in every wave since Wave 5, and has also collected expenditure information in the self-completion questionnaire every wave since Wave 5. Information about difficulties caused by disability was collected by HILDA in Waves 4 and 9. The expenditure data in HILDA is less detailed than in the HES and collected on the self-completion questionnaires rather than in a personal interview, as in the HES. Questions about expenditure are also asked as recall questions for a weekly, monthly or annual period rather than records of actual expenditure over a two-week period.

Table 1 indicates which variables are available in each dataset and variables that would be needed to conduct a comparative analysis of the costs of care. One other survey with detailed data on care and disability is the SDAC; however, it has no data on expenditure and limited data on income. It is possible that a sub-sample of this survey could be selected for a follow-up survey in order to complete expenditure diaries. A more detailed description of the variables in the dataset is in Table A1 (Appendix A).

**Table 1: Comparative approach: relevant variables in existing datasets**

<b>Variable</b>	<b>Household Expenditure Survey 2003–04</b>	<b>Household, Income and Labour Dynamics in Australia survey</b>
Number of people with a disability in household	No	Yes
Whether person has a disability	Limited	Yes
Severity of disability	No	Limited
Type of disability	No	Yes
Number of carers in household	No	Yes
Whether a carer	Limited	Limited
Whether a primary carer or has main responsibility for care	No	Yes
Whether caring for someone in their household or someone elsewhere	No	Yes
Relationship to care recipient	No	Yes
Household composition	Yes	Yes
Number of adults in household	Yes	Yes
Number of children in household	Yes	Yes
Age of children in household	Yes	Yes
Employment status	Yes	Yes
Hours worked	Yes	Yes
Household income (gross)	Yes	Yes
Household income (disposable)	Yes	Yes
Equivalentised income	Yes	Yes
Main source of household income	Yes	Yes
Whether receiving government pension or benefit	Yes	Yes
Housing costs	Yes	Yes
Food	Yes	Yes
Fuel	Yes	Yes
Alcohol	Yes	Yes
Clothing	Yes	Yes
Durables	Yes	Yes
Transport	Yes	Yes
Fees for support services	Yes	No
Medicines	Yes	Yes
Health services	Yes	Yes
Laundry	No	No
Telephone	Yes	Yes
Leisure	Yes	Yes
Domestic services	Yes	No
Total weekly spending	Yes	Yes
Total health care costs	Yes	Yes
Use of formal services for person with disability	No	No
Number of formal services used	No	No
Costs of formal services	No	No

### Standard of living approach

The standard of living approach uses multivariate analysis to estimate differences in standard of living outcomes for households with a person with disability and without, after controlling for income and other factors. As indicated above for the comparative method, it may be possible to disaggregate the costs of care from the costs of disability by comparing households with and without persons with disability and/or carers. The variables identifying the number of carers in the household and the number of people with a disability in the household and severity of disability are included to estimate the difference in standard of living outcomes for these characteristics. The ratio of the coefficients on disability and caring, to coefficient on income provide the basis for calculating relative need.

The unit of analysis in this approach is most commonly also the household, rather than the individual. Zaidi and Burchardt (2005) argue that the indicator of standard of living should be measured at the same unit of analysis as the income variable used in the analysis. Income should be measured at the household level in line with assumptions about shared resources and equivalent standards of living for individuals within households. Zaidi and Burchardt (2005) indicate that the standard of living indicator used in such an analysis must not be 'a restatement of income', nor systematically related to disability or caring. In addition, it should be measured over the same period of time as the income variable used in the analysis. For this analysis to be effective, the standard of living indicator should be elastic; that is, variations in resources must relate to changes in the indicator, preferably over the entire income distribution.

As Zaidi and Burchardt (2005) note, the income variables used in the analysis should represent available resources: thus, disposable income should be used. An issue needing to be addressed is whether before-housing or after-housing costs income is used. If housing costs are considered to be at the discretion of the household then after-housing costs income should probably be used. If not, then before-housing income should be used. The effect of household composition on standard of living, given income, needs to be controlled for, either by using equalised disposable income or by using disposable income and adding the number of children and adults into the model. The relationship between income and the standard of living indicator needs to be tested empirically: studies have used log income (Zaidi & Burchardt 2005), income minus income squared (Berthoud, Lakey & McKay 1993), and log-linear (Saunders 2007).

The disability variables used in the analysis should include the severity of disability. The carer variable should indicate degree of caring responsibility (main carer, other carer and time spent caring) and whether a co-resident or ex-resident carer. Other control variables used in the analysis should be those that have an effect on the needs of the household (Zaidi & Burchardt 2005). Each variable should be included on the basis of a clear hypothesis on the importance of the variable 'in the relationship between standard of living, income, disability' and caring (Zaidi & Burchardt 2003, p. 15).

The variables required for this analysis are:

- ▶ a standard of living indicator at the household level (for example, subjective perceptions of 'prosperity', ownership of consumer durables, self-reported data on household saving habits, financial stress indicators)
- ▶ household income (before and after-housing costs)
- ▶ household composition (partnered status, number and age of children)
- ▶ disability (different models for severity of disability and type of disability)
- ▶ carer (co-resident or ex-resident, main carer or other carer)
- ▶ sex
- ▶ age
- ▶ education
- ▶ housing tenure
- ▶ region.

A number of nationally representative household surveys contain some of these variables. These include the HES, the SDAC and the HILDA survey. In addition, given the higher prevalence of care and disability in Indigenous communities, a potential source for estimating the costs of disability and care in Indigenous communities is the National Aboriginal and Torres Strait Islander Social Survey (NATSISS). The variables needed for the analysis are outlined in Table 2 below (more details are in Table A2 in the Appendix).

Table 2 shows that, currently, the best data for a standard of living approach is the HILDA survey. The main issue with the HILDA survey with regard to replicating Zaidi and Burchardt's (2005) analysis is that standard of living variables in this survey are collected from individuals and not with respect to the entire household, whereas they should be measured at the same level as the income variables. Solutions to this dilemma would be to average out the individual responses to the standard of living question or consider a method that would use individuals rather than the household as the unit of analysis. The HES currently lacks variables on disability and caring, which if included in the future would make HES a useful data source for this approach to estimating direct costs of care. The SDAC has no standard of living variables at this stage. Inclusion of these variables in future SDAC surveys would enable the rich data on disability and carers to be utilised for this method. It would be important to consider the costs of disability and caring for Indigenous Australians also. The NATSISS currently collects data on standard of living variables and, if data on caring and disability in the whole household were to be collected, as well as more comprehensive income variables, this survey would be a very useful resource for examining the costs borne by carers resulting from their informal caring for Indigenous Australians.

**Table 2: Standard of living approach: relevant variables in national datasets**

Variable	Household Expenditure Survey (HES) 2003–04	Survey of Disability, Ageing and Carers (SDAC) 2003	Household, Income and Labour Dynamics in Australia (HILDA) survey	National Aboriginal and Torres Strait Islander Social Survey (NATSISS) 2002
Number of people with a disability in household	No	Yes	Yes	No
Whether person has a disability	Limited	Yes	Yes	Yes
Severity of disability	No	Yes	Limited	Yes
Type of disability	No	Yes	Yes	Yes
Number of carers in the household	No	Yes	Yes	No
Whether a carer	Limited	Yes	Limited	No
Whether a primary carer or has main responsibility for care	No	Yes	Yes	No
Whether caring for someone in their household or someone elsewhere	No	Yes	Yes	No
Relationship to care recipient	No	Yes	Yes	No
Age	Yes	Yes	Yes	Yes
Sex	Yes	Yes	Yes	Yes
Household composition	Yes	Yes	Yes	Yes
Number of adults in household	Yes	Yes	Yes	Yes
Number of children in household	Yes	Yes	Yes	Yes
Age of children in household	Yes	Yes	Yes	Yes
Household income (gross)	Yes	Limited	Yes	Yes, topcoded
Household income (disposable)	Yes	Limited	Yes	No
Equivalised income	Yes	Limited	Yes	No
Main source of household income	Yes	Yes	Yes	Yes
Whether receiving government pension or benefit	Yes	Yes	Yes	Yes
Education	Yes	Yes	Yes	Yes
Housing tenure	Yes	Yes	Yes	Yes
Housing costs	Yes	No	Yes	Yes
Financial stress indicators	Yes	No	Yes	Yes
Prosperity indicators	No	No	Yes	No
Level of household savings	Yes	No	Yes	No
Location of household	Yes	Yes	No	Yes
Whether uses formal services to support person with disability	No	Yes	No	No
Number of formal services used	No	Yes	No	No

### 3.3 Summary

This section reviews four methods used to estimate the direct costs of disability and the appropriateness of applying these methods to examine the costs of care. To date few studies have examined direct costs of care. The existing research, although it provides some basic data on these costs, fails to address the complexity of the relationship between the extra costs of disability and those related to care.

The four methods reviewed include:

- ▶ **the subjective approach**—asking people how much they are required to spend to meet their needs
- ▶ **the budget standards approach**—estimating what people need to achieve a particular standard of living
- ▶ **the comparative approach**—using expenditure data to compare the consumption of households
- ▶ **the standard of living approach**—estimating the difference in income required by different types of household to achieve a similar standard of living.

Each approach has advantages and disadvantages. One advantage of the subjective and the budget standards approaches is that they ask people or develop expert assessments of what carers and people with disability need. However, to apply these methods to the cost of care would require separate research projects to collect the specific information necessary for the analysis.

In contrast, the comparative approach and the standard of living approach, in theory, can be conducted using existing national datasets. However, the data scoping reveals several major gaps. The most promising datasets include:

- ▶ HES, although information on informal care and disability would be required
- ▶ HILDA, which contains good information on informal care and disability but limited data on expenditure and financial stress at the household level. This in turn raises an issue regarding replicating previous analyses but may also be a strength of a modified approach
- ▶ SDAC, which has limited information on income and no information on expenditure and standard of living.

So, additional variables would be required to maximise the potential of these existing data sources to produce a more robust analysis of the extra costs of care.



## 4 Living standards of carers

### 4.1 Introduction

The analysis in this section focuses on four measures of living standards for carers and compares their situation with non-carers. The four measures are:

- low income
- low income given housing costs
- subjective perceptions of prosperity
- financial stress.

Previous research in Australia has examined the rates of poverty and financial stress of many population subgroups. However, with the exception of some specialised surveys (Cummins et al. 2007; Edwards et al. 2008) and one recent study of care and employment (Thomson et al. 2008), few studies have focused on aspects of living standards of informal carers. The inclusion of a carer question in Wave 5 of the HILDA survey provides a unique opportunity to examine the economic circumstances of a nationally representative sample of informal carers. The analysis in this section aims to extend Australian research, by using the HILDA data to examine the effect of housing costs on income poverty rates, and carers' own subjective perceptions of their wellbeing. The analysis will also identify which carers are more likely to be poor with respect to the four aspects of economic disadvantage.

This section of the report first outlines the four different concepts and measures of living standards used in the analysis. It then briefly reviews the extant research on carers, poverty and financial stress. The study then describes the HILDA data and methods used. The following subsections report the findings regarding the levels of disadvantage experienced by carers compared to non-carers on all measures, the groups of carers who are more likely to be poor, and whether caring increases the risk of economic disadvantage, when we control for other factors associated with economic disadvantage.

### 4.2 Four measures of economic disadvantage

There are many approaches to conceptualising and measuring living standards and poverty. Concepts of poverty refer to the idea or meaning of poverty encapsulated in a particular approach, whereas measures refer to the specific way in which a concept of poverty is operationalised (Lister 2004). This study draws upon four such approaches: (1) and (2) income poverty—calculated (1) before and (2) after-housing costs; (3) subjective poverty; and (4) financial stress. These approaches measure different concepts of poverty. Income poverty approaches identify those with low incomes relative to others in their community, subjective poverty measures provide insight into how people themselves perceive their circumstances, and financial stress measures offer the opportunity to gauge how people manage on their incomes, by assessing financial or living standard outcomes. Studies have shown that groups disadvantaged on one dimension may not be disadvantaged on others and correlations between the dimensions are relatively low (Bradshaw & Finch 2003; Marks 2007). While income poverty has historically been the most commonly used measure of economic disadvantage, many studies now use other indicators. The alternate indicators may be regarded as assessing different dimensions of poverty (for example, Bradshaw & Finch 2003; Saunders, Naidoo & Griffiths 2007) or used to supplement income measures when defining the poor (for example, Saunders, Hill & Bradbury 2008; Whelan & Maître 2007). Each concept is discussed briefly below and the measures used in this study to operationalise the concepts are outlined.

#### **Income poverty—before and after-housing costs**

Income poverty measures define the poor as those whose income falls below a particular standard—defined either in relation to specified goods (as in an absolute measure) or as a proportion of average incomes in the community (a relative income measure). Conceptually, income poverty measures describe a lack of capacity

‘to meet [minimum] needs within the behavioural constraints (for example, expenditure patterns) typical within a community’ (Sen 1981, p. 28). Relative income measures are a useful indicator of those whose incomes are low in comparison to others in their community and who may lack such capacity to consume. However, as Sen (1981, 1985a, 1985b) has pointed out, an income poverty measure cannot take into account differences in prices associated with residing in different locations or the different needs of specific individuals, such as those with disability or caring responsibilities. Thus, the disadvantage of groups with needs that are higher than, or different to, the average may not be fully encapsulated within this measure. Alternatively, the disadvantage of some groups may be overemphasised, as income poverty lines do not account for other resources, including savings, accumulated wealth, and services provided by governments, which may contribute to a household’s standard of living (Harmer 2008).

This analysis uses a standard relative income poverty measure—50 per cent of median equivalised disposable annual household income. Annual household disposable income is adjusted for household size using an equivalence scale. This equivalence scale (‘modified OECD’) allocates a weight of 1 for the first adult, 0.5 for each subsequent adult over 15 years, and 0.3 for each child under 15 years. The median income is established in each year of the data and the poverty line is set at 50 per cent of the median income. Individuals living in households with income below this line are classified as poor on the before-housing income poverty measure.

One major variation in costs that can be taken into account in an income poverty measure, given appropriate data, is housing. Individuals living in homes that are owned outright will have lower housing costs and greater discretionary income for other consumption than those who rent or who are buying their home. Housing costs are calculated in this analysis using data on rent and first and second mortgages. After-housing costs income is calculated by subtracting annual housing costs (repayments for first and second mortgages for purchasers and rental costs for renters) from annual disposable income and adjusting for housing size using the same equivalence scale as above. The after-housing costs income poverty line is set at 50 per cent of this median equivalised income. Individuals classified as poor on this measure are more likely to face high housing costs.

### **Subjective poverty**

Subjective poverty refers to whether individuals perceive themselves to be poor, rather than having ‘experts’ define their situation. There are a number of approaches to defining subjective poverty (Pantazis, Gordon & Levitas 2006). Some approaches establish an income poverty line by asking how much money people think they would need to avoid poverty and by asking people how their income compares with this minimum (Bradshaw & Finch 2003; Pantazis, Gordon & Levitas 2006). In the HILDA data, subjective poverty is able to be measured by a response to a general question about prosperity in the self-completion questionnaire:

Given your current needs and financial responsibilities, would you say that you and your family are ...

- ▶ prosperous
- ▶ very comfortable
- ▶ reasonably comfortable
- ▶ just getting along
- ▶ poor, or
- ▶ very poor?

Following the approach used by Marks (2007), individuals are classified in subjective poverty if they respond that they are poor or very poor on these questions. The subjective approach permits the perceptions of the individual to be heard and provides an alternative perspective on poverty. However, these measures also have limitations because they are based on opinions that may vary due to changes in individual financial circumstances, expectations and experiences (Marks 2007).

### **Financial stress**

Financial stress measures are one of a number of approaches to measuring disadvantage that adopt a more direct approach to assessing living standards. These measures focus on living standard outcomes, rather than resources. Other approaches to assessing disadvantage in this category are deprivation indicators, which identify ‘an enforced lack of socially perceived necessities’ (Mack & Lansley 1985, p. 39; Saunders, Naidoo

& Griffiths 2007), and social exclusion measures (Saunders, Naidoo & Griffiths 2007). Financial stress indicators measure cashflow issues and financial hardship by asking respondents whether they have experienced particular financial problems (for example, unable to pay bills) or gone without essentials (for example, meals or heating) due to a lack of money. In Australia, financial stress indicators have been included in a number of ABS surveys, including the HES and the General Social Survey. Previous research has identified groups who experience disadvantage on these measures (Bray 2001; McColl, Pietsch & Gatenby 2001).

In the HILDA data, in the self-completion questionnaire, seven questions refer to cashflow problems and lack of essentials. These are in the format:

Since January (year) did any of the following happen to you **because of a shortage of money?**

- ▶ Could not pay electricity, gas or telephone bills on time
- ▶ Could not pay the mortgage or rent on time
- ▶ Pawned or sold something
- ▶ Went without meals
- ▶ Was unable to heat home
- ▶ Asked for financial help from friends or family
- ▶ Asked for help from welfare organisations.

In this analysis, respondents who indicated that they experienced two or more of these seven indicators were classified as experiencing financial stress.

While financial stress indicators are more direct measures of living standard outcomes and may be able to identify groups who have additional costs and needs that are not accounted for in an income poverty measure, they also have limitations. Responses to these questions are based on an individual's expectations and expenditure priorities, which may adapt to changing circumstances and differ from the list of items in any survey. Previous research has indicated that some demographic groups may be more prone to experiencing financial stress (Bray 2001; La Cava & Simon 2003; Marks 2007; McColl, Pietsch & Gatenby 2001). Consistent findings in these studies have been that younger people, families with more children, lone parents, being unemployed and not owning one's own home are associated with higher self-reported financial stress.

### 4.3 Carers, economic disadvantage and poverty

There are a number of reasons why carers might be expected to experience greater economic disadvantage than other population groups. An individual who provides informal care contributes time, effort and resources to their caring role. Time contributions for care may lessen the time available for paid work, leading to lower income from employment. Australian and UK research has shown overall that carers have lower employment rates and lower incomes than non-carers (for example, Bittman, Hill & Thomson 2007; McKay & Atkinson 2007). Recent modelling by NATSEM suggests that female primary carers of a child or a partner with a disability incur substantial lifetime earnings penalties, including reduced superannuation contributions (Nepal et al. 2008). Research in the United Kingdom and the United States has also shown that parents of a child with disability have lower employment rates than parents of children without disability (McKay & Atkinson 2007; Parish et al. 2008).

If carers contribute resources to their caring role, and the caring role generates higher needs for the carer, the same level of income may not translate into the same standard of living for carers and non-carers. Australian research has consistently shown that carers are more likely than the general population to experience economic disadvantage and financial stress than non-carers. Edwards et al. (2008) examined four measures of financial hardship for carers in receipt of income support: inability to pay electricity or phone bills on time; inability to pay mortgage or rent on time; pawned or sold something; and asked for financial help from family or friends. They compared the incidence of financial stress on each indicator for carers on income support and the general population. They found that these carers had rates of financial stress that were approximately twice that of the general population.

Cummins et al. (2007) examined the wellbeing of carers contacted through carers associations on a number of domains and found that these carers, particularly the female carers, scored lower on wellbeing overall compared with other groups. They found that carers scored lower on a number of items relating to satisfaction

with financial circumstances, including ability to save money, savings and investments, financial security and perceptions that their financial situation was improving. Carers were almost twice as likely as the general population to state that they worried about their income covering their expenses. Cummins et al. (2007) found that carers wellbeing was lower than the general population at every income level and suggest that this is due to extra costs of caring. Reporting on this study, Hughes noted that 'certainty in relation to income and relationships' has a strong effect on a person's sense of wellbeing and that carers were a vulnerable population with regards to these two factors (2007, p. 32).

Thomson et al. (2008) used the first four waves of the HILDA survey to examine income poverty and financial stress for a random sample of carers with different levels of care responsibilities and participation in paid employment. They found that employees were less likely to be in income poverty than non-employees irrespective of levels of care provided. Just over one-third of carers (35 per cent) who were caring for 20 hours a week or more and not in paid employment were in income poverty. This figure compared with 9 per cent of such carers who were in employment. However, multivariate analysis showed that caring did not exert an independent effect on the probability of being in income poverty after factors such as employment, education, and own disability status were accounted for.

Thomson et al. (2008) considered the financial stress of carers, using the seven self-reported financial stress indicators in the HILDA data listed above and a question about the ability to raise \$2,000 in an emergency. The authors found that over 50 per cent of carers with high levels of care responsibilities (20 hours a week or more) and who were not in employment reported at least one indicator of financial stress, and one-quarter of this group reported three or more of the indicators. Multivariate analysis of multiple financial stress (two or more of the eight indicators) revealed that, for women, all levels of caring, and high levels of caring for men, increased the likelihood of experiencing financial stress. This finding held even when controlling for age, education, family composition, employment status, the carer's own disability status, CALD status, home ownership and household income levels. The authors suggest that this finding may be indicative of the additional costs incurred by carers, which are not fully captured within an income poverty measure. Analysis of the effect of the duration of care on financial stress suggested that the first year of care is one in which carers are more likely to experience financial stress. Thus, Thomson et al. (2008) hypothesised that it is the adjustments that are required to be made at the onset of care responsibilities that impose the greatest financial strain on carers. This finding accords with results from a survey conducted by Carers UK (2007a), which noted that financial difficulties were often experienced in the first year of caring.

Research in the United Kingdom and Ireland also highlights the financial strains of informal caring. UK research finds that child disability was a key factor associated with lower income among couples and that caring was associated with a greater negative impact on incomes than disability among couples (McKay & Atkinson 2007, p. 46). This report found that, controlling for participation in paid work, carers were more likely to experience most indicators of deprivation than non-carers (McKay & Atkinson 2007, pp. 50–51). Another UK study found that around one-third of carers had been in debt due to caring, struggled to pay essential bills or could not afford house repairs (Carers UK 2007a). This study also found that nearly three-quarters of carers had 'cut back' on holidays and leisure activities, and over one-half had 'cut back' on buying clothes and going out with friends.

A study of poverty and social exclusion in Ireland found that carers had higher poverty rates than non-carers on relative income measures, a subjective poverty measure and deprivation measures (Scullion & Hillyard 2005). They also found that carers were more likely than non-carers to report poor housing, problems in their neighbourhood, and that they were economising on food and clothing. Carers who were in income poverty were more likely than non-carers in income poverty to have economising behaviours with respect to use of utilities, visits to family and friends, postponing visits to dentists, and cutting back on food, medicines or heating.

### **Which carers are more likely to be financially disadvantaged?**

Australian research (Thomson et al. 2008) has shown that carers with the highest risk of income poverty were males and females who were not employed and without a partner. Female carers who had lower levels of education, disability themselves or were born in a non-English speaking country also had a higher risk of income poverty than other carers. Factors that increased the risk of financial stress for male and female carers were being younger, not employed full-time, with disability, and not a home owner. This study found that, among male carers, caring for 20 hours or more was associated with a higher risk of financial stress. Female carers without a partner also had an increased risk of financial stress.

Similar findings are reported in UK research, which indicates that carers caring for 20 or more hours a week, who are in poor health themselves, have lower levels of education, are not in paid employment, or caring for a child under 19 years were more likely to report that they were struggling financially than other carers (Yeandle et al. 2007). Carers UK found that working-age carers (particularly carers aged in their 30s and 40s) and carers of a child with disability were more likely than other carers to say that they were experiencing financial hardship and had given up or were cutting back on items due to their caring role (Carers UK 2007a).

This study uses the two waves of the HILDA survey (2005 and 2006), which provide new data on a random sample of carers and non-carers to address a number of questions:

- ▶ Overall do carers have higher rates of before-housing income poverty, after-housing income poverty, subjective poverty and financial stress than non-carers?
- ▶ Are carers more likely than non-carers to be persistently poor?
- ▶ Which groups of carers—distinguished by care characteristics—are poor?
- ▶ Does caring have an independent effect on the measures of poverty, after we control for other factors?
- ▶ What aspects of the carers' care situation and sociodemographics are associated with each of the poverty measures?
- ▶ Which sociodemographic groups of carers have high poverty rates compared with non-carers?
- ▶ Which sociodemographic factors are associated with poverty for carers?

## 4.4 Data and method

The analysis uses two waves (5 and 6) of the HILDA survey. The HILDA survey is a nationally representative panel survey, which commenced in 2001 with a sample of 7,862 households (13,969 people) (Watson & Wooden 2002). The reference population for the Wave 1 sample consisted of occupants of private dwellings in Australia, excluding people living in remote and sparsely populated areas and some other categories (see Watson & Wooden 2002, p. 3). Technical details about the survey design and other matters are available in Watson (2008). Data for the HILDA survey is collected through face-to-face interviews and on a self-completed questionnaire given to all individuals in selected households aged 15 years and over. The HILDA survey aims to collect information about employment, income and housing, each year, for individuals and households. In addition, the HILDA survey gathers a comprehensive array of data on employment, education and family formation histories, sociodemographic data, self-rated health, and individual responses to questions about prosperity and financial stress. Commencing in 2005 (Wave 5 of the data), the HILDA survey included questions on the provision of informal care in the personal interviews for all respondents aged 15 years and over. These questions identify the main carer and other carers of people residing within the household and elsewhere. All waves of the data include additional questions that can be used to identify other carers, as detailed below.

HILDA is thus one of the few datasets in Australia that currently has a carer variable and a range of indicators of living standards. This combination of variables makes HILDA a useful source of data for examining different dimensions of poverty for carers. In addition, Wave 6 of the HILDA has data on wealth, debts and assets, which permit consideration of the extent of resources other than income that households and individuals possess and their relationship to living standards. As a longitudinal survey, HILDA also permits the analysis of whether individuals have lower living standards for extended periods of time.

### Definitions of carers in the data

The HILDA survey asks all persons aged 15 and over:

- ▶ Is there anyone in this household [or living elsewhere] who has a long-term health condition, who is elderly or who has a disability, and for who you care or help on an ongoing basis with any of the types of activities listed on SHOWCARD K7? [Showcard K7 consists of activities grouped under the headings: self care, communication and mobility].
- ▶ In addition respondents are asked: who they provide care for and whether they are the main carer of the person (that is, the person who provides most of their care).

Individuals who responded positively to these questions are classified in this analysis as ‘self-identified carers’. Within this category, they are also distinguished by whether they provide care for a person within the household (co-resident carer) or for a person living elsewhere (ex-resident carer) and whether they are the main carer of a person (co-resident or ex-resident main carer) or not (co-resident or ex-resident carer). In some of the analyses, the self-identified carers are also distinguished by their relationship to the care recipient.

In addition to the self-identified carers, additional individuals have been classified as ‘other carers’ for this analysis:

- ▶ Individuals who indicated that they received Carer Payment or Carer Allowance were classified as ‘receiving benefit for care’.
- ▶ Individuals who indicated that they were working part time (rather than full time) due to caring responsibilities for another adult, or that their main activity, since last working, is caring for a person with disability or illness, were classified as ‘work-affected carers’.
- ▶ Individuals who reported in the time-use questions in the self-completion questionnaire that they spent time caring for an adult have been classified as ‘spending time caring for an adult’.

Table 3 shows the sample sizes and weighted proportion of carers in each of the categories for Waves 5 and 6 of the HILDA data. Around 45 per cent of self-identified carers in each year were co-resident main carers. A further 13 to 14 per cent cared for someone in their home but shared the care with others. Around 10 per cent provided the main support to someone living outside their home, whereas a further 31 per cent provided some care, but not the main support to an ex-resident. Among the other carers, 12 to 13 per cent were receiving Carer Payment or Carer Allowance, 2 to 3 per cent were work-affected carers and, approximately 85 per cent were individuals who had indicated that they had spent time caring for an adult. In the latter group the majority provide fewer than five hours a week of care. Individuals caring for fewer than five hours a week have been excluded from the final sample of ‘carers’ in this analysis. A description of the demographic characteristics for the samples is in the Appendix (Table A3 and Table A4).

**Table 3: Carers identified in the HILDA data**

	Wave 5		Wave 6	
	Sample size	Weighted %	Sample size	Weighted %
Self-identified carers				
Co-resident main carer	375	43.6	422	47.0
Co-resident other carer	109	13.6	111	13.3
Ex-resident main carer	122	12.0	103	9.1
Ex-resident other carer	315	30.8	343	30.5
Total self-identified carers	921	100.0	979	100.0
Other carers				
Receiving benefit for care	59	13.0	58	12.0
Work-affected carers	16	3.1	12	1.7
Spent time caring for an adult				
Less than five hours	262	52.5	270	53.3
Five or more hours	147	31.5	158	32.6
Total	409		428	
Total other carers	484	100.0	498	100.0
<b>Total carers</b>	<b>1,405</b>		<b>1,477</b>	
<b>Carer sample for analysis<sup>(a)</sup></b>	<b>1,143</b>		<b>1,207</b>	

(a) Consists of all self-identified carers, carers receiving benefit or work-affected carers and those caring for five or more hours a week.  
 Note: Due to rounding, percentages may not add to 100 per cent.  
 Source: HILDA release 6.0, Waves 5 and 6.

The unit of analysis in this study is the individual, because it is the individual who is identified as a carer and who responds to the questions on subjective poverty and financial stress. Assuming sharing of resources within households and the equivalent standard of living for individuals within households, poverty rates are calculated for households and all individuals within the household are allocated that poverty status.

The analysis examines the poverty levels on each of the measures and identifies which groups of carers are classified as poor on each measure. In addition, multivariate analysis is undertaken to examine whether the provision of informal care is an independent predictor of poverty on each of the measures, when other factors influencing living standard outcomes are controlled for. Multivariate analysis of the carer sample is also undertaken to identify factors associated with higher risks of poverty for carers. As the dependent variables are all dichotomous outcomes, logistic regression is used for the analysis. Definitions of variables are provided in Appendix A.

Approximately 10 per cent of the carer and non-carer groups had missing values for the subjective poverty and financial stress questions. These individuals have been excluded from the total when estimating the proportion of carers who experience subjective poverty and financial stress. This approach assumes that the missing data is 'missing completely at random' and, thus, proportionately distributed between those who report stress and those who do not for both carers and non-carers.

The HILDA survey is a complex stratified and clustered survey design. The analysis uses the strata, cluster and cross-sectional and longitudinal person level weights to estimate poverty rates and to weight the logistic regressions.

## 4.5 Income poverty, subjective poverty, and financial stress for carers and non-carers

### Means and distributions

#### *Incomes, housing costs, assets, debts and wealth*

Tables 4 and 5 report the means for the income, housing costs, assets, debts and wealth variables for non-carers and carers in Waves 5 and 6 of the HILDA data. The means for all carers and the subset of self-identified carers are reported. In both 2005 and 2006, all carers and self-identified carers had lower gross, disposable and equivalised incomes before-housing costs than non-carers. Although carers had lower average housing costs than non-carers, they also had lower average equivalised incomes, after-housing costs were subtracted from their disposable income. Wave 6 data provides additional information on assets, debts and wealth (which is simply assets minus debts). On average, carers had higher levels of assets and lower levels of debt than non-carers, which led to higher levels of wealth for carers. Given that carers are likely to be older than non-carers, this finding is not surprising.

**Table 4: Means for income, housing costs, assets, debts and wealth variables in HILDA Wave 5 (2005) by carer status**

	Non-carers	Carers	Self-identified carers
Annual gross household income (\$)	80,866 <sup>(a)</sup>	69,019 <sup>(a)</sup>	71,880
Annual disposable household income (before-housing costs) (\$)	64,989 <sup>(a)</sup>	57,428 <sup>(a)</sup>	59,404
Annual disposable household income (after-housing costs) (\$)	56,482 <sup>(a)</sup>	51,141 <sup>(a)</sup>	52,919
Equivalised annual disposable household income (before-housing costs) (\$)	34,644 <sup>(a)</sup>	30,408 <sup>(a)</sup>	31,482
Equivalised annual disposable income (after-housing costs) (\$)	29,935 <sup>(a)</sup>	27,021 <sup>(a)</sup>	27,940
Housing costs (\$)	8,507 <sup>(a)</sup>	6,286 <sup>(a)</sup>	6,485
<b>Sample size</b>	<b>11,554</b>	<b>1,143</b>	<b>915</b>

(a) Denotes significant difference between carers and non-carers  $t$ -test  $p < 0.05$ .

Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Wave 5.

**Table 5: Means for income, housing costs, assets, debts and wealth variables in HILDA Wave 6 (2006) by carer status**

	Non-carers	Carers	Self-identified carers
Annual gross household income (\$)	87,763 <sup>(a)</sup>	72,534 <sup>(a)</sup>	73,397
Annual disposable household income (before-housing costs) (\$)	71,064 <sup>(a)</sup>	60,870 <sup>(a)</sup>	61,611
Annual disposable household income (after-housing costs) (\$)	61,457 <sup>(a)</sup>	54,196 <sup>(a)</sup>	54,896
Equivalised annual disposable household income (before-housing costs) (\$)	37,787 <sup>(a)</sup>	32,371 <sup>(a)</sup>	32,666
Equivalised annual disposable income (after-housing costs) (\$)	32,488 <sup>(a)</sup>	28,788 <sup>(a)</sup>	29,059
Housing costs (\$)	9,607 <sup>(a)</sup>	6,675 <sup>(a)</sup>	6,714
Household assets (\$)	822,404	832,069	852,655
Household debts (\$)	136,691 <sup>(a)</sup>	94,698 <sup>(a)</sup>	98,391
Net household wealth (\$)	686,063	733,686	749,414
<b>Sample size</b>	<b>11,621</b>	<b>1,205</b>	<b>978</b>

(a) Denotes significant difference between carers and non-carers *t*-test  $p < 0.05$ .

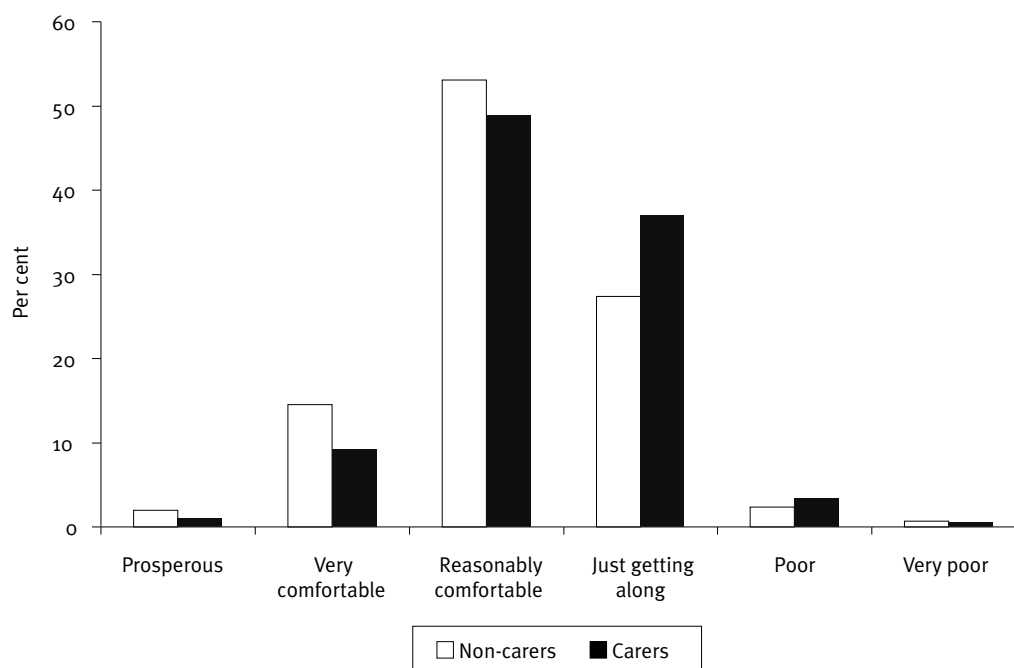
Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Wave 6.

### Subjective poverty

Figure 1 shows the distribution of responses to the question indicating subjective poverty by carer status in 2006. Irrespective of carer status, the majority of respondents indicated that they were ‘reasonably comfortable’ (53 per cent of non-carers and 49 per cent of carers) or ‘just getting along’ (27 per cent of non-carers and 37 per cent of carers). Non-carers were statistically significantly more likely than carers to indicate that they were very comfortable or reasonably comfortable, whereas carers were significantly more likely to say that they were just getting along or poor. Very few respondents indicated that they perceived their financial situation to be very poor.

**Figure 1: Distribution of subjective poverty by carer status (2006) (weighted percentages)**



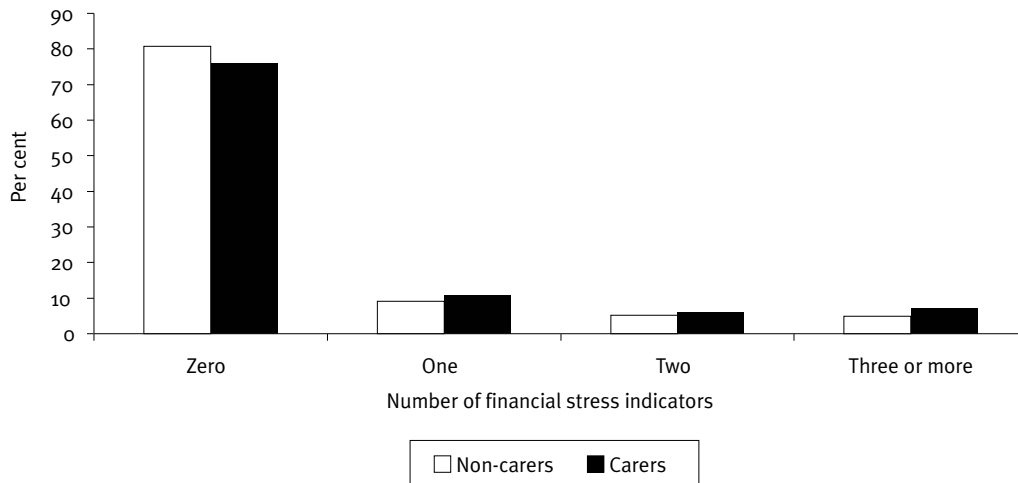
Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Wave 6.

### Financial stress

Figure 2 reports the number of financial stress indicators reported by carers and non-carers. The majority of carers and non-carers report none of the financial stress indicators (81 per cent of non-carers and 76 per cent of carers; statistically significant difference  $p < 0.05$ , chi square test). Carers were slightly more likely to report one, two or three indicators of financial stress than non-carers, but these differences were not statistically significant. Around 7 per cent of carers reported three or more financial stress indicators compared with 5 per cent of non-carers. Financial stress is defined in the rest of this analysis as reporting two or more indicators.

**Figure 2: Distribution of financial stress indicators by carer status (2006) (weighted percentages)**



Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Wave 6.

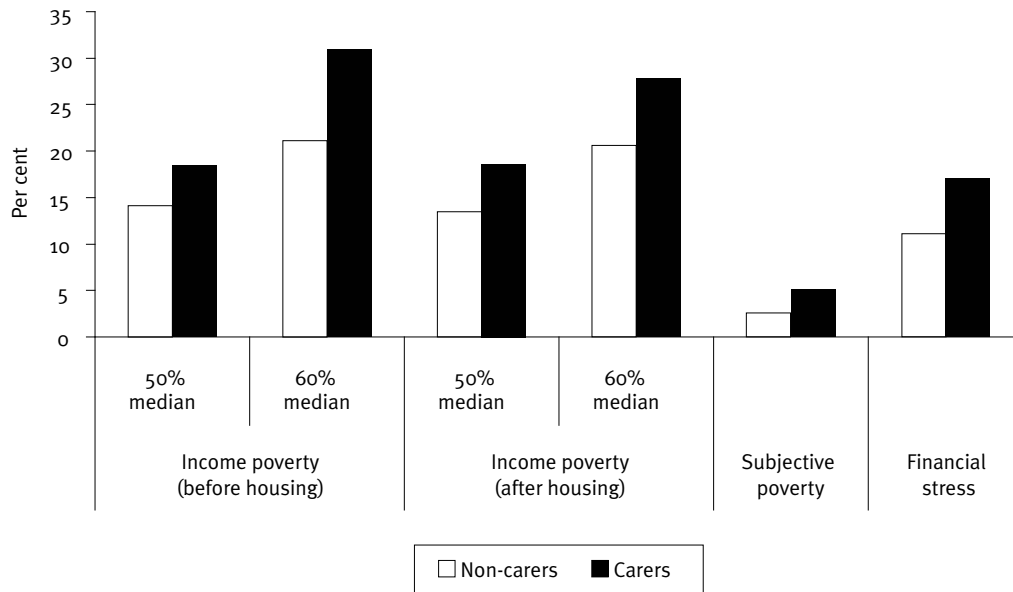
### Overall poverty rates for carers and non-carers

Figures 3 and 4 and Table 6 report the overall poverty rates on each of the economic disadvantage measures for carers and non-carers in 2005 and 2006. Income poverty rates (before and after-housing costs), calculated at 60 per cent of median income, are also included to show the sensitivity of the income poverty rates to the poverty line threshold.

Carers had higher levels of poverty than non-carers on all measures. In both years, around 17 to 18 per cent of carers were poor on the before-housing income poverty measure (50 per cent median). The poverty rate of carers on this measure was 5 percentage points higher than non-carers. The graphs show that the before-housing and after-housing income poverty rates are sensitive to changes in the poverty line threshold. The before-housing income poverty rate for carers increased to around 30 per cent when the higher poverty line (60 per cent median) was used. The poverty rate for non-carers also increased to 20 per cent with the 60 per cent median threshold. This meant that carers had a poverty rate that was 10 percentage points higher than non-carers using the higher poverty line. After-housing income poverty rates for both poverty line thresholds were fairly similar to the before-housing income poverty rates for carers and non-carers.

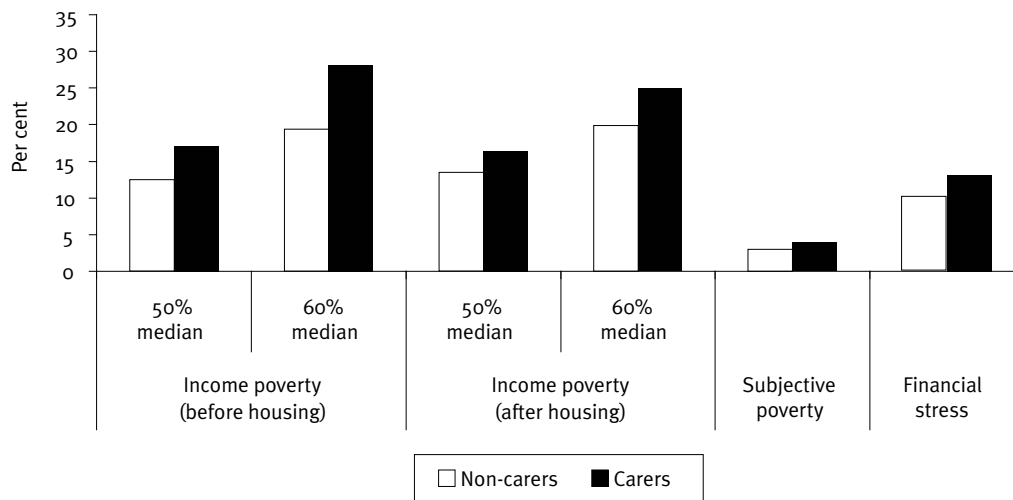
Subjective poverty rates were relatively low compared with the other measures. Around 4 to 5 per cent of carers reported that they were poor on this measure compared with 2 to 3 per cent of non-carers. Financial stress was slightly higher for carers and non-carers in 2005 than in 2006, although carers had higher rates in both years. Seventeen per cent of carers reported financial stress in 2005 compared with 13 per cent of carers in 2006. Eleven per cent of non-carers were disadvantaged on this measure in 2005 compared with 10 per cent in 2006.

**Figure 3: Poverty rates HILDA Wave 5 (2005) (weighted percentages)**



Note: Weighted by strata, cluster and cross-sectional responding person weights.  
 Source: HILDA release 6.0

**Figure 4: Poverty rates HILDA Wave 6 (2006) (weighted percentages)**



Note: Weighted by strata, cluster and cross-sectional responding person weights.  
 Source: HILDA release 6.0

**Table 6: Poverty rates in HILDA Waves 5 and 6 by carer status (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty	Financial stress
	50% median	60% median	50% median	60% median		
Wave 5 (2005)						
Carers	18.4 <sup>(a)</sup>	30.9 <sup>(a)</sup>	18.6 <sup>(a)</sup>	27.9 <sup>(a)</sup>	5.1 <sup>(a)</sup>	17.1 <sup>(a)</sup>
Non-carers	14.1 <sup>(a)</sup>	21.1 <sup>(a)</sup>	13.5 <sup>(a)</sup>	20.6 <sup>(a)</sup>	2.6 <sup>(a)</sup>	11.1 <sup>(a)</sup>
Wave 6 (2006)						
Carers	17.1 <sup>(a)</sup>	28.2 <sup>(a)</sup>	16.4 <sup>(a)</sup>	24.9 <sup>(a)</sup>	3.9 <sup>(a)</sup>	13.1 <sup>(a)</sup>
Non-carers	12.5 <sup>(a)</sup>	19.4 <sup>(a)</sup>	13.5 <sup>(a)</sup>	19.9 <sup>(a)</sup>	3.0 <sup>(a)</sup>	10.1 <sup>(a)</sup>

(a) Denotes statistically significant difference between carers and non-carers, chi-square test  $p < 0.05$ .

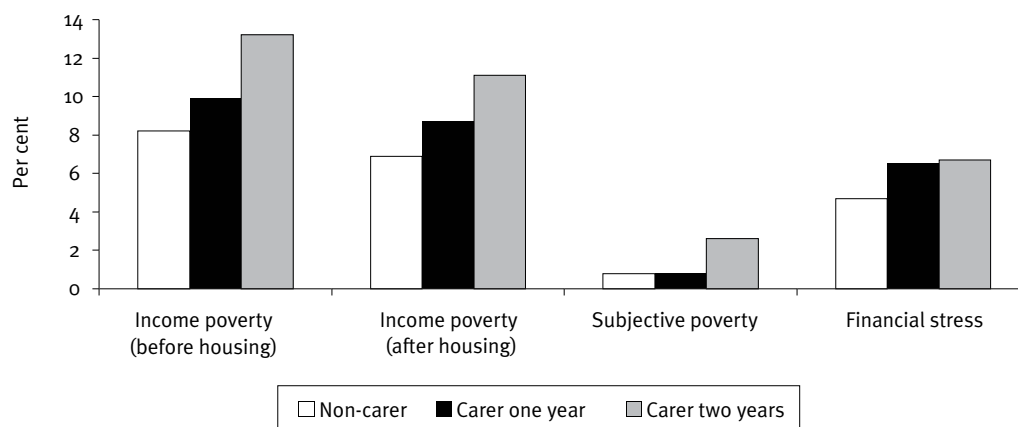
Notes: Weighted by strata, cluster and cross-sectional responding person weights.

Financial stress defined as reporting two or more indicators.

Source: HILDA release 6.0, Waves 5 and 6.

### Persistent poverty

The HILDA survey offers the possibility of identifying whether individuals stay poor over an extended period or whether their financial circumstances change from year to year. Figure 5 shows the proportions of individuals who were disadvantaged on each of the measures for two years by the length of time they were a carer in 2005 and 2006. The graph suggests that longer periods of care are accompanied by increasing levels of disadvantage on all measures. Individuals who were carers for both years had statistically significantly higher rates of persistent poverty than non-carers on all measures, except for before-housing income poverty. In particular, those caring for two years were more likely than non-carers and those caring for only one year to perceive themselves to be poor.

**Figure 5: Persistent poverty by duration of care: proportion in poverty for two years (2005 and 2006) (weighted percentages)**

Notes: Income poverty is calculated at 50 per cent median poverty line.

Weighted by strata, cluster and longitudinal person weights.

Source: HILDA release 6.0, Waves 5 and 6.

Table 7 shows the rates of poverty for a single year and persistent poverty in more detail by the duration of care. Carers who were providing support for two years were more likely to be in poverty for one year on most measures except for subjective poverty. The provision of care for one of the two years was also associated with higher rates of before-housing poverty (for one year) and financial stress (for one or two years), but not higher rates of poverty on the other measures.

**Table 7: Years in poverty by duration of care (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress		n
	1 year (%)	2 years (%)	1 year (%)	2 years (%)	1 year (%)	2 years (%)	1 year (%)	2 years (%)	
Non-carer both years	10.7	8.2	13.1	6.9	3.2	0.8	9.1	4.7	8,562
Carer 1 year	14.1	9.9	12.8	8.7	7.1	0.8	12.4	6.5	817
Carer 2 years	16.0	13.2	20.0	11.1	4.3	2.6	12.9	6.7	561
<b>Total</b>									<b>9,940</b>

Notes: Income poverty is calculated at 50 per cent median poverty line. Weighted by strata, cluster and longitudinal person weights.

Source: HILDA release 6.0, Waves 5 and 6.

### Cumulative poverty measures

While the dimensions of economic disadvantage and poverty can be considered separately, some analyses also use a combination of the measures as a strategy for identifying the proportion of the population whose income poverty status is confirmed by the presence of other indicators of disadvantage, such as financial stress (for example, Marks 2007; Saunders & Hill 2008). Table 8 reports on the rates of poverty for combinations of measures for carers and non-carers in 2005 and 2006. While the poverty rates drop dramatically for carers and non-carers when income poverty is combined with other measures, in nearly all cases, carers still have statistically significantly higher levels of disadvantage, whichever cumulative measure is used.

**Table 8: Poverty rates for combinations of measures (weighted percentages)**

	Carers	Non-carers
Wave 5 (2005)		
Before-housing income poverty	18.4 <sup>(a)</sup>	14.1 <sup>(a)</sup>
After-housing income poverty	18.6 <sup>(a)</sup>	13.5 <sup>(a)</sup>
Before-housing income poverty + subjective poverty	1.1	0.8
After-housing income poverty + subjective poverty	1.2	0.8
Before-housing income poverty + financial stress	4.7 <sup>(a)</sup>	2.2 <sup>(a)</sup>
After-housing income poverty + financial stress	5.6 <sup>(a)</sup>	2.6 <sup>(a)</sup>
Before-housing income poverty + subjective poverty + financial stress	1.0 <sup>(a)</sup>	0.4 <sup>(a)</sup>
After-housing income poverty + subjective poverty + financial stress	1.1 <sup>(a)</sup>	0.5 <sup>(a)</sup>
Wave 6 (2006)		
Before-housing income poverty	17.1 <sup>(a)</sup>	12.5 <sup>(a)</sup>
After-housing income poverty	16.4 <sup>(a)</sup>	13.5 <sup>(a)</sup>
Before-housing income poverty + subjective poverty	0.9	0.9
After-housing income poverty + subjective poverty	0.9	1.0
Before-housing income poverty + financial stress	3.2 <sup>(a)</sup>	1.9 <sup>(a)</sup>
After-housing income poverty + financial stress	4.2 <sup>(a)</sup>	2.4 <sup>(a)</sup>
Before-housing income poverty + subjective poverty + financial stress	0.6	0.5
After-housing income poverty + subjective poverty + financial stress	0.6	0.6

(a) Denotes statistically significant difference between carers and non-carers, chi-square test  $p < 0.05$ .

Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Waves 5 and 6.

## 4.6 Poverty rates for carers: care characteristics

A number of features of the care situation may influence the living standards of carers. Carers sharing a home with the person with disability may be on-call for greater periods, have less opportunity to spend time in paid work and, hence, have lower income compared with carers who care for a person outside the home. Having the main responsibility for providing care will also limit income generating activities compared with a person who shares the care with others. The relationship of the carer to the person with disability or illness may also be an indicator of the intensity of care responsibilities.

Table 9 reports the poverty rates in Wave 5 (2005), for self-identified carers disaggregated by aspects of their care situation, and for other carers categorised by the means of identifying them within the data. Co-resident main carers generally have high poverty rates for self-identified carers on the income poverty measures. Nearly one-quarter of this group were poor on either income poverty measure (50 per cent median), 6 per cent were poor on the subjective poverty measure, and 15 per cent reported financial stress. Spouse carers and carers of young children had relatively high income poverty rates. Carers of young children had after-housing income poverty rates of 30 per cent compared with before-housing income poverty rates of 21 per cent, indicating that this group experiences high housing costs. They also reported the highest rates of financial stress among these groups of carers, with over one-third (35 per cent) having lower living standards on this measure.

'Other carers' who had reported that they received a benefit for care or their work had been affected by their caring role also had relatively high poverty rates on all measures. Around one-third of this group were income poor, both before and after-housing costs, and experienced financial stress.

**Table 9: Poverty rates by care characteristics, HILDA Wave 5 (2005) (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty	Financial stress
	50% median	60% median	50% median	60% median		
Self-identified carers						
Co-resident main carer	22.5	40.8	23.1	35.9	5.6	15.3
Co-resident other carer	12.4 <sup>(a)</sup>	26.9	17.0 <sup>(a)</sup>	24.0	n.p.	19.2 <sup>(a)</sup>
Ex-resident main carer	13.4 <sup>(a)</sup>	20.3 <sup>(a)</sup>	10.1 <sup>(a)</sup>	19.9 <sup>(a)</sup>	4.1 <sup>(a)</sup>	13.0 <sup>(a)</sup>
Ex-resident other carer	13.9	18.9	15.0	19.3	5.3 <sup>(a)</sup>	14.2
Care recipient is:						
Spouse	29.3	49.6	26.8	43.7	6.4	12.3
Parent	12.9	20.9	13.7	20.2	3.9 <sup>(a)</sup>	14.0
Adult child	8.3 <sup>(b)</sup>	20.4 <sup>(a)</sup>	13.4 <sup>(a)</sup>	15.7 <sup>(a)</sup>	n.p.	n.p.
Young child	21.4	36.0	30.1	37.9	5.4 <sup>(a)</sup>	34.7
Other relative	12.5 <sup>(a)</sup>	22.5	15.0	20.0	n.p.	17.7
Other person	18.8	32.2	17.6	26.5	8.8 <sup>(a)</sup>	11.1 <sup>(a)</sup>
<b>Total self-identified carers</b>	<b>17.4</b>	<b>29.7</b>	<b>18.2</b>	<b>27.2</b>	<b>4.8</b>	<b>15.1</b>
Other carers						
Receiving benefit for care/ work-affected carers	34.0	47.3	31.4	44.2	8.5 <sup>(a)</sup>	32.7
Spent five or more hours caring for an adult	17.6	30.7	14.8	24.4	5.6 <sup>(a)</sup>	21.9
<b>Total other carers</b>	<b>23.1</b>	<b>36.3</b>	<b>20.5</b>	<b>31.1</b>	<b>6.5<sup>(a)</sup></b>	<b>25.3</b>
<b>Total carers</b>	<b>18.4</b>	<b>30.9</b>	<b>18.6</b>	<b>27.9</b>	<b>5.1</b>	<b>17.1</b>
<b>Non-carers</b>	<b>14.1</b>	<b>21.1</b>	<b>13.5</b>	<b>20.6</b>	<b>2.6</b>	<b>11.1</b>

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

(b) Denotes that the relative standard error of the estimate is over 50 per cent, and thus the estimate is considered unreliable.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Wave 5.

Table 10 reports the poverty rates in HILDA Wave 6 data for 2006. There are some consistencies and marked differences in the findings compared with data for 2005. Co-resident main carers and spouse carers still reported relatively high levels of poverty on most measures. However, carers of young children had relatively low poverty rates in this year. Similarly, the high rates of poverty in 2005 of carers who did not self-identify as a carer but were receiving a benefit for care or had had their work affected by caring responsibilities were not replicated in 2006.

**Table 10: Poverty rates by care characteristics, HILDA Wave 6 (2006) (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty	Financial stress
	50% median	60% median	50% median	60% median		
Self-identified carers						
Co-resident main carer	22.5	38.6	18.3	30.8	4.7	13.3
Co-resident other carer	8.9 <sup>(a)</sup>	14.8 <sup>(a)</sup>	6.7 <sup>(a)</sup>	13.9 <sup>(a)</sup>	n.p.	6.9 <sup>(a)</sup>
Ex-resident main carer	15.9 <sup>(a)</sup>	25.0	18.6 <sup>(a)</sup>	23.8	n.p.	11.7 <sup>(a)</sup>
Ex-resident other carer	13.8	19.6	14.8	19.8	4.5 <sup>(a)</sup>	15.2
Care recipient is:						
Spouse	31.2	50.6	23.3	39.5	5.6 <sup>(a)</sup>	12.1
Parent	12.0	19.7	14.3	18.6	3.3 <sup>(a)</sup>	11.8
Adult child	9.7 <sup>(a)</sup>	15.7 <sup>(a)</sup>	10.8 <sup>(a)</sup>	15.0 <sup>(a)</sup>	5.3 <sup>(a)</sup>	5.8 <sup>(a)</sup>
Young child	12.2 <sup>(a)</sup>	23.6	10.3 <sup>(a)</sup>	23.0	n.p.	19.9
Other relative	8.8 <sup>(a)</sup>	19.9 <sup>(a)</sup>	9.1 <sup>(a)</sup>	13.8	6.6 <sup>(a)</sup>	16.9
Other person	21.2	34.3	19.4 <sup>(a)</sup>	30.4	5.5 <sup>(a)</sup>	19.0
<b>Total self-identified carers</b>	<b>17.4</b>	<b>28.4</b>	<b>15.7</b>	<b>24.5</b>	<b>4.2</b>	<b>12.9</b>
Other carers						
Receiving benefit for care/or work-affected carers	17.5 <sup>(a)</sup>	40.6	23.5	34.3	n.p.	14.8 <sup>(a)</sup>
Spent five or more hours caring for an adult	15.0 <sup>(a)</sup>	21.7	17.5	22.9	n.p.	13.7
<b>Total other carers</b>	<b>15.8</b>	<b>27.4</b>	<b>19.3</b>	<b>26.3</b>	<b>2.3<sup>(a)</sup></b>	<b>14.0</b>
<b>Total carer</b>	<b>17.1</b>	<b>28.2</b>	<b>16.4</b>	<b>24.9</b>	<b>3.9</b>	<b>13.1</b>
<b>Non-carers</b>	<b>12.5</b>	<b>19.4</b>	<b>13.5</b>	<b>19.9</b>	<b>3.0</b>	<b>10.1</b>

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Wave 6.

## 4.7 Do different aspects of caring have a greater effect on disadvantage?

The higher poverty and financial stress rates of carers may be attributed to current commitments and costs of caring, or may be partially explained by other factors such as interrupted work histories or poor health, which might characterise carers as a group. Multivariate analysis offers the opportunity to explore whether caring, and which forms of caring, are independent predictors of poverty and disadvantage when controlling for other factors. Tables A5 to A8 (Appendix A) report the results of logistic regressions, which examine whether caring is associated with the different measures of poverty. Controls used in the regression are: sex and age of the carer, Indigenous and CALD status, family composition, human capital (highest education qualification and years of work experience), and class background (parental occupation and household wealth). The models predicting subjective poverty and financial stress also control for household income. It is arguable that the effect of caring on disadvantage may operate through some of these other variables in the regression, particularly income and wealth, because long-term carers may not have had the opportunity to accumulate wealth, for example, if they experienced additional costs. The models were estimated without the wealth and income variables where relevant and the substantive results reported generally remain the same.

Table A5 reports the results for the multivariate analysis of before-housing income poverty. Three sequential models are used to examine the effect of different forms of caring. Model 1 contains a dummy variable indicating whether the person is a carer or not. Model 2 disaggregates the carers into types of carers using a number of dummy variables (whether main carer or not and whether living with care recipient, and whether 'other carer'). In Model 3, variables identifying the care recipient of self-identified carers are included. The previous sections showed that carers had higher levels of poverty on this measure. The results in Model 1 with just the singular care dummy indicate that, on average, caring does not independently increase the risk of before-housing income poverty after other factors are accounted for. Model 2 disaggregates by type of carer and finds the same results for all these groups. However, when variables denoting the relationship with the care recipient are included in Model 3, it is clear that caring for a spouse significantly increases the risk of before-housing income poverty.

Table A6 reports the results of the same models for predicting after-housing income poverty. There are similar findings as for the before-housing income poverty measure. Overall, caring did not increase the risk of after-housing income poverty, reiterating the finding above that, on average, carers do not have higher housing costs than non-carers. However, Model 3 in Table A6 indicates that spouse carers are more likely than other carers to be in after-housing income poverty even after taking into account all control factors.

The results of the models examining the effects of care and other factors on subjective poverty are reported in Table A7. Caring does not have an independent effect on the probability of subjective poverty in Models 1 and 2 in this table. However, in Model 3 it is evident that carers of 'other relatives' have an increased risk of subjective poverty. (The removal of the income and wealth variables from the regression results in spouse carers having a greater risk of subjective poverty.)

The predictors of financial stress are reported in the three models in Table A8. Caring increases the risk of experiencing financial stress in all models reported in this table. This increased risk is found for carers who are co-resident main carers and ex-resident other carers, carers of parents and carers of 'other relatives' and 'other friends'. (Caring for a spouse was also associated more strongly with financial stress with the removal of the income and wealth variables.) Given that financial stress may be considered to be a more direct measure of disadvantage, these groups of carers may be the ones who face the higher costs of caring.

## 4.8 Which sociodemographic groups of carers have high poverty rates compared with non-carers?

The previous section examined the available data in HILDA about the characteristics of the care situation and their relationship to the different measures of economic disadvantage. This section considers the sociodemographic characteristics of carers that are more strongly associated with the different measures of poverty. The analysis first considers the bivariate relationships, and which subgroups of carers report higher poverty rates. The multivariate analysis in Section 4.9 then considers which factors have an independent effect on the risk of poverty for carers.

Women in the non-carer population were more likely to be poor than men on the income measures but the difference between men and women was not statistically significant for the carer population (Table 11). There were no significant sex differences for carers or non-carers with respect to subjective poverty or financial stress.

**Table 11: Poverty rates for carers and non-carers by sex (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
Male	16.5	12.8	18.0	12.7	6.8	2.7	14.8	10.5
Female	19.5	15.4	18.9	14.4	4.2	2.6	18.5	11.8
Wave 6 (2006)								
Male	15.9	10.8	15.4	12.5	5.0	3.0	16.1	9.9
Female	17.9	14.3	16.9	14.5	3.1	2.6	11.3	9.1

Note: Weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Waves 5 and 6.

Previous research shows that poverty rates differ by age and that older people report higher income poverty rates but lower rates of financial stress. While carers aged 65 years and over had relatively high rates of before-housing income poverty (around 25 per cent) they have relatively low rates of poverty on other measures compared with the other age groups in 2005 (Table 12). In 2006, there is a similar finding, with the exception that older carers report relatively high rates of after-housing income poverty as well as before-housing income poverty. Carers aged 25 to 44 years report average before-housing income poverty rates in both years, but higher rates of after-housing income poverty, and the highest rates of subjective poverty and financial stress. This age group is more likely to have young children and not be home owners, both of which are associated with high housing costs (larger family and buying or renting a home) and financial stress. Young carers (aged 15 to 24 years) also report relatively high levels of financial stress, but do not report high levels of subjective poverty.

**Table 12: Poverty rates for carers and non-carers by age group (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
15–25 years	21.5	14.2	21.0	17.3	4.5 <sup>(a)</sup>	1.9	23.6	12.2
25–44 years	20.0	7.4	25.0	10.6	8.6	3.3	36.6	17.1
45–64 years	14.6	12.0	16.6	12.2	4.9	2.8	11.4	6.8
65 years and over	24.5	34.8	13.6	18.7	n.p.	1.5	2.8	3.9
Wave 6 (2006)								
15–25 years	14.9	10.7	18.5	14.4	n.p.	2.0	17.4	12.0
25–44 years	15.9	6.1	18.7	11.2	6.3	3.3	25.1	14.1
45–64 years	13.9	10.5	12.4	11.6	3.4	3.7	9.9	7.7
65 years and over	27.3	34.8	22.0	21.5	n.p.	3.1	4.7 <sup>(a)</sup>	2.9

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Waves 5 and 6.

Table 13 reports the poverty rates for carers and non-carers by Indigenous and CALD status, which in this analysis is proxied by whether the first language spoken was not English. The sample size of Indigenous carers is very small in HILDA, leading to few statistically significant results, and so the results must be interpreted with some caution. While Indigenous carers generally had much higher than average poverty rates than non-Indigenous carers on all measures for which data are available, Indigenous carers had lower income poverty rates (before and after-housing costs) than Indigenous non-carers. Indigenous carers reported very high rates of financial stress (46 per cent and 36 per cent in 2005 and 2006 respectively), compared with non-Indigenous carers (16 per cent and 13 per cent).

Carers whose first language spoken was not English had higher poverty rates than carers whose first language was English on all income measures. They also generally had higher poverty rates than non-carers from CALD backgrounds on most measures. One-quarter of CALD carers were in income poverty in 2005 (before and after-housing costs) and this increased to over one-third in 2006. Around one-fifth of CALD carers reported financial stress and 5 to 6 per cent perceived themselves to be poor.

**Table 13: Poverty rates for carers and non-carers by Indigenous status and first language spoken (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
First language English	16.4	13.0	16.9	12.4	5.0 <sup>(a)</sup>	2.5	16.6	11.1
First language not English	26.5	20.9	25.4	20.3	5.9 <sup>(a)</sup>	3.7 <sup>(a)</sup>	20.0	11.8
Indigenous	30.7 <sup>(a)</sup>	32.6	37.1	40.1	n.p.	6.9	46.1	25.1
Non-Indigenous	18.0	13.8	18.0	13.2	5.3	2.6	16.4	10.9
Wave 6 (2006)								
First language English	12.9	11.6	12.2	12.0	3.7	3.0	12.3	10.0
First language not English	36.8	17.8	36.0	21.8	4.7	3.2	17.2	10.5
Indigenous	22.1 <sup>(a)</sup>	25.1	14.2 <sup>(a)</sup>	28.5	n.p.	4.0 <sup>(a)</sup>	35.8 <sup>(a)</sup>	22.2
Non-Indigenous	17.0	12.3	16.4	13.2	3.9	3.0	12.7	9.8

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Waves 5 and 6.

As expected, the after-housing income poverty rates of carers who own their own home is half their before-housing income poverty rates in both years (reduces from 16 per cent to 8 per cent in 2006) (Table 14). By contrast, the after-housing poverty rates of carers with mortgages are twice those of their before-housing income poverty rates. Carers who are private and public renters also have higher after-housing income poverty rates than before-housing income poverty rates although the difference is much greater for private renters. Carers renting (both public and private) have relatively high subjective poverty and financial stress rates compared with carers who own or are buying their home, although home buyers have much higher rates than home owners. This finding possibly reflects the lower levels of accumulated resources in the renting and buying groups compared with those who own their home.

**Table 14: Poverty rates for carers and non-carers by housing tenure (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
Home owner	18.3	17.7	8.7	7.5	2.0 <sup>(a)</sup>	1.2	5.0	3.6
Has mortgage	9.3	4.6	15.7	8.7	6.5 <sup>(a)</sup>	1.5	21.4	8.8
Private renter	19.1	15.4	30.4	22.6	7.0 <sup>(a)</sup>	5.4	32.5	25.4
Public renter	36.9	51.2	43.2	55.0	7.9 <sup>(a)</sup>	11.4	30.9	25.7
Other	40.0 <sup>(a)</sup>	28.0	33.9 <sup>(a)</sup>	16.4	n.p.	3.5 <sup>(a)</sup>	27.3 <sup>(a)</sup>	16.0
Wave 6 (2006)								
Home owner	16.5	16.3	8.1	7.5	1.5 <sup>(a)</sup>	1.5	4.1	3.1
Has mortgage	6.5	3.7	13.2	9.6	4.7	1.8	17.2	8.7
Private renter	24.3	13.5	32.3	21.7	8.3	5.7	30.0	21.8
Public renter	46.5	45.9	50.7	47.6	9.0	12.8	23.7	25.5
Other	19.3 <sup>(a)</sup>	28.4	n.p.	19.7	n.p.	2.8 <sup>(a)</sup>	n.p.	5.6 <sup>(a)</sup>

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Waves 5 and 6.

**Table 15: Poverty rates for carers and non-carers by percentage of household income from government transfers (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Income from government transfers Wave 5 (2005)								
<10%	2.4 <sup>(a)</sup>	3.8	3.8	5.5	3.0 <sup>(a)</sup>	1.2	9.7	7.7
10% to 50%	5.5	9.0	9.4	13.7	7.6	3.6	21.2	17.6
50% to 90%	22.4	28.9	22.9	26.5	5.0 <sup>(b)</sup>	5.2	20.0	14.6
>90%	59.3	79.2	52.7	55.1	6.2 <sup>(b)</sup>	8.3	23.9	18.4
Income from government transfers Wave 6 (2006)								
<10%	2.5 <sup>(a)</sup>	2.6	4.8 <sup>(a)</sup>	5.0	1.9 <sup>(a)</sup>	1.2	6.6	7.1
10% to 50%	5.8 <sup>(a)</sup>	7.4	6.4 <sup>(a)</sup>	12.9	4.6 <sup>(a)</sup>	4.8	17.2	15.2
50% to 90%	23.2	25.9	23.6	25.9	2.6 <sup>(a)</sup>	5.8	11.9	12.4
>90%	58.6	79.6	48.8	60.6	8.0	8.9	22.1	17.1

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Note: Government transfers include family payments; percentages are weighted by strata, cluster and cross-sectional responding person weights.

Source: HILDA release 6.0, Waves 5 and 6.

Table 15 reports the poverty rates of carers and non-carers by the proportion of household income that is received from government transfers (including family payments). When comparing carers and non-carers across these categories we are referring to **composition** of income rather than **levels** of income. Nearly 60 per cent of the carers who are highly reliant on government transfers (more than 90 per cent of household income) are in before-housing income poverty compared with almost 80 per cent of non-carers in this category. However, the rates of financial stress for carers were 5 to 6 percentage points higher than those of non-carers. This finding suggests that carers may have higher levels of incomes, but possibly more costs than other benefit recipients in this category.

Among carers who receive between 50 and 90 per cent of their income from government transfers, just over 20 per cent are in both before-housing and after-housing income poverty. Carers who received less than 50 per cent of their income from government benefits have lower rates of income poverty than carers with higher levels of government transfers, but it is only the carers who receive less than 10 per cent of their income from transfers who have relatively low rates of financial stress.

Carers in receipt of disability pension and allowances had relatively high rates of poverty on a number of measures, particularly financial stress measures, suggesting that these carers had costs not met with their income (Table 16). Carers receiving the Age Pension had relatively high rates of before-housing income poverty but relatively low rates of after-housing income poverty and financial stress.

**Table 16: Poverty rates for carers and non-carers by income support payment (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
Carer Payment	23.7		26.8		7.1 <sup>(c)</sup>		15.9	
Disability Support Pension	36.9	40.7	43.8	38.2	13.7 <sup>(c)</sup>	13.5	36.1	25.9
Parenting Payment <sup>(a)</sup>	27.9	40.2	15.2	20.8	n.p.	2.2	2.7 <sup>(c)</sup>	4.8
Age Pension	29.0	41.5	14.4	21.4	n.p.	2.5	3.6 <sup>(c)</sup>	5.3
Allowance <sup>(b)</sup>	35.0	32.9	26.2	34.9	8.4 <sup>(c)</sup>	8.9	36.6	28.6
Wave 6 (2006)								
Carer Payment	27.4		20.1		6.0 <sup>(c)</sup>		13.0	
Disability Support Pension	37.0	39.7	34.7	36.8	8.0 <sup>(c)</sup>	13.5	28.8	26.5
Parenting Payment <sup>(a)</sup>	30.8	41.2	26.6	24.7	2.7 <sup>(c)</sup>	4.0	5.7	3.4
Age Pension	32.1	14.6	26.0	14.7	n.p.	4.2	5.9	3.2
Allowance <sup>(b)</sup>	26.5	27.2	32.0	33.9	n.p.	9.2	40.9	25.5

(a) Parenting Payment comprises recipients of Parenting Payment Partnered and Parenting Payment Single.

(b) Allowance comprises recipients of: Newstart Allowance, Mature Age Allowance, Sickness Allowance, Widow Allowance, Partner Allowance, Youth Allowance and Austudy or Abstudy.

(c) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.

n.p. denotes not available for publication.

Source: HILDA release 6.0, Waves 5 and 6.

Carers who indicated that they were unemployed had high poverty rates on all measures for which data was available (Table 17). Income poverty rates were fairly similar for carers and non-carers; however, carers who were employed generally had higher rates of financial stress than their non-carer counterparts. Unemployed carers appeared to face higher housing costs, because their after-housing income poverty rates were higher than their before-housing income poverty rates. In 2005, 44 per cent of unemployed carers were in financial stress and this rate was 51 per cent in 2006. Carers who were not in the labour force had lower poverty rates than unemployed carers on a number of measures.

**Table 17: Poverty rates for carers and non-carers by employment status (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
Employed full-time	3.8 <sup>(a)</sup>	3.9	7.2	6.5	5.0 <sup>(a)</sup>	1.2	14.5	10.2
Employed part-time	10.5	9.6	10.9	12.2	2.7 <sup>(a)</sup>	2.5	20.1	10.8
Unemployed	38.6 <sup>(a)</sup>	23.8	42.6 <sup>(a)</sup>	29.2	n.p.	8.3	43.5	28.1
Not in the labour force	28.1	29.9	26.2	22.4	5.8	4.2	15.9	11.0
Wave 6 (2006)								
Employed full-time	3.0 <sup>(a)</sup>	2.9	6.3	6.2	3.0 <sup>(a)</sup>	1.7	10.8	8.8
Employed part-time	10.7	7.2	11.2	11.4	2.9 <sup>(a)</sup>	2.2	16.5	10.8
Unemployed	32.4 <sup>(a)</sup>	21.1	40.2	28.3	n.p.	12.6	51.4	24.9
Not in the labour force	27.4	28.5	23.3	23.5	4.2	4.5	11.4	9.9

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.  
 Notes: Weighted by strata, cluster and cross-sectional responding person weights.  
 n.p. denotes not available for publication.  
 Source: HILDA release 6.0, Waves 5 and 6.

Educational qualifications can be indicative of class background, and of a component of human capital, which may lead to higher living standards. Carers with university qualifications (Bachelor degree or above) had relatively low before and after-housing income poverty rates (Table 18). However, the capacity of higher education to protect from economic disadvantage was not so clearly demonstrated on the financial stress measures. Carers with Year 12 or less had generally higher income poverty rates, yet the findings for financial stress and subjective poverty were less consistent. This perhaps reflects the fact that many of those with lower levels of educational qualifications are in older age groups and may be less likely to report subjective poverty or financial stress.

**Table 18: Poverty rates for carers and non-carers by educational qualifications (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Wave 5 (2005)								
Bachelor degree or above	6.8	6.2	9.7	7.4	n.p.	2.1	13.4	7.0
Certificate	12.9	11.5	16.6	12.2	7.7	3.0	16.6	13.0
Year 12	16.5	11.4	14.6	12.8	5.5	2.2	18.5	13.1
Less than Year 12	28.1	21.6	25.2	18.1	4.9	2.8	18.6	11.0
Wave 6 (2006)								
Bachelor degree or above	6.5	4.1	14.6	6.6	3.0 <sup>(a)</sup>	1.4	12.5	6.2
Certificate	16.6	9.7	14.4	11.8	6.0	3.1	16.6	11.0
Year 12	20.6	9.5	23.6	13.4	n.p.	2.6	16.8	11.9
Less than Year 12	20.7	21.0	16.5	18.7	3.0	3.9	9.9	10.7

(a) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.  
 Notes: Weighted by strata, cluster and cross-sectional responding person weights.  
 n.p. denotes not available for publication.  
 Source: HILDA release 6.0, Waves 5 and 6.

Carers living alone, who were obviously caring for someone outside their household, generally had relatively high poverty rates on a number of the measures compared with other carers (Table 19). Carers living alone had high before-housing income poverty rates (32 per cent and 37 per cent in 2005 and 2006 respectively), most likely reflecting their sole earner status. They had slightly lower after-housing income poverty rates. By contrast, carers living in lone-parent households, who also had relatively high income poverty rates, had lower before-housing income poverty rates than after-housing income poverty rates. This finding possibly reflects the fact that they experienced higher housing costs than lone persons due to their need for larger homes for their children. Carers who were living in couple with children households had relatively low income poverty rates, but also had higher after-housing income poverty rates than before-housing income poverty rates, whereas the reverse was true for couples without children. Carers living in mixed households, lone-parent households and lone-person households had higher rates of financial stress than carers living in couple households with or without children.

**Table 19: Poverty rates for carers and non-carers by household composition (weighted percentages)**

	Income poverty (before housing)		Income poverty (after housing)		Subjective poverty		Financial stress	
	Carers	Non- carers	Carers	Non- carers	Carers	Non- carers	Carers	Non- carers
Wave 5 (2005)								
Couple only	22.4	15.3	16.0	10.7	4.2 <sup>(b)</sup>	1.7	7.0	6.1
Couple with children only <sup>(a)</sup>	9.8	6.2	13.4	8.1	5.6	1.6	18.0	9.7
Mixed family	15.6 <sup>(b)</sup>	13.6	20.3	15.9	4.3 <sup>(c)</sup>	4.6	28.2	16.7
Lone parent	26.4	17.5	31.0	20.6	5.8 <sup>(b)</sup>	6.1	28.1	22.1
Lone person	31.5	34.2	28.6	29.6	7.1 <sup>(b)</sup>	5.2	24.4	16.2
Wave 6 (2006)								
Couple only	24.7	15.2	20.4	10.3	2.5 <sup>(b)</sup>	1.7	6.4 <sup>(b)</sup>	5.0
Couple with children only <sup>(a)</sup>	7.6	4.8	9.8	7.2	3.1 <sup>(b)</sup>	1.9	13.0	9.1
Mixed family	12.6	6.5	10.0 <sup>(b)</sup>	12.7	7.4 <sup>(b)</sup>	3.2	19.6	16.4
Lone parent	18.9	15.6	20.8	21.2	3.7 <sup>(b)</sup>	6.8	18.3	18.8
Lone person	36.5	32.9	34.9	33.5	8.0 <sup>(b)</sup>	6.2	26.5	14.2

(a) Children defined as children under 15 years, dependent students and non-dependent children.

(b) Denotes relative standard error between 25 per cent and 50 per cent, and estimate should be treated with caution.

(c) Estimate has a relative standard error of >50 per cent.

Notes: Weighted by strata, cluster and cross-sectional responding person weights.  
n.p. denotes not available for publication.

Source: HILDA release 6.0, Waves 5 and 6.

Generally, carers had higher poverty rates than non-carers in all demographic subgroups except for those aged over 65 years, Indigenous persons, public renters, when comparing persons by proportion of income from government transfers, and by type of government benefit received. The different dimensions of poverty considered in this section may be interpreted as reflective of different aspects of economic disadvantage—low incomes, high housing costs, feeling poor and not managing financially.

## 4.9 Multivariate analysis— which carers are more likely to be in poverty?

The previous section considered the poverty rates of different population subgroups of carers and non-carers. The multivariate analysis in this section employs logistic regression analysis to examine the factors that have an independent association with each measure of poverty when all the other factors are controlled for. The analysis uses only the subset of carers (n=1,207) to identify the factors associated with disadvantage on the different poverty measures. The results are reported in Table A9 (Appendix A). Again, all the models were also estimated with the exclusion of the wealth and income variables, and the results are robust to their exclusion, except where noted.

### **Before-housing income poverty**

Carers who were more likely to be poor on a before-housing income poverty measure were those: of CALD backgrounds, with disability, with less than university education, who had been employed for a smaller proportion of the time since they had left school, or who had lower levels of wealth. These characteristics may all be associated with lower income earning potential. Carers from CALD backgrounds may have more difficulty accessing employment and may experience discrimination in the labour market. If they have recently migrated to Australia, they may also be less likely to have extended family living close by who could support them to engage in the labour market alongside their carer role. They may also face additional difficulties accessing formal services to support their caring role. Carers with disabilities may experience additional barriers to gaining income. Carers with lower levels of human capital (education and work history) are also more likely to have lower wages and employment opportunities.

### **After-housing income poverty**

Carers with high housing costs (relative to income) were CALD carers, those with disability, those who had spent less time employed, and carers with lower levels of wealth. These characteristics of carers are very similar to the characteristics that increased the risk of before-housing income poverty for carers, with the exception of education qualifications. What this suggests is that these carers are less likely to own their homes and more likely to be paying off mortgages or renting. A challenge for these carers may be to meet their housing costs and maintain their caring role. (The removal of the wealth variable from the regression caused the presence of children to be associated with after-housing income poverty, suggesting that carers who may be providing support for a person with disability while raising children may also be facing high housing costs.)

### **Subjective poverty**

Carers who were more likely to perceive themselves as poor were those with a disability, who have spent more time unemployed and carers with lower levels of wealth. This finding confirms that the accumulation of disadvantage through both the caring role and the experience of disability significantly affects individuals' perceptions of their living standards. It also highlights the key role of inherited or accumulated wealth and labour market income in facilitating participation in social activities and meeting financial commitments in the Australian context. The removal of the income and wealth variables resulted in carers without partners and with higher numbers of children also having a higher risk of subjective poverty, suggesting that lone-parent carers subjectively experience more financial burdens.

### **Financial stress**

Carers who were more likely to be in financial stress (with higher costs) were male carers, younger carers, those without a partner, those with more children and those in receipt of lower levels of income. Male carers may be more likely to be caring for their spouses than female carers, which may indicate that the household experiences greater financial stress than situations where a male in the household is able to continue in the breadwinning role. This scenario may be due to their specific care situations involving higher costs. Age was a factor associated with higher financial stress among the carers group, with younger carers more likely to report financial stress. This finding may be indicative of less experience in managing money and less opportunity to

accumulate resources that may buffer periods of increased financial outlays. Carers living without a partner may be more greatly disadvantaged due to having a single income with which to defray all additional costs of caring, and those with children may find that expenses associated with raising children compete with expenses required to meet the needs of disability and caring. Lower levels of income as a predictor of financial stress is not a surprising finding and may indicate that certain levels of cash flow are insufficient to meet all requirements in care situations. The removal of the income and wealth variables suggested that those with fewer years employed were also more likely to experience financial stress implying that they may have experienced more years of reduced income leading to reduced savings and resources.

## 4.10 Summary

The analysis in this section of the report employed four methods to examine different dimensions of poverty for carers. Overall, at the aggregate level, carers were found to have higher levels of poverty than non-carers on all dimensions. The difference between carers and non-carers was most pronounced on the financial stress measure, which may indicate that carers have high costs associated with their caring role. The analysis employed multivariate models to assess whether the poverty of carers was associated with care characteristics or sociodemographic characteristics. While caring did not appear to increase the risk of income poverty for most carers, it did increase the risk of financial stress when all other factors were controlled for. The analysis reported on the levels of poverty for carers distinguished by sociodemographic groups. Income poverty rates were highest for carers who received more than 90 per cent of their household income from government transfers. Subjective poverty rates were highest for carers who were renting and carers in receipt of Disability Support Pension. Highest levels of financial stress were reported by unemployed carers, Indigenous carers and those in receipt of an allowance. Multivariate analysis of the carer sample highlighted the sociodemographic factors that increased the risk of each dimension of poverty: CALD background, disability and interrupted employment histories were associated with income poverty, whereas males and lone parents had a higher risk of financial stress. Low levels of wealth were associated with an increased risk of poverty on all measures, apart from financial stress.



## 5 Conclusion

In Australia, informal care is the key pillar of community care policy and is the major source of assistance provided to people with disability and chronic illness. Informal carers contribute greatly to the economic and social fabric of the community, yet this role is often undertaken at substantial cost to the individual carer. This study has investigated what is known about the indirect and direct costs of informal caring, the methods for examining the direct costs of care and the data needed for these analyses, and four different dimensions of the living standards of carers.

Providing support to an older person or someone with a long-term or chronic illness or with disability may incur costs. Conceptually, this research found that the impact of caring may be interpreted as having ‘direct or indirect’ costs for the carers. The magnitude of these costs is influenced by a number of factors encompassing: the type and severity of illness or disability, and the availability of other informal and formal support.

Indirect costs of care comprise opportunity, time and health costs. Research from both Australia and overseas demonstrates that the indirect costs of care are significant. Carers are less likely to be employed, and more likely to work fewer hours and receive less income, which has implications for their current and long-term financial security. The literature also shows that caring can impact negatively on carers’ physical and mental health, as a result of the demands and time constraints.

To understand direct costs requires a conceptual distinction to be made between the direct costs of disability and the direct costs of caring. The direct costs of disability are expenses arising from the needs associated with disability, which may be borne by the person with disability, the carer or a range of other sources (for example, government, NGOs, insurance companies). The ‘direct costs of care’ refer to the additional monetary expenses incurred by carers as a result of taking on the caring role, which may include home modifications or transport, and health costs for carers to mitigate the stresses associated with caring.

The research on the direct costs of care, although limited, provides some indicative information on the types and magnitude of additional costs that may be incurred as a result of providing informal support. The research indicates that carers often have additional expenditure on items such as heating and cleaning expenses, and costs associated with travel, communication and services. Carers also pool income within the household with the person for whom they care and at times assist the person with disability to cover their costs. Strategies adopted by carers to enable them to manage on limited income include reducing spending in other areas such as holidays and leisure activities.

The method adopted by most of the available research on the direct costs of care is based on asking carers to indicate how they spend their income. However, other approaches used in the estimation of the direct costs of disability provide a potentially useful framework for investigating the direct costs of care.

These approaches include:

- **the subjective approach**—asking people how much they are required to spend to meet their needs
- **the budget standards approach**—developing budgets to account for what people need to achieve a particular standard of living
- **the comparative approach**—comparing expenditure data and patterns of consumption in different types of households
- **the standard of living approach**—estimating the difference in income required by different types of household to achieve a similar standard of living.

Each of these methods could potentially be applied to estimating the costs of disability, although each relies on the availability of certain specific types of data. The two most promising approaches, based on available data and the amount of resources required to collect the necessary data, are the comparative approach and the standard of living approach. These methods require large scale datasets on household expenditure and the

standard of living. Currently, HES, SDAC, HILDA and the NATSISS contain some of the variables required for these approaches. However, there are several gaps, such as:

- ▶ HES—very limited information on disability and informal care
- ▶ SDAC—limited information on income and no information on expenditure and standard of living or financial stress
- ▶ HILDA—limited information on financial stress at the household level, but this issue could be overcome by developing a methodology using individual financial stress indicators
- ▶ NATSISS—limited information on income and no information on disability and informal care.

If additional variables to rectify these gaps were included in the data collection for these national datasets, their potential usefulness for estimating the direct costs of care would be enhanced.

This study also examined the living standards of carers using four measures of poverty. At the aggregate level, carers were found to have higher poverty rates than non-carers on all measures, particularly financial stress. Multivariate analysis suggested that some of the income poverty of carers is explained by their sociodemographic characteristics. However, the analysis provided clear evidence that caring itself increases financial stress, even controlling for all demographic factors. This finding is perhaps indicative of additional costs associated with care. Spouse carers were found to be particularly disadvantaged in terms of low income and high housing costs, and with respect to subjective poverty and financial stress, when income and wealth variables were removed from the model. Carers assisting a parent appeared more likely to experience financial stress.

Research shows that many individuals will encounter the challenges of taking on an informal care role at some point in their life for a parent, child, spouse or friend. The findings in this study indicate the different dimensions of disadvantage for carers and highlight which carers might be most assisted by government policies to support carers. The analysis showed that having a CALD background, or being a carer with disability was associated with low income and relatively high housing costs. The factors underpinning their lower incomes and housing situations were not able to be identified in this research, but may be the subject of future and research and policy attention. Carers with disabilities themselves were also more likely to subjectively assess their situation as disadvantaged, perhaps highlighting the cumulative effect of disability and care in achieving social participation and financial security in the current Australian context. Interrupted employment histories were associated with an increased risk of income poverty and subjective poverty, but not an increased risk of financial stress. Such disrupted employment patterns are likely to be common among carers who have had long-term care responsibilities. Policies supporting carers to maintain attachment to the labour market, such as flexible workplace arrangements, additional training to assist carers to re-enter the paid workforce, and formal services to assist the caring role, are essential to ensure carers' long-term financial security and retirement incomes. Higher household wealth was associated with lower risk of poverty on all measures, except financial stress, highlighting the importance of the ability to save and accumulate resources to moderate the impact of periods of increased or unanticipated financial costs.

Factors most strongly associated with an increased risk of financial stress, and thus perhaps higher costs of caring, were being male, younger, a lone parent, having a larger number of children, and being in receipt of relatively low levels of income. Previous research suggests that males are more likely to be caring for a spouse. Thus, the lack of another adult to provide support more generally within in the household may have implications for different types of additional costs (such as child care, transport, meals), in order to maintain the functioning of the household. These additional costs may be encountered by lone parents as well, particularly in the case of households with greater numbers of children. Policies aimed at providing financial support for families may need to take account of the additional costs incurred by carers within families. Research has highlighted the vulnerability of young people who are carers, who may lack access to information and financial resources to ease the stresses of their caring role. Recent initiatives by all levels of government to target additional support for young carers are important factors in alleviating the impact of caring responsibilities at younger ages.

Extant research on carers provides extensive evidence on the indirect costs of care, which may have long-term effects on informal carers' financial security, social participation and health. The effects are greater for those carers providing intensive support. Less is known about the direct costs of caring, although surveys of carers themselves reveal additional expenses in some domains, while carers cut back on other aspects of spending.

Future research could extend the study of many issues raised in this analysis and which were beyond the scope of this present study. A key issue is the double burden faced by carers who also have non-adult children to care for, and 'sandwich carers', those carers who are providing care for a frail elderly parent as well as young or adult children. The long-term financial, social and employment impact of caring for a child with disability may lead to persistent disadvantage and poverty across generations. With the inclusion of the carer variables in all waves subsequent to Wave 5 of the HILDA data, future research could explore the longitudinal possibilities of the HILDA data to identify the prevalence of persistent poverty and financial stress among carers, and the impacts of transitions in and out of the caring role.

Further research is also required to identify the specific costs that carers encounter and how policy could assist in defraying the costs of these needs. The scoping of available datasets indicates that future research could develop more robust and comprehensive estimates of the direct costs of caring, if additional variables were added to the datasets. The evidence on living standards in Australia highlights carers' economic disadvantage using a number of indicators. The evidence of increased financial stress for carers is compelling and is likely to be an indicator of substantial costs associated with caring. This research has identified groups that may be more vulnerable on different dimensions of poverty. The evidence presented in this report raises issues that might inform the policy agenda when the circumstances of carers are being considered.



# Appendix A

**Table A1: Comparative approach: availability of relevant variables in existing datasets**

Variable	Level	Household Expenditure Survey 2003–04	Household, Income and Labour Dynamics in Australia survey Wave 6
Number of people with a disability in household	Household	No	Yes
Whether person has a disability	Person	No direct question on disability; only disability pension	Yes
Severity of disability	Person	No	Only degree of work restriction for disability
Type of disability	Person	No	Yes
Number of carers in household	Person	No	Yes
Whether a carer	Person	No direct question on carer; only carer payment	Yes—but restricted to caring for someone who needs assistance for self-care, communication and mobility. Not as thorough as SDAC identification of carer
Whether a primary carer or has main responsibility for care	Person	No	Yes
Whether caring for someone in their household or someone elsewhere	Person	No	Yes
Relationship to care recipient	Person	No	Yes
Household composition	Household	Yes	Yes
Number of adults in household	Household	Yes	Yes
Number of children in household	Household	Yes	Yes
Age of children in household	Household	Yes	Yes
Employment status	Person	Yes	Yes
Hours worked	Person	Yes	Yes
Household income (gross)	Household	Yes	Yes
Household income (disposable)	Household	Yes	Yes
Equivalised income	Household	Yes	Yes
Main source of household income	Household	Yes	Yes

**Table A1: Comparative approach: availability of relevant variables in existing datasets (continued)**

<b>Variable</b>	<b>Level</b>	<b>Household Expenditure Survey 2003–04</b>	<b>Household, Income and Labour Dynamics in Australia survey Wave 6</b>
Whether receiving government pension or benefit	Person	Yes	Yes
Housing costs	Household	Weekly expenditure on current housing costs (selected dwellings); weekly expenditure on other capital housing costs, numeric	Yes
Food	Household	Weekly expenditure on food and non-alcoholic beverages	Total weekly expenses on groceries including food, cleaning products, pet food and personal care products, based on recall best estimate
Fuel	Household	Weekly expenditure on domestic fuel and power	Total annual expenses on electricity bills, gas bills, other heating fuel, based on recall best estimate
Alcohol	Household	Weekly expenditure on alcoholic beverages	Total weekly expenses on alcohol, based on recall best estimate
Clothing	Household	Weekly expenditure on clothing and footwear (detailed items)	Total monthly expenses on men's clothing and footwear, women's clothing and footwear, children's clothing and footwear, based on recall best estimate
Durables	Household	Weekly expenditure on white goods and other electrical appliances	Annual expenses on household appliances such as ovens, fridges, washing machines and air conditioners, based on recall best estimate
Transport	Household	Weekly expenditure on transport	Total weekly expenses for motor vehicle fuel, engine oil, based on recall best estimate
Fees for support services	Household	None but weekly expenditure on home help	No
Medicines	Household	Weekly expenditure on medicines, pharmaceuticals products and prescriptions	Annual expenses on medicines, pharmaceuticals products and prescriptions, based on recall best estimate
Health services	Household	Weekly expenditure on medical care and health expenses	Annual expenses on fees paid to doctors, dentists, opticians, physiotherapists, chiropractors and any other health practitioner, based on recall best estimate
Laundry	Household	No	No
Telephone	Household	Weekly expenditure on mobile, telephone and facsimile	Total monthly expenses on telephone rent and calls and internet charges, based on recall best estimate

**Table A1: Comparative approach: availability of relevant variables in existing datasets (continued)**

<b>Variable</b>	<b>Level</b>	<b>Household Expenditure Survey 2003–04</b>	<b>Household, Income and Labour Dynamics in Australia survey Wave 6</b>
Leisure	Household	Weekly expenditure on recreation	Total weekly expenses on meals eaten out; total annual expenses holidays and holidays costs, based on recall best estimate
Domestic services	Household	Weekly expenditure on housekeeping and cleaning services	No
Total weekly spending	Household	Total household expenditure (including selected other payments)	Yes
Total health care costs	Household	Weekly expenditure on medical care and health expenses	Annual expenses on fees paid to doctors, dentists, opticians, physiotherapists, chiropractors and any other health practitioner; private health insurance; annual expenses on medicines, pharmaceuticals products and prescriptions, based on recall best estimate
Whether uses formal services to support person with disability	Household	No, but weekly expenditure on home help	No
Number of formal services used	Household	No	No
Costs of formal services	Household	No, but weekly expenditure on goods and services	No

**Table A2: Standard of living approach: availability of relevant variables in existing datasets**

Variable	Household Expenditure Survey 2003-04	Survey of Disability, Ageing and Carers 2003	Household, Income and Labour Dynamics in Australia survey	National Aboriginal and Torres Strait Islander Social Survey 2002
Number of people with a disability in household	No	Yes	Yes	No
Whether person has a disability	No direct question on disability; only disability pension	Yes	Yes	Yes
Severity of disability	No direct question on disability; only disability pension	Yes	No—only degree of work restriction for disability	Yes
Type of disability	No	Yes	Yes	Yes
Whether a carer	No direct question on carer; only carer payment	Yes	Yes—but restricted to caring for someone who needs assistance for self-care, communication and mobility; Not as thorough as SDAC identification of carer	No direct question on carer—only question identifying recipients of carer allowance
Whether a primary carer or has main responsibility for care	No	Yes	Yes	No
Whether caring for someone in their household or someone elsewhere	No	Yes	Yes	No
Relationship to care recipient	No	Yes	Yes	No
Age	Yes	Yes	Yes	Yes
Sex	Yes	Yes	Yes	Yes
Household composition	Yes	Yes	Yes	Yes
Number of adults in household	Yes	Yes	Yes	Yes

Table A2: Standard of living approach: availability of relevant variables in existing datasets (continued)

Variable	Household Expenditure Survey 2003–04	Survey of Disability, Ageing and Carers 2003	Household, Income and Labour Dynamics in Australia survey	National Aboriginal and Torres Strait Islander Social Survey 2002
Age of children in household	Yes	Yes	Yes	Yes
Household income (gross)	Yes	Yes — but limited in ranges only	Yes	Yes — topcoded.
Household income (disposable)	Yes	Yes — but limited in ranges only	Yes	No
Equivalised income	Yes	Yes — but limited in ranges only	Yes	Only equivalised gross income
Main source of household income	Yes	Yes	Yes	Yes
Whether receiving government pension or benefit	Yes	Yes	Yes	Yes
Education	Yes	Yes	Yes	Yes
Housing tenure	Yes	Yes	Yes	Yes
Housing costs	Yes	No	Yes	Yes — weekly rent and mortgage payments

**Table A2: Standard of living approach: availability of relevant variables in existing datasets (continued)**

Variable	Household Expenditure Survey 2003–04	Survey of Disability, Ageing and Carers 2003	Household, Income and Labour Dynamics in Australia survey	National Aboriginal and Torres Strait Islander Social Survey 2002
Financial stress indicators	<p>Yes</p> <p><b>7 financial stress questions:</b>  <b>In the past year, have any of the following happened to [you/your household] because of a shortage of money?</b></p> <ol style="list-style-type: none"> <li>Sought assistance from welfare/ community organisations due to shortage of money</li> <li>Pawned or sold something due to shortage of money</li> <li>Sought financial help from friends/family due to a shortage of money</li> <li>Unable to heat home due to shortage of money</li> <li>Went without meals due to shortage of money</li> <li>Could not pay gas/ electricity/telephone bill on time due to shortage of money</li> <li>Could not pay registration/ insurance on time due to shortage of money</li> </ol>	<p>No</p>	<p>Yes</p> <p><b>7 financial stress questions:</b>  <b>Since January 2006, did any of the following happen to you because of a shortage of money?</b></p> <ol style="list-style-type: none"> <li>Could not pay electricity, gas or telephone bills on time</li> <li>Could not pay the mortgage or rent on time</li> <li>Pawned or sold something</li> <li>Went without meals</li> <li>Was unable to heat home</li> <li>Asked for financial help from friends or family</li> <li>Asked for help from welfare organisations</li> </ol>	<p>Yes</p> <p><b>Financial stress and cashflow questions:</b></p> <ul style="list-style-type: none"> <li>Had days without money for basic living expenses in last 12 months</li> <li>Had days without money for basic living expenses in last 2 weeks</li> </ul> <p>Strategies to meet basic living expenses in last 12 months:</p> <ul style="list-style-type: none"> <li>Used short-term loans</li> <li>Pawned or sold something</li> <li>Did not have meals</li> <li>Sought assistance from welfare/community organisations</li> <li>Sought assistance from friends or family</li> <li>Ran up a tab (book up) at local store</li> <li>Gave someone else access to key card</li> </ul> <p>Cashflow problems:</p> <ul style="list-style-type: none"> <li>Could not pay electricity, gas, or telephone bills on time<sup>NR</sup></li> <li>Could not pay mortgage or rent payments on time<sup>NR</sup></li> <li>Could not pay for car registration or insurance on time</li> <li>Could not make minimum payment on credit card<sup>NR</sup></li> <li>Was unable to heat or cool the home<sup>NR</sup></li> </ul>

Table A2: Standard of living approach: availability of relevant variables in existing datasets (continued)

Variable	Household Expenditure Survey 2003–04	Survey of Disability, Ageing and Carers 2003	Household, Income and Labour Dynamics in Australia survey	National Aboriginal and Torres Strait Islander Social Survey 2002
Prosperity indicators—whether perceive oneself to be poor or how managing on one's income (Describe the indicators)	No	No	Yes Given your current needs and financial responsibilities, would you say that you and your family are: <ul style="list-style-type: none"> <li>• Prosperous</li> <li>• Very comfortable</li> <li>• Reasonably comfortable</li> <li>• Just getting along</li> <li>• Poor</li> <li>• Very poor</li> </ul>	No
Level of household savings (Yes or No)	Yes Thinking of [your/your household's] situation over the last 12 months, which one of the following statements best describes [your/your household's] situation? <ul style="list-style-type: none"> <li>• Spend more than we get</li> <li>• Just break even most weeks</li> <li>• Able to save money some weeks</li> </ul>	No	Yes Which of the following statements comes closest to describing your (and your family's) savings habits? <ul style="list-style-type: none"> <li>• Don't save: usually spend more than income</li> <li>• Don't save: usually spend whatever is left over at the end of the month—no regular plan</li> <li>• Spend regular income, save other income</li> <li>• Save regularly by putting money aside each month</li> </ul>	No
Location of household—ARIA index	State or territory of residence and whether resides in capital city or balance of state	State or territory and whether resides in major cities, inner regional or other areas	Yes—state or territory, remoteness, major statistical region and section of state	State and remoteness indicator

**Table A2: Standard of living approach: availability of relevant variables in existing datasets (continued)**

Variable	Household Expenditure Survey 2003-04	Survey of Disability, Ageing and Carers 2003	Household, Income and Labour Dynamics in Australia survey	National Aboriginal and Torres Strait Islander Social Survey 2002
Whether uses formal services to support person with disability	No	Yes	No	No
Number of formal services used	No	Yes	No	No

Note: NR=Non remote only data items.

**Table A3: Composition of the carer and non-carer samples: Wave 5 (2005)**

	Carer sample for analysis		Non-carers	
	n	Weighted %	n	Weighted %
Sample size	1,143		11,616	
Male	399	35.9	5,631	50.9
Female	744	64.1	5,985	49.1
Age (years)				
15–25	81	7.8	2,267	18.7
25–44	331	26.3	4,235	37.2
45–64	526	46.9	3,355	29.2
65 and over	205	18.9	1,759	14.9
Indigenous	33	3.1	243	1.9
Non-Indigenous	1,110	96.9	11,373	98.1
First language spoken English	994	80.2	10,462	85.5
First language not English	149	19.8	1,154	14.5
Housing tenure <sup>(a)</sup>				
Owner	482	42.6	3,888	34.5
Has mortgage	346	27.2	4,278	37.6
Private renter	194	17.6	2,637	20.5
Public renter	97	10.6	478	4.7
Other	24	2.0	328	2.5
Proportion of household income from government transfers				
<10%	444	37.6	7,398	63.3
10% to 50%	297	26.4	2,126	19.0
50% to 90%	172	14.3	951	8.0
>90%	230	21.7	1,141	9.7
Type of benefit received				
Carer Payment	182	17.1		
Disability Support Pension	82	8.2	426	4.0
Parenting Payment	79	6.3	352	2.8
Age Pension/Wife Pension/Service Pension Allowance	202	18.8	1,477	12.9
Not known	52	4.1	241	2.0
Employed full-time	338	28.2	2,519	44.5
Employed part-time	225	18.0	2,465	19.9
Unemployed	38	3.0	361	3.2
Not in the labour force	542	50.8	3,571	32.4
Education				
Bachelor degree or above	206	16.2	2,351	18.8
Certificate	347	30.1	3,409	28.9
Year 12	143	14.0	1,731	16.1
Less than Year 12	447	39.7	4,125	36.2
Household composition				
Couple only	370	31.8	3,163	26.2
Couple with children	383	35.1	4,623	42.9
Mixed family	132	11.6	888	8.1
Lone parent	142	14.2	961	8.8
Lone person	116	7.3	1,981	13.9

(a) Seven persons in the sample did not have information about household type and were not included in the analysis of this variable.

Note: Weighted using strata, cluster and cross-sectional responding person weights for Wave 5.

Source: HILDA release 6.0, Wave 5.

**Table A4: Composition of the carer and non-carer samples: Wave 6 (2006)**

	Carer sample for analysis		Non-carers	
	n	Weighted %	n	Weighted %
Sample size	1,207		11,698	
Male	434	39.0	5,646	50.6
Female	773	61.0	6,052	49.4
Age (years)				
15–25	83	5.8	2,348	18.9
25–44	347	27.6	4,182	36.8
45–64	550	47.1	3,363	29.3
65 and over	227	19.6	1,805	14.9
Indigenous	26	1.9	258	1.9
Non-Indigenous	1,181	98.1	11,440	98.1
First language spoken English	1,064	82.5	10,539	85.4
First language not English	143	17.5	1,159	14.6
Home owner	515	46.5	3,797	33.7
Has mortgage	373	29.2	4,344	37.8
Private renter	204	13.8	2,758	21.6
Public renter	84	8.0	475	4.5
Other housing tenure	31	2.6	324	2.4
Proportion of household income from government transfers				
<10%	520	39.7	7,279	62.0
10% to 50%	297	27.1	2,309	20.7
50% to 90%	174	13.9	1,003	8.1
>90%	216	19.3	1,107	9.2
Type of benefit received				
Carer Payment	170	13.8		
Disability Support Pension	74	6.9	430	3.9
Parenting Payment	86	6.2	347	2.7
Age Pension/Wife Pension/Service Pension Allowance	207	19.0	1,473	12.4
Not known	62	5.3	699	5.8
Not known	95	8.1	248	2.0
Employed full-time	370	29.4	5,265	45.1
Employed part-time	257	19.2	2,465	19.8
Unemployed	39	2.3	393	3.0
Not in the labour force	541	49.2	3,575	32.1
Education				
Bachelor degree or above	213	16.1	2,415	19.3
Certificate	380	30.6	3,441	29.2
Year 12	130	11.7	1,780	16.7
Less than Year 12	484	41.6	4,062	34.8
Household composition				
Couple only	398	32.1	3,134	25.7
Couple with children	423	36.5	4,650	42.4
Mixed family	152	12.1	955	8.8
Lone parent	123	12.3	952	9.1
Lone person	111	7.0	2,007	14.0

Note: Weighted using strata, cluster and cross-sectional responding person weights for Wave 6. Due to rounding, percentages may not add to 100 per cent.

Source: HILDA release 6.0, Wave 6.

**Definition of housing costs**

Housing costs are based on the variables in HILDA indicating the usual monthly repayment on the first and second mortgages on the house for those paying off their homes and the usual monthly rent for renters.

**Definitions of variables used in regressions**

Where possible, continuous variables are centred around their mean in the regression to give the intercept a more meaningful interpretation.

Age is entered in single years in the regression and centred around its mean of 44. Proportion of time spent employed is centred around a mean of 75.9 per cent and divided by 10 to provide a meaningful coefficient. Parental occupation is based on father's occupation when the person was aged 14 years according to the two-digit Australian Standard Classification of Occupations (ASCO) scale. If the father's occupation was not indicated, the mother's occupation was used. If neither was available the respondent was classified as parental occupation 'not known' for the regression analysis. Occupation was centred at its mean of around 45 and divided by 10 to gain a more meaningful coefficient. Wealth was centred around a mean of \$601,135 and divided by \$100,000. Income was centred around a mean of \$35,685 and divided by 10,000.

The intercept thus represents the probability of being in poverty for a non-carer, female, aged 44 years, non-Indigenous, first language spoken is English, without a disability, without a partner or children, with average proportion of time spent in employment, no years unemployed, of average class background (parental occupation and wealth) and earning an income of around \$35,685.

**Table A5: Logistic regression: effects of caring on before-housing income poverty**

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Intercept	-2.219	0.131	<i>p</i> <0.01	-2.223	0.130	<i>p</i> <0.01	-2.196	0.129	<i>p</i> <0.01
Male	0.161	0.067	<i>p</i> <0.05	0.168	0.067	<i>p</i> <0.05	0.153	0.067	<i>p</i> <0.05
Age	0.034	0.003	<i>p</i> <0.01	0.034	0.003	<i>p</i> <0.01	0.034	0.003	<i>p</i> <0.01
First language spoken not English	0.619	0.118	<i>p</i> <0.01	0.622	0.118	<i>p</i> <0.01	0.617	0.118	<i>p</i> <0.01
Indigenous	0.585	0.217	<i>p</i> <0.01	0.584	0.218	<i>p</i> <0.01	0.584	0.216	<i>p</i> <0.01
Has disability	0.434	0.086	<i>p</i> <0.01	0.435	0.085	<i>p</i> <0.01	0.440	0.085	<i>p</i> <0.01
Has partner (married or de facto)	-0.519	0.101	<i>p</i> <0.01	-0.522	0.101	<i>p</i> <0.01	-0.546	0.101	<i>p</i> <0.01
Number of children <15 years	0.014	0.060	n.s.	0.016	0.061	n.s.	0.020	0.061	n.s.
Education									
Degree	-1.017	0.146	<i>p</i> <0.01	-1.019	0.147	<i>p</i> <0.01	-1.024	0.148	<i>p</i> <0.01
Certificate	-0.364	0.088	<i>p</i> <0.01	-0.364	0.089	<i>p</i> <0.01	-0.361	0.090	<i>p</i> <0.01
Year 12	-0.353	0.107	<i>p</i> <0.01	-0.350	0.108	<i>p</i> <0.01	-0.357	0.108	<i>p</i> <0.01
% years employed (divided by 10)	-0.157	0.016	<i>p</i> <0.01	-0.157	0.015	<i>p</i> <0.01	-0.156	0.016	<i>p</i> <0.01
% years unemployed	0.011	0.003	<i>p</i> <0.01	0.011	0.003	<i>p</i> <0.01	0.011	0.003	<i>p</i> <0.01
Years in labour force unknown	0.678	0.117	<i>p</i> <0.01	0.680	0.117	<i>p</i> <0.01	0.664	0.119	<i>p</i> <0.01
Parental occupation (divided by 10)	-0.005	0.014	n.s.	-0.004	0.014	n.s.	-0.003	0.014	n.s.
Parental occupation unknown	0.053	0.186	n.s.	0.057	0.185	n.s.	0.043	0.185	n.s.
Wealth (\$100,000)	-0.095	0.031	<i>p</i> <0.01	-0.095	0.031	<i>p</i> <0.01	-0.093	0.031	<i>p</i> <0.01



**Table A6: Logistic regression: effects of caring on after-housing income poverty**

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Intercept	-2.135	0.142	p<0.01	-2.145	0.143	p<0.01	-2.127	0.143	p<0.01
Male	0.149	0.073	p<0.05	0.164	0.074	p<0.05	0.145	0.074	p<0.05
Age	0.015	0.003	p<0.01	0.150	0.003	p<0.01	0.015	0.003	p<0.01
First language not English	0.844	0.124	p<0.01	0.848	0.124	p<0.01	0.839	0.125	p<0.01
Indigenous	0.452	0.220	p<0.05	0.451	0.220	p<0.01	0.457	0.223	p<0.05
Has disability	0.397	0.084	p<0.01	0.399	0.084	p<0.01	0.400	0.084	p<0.01
Has partner (married or de facto)	-0.737	0.094	p<0.01	-0.736	0.094	p<0.01	-0.755	0.095	p<0.01
Number of children <15 years old	0.165	0.052	p<0.01	0.164	0.053	p<0.01	0.173	0.053	p<0.01
Education									
Degree	-0.475	0.127	p<0.01	-0.479	0.127	p<0.01	-0.481	0.127	p<0.01
Certificate	-0.114	0.087	n.s.	-0.117	0.087	n.s.	-0.111	0.088	n.s.
Year 12	-0.052	0.126	n.s.	-0.045	0.125	n.s.	-0.058	0.126	n.s.
% years employed (divided by 10)	-0.120	0.015	p<0.01	-0.121	0.015	p<0.01	-0.119	0.015	p<0.01
% years unemployed	0.012	0.003	p<0.01	0.011	0.003	p<0.01	0.012	0.003	p<0.01
Years in labour force unknown	0.598	0.134	p<0.01	0.605	0.134	p<0.01	0.590	0.136	p<0.01
Parental occupation (divided by 10)	0.000	0.013	n.s.	0.001	0.014	n.s.	0.000	0.014	n.s.
Parental occupation unknown	-0.045	0.238	n.s.	-0.028	0.240	n.s.	-0.052	0.238	n.s.
Wealth (\$100,000)	-0.078	0.034	p<0.05	-0.078	0.037	p<0.05	-0.078	0.037	p<0.05
All carers	0.120	0.120	n.s.						

Table A6: Logistic regression: effects of caring on after-housing income poverty (continued)

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Type of carer									
Co-resident primary			n.s.	0.086	0.160	n.s.			
Co-resident			$p < 0.1$	-0.762	0.429	$p < 0.1$			
Ex-resident primary			$p < 0.1$	0.656	0.371	$p < 0.1$			
Ex-resident			n.s.	0.275	0.202	n.s.			
Other <sup>(a)</sup>			n.s.	0.321	0.370	n.s.	0.314	0.384	n.s.
Carer for >4 hours a week			n.s.	0.087	0.315	n.s.	0.093	0.325	n.s.
Care recipient is:									
Spouse							0.450	0.206	$p < 0.05$
Parent							0.286	0.218	n.s.
Child <15 years old							-0.621	0.377	n.s.
Child >14 years old							-0.421	0.439	n.s.
Other relative							-0.469	0.341	n.s.
Other person							0.068	0.272	n.s.
<b>Sample size</b>	<b>12,826</b>			<b>12,826</b>			<b>12,826</b>		

(a) 'Other carers' are those who are work-affected carers or receiving Carer Payment or Carer Allowance but did not identify as a carer.

Notes: Weighted by strata, cluster and cross-sectional responding person weights; n.s.= not significant.

Source: HILDA release 6.0, Wave 6.

Table A7: Logistic regression: effects of caring on subjective poverty

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Intercept	-4.079	0.275	<i>p</i> <0.01	-4.081	0.247	<i>p</i> <0.01	-4.094	0.249	<i>p</i> <0.01
Male	0.118	0.133	n.s.	0.118	0.133	n.s.	0.123	0.132	n.s.
Age	0.001	0.006	n.s.	0.001	0.006	n.s.	0.001	0.005	n.s.
First language not English	0.114	0.228	n.s.	0.118	0.228	n.s.	0.114	0.227	n.s.
Indigenous	-0.563	0.423	n.s.	-0.566	0.424	n.s.	-0.579	0.427	n.s.
Has disability	0.759	0.163	<i>p</i> <0.01	0.760	0.163	<i>p</i> <0.01	0.760	0.163	<i>p</i> <0.01
Has partner (married or de facto)	-0.666	0.175	<i>p</i> <0.01	-0.671	0.175	<i>p</i> <0.01	-0.696	0.206	<i>p</i> <0.01
Number of children <15 years	0.096	0.088	n.s.	0.098	0.088	n.s.	0.111	0.088	n.s.
Education									
Degree	-0.117	0.249	n.s.	-0.119	0.247	n.s.	-0.104	0.246	n.s.
Certificate	0.186	0.167	n.s.	0.186	0.167	n.s.	0.197	0.168	n.s.
Year 12	-0.198	0.221	n.s.	-0.204	0.220	n.s.	-0.196	0.221	n.s.
% years employed (divided by 10)	0.035	0.030	n.s.	0.036	0.030	n.s.	0.035	0.031	n.s.
% years unemployed	0.015	0.005	<i>p</i> <0.01	0.015	0.005	<i>p</i> <0.01	0.015	0.005	<i>p</i> <0.01
Years in labour force unknown	-0.105	0.255	n.s.	-0.106	0.256	n.s.	-0.113	0.258	n.s.
Parental occupation (divided by 10)	-0.004	0.022	n.s.	-0.002	0.022	n.s.	-0.002	0.022	n.s.
Parental occupation unknown	-0.027	0.286	n.s.	-0.027	0.285	n.s.	-0.036	0.283	n.s.
Income (\$10,000) <sup>(a)</sup>	-0.358	0.064	<i>p</i> <0.01	-0.359	0.064	<i>p</i> <0.01	-0.358	0.063	<i>p</i> <0.01
Wealth (\$100,000)	-0.112	0.062	<i>p</i> <0.1	-0.112	0.062	<i>p</i> <0.1	-0.113	0.062	<i>p</i> <0.1
All carers	0.192	0.213	n.s.						

Table A7: Logistic regression: effects of caring on subjective poverty (continued)

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Type of carer									
Co-resident primary				0.280	0.287	n.s.			
Co-resident				0.098	0.547	n.s.			
Ex-resident primary				0.230	0.551	n.s.			
Ex-resident				0.564	0.353	n.s.			
Other <sup>(a)</sup>				-1.188	1.038	n.s.	-1.190	1.043	n.s.
Carer >4 hours a week				-0.351	0.541	n.s.	-0.343	0.541	n.s.
Care recipient is									
Spouse							0.528	0.351	n.s.
Parent							0.247	0.381	n.s.
Child <15 years old							-0.511	0.832	n.s.
Child >14 years old							0.505	0.524	n.s.
Other relative							0.877	0.434	<i>p</i> <0.05
Other person							0.254	0.434	n.s.
<b>Sample size</b>	<b>11,643</b>			<b>11,643</b>			<b>11,643</b>		

(a) 'Other carers' are those who are work-affected carers or receiving Carer Payment or Carer Allowance but did not identify as a carer.

Notes: Weighted by strata, cluster and cross-sectional responding person weights; n.s. = not significant.

Source: HILDA release 6.0, Wave 6.



Table A8: Logistic regression: effects of caring on financial stress (continued)

	Model 1 All carers			Model 2 Types of carers			Model 3 Care recipients		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Type of carer									
Co-resident primary				0.462	0.198	$p < 0.05$			
Co-resident				-0.344	0.394	n.s.			
Ex-resident primary				0.622	0.371	$p < 0.1$			
Ex-resident				0.876	0.202	$p < 0.01$			
Other <sup>(a)</sup>				0.174	0.362	n.s.	0.161	0.374	n.s.
Carer >4 hours a week				0.387	0.278	n.s.	0.377	0.293	n.s.
Care recipient is:									
Spouse							0.425	0.239	$p < 0.1$
Parent							0.505	0.240	$p < 0.05$
Child <15 years old							0.347	0.324	n.s.
Child >14 years old							-0.342	0.464	n.s.
Other relative							0.670	0.315	$p < 0.05$
Other person							0.807	0.286	$p < 0.01$
<b>Sample size</b>							<b>11,643</b>		<b>11,643</b>

(a) 'Other carers' are those who are work-affected carers or receiving Carer Payment or Carer Allowance but did not identify as a carer.

Notes: Weighted by strata, cluster and cross-sectional responding person weights; n.s.= not significant.

Source: HILDA release 6.0, Wave 6.

**Table A9: Logistic regression: effect of sociodemographic characteristics on carers' poverty**

	Before-housing income poverty			After-housing income poverty			Subjective poverty			Financial stress		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Intercept	-2.524	0.299	<i>p</i> <0.01	-2.894	0.357	<i>p</i> <0.01	-4.676	0.591	<i>p</i> <0.01	-2.884	0.426	<i>p</i> <0.01
Male	0.187	0.231	n.s.	0.232	0.216	n.s.	0.345	0.378	n.s.	0.564	0.238	<i>p</i> <0.05
Age	0.016	0.008	<i>p</i> <0.1	0.010	0.007	n.s.	0.006	0.012	n.s.	-0.025	0.008	<i>p</i> <0.01
First language spoken not English	1.323	0.277	<i>p</i> <0.01	1.307	0.293	<i>p</i> <0.01	0.330	0.567	n.s.	0.286	0.332	n.s.
Indigenous <sup>(a)</sup>	0.353	0.651		-0.244	0.550		-	-	-	-	-	-
Has disability	0.552	0.208	<i>p</i> <0.01	0.495	0.209	<i>p</i> <0.05	0.820	0.404	<i>p</i> <0.05	0.080	0.258	n.s.
Has partner (married or de facto)	-0.186	0.219	n.s.	-0.150	0.241	n.s.	-0.730	0.448	n.s.	-0.636	0.271	<i>p</i> <0.05
Number of children <15 years	0.030	0.100	n.s.	0.142	0.096	n.s.	0.264	0.167	n.s.	0.332	0.102	<i>p</i> <0.01
Education												
Degree	-0.836	0.389	<i>p</i> <0.05	0.450	0.325	n.s.	0.509	0.625	n.s.	0.769	0.426	<i>p</i> <0.1
Certificate	0.109	0.228	n.s.	0.206	0.254	n.s.	0.869	0.484	<i>p</i> <0.1	0.755	0.279	<i>p</i> <0.01
Year 12	0.101	0.341	n.s.	0.511	0.322	n.s.	-0.186	0.685	n.s.	0.347	0.373	n.s.
% years employed (divided by 10)	-0.144	0.042	<i>p</i> <0.01	-0.125	0.042	<i>p</i> <0.01	0.032	0.069	n.s.	-0.009	0.051	n.s.
% years unemployed	0.005	0.012	n.s.	0.004	0.010	n.s.	0.026	0.012	<i>p</i> <0.05	0.010	0.012	n.s.
Years in labour force unknown	0.300	0.388	n.s.	0.422	0.357	n.s.	0.591	0.586	n.s.	0.094	0.380	n.s.

Table A9: Logistic regression: effect of sociodemographic characteristics on carers' poverty (continued)

	Before-housing income poverty			After-housing income poverty			Subjective poverty			Financial stress		
	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance	Estimate	Standard error	Significance
Parental occupation (divided by 10)	-0.007	0.038	n.s.	-0.019	0.038	n.s.	-0.001	0.071	n.s.	-0.058	0.040	n.s.
Parental occupation unknown	0.463	0.472	n.s.	0.287	0.421	n.s.	1.014	0.801	n.s.	0.202	0.601	n.s.
Income (\$10,000)							-0.022	0.210	n.s.	-0.327	0.144	$p < 0.05$
Wealth (\$100,000)	-0.094	0.043	$p < 0.05$	-0.144	0.055	$p < 0.05$	-0.217	0.061	$p < 0.01$	-0.128	0.082	n.s.
<b>Sample size</b>	<b>1,205</b>			<b>1,205</b>			<b>1,100</b>			<b>1,100</b>		

(a) Indigenous variable not included in subjective poverty and financial stress regressions due to small numbers.

Notes: Weighted by strata, cluster and cross-sectional responding person weights; n.s.= not significant.

Source: HILDA release 6.0, Wave 6.



# List of shortened forms

ABS	Australian Bureau of Statistics
AMP.NATSEM	Australian Mutual Providence Society (former name); National Centre for Social and Economic Modelling (University of Canberra)
ARIA	Accessibility/Remoteness Index of Australia
ASCO	Australian Standard Classification of Occupations
BHPS	British Household Panel Survey (UK)
BSU	Budget Standards Unit
CALD	Culturally and linguistically diverse
DWP	Department for Work and Pensions (UK)
EU-SILC	European Union survey on income and living conditions
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
FES	Family Expenditure Survey (UK)
FRS	Family Resources Survey (UK)
HES	Household Expenditure Survey
HILDA	Household, Income and Labour Dynamics in Australia
HMSO	Her Majesty's Stationery Office (UK)
IVM	Itemised variant model
IZA	Institute for the Study of Labor (Germany)
MIAESR	Melbourne Institute of Applied Economic and Social Research
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NGOs	Non-government organisations
OECD	Organisation for Economic Co-Operation and Development
OLS	Ordinary least squares
QoL	Quality of life
SDAC	Survey of Disability, Ageing and Carers
SPRC	Social Policy Research Centre (University of New South Wales)
TOCC	Taskforce on Care Costs
UNSW	University of New South Wales



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