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Identifying isolated carers: Contacting carers with unmet needs for information and support

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IDENTIFYING ISOLATED CARERS CONTACTING CARERS WITH UNMET NEEDS FOR INFORMATION AND SUPPORT

FINAL REPORT FOR
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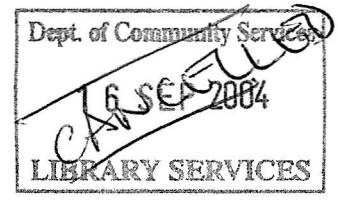

Identifying isolated carers: Contacting carers with unmet needs for information and support

Final Report for the Australian Research Council Linkage Grant project

Authors and Acknowledgements

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Michael Bittman, Kimberly Fisher, Trish Hill, Denise Thompson and Cathy Thomson

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Executive Summary

Introduction

This report presents the findings of an Australian Research Council (ARC) funded Linkage Project called 'Reaching isolated carers: Contacting carers with unmet needs for information and support'. The Industry Partners on this project were the New South Wales Department for Women, the NSW Department of Ageing, Disability and Home Care, the NSW Department of Community Services, NSW Health and Carers NSW.

For the purposes of the project, an 'isolated' or 'hidden' carer was defined either as a person who was providing informal (unpaid) care for someone unable to care for themselves but who did not self-identify as a carer, or a person who did identify as a 'carer' but who did not access formal services for assistance despite having high needs. Two methods of identifying 'isolated' carers were deployed, using innovative analyses of two surveys, the 1998 *Survey of Disability, Ageing and Carers* (SDAC) and the Australian Bureau of Statistics' (ABS) 1997 *Time Use Survey*

Background

According to the most recent official survey there are 2.3 million carers in Australia, the majority (56 per cent) of whom are women (ABS, 1999: 10). Like other industrialised countries, Australia has seen a shift in policy direction away from formal institutional care towards informal 'care in the community' (Bryson and Mowbray, 1981; Ungerson and Kember, 1997; Schofield et al, 1998; Fine, 1999). This increased emphasis on community care involves a number of factors, including concerns about the high cost of providing institutional care for an ageing population and for younger people with disabilities and those with mental illness, as well as an acknowledgement that those needing assistance prefer to live at home (Dalley, 1988). At the same time, feminist analysts of social policy have pointed out that community care policies rely on women's unpaid labour. The policy of care in the community represents a transfer of responsibility for care from the state to the family, which in practice means care provided by women (Land, 1978; Ungerson and Kember, 1997). Consequently, the public discussion of informal care has simultaneously praised the financial savings and the social benefits to be gained from informal care, and expressed anxiety about the demands placed on women carers (Brody, 1981; Finch and Groves, 1983; Schofield, et al, 1998).

It is well documented that caring can place significant stress upon carers and their relationships, and inhibit their social and economic participation. Carers often perform physically and mentally demanding tasks. They have low levels of social contact and little financial independence, and lower levels of employment, poorer health and higher levels of stress compared to non-carers of a comparable age in similar social circumstances (Brodaty and Hadzi-Pavlovic, 1990; Scholfield et al 1998: Watson and Mears, 1999). Research shows that community services designed to support carers can make a significant difference to their health and welfare (Thomson, Fine and Brodaty, 1997; Schofield et al, 1998; Braithwaite 1998; Watson and Mears, 1999; Parker, 2000; Zarit et al, 1998). Access to support and services may assist carers to preserve their health, wellbeing and social participation and enable them to sustain their caring role over a longer period of time. It may also help them to combine paid work with their caring activities. Maintaining labour force participation not only preserves

income security, it ensures greater independence over the whole course of a carer's life.

Despite the existence of formal services and the undoubted benefits to carers of using them, carers' service use remains low. Understanding why carers do not take up services is a complex issue and could be the result of a number of inter-related factors, including the lack of need, targeting policies or the characteristics of the services themselves. Prohibitive costs, inconvenient hours of operation or lack of availability may all contribute to low take-up of support services by carers (Beisecker, et al., 1996; Thomson, Fine and Brodaty, 1997; Knapman and Waite, 1997.). Moreover, there is reason to believe that services designed to support carers are not evenly distributed through Australia. Access to service provision is more difficult in regional and remote areas than in the capital cities, if for no other reason than the sheer distance involved.

One major reason for the low take-up of services, however, is the failure of carers to identify themselves as such. Research into the care of adults suggests that a sizeable part of the population of people providing care do not recognise themselves as carers or experience difficulty accepting that they have adopted a caring role (Misic 1996: 14 Thomson, Fine and Brodaty, 1997; Bittman et al. (in press); Bittman and Thomson 2000; Braithwaite 1990).

Some insight into the reasons why carers do not view themselves as carers is given in Graham's (1983) celebrated distinction between 'caring for' and 'caring about'. 'Caring for' is related to the physical tasks associated with providing assistance, while 'caring about' involves the emotional relationship between the carer and care recipient. Among carers who do not self-identify as carers, the dimension of 'caring for' is subsumed and concealed by the dimension of 'caring about' (Dalley, 1988). As Parker has pointed out, 'the term "carer" tends to obscure the relationship that usually predates the situation which led to the need to provide care' (Parker, 2000: 3). While services are targeted at those most in need of assistance, a major factor limiting the take-up of services is the failure of carers to identify themselves as carers and hence in need of assistance. This failure even to be aware of the need for support services is tantamount to being 'isolated'. Under these circumstances, it is difficult for those responsible for the delivery of services to know whether services are reaching those they are intended to support.

To date research on carers and service use has been limited to the study of the characteristics of those who use services (Twigg and Atkin; 1994; Braithwaite, 1998; Gill, Hinrichsen and DiGiuseppe, 1998). But without information about carers who are not currently using services although they need them, it is impossible to plan adequately for effective service delivery or equitable access to services. This study used two sources of information to identify the characteristics of isolated carers. Each is outlined below.

ABS Survey of Disability and Carers

One source of information for identifying the characteristics of carers who are not using community services is the ABS *Survey of Disability, Ageing and Carers* (SDAC) (ABS, 1999). This nationally representative survey of care recipients and self-identified carers provides extensive information on many aspects of the care

situation and the need for assistance and the use of informal and formal support by care recipients. This information provides an opportunity to identify the categories of carers who are not using formal services, as well as the factors that impede or promote service use by carers and hence the major gaps in service delivery.

The information contained in SDAC of specific relevance to this project is data on care recipients' use of formal services for assistance in each of nine activities of daily living and data on primary carers' use of respite services.

Although the focus of this analysis of SDAC is on the non-use of services is intended to identify isolated or hidden carers. Previous research has found that need factors play a significant role in determining formal service use (See Bass and Noelker 1987). One of the reasons that carers did not use services is because they did not need them This present analysis takes that possibility into account in order to define the factors other than need that were implicated with service non-use. It holds constant the 'need' characteristics in the care situation, such as degree of disability, intensity of caring, the sense of being burdened and the carer's health, while varying socio-demographic characteristics which could predispose or enable carers and their care recipients to make use of formal services (or alternatively, hinder them).

There are two clear findings from the analysis of community service use in Australia using the SDAC. First community services are more likely to be used by carers and care recipients who have high needs such as high levels of disability, carers reporting high levels of burden and those providing more intensive amounts of care. This may reflect the current targeting of services to carers who have higher needs or may suggest that carers themselves only seek help when their level of need is relatively high and perhaps at a crisis point. Second factors associated with low service use were also associated with disadvantage including youth, CALD background, low levels of education, low income, receipt of government benefit and living in relatively socio-economically disadvantaged areas.

There is relatively little information in SDAC on why it is that the majority of carers do not use formal community services to support them in their caring role. However, there is information about the reasons why primary carers do not use respite services. The majority of primary carers (55 per cent) said they did not use respite care because they did not need to. Only 13 per cent had ever used it. There were 6 per cent who said they did not use it because they did not want to, and another 6 per cent who said their care recipient did not want it. A further 12 per cent said they either 'did not know about it' or 'had not heard of it', while 4 per cent reported availability barriers. On this information it does not appear that the majority of primary carers experience an unmet need for services. Nonetheless, efforts could be made to address information and accessibility issues for the small proportion of primary carers (16 per cent) who gave these factors as reasons for not accessing respite care.

Time Use Survey

People who do not recognise their role as adult carers are not likely to emerge in the survey data including the SDAC that serve as the basis for policy on adult care to date. The ABS Time Use Survey provides a unique opportunity to locate the characteristics of carers who do not self-identify. Survey respondents are not only

asked whether or not they are carers, they are also asked to record their activities, what kinds of activities they are, and how long they spend doing these activities.

Time Use Survey data offer two possibilities for locating non-identified carers: noting people who answer that they are not adult carers to individual questionnaire items but who record adult care activities in their time diaries; profiling the time signatures of carers, then identifying other diarists who do not claim to be carers, who do not record adult care directly in their diaries, and who have no other obvious care responsibilities. This information can be used to identify a distinctive pattern of time-use by carers – a characteristic 'time signature' which can be used to identify isolated carers (Bittman and Thomson, 2000). Because individuals in the survey both self-identify as carers and report in their diaries on the care activities they do, it is possible to locate discrepancies between their activities and how they identify themselves.

The development of the time signature profile of carers confirmed six themes about the impact of care on the daily activities of carers which emerged in focus groups with carers conducted as part of a previous research project:

- Adult carers spend more time undertaking all forms of care activities and voluntary work than adult who are not carers;
- Adult carers engage in more episodes of domestic work and also spend more time performing domestic chores;
- Adult carers spend less time in paid work and personal care activities (particularly sleep);
- Adult carers have particularly busy days;
- Adult carers have less time for leisure activities, and tend to enjoy their free time in more frequent but shorter episodes than the rest of the Australian population. Self-identified primary carers and non-identified carers additionally are less likely to be able to eat out in restaurants;
- Adult carers give more of their time to others and have less time for themselves than other Australians.

This analysis found that adult care responsibilities even change the range of activities, which people most frequently perform on a daily basis. When diarists recorded adult care in their time diaries, they most often reported concentrating only on this care rather than performing adult care in conjunction with other activities. For the nearly 20% of adult care time that did include secondary activities, however, identified carers were more likely to report adult care as both a main activity and a secondary activity. Non-identified carers, in contrast, were more likely to record adult care only as a secondary activity done at the same time as they focussed on another activity.

Relatively few people aged less than 30 provide adult care, and young carers tend to differ markedly from older adult carers. Older carers are more likely to be women, to live in couples, to feel time pressured, to have a disability themselves, and either to not work or to work part-time. Self-identified primary cares and non-identified carers (both those who record adult care in their time diaries and possible carers) are more likely to rely on income support and family financial transfers as their main source of income.

Non-identified carers are more likely to be older, to live in households with a member needing care, and, curiously, also to live in households where a member has some university level education. The key issue may be education about services for carers – particularly for older carers, rather than a problem of general education.

Carers with Special Needs

The report also examines the characteristics of carers with special needs including carers with poor health, young carers and carers from CALD or ATSI backgrounds using where possible data from both the SDAC and the Time Use Survey.

Overall the findings of the multivariate analysis of carers with poor health using SDAC indicated a number of key points.

- The only factor that emerges as consistently associated with being a primary carer in poor health with a care recipient who is not using any support services is *being born in a country other than Australia or north-western Europe.*
- However, there is a strong association between the experience of 'carer burden' among primary carers with poor health, and the non-use of services by their care recipients.
- There is also a strong association between the care recipient's level of disability and service non-use among the care recipients of primary carers reporting poor health. Among primary carers with poor health, those whose care recipients have less severe levels of disability are less likely to make use of formal services than those whose care recipients have a 'profound' disability.
- Low income and living in a socio-economically disadvantaged area are also associated with less use of services among primary carers in poor health, although to a less consistent degree than the above three factors.

In terms of young carers the analysis of SDAC found that they were less likely to use formal services if:

- their youngest care recipient was under 45 years;
- they did not live in a lone parent household;
- they lived in relatively socio-economically disadvantaged areas
- they worked fulltime;
- they lived in a capital city; and
- their care recipient did not have a profound disability.

Young carers in the Time Use Survey are equally likely to be men or women. There is some indication that young people from minority groups are more likely to be carers and more likely to live in households in receipt of income support. The 'self-identified other carers' are more likely to work part-time or to be unemployed and not seeking work. 'Self-identified primary carers' are less likely to be students, and 'possible carers' are less likely to be unemployed.

Analysis of the characteristics of carers from CALD and ATSI backgrounds was not possible using data from SDAC or the Time Use Survey because the sample size of each of these groups was too small. However other qualitative research into barriers to

accessing services found that there were many common issues facing these carers. Many were unwilling to use services after having had a bad experience while others found that mainstream services were culturally inappropriate. Further quantitative data and research on the characteristics of carers from CALD and ATSI backgrounds is required.

Time Spent Caring

One aspect of the experience of being a carer involves the time requirements different groups of carers typically commit to this role. SDAC and the Time Use Survey, however, are national data sets, and include two different types of time estimates. SDAC asked primary carers if their typical weekly care commitment required fewer than 20 hours, 20 to 39 hours, or 40 or more hours of work, while the information recorded in the time diaries allows the summation of the time actually recorded as care. Moreover, information gained from the patterns of carers' daily activities can be used to build more precise estimates of the average time different groups of carers spend daily doing care-related activities.

The estimates of the weekly hours devoted to care differ considerably between the two surveys. These differences may in part arise from the different sample populations and the different means of data collection, or they may reflect limitations in either or both of the data sets. In particular, the level of hours in the three categories offered to respondents in the SDAC may have skewed results. Carers who perform around 13 or more hours of care per week may recognise that their caring responsibilities make a considerable impact on their week, and feel reluctant to choose the smallest category of time on offer. Time diary researchers often argue that diary-based estimates of most activities are more reliable than direct questions asking people to estimate the time they spend performing activities (Gershuny 2000; Niemi 1993); however, time diary data has been shown to significantly underestimate time spent performing child care (Ironmonger 2002). It may well be that time diaries also under-report adult care – especially by not capturing supervisory time or time where carers rearrange their schedules to be nearby to their care recipient in case their services are needed.

These limitations aside, the findings demonstrates that the caring role makes a significant impact on the daily lives of carers, as carers commit a median time of over an hour of care each day. Nearly half of all carer households perform the equivalent of part-time or full-time working hours to look after their friends and family members. Thus the costs to public service providers to replace such informal present care arrangements would be considerable.

Policy Implications

It is well documented that the use of appropriate support services by carers can assist them to maintain their caring role. One of the key aims of this project is to identify the demographic characteristics of carers who may be not be accessing services despite their evident need. Identifying these carers can assist policy makers to design and target services more effectively. There are a few key policy implications that follow from the findings of this report.

- Further investigation of why carers are not using community services is needed. This investigation should focus on three groups of carers who are less likely to be accessing community services:

  - younger carers (under 45 years of age);

  - carers from CALD backgrounds; and

  - carers who live in relatively more socio-economically disadvantaged areas.

- More information about respite and other community services needs to be disseminated, as there is a small but not insignificant group of carers and care recipients who are unaware of these services.
- Access to, and affordability of, community services needs to be addressed. Further analysis might be able to reveal which groups of carers find access and affordability a particular problem.
- There needs to be a general effort to encourage carers and care recipients to view community services as appropriate forms of support.
- The need to raise awareness and understanding about the issues involved in caring to assist carers to self-identify.

Future research

Given the limitations in the ABS data encountered in the course of this analysis using both the SDAC and Time Use Survey, it is clear there are gaps in the data on carers. In particular, there is a need for:

- more data on the service use of carers who do not live with the people they care for,
- more direct data on carers' perceptions of their need for services (and not just respite services) in their care situation,
- more data on Indigenous carers and carers from CALD backgrounds, and
- more data on the regional distribution of carers.

One way of gaining greater insight into the extent and distribution of caring in the community, and of the situation of carers from smaller population groups, is to go beyond sample surveys such as SDAC and include a question identifying carers in the Census.

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ARC	Australian Research Council
ATSI	Aboriginal and Torres Strait Islander
CALD	culturally and linguistically diverse
CURF	Confidentialised Unit Record File
DADHC	Department of Ageing, Disability and Home Care
IRSED	Index of Relative Socio-Economic Disadvantage
LGA	Local Government Area
LPA	Local Planning Area (of DADHC)
NESB	Non-English speaking background
OECD	Organisation for Economic Co-operation and Development
SDAC	ABS Survey of Disability Aging and Carers
SES	socio-economic status

1 Introduction

This report presents the findings of an Australian Research Council (ARC) funded Linkage Project *Reaching Isolated Carers: Contacting Carers with Unmet Needs for Information and Support*. For the purposes of the project, an 'isolated' or 'hidden' carer was defined either as a person who was providing informal (unpaid) care for someone unable to care for themselves but who did not self-identify as a carer, or a person who did identify as a 'carer' but who did not access formal services for assistance despite having high needs.

Two methods of identifying 'isolated' carers were deployed, using innovative analyses of two surveys, the 1998 *Survey of Disability, Ageing and Carers* (SDAC) and the Australian Bureau of Statistics' (ABS) 1997 *Time Use Survey*.

In the case of SDAC, the carers surveyed were either self-identified or identified as such by someone else in the household. It was clear that they *were* carers, and hence there was no question about their status *as* carers. However, they were 'isolated' carers to the extent that they used the formal community care services to a lesser extent than might have been expected given the level of need and the average usage among similarly placed carers. This aspect of the research project aimed to identify the needs and characteristics of those carers who were 'isolated' in this sense.

The definition of service non-use in the care situation in this analysis was two-fold. In the case of non-primary carers, it required only that the carer had at least one care recipient who needed assistance but did not use formal services for that activity; in the case of primary carers, it also included the non-use of respite services. The definition of service non-use was confined to those activities where a care recipient actually needed assistance; since not all care recipients needed assistance for all of the nine activities listed in SDAC (see Table 2.1).

The information from SDAC, together with data from the 1996 Census, was also used to map the geographical locations of 'isolated' carers throughout NSW (see Section 2.6).

The analysis of the ABS Time Use Survey was aimed towards the task of attempting to locate non-self-identified carers by means of a carer's 'time signature'. This involved investigating the daily activity patterns recorded in their time diaries by people who did identify themselves as carers, and then searching for other diarists who exhibited similar time signatures. By this means, it was hoped to estimate the size of the non-self-identified carer population (see Section 3).

The Industry Partners on this project were the New South Wales Department for Women, the NSW Department of Ageing, Disability and Home Care, the NSW Department of Community Services, NSW Health and Carers NSW.

Background

According to the most recent official survey there are 2.3 million carers in Australia, the majority (56 per cent) of whom are women (ABS, 1999: 10). Like other industrialised countries, Australia has seen a shift in policy direction away from formal institutional care towards informal 'care in the community' (Bryson and

Mowbray, 1981; Ungerson and Kember, 1997; Schofield et al., 1998; Fine, 1999). This increased emphasis on community care involves a number of factors, including concerns about the high cost of providing institutional care for an ageing population and for younger people with disabilities and those with mental illness, as well as an acknowledgement that those needing assistance prefer to live at home (Dalley, 1988). At the same time, feminist analysts of social policy have pointed out that community care policies rely on women's unpaid labour. The policy of care in the community represents a transfer of responsibility for care from the state to the family, which in practice means care provided by women (Land, 1978; Ungerson and Kember, 1997). Consequently, the public discussion of informal care has simultaneously praised the financial savings and the social benefits to be gained from informal care, and expressed anxiety about the demands placed on women carers (Brody, 1981; Finch and Groves, 1983; Schofield, et al., 1998).

In 1985 the *Home and Community Care Act* established joint Commonwealth-State responsibility for the delivery of domiciliary services to the frail aged and young people with disabilities. Since that time, there has been a steady increase in the number and type of community services provided, including Home Care, Community Nursing, Meals on Wheels, Community Transport and respite services.

Despite this, the policy cornerstone of human services is care in the home, not the provision of formal, publicly funded resources. Research has shown that formal services complement rather than substitute for informal care (Litwak 1985; Chappell and Blanford 1991). It is estimated that informal carers provide 74 per cent of all the care that enables disabled and older people to remain at home (DHSH 1995). According to the Australian Institute of Health and Welfare (AIHW), the estimated dollar value of unpaid caring labour is approximately double the expenditure on formal welfare services (1999: 32). Most authorities predict that the need for informal care will grow as the population ages and as government policies continue to emphasise de-institutionalisation and care in the community (National Commission of Audit, 1996; OECD, 1998; OECD, 1999).

Because informal carers remain the chief pillar of the system by providing the bulk of the support needed to keep the frail aged and young people with disabilities living at home (Department of Human Services and Health (DHSH), 1995), it is important to know who they are and what they need to enable them to continue caring. Operating against a background of finite resources, those responsible for planning human services want to be able to concentrate services for care recipients and their carers where they are most needed. Given that resources are limited, targeting strategies have emerged to direct services to those most in need. Yet there appear to be a significant number of carers who would benefit from the support of community services but who do not take them up (McCabe et al., 1995; Yeatman, 1996; Schofield et al, 1998). Moreover, those who require care but who do not have carers are often seen as having more urgent needs than those who already have carers (Parker, 1990; Bebbington and Davies, 1993). This can result in scarce services being directed away from carers.

It is well documented that caring can place significant stress upon carers and their relationships, and inhibit their social and economic participation. Carers often perform physically and mentally demanding tasks. They have low levels of social contact and little financial independence, and lower levels of employment, poorer health and

higher levels of stress compared to non-carers of a comparable age in similar social circumstances (Brodaty and Hadzi-Pavlovic, 1990; Scholfield et al., 1998: Watson and Mears, 1999). Research shows that community services designed to support carers can make a significant difference to their health and welfare (Thomson, Fine and Brodaty, 1997; Schofield et al, 1998; Braithwaite 1998; Watson and Mears, 1999; Parker, 2000; Zarit et al., 1998). Access to support and services may assist carers to preserve their health, wellbeing and social participation and enable them to sustain their caring role over a longer period of time. It may also help them to combine paid work with their caring activities. Maintaining labour force participation not only preserves income security, it ensures greater independence over the whole course of a carer's life.

Without support and information on how to access services, carers may be unable to continue caring. The use of community services by the carer or care recipient may reduce the pressures on carers and assist them to maintain their caring role. It may also reduce the incidence of crisis in their care situation and hence the likelihood of inappropriate and premature institutionalisation of the care recipient.

Moreover, information on the types of carers who are not accessing formal services would help in the design of appropriate information campaigns and targets for service delivery. By identifying groups of carers and factors associated with service non-use, service providers would be able to improve the targeting of the resources available to support carers.

Isolated carers

Despite the existence of formal services and the undoubted benefits to carers of using them, carers' service use remains low. Understanding why carers do not take up services is a complex issue and could be the result of a number of inter-related factors, including the targeting policies discussed above. Service use may also be inhibited by the characteristics of the services themselves. Prohibitive costs, inconvenient hours of operation or lack of availability may all contribute to low take-up of support services by carers (Beisecker, et al., 1996; Thomson, Fine and Brodaty, 1997; Knapman and Waite, 1997). Moreover, there is reason to believe that services designed to support carers are not evenly distributed through Australia. Access to service provision is more difficult in regional and remote areas than in the capital cities, if for no other reason than the sheer distance involved.

One major reason for the low take-up of services, however, is the failure of carers to identify themselves as such. Research into the care of adults suggests that a sizeable part of the population of people providing care do not recognise themselves as carers (Misic 1996; Thomson, Fine and Brodaty). A project funded by Carers NSW in 1995, which aimed to uncover the needs of carers from non-English-speaking backgrounds (NESB[1]), found that around 14 per cent of the NESB carers surveyed did not see themselves as carers (Misic 1996). Focus groups conducted for a previous ARC project by the SPRC and Carers NSW, as well as previous qualitative research

[1] People from non-English speaking backgrounds (NESB) are now referred to as people from culturally and linguistically diverse backgrounds (CALD). The findings reported here refer to people from NESB as this was the conventional terminology used when the research was conducted.

conducted in Australia and reviews of the literature from other countries about the circumstances faced by carers, have revealed that some carers experience difficulty accepting that they have adopted a caring role (Bittman et al., (in press); Bittman and Thomson 2000; Braithwaite 1990).

There are many reasons why some carers do not see themselves as carers. The processes by which many adults come to need care often entail tragic or distressing elements. Denial of the nature of the problems faced by their loved ones, and hence of their entry into the caring role, can serve as a coping strategy for some carers. Some adults develop a need for care slowly over time as a consequence of gradual deterioration caused by a mild form of a chronic illness or by aging, and both the people needing and those providing care may simply not recognise that the accumulation of minor adjustments which they have made to their lifestyles over a long period have reached a level that has transformed their relationship into one of carer and care recipient. Developed countries have tended to place little economic value on the provision of care to adults. This is reflected in the increasing tendency of governments across the OECD to encourage families to provide an increasing share of adult care on an unpaid and informal basis in the home, and in the generally low wages paid to most workers in the adult care sector of the workforce (Hennessy 1997; Jacobzone 1999; Jenson and Jacobzone 2000). While family members – particularly women – often feel expected to assume the role of carer when a friend or family member needs help, public discourse about the role of being a carer offers little guidance to new carers (Bittman et al., (in press); Braithwaite 1990). In consequence of the limited discourse around caring, and of the relatively low economic value attached to this work, some carers may feel reluctant to adopt this identity. A number of OECD governments have grown increasingly concerned about the cost of expenditure on the needs of the aging population and people with disabilities, and many have adopted cost-cutting measures by tightening criteria to receive care-related benefits (Neysmith 2000). Some people providing care who apply for assistance and then are told that they do not meet the qualifying criteria may conclude that they will not actually become carers until their circumstances do meet the revised criteria.

Moreover, some carers assume that the activities of caring are simply those expected of any spouse, parent, child or friend of the care recipient. Earlier research with focus groups revealed that many carers viewed caring activities simply as domestic chores, no different in kind from the other tasks they performed as part of running a household (Bittman and Thomson, 2000).

Some insight into the reasons why carers do not view themselves as carers is given in Graham's (1983) celebrated distinction between 'caring for' and 'caring about'. 'Caring for' is related to the physical tasks associated with providing assistance, while 'caring about' involves the emotional relationship between the carer and care recipient. Among carers who do not self-identify as carers, the dimension of 'caring for' is subsumed and concealed by the dimension of 'caring about' (Dalley, 1988). As Parker has pointed out, 'the term "carer" tends to obscure the relationship that usually predates the situation which led to the need to provide care' (Parker, 2000: 3). While services are targeted at those most in need of assistance, a major factor limiting the take-up of services is the failure of carers to identify themselves as carers and hence in need of assistance. This failure even to be aware of the need for support services is tantamount to being 'isolated'. Under these circumstances, it is difficult for those

responsible for the delivery of services to know whether services are reaching those they are intended to support.

Method

General

The project aimed to use a newly developed method for identifying isolated carers with unmet needs, even where they do not self-identify as carers. It built on previous qualitative and quantitative research conducted by Cathy Thomson, Michael Bittman and Kate Norris at the Social Policy Research Centre (SPRC).

To date research on carers and service use has been limited to the study of the characteristics of those who use services (Twigg and Atkin; 1994; Braithwaite, 1998; Gill, Hinrichsen and DiGiuseppe, 1998). But without information about carers who are not currently using services although they need them, it is impossible to plan adequately for effective service delivery or equitable access to services.

SDAC

One source of information for identifying the characteristics of carers who are not using community services is the ABS *Survey of Disability, Ageing and Carers* (SDAC), (ABS, 1999). This nationally representative survey of care recipients and self-identified carers provides extensive information on many aspects of the care situation and the need for assistance and the use of informal and formal support by care recipients. This information provides an opportunity to identify the categories of carers who are not using formal services, as well as the factors that impede or promote service use by carers and hence the major gaps in service delivery.

The information contained in SDAC of specific relevance to this project is data on care recipients' use of formal services for assistance in each of nine activities of daily living (see Table 2.1), and data on primary carers' use of respite services. The data on care recipients and the data on their carers are not automatically linked in SDAC, and hence complex manipulations of the SDAC Confidentialised Unit Record File (CURF) were needed in order to create care dyads in which each carer was connected with her/his care recipient(s) as one unit. This enabled the totality of each care relationship to be investigated, and provided a more complete picture of formal service use than focusing on care recipients alone.

Although the focus of this analysis of SDAC on the non-use of services is intended to identify isolated or hidden carers. Previous research has found that need factors play a significant role in determining formal service use (See Bass and Noelker 1987). One of the reasons that carers did not use services is because they did not need them (see Figure 2.3). This present analysis takes that possibility into account in order to define the factors other than need that were implicated with service non-use. It holds constant the 'need' characteristics in the care situation, such as degree of disability, intensity of caring, the sense of being burdened and the carer's health, while varying socio-demographic characteristics which could predispose or enable carers and their care recipients to make use of formal services (or alternatively, hinder them) (See Table 2.7 and Table 2.8). Identifying such characteristics could help policy makers to develop more accessible and better targeted services for specific socio-demographic groups within the carer community.

Maps

Lack of information about the effect of location on the provision of services is currently inhibiting the effective planning of human services. Developing more reliable indicators of the needs of isolated carers for services by location will be one of the practical outcomes of this project

Initially, the project aimed to use SDAC and Time Use Survey data to identify the socio-demographic characteristics of carers who were not using formal services, in order to develop models that could predict which carers within the total population would be more likely not to use services. It was intended to use imputations based on these models, together with regional data from the Census, to map the regional distribution of carers who were not using formal services. For the predictions to be robust, it was essential that these carers displayed some distinctive characteristics when compared to the rest of the population. However, extensive investigation failed to identify any such distinctive characteristics. This finding can be explained by the sheer diversity of the carer population due to the fact that anyone, at any point in time, can become a carer due to accident or misfortune.

Nonetheless, despite the limitations imposed by the data on producing complex prediction models, it was possible to generate maps providing *indicative* locations of regions in NSW where carers who were less likely to be using services were living. These maps were based on the socio-economic status of the carer's local area from the 1996 Census, and the estimated prevalence of carers in the population for each region from SDAC.

Time use

The ABS Time Use Survey provides a unique opportunity to locate the characteristics of carers who do not self-identify. Survey respondents are not only asked whether or not they are carers, they are also asked to record their activities, what kinds of activities they are, and how long they spend doing these activities. This information can be used to identify a distinctive pattern of time-use by carers – a characteristic 'time signature' which can be used to identify isolated carers (Bittman and Thomson, 2000). Because individuals in the survey both self-identify as carers and report in their diaries on the care activities they do, it is possible to locate discrepancies between their activities and how they identify themselves.

Data from the ABS *1997 Time Use Survey* (ABS, 1998) (collected through respondents completing diaries) were used to devise an innovative technique based on 'time signatures' for identifying 'isolated' carers and the hidden dimensions of their care-giving. This component of the project built on the success of a previous collaboration (with Carers NSW) sponsored by the ARC. This earlier project used a mixture of qualitative and quantitative methods to study how caring for a frail adult or a child with disabilities affected the daily activities of carers. A key finding was that the effect of being a carer on daily activities is subtle. Few carers named their activities as 'caring', describing them instead as domestic activities undertaken on their own behalf as well as on behalf of the care recipients (Bittman and Thomson, 2000). It was this that led to the formulation of the notion of a carer's 'time signature' (a specific pattern of time-use) that would allow analysts and policy makers to recognise carers who do not self-identify as such.

Outline of Report

Section 1 outlines the background to the project and the methods used. Section 2 examines the characteristics of carers not using services analysing the SDAC. Following this in Section 3 is an attempt to profile identified and non-identified carers using the Time Use Survey data. Section 4 examines the characteristics of carers with special needs. Next is a discussion of the estimated time spent in daily activities based on analysis of the preceding Sections. The final Section summarises the main findings, and discusses policy implications and future research questions.

2 The Survey of Disability, Ageing and Carers

This section of the report uses the 1998 ABS *Survey of Disability Ageing and Carers* (SDAC), (ABS, 1999) to identify the characteristics of carers who are not using community services. The information from this survey provides an opportunity to identify the categories of carers who are not using formal services, as well as the factors that either impede or promote service use by carers. This involved a multivariate analysis of the data on non-use of formal services by care recipients and of respite care by primary carers.

SDAC is a national survey that collects information on the prevalence of disability and the need for support of persons with disabilities and of aged persons, and on their demographic and socio-economic characteristics. Care recipients are asked whether assistance is provided by an informal carer or by formal services and, if they are not using formal services, why they are not. The survey also collects information about the carers and the caring situation, including the need for and use of respite services and the reasons for not using respite services. (In the case of respite services, the information relates only to primary carers because only primary carers were given an extra questionnaire to fill in as part of the survey).

The survey has been conducted every five years since 1981, the most recent in 1998. It contains the most comprehensive and representative data in Australia about persons who are frail aged or have disabilities or long-term illnesses, and their carers. In particular, it provides extensive information on the need for assistance, and the formal and informal support received by individuals in the context of their caring situation.

While it is the most comprehensive data on service use in Australia, only in the case of co-residential carers was it possible to link the information on service use in the care recipients' disability file with their carers' household and personal information. Hence, this present analysis is confined to situations where care recipients actually live with their carers. Currently in Australia there is no major survey that provides information about the service use by carers and care recipients who reside in separate households.

The ABS makes a distinction between 'carers' and 'primary carers', a difference based on the intensity of the care given – '*any* informal assistance' in contrast to '*the most* informal assistance' (see below). Among those defined in the 1998 SDAC as 'carers', co-residents comprised approximately 75 per cent, while among the 'primary carers' 80 per cent were co-resident. This may be an overestimate of the proportion of co-resident carers, as the 1997 *Time Use Survey* found that co-residential carers comprised only 63.4 per cent of primary carers (who were called 'principal carers' in that survey – the terminology is equivalent to 'primary' in the 1998 SDAC). The Time Use Survey also found that around 7 per cent of the total population were carers for someone outside the home, in contrast to SDAC which found that only 3.6 per cent of the population were carers for persons living elsewhere. The discrepancies may be a consequence of the ways in which carers were identified in each of the surveys. In SDAC they were identified by 'any responsible adult', and this person may not have been aware of the extent of caring by all persons in the household. In contrast, in the Time Use Survey carers were asked to self-identify. Moreover, the types of assistance defined as 'care' may have been less stringent in the latter survey than in SDAC.

2.1 Data

Definitions and samples

There is no simple 'yes' or 'no' answer to the question of whether or not carers access formal services to help their care recipients in activities of daily living – there are too many factors involved. SDAC, for example, asks care recipients if they require assistance for each of nine activities (outlined in Table 2.1), and the data show that not all care recipients need help for all nine activities. Moreover, what is associated with the non-use of services is not the individual carer, but certain characteristics that are more likely than others to mean that carers will not access services. These are the independent variables described in Section 2.2 that may or may not influence whether carers access formal help. Hence the question of which carers do not use services for what activities has multiple answers.

Carer

A 'carer' is defined by the ABS for the purposes of the 1998 SDAC as 'a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or persons who are elderly (i.e. aged 60 or over). The assistance has to be ongoing, or likely to be ongoing, for at least six months'. The ABS goes on to say that, in the case of carers living in different households from their care recipients, the survey provides no specific information about the types of activities the carers perform. Assistance by ex-resident carers is referred to simply as 'everyday types of activities' without specific information on what kinds of activities they are; while in the case of carers living in the same households as their care recipients, information is collected on all nine of the activities listed in Table 2.1 (ABS, 1999: 65).

In the 1998 SDAC there were 4727 carers (2055 male and 2672 female). Of these, around 75 per cent (3535 - 1702 male and 1833 female) were co-resident carers. In this present analysis, 20 of these carers were excluded from the sample as they were caring for persons who did not have information on service use in the disability level file. After discussion with the research partners, it was decided to exclude from this analysis as well carers under the age of ten, although the age of the youngest carers identified by services is six years (Commonwealth Department of Family and Community Services, 2002, p.10). Carers NSW operates with a definition of carers aged seven and upwards, but it was not possible to include carers aged seven to nine years as the age groups in the SDAC are in five-year intervals. There were 54 carers aged five to ten. Subtracting these from the total number of co-resident carers, together with the 20 carers mentioned earlier, leaves a sample of 3461 co-resident carers for this present analysis.

Primary carer

Amongst the carer sample is the subset of primary carers. A primary carer is defined as 'a person of any age who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care)' (ABS, 1999: 71).

In the 1998 SDAC there were 918 primary carers, of whom 726 were co-resident. All were 10 years of age or older. Three primary carers were deleted from the sample as their care recipients did not appear in the disability level file and thus there was no information on the care recipient's service use. This present analysis is conducted on the remaining 723 primary carers who lived with their main care recipients. Of these co-resident primary carers, 623 (86 per cent) lived with one care recipient, 99 (13 per cent) lived with two care recipients, two primary carers (0.5 per cent) lived with three care recipients, and one lived with four care recipients (0.1 per cent).

Activities

The nine activities for which care recipients required assistance, and for which information was collected in SDAC, are outlined in Table 2.1 below. For the first five of these activities – self-care, housework, meal preparation, paperwork and property maintenance – all care recipients in the SDAC sample required assistance. Because the sample was one hundred per cent for all of these activities, they have been grouped together for most of the analyses described below into a single category called 'five activities'. For the other four activities only some care recipients needed assistance, giving a different sample size for each of these activities, and so they are treated separately.

Samples for multivariate analysis

Hence, there were eight samples used in the analysis: four sets of carers and four sets of primary carers, grouped according to the activities for which the formal services were required. One set each of carers and primary carers comprised those whose care recipients needed assistance for the 'five activities' mentioned above, while there were three sets each for each of the other activities where the sample size was smaller – 'mobility', 'health care' and 'transport'. The activity of 'communication' was not included because the sample size was too small for multivariate analysis. In the case of the primary carer samples, respite care was considered as well as the other formal services, in order to identify those primary carers who were not receiving support from any source.

The next two tables report the percentage of both carers (Table 2.2) and primary carers (Table 2.3) who had care recipients needing assistance for each of the activities, as well as the sample size for each analysis and the percentage of carers whose care recipients did not use formal services for the activities. Column one in each table reports the weighted proportions of carers who had care recipients who needed help in that particular task. Column two reports the number of cases in each sample. Column three reports the percentage of carers whose care recipients needed assistance and did not use any formal services. For example, in the case of the primary carers Table 2.3 shows that 76.0 per cent (538 primary carers) were caring for someone who needed assistance for health care. Of these 538 primary carers, 46 per cent did not use formal services for 'health care'.

Table 2.1 Activities and tasks in SDAC 1998

Activity	Tasks
Self-care	Showering/bathing
	Dressing
	Eating
	Toiletting
	Bladder/bowel control
Housework	Household chores such as:
	Washing
	Vacuuming
	Dusting
Meal preparation	Preparing ingredients
	Cooking food
Paperwork	Reading/writing tasks such as :
	Checking bills/bank statements
	Writing letters
	Filling in forms
Property maintenance	Changing light bulbs/tap washers/car registration stickers
	Making minor home repairs
	Mowing lawns/watering/pruning shrubs/light weeding/planting
	Removing rubbish
Communication	Understanding family/friends
	Being understood by family/friends
	Understanding strangers
	Being understood by strangers
Mobility	Getting into/out of bed/chair
	Moving about usual place of residence
	Moving about a place away from the usual residence
Health care	Foot care
	Taking medications/administering injections
	Dressing wounds
	Using medical machinery
	Manipulating muscles or limbs
Transport	Going to places away from the usual place of residence

Source: ABS, 1999: 59

Table 2.2 Need for services, sample sizes and service non-use among care recipients of co-resident carers

	Carers		
Activity	**Need assistance for task[a] %**	**Sample size for analysis**	**Service non-use [b] %**
Five activities[c]	100	3461	79.1
Health care	47.9	1653	54.4
Mobility	44.6	1525	75.3
Transport	44.6	1508	83.4
Communication	14.9	516	39.5

Source: ABS, 1999

Notes:

a. Percentage of co-resident primary carers who have care recipients who need assistance
b. Percentage of co-resident primary carers who have care recipients who need assistance and do not use formal services or respite care.
c. Five activities are housework, meal preparation, paperwork, property maintenance, self-care

All percentage estimates are weighted by carer weights

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Table 2.3 Need for services, sample sizes and service non-use among care recipients of co-resident primary carers.

	Primary carers		
Activity	**Need assistance for task[a]**	**Sample size for analysis**	**Service non-use [b]**
	%		%
Five activities[c]	100	723	62.1
Health care	76.0	538	46.0
Mobility	79.9	572	63.7
Transport	65.3	463	69.4
Communication	28.3	204	27.5

Notes: As for Table 2.2
All percentage estimates are weighted by primary carer weights

Limitations of the data

There are a number of important qualifications to the analysis that must be noted at the outset.

Underestimate of carers

The first of these is that, while SDAC contains the most comprehensive data on carers in Australia, it probably underestimates the actual number of carers because the carers in SDAC were identified by a single 'responsible adult' in the household instead of being self-identified. It is possible that the person who answered the question may not have been aware of the extent to which someone else might have engaged in caring activities. An additional factor is that some carers do not recognise the activity they are doing as care, seeing it instead as simply part of their domestic or familial role, and hence not identifying themselves as carers. Given these two factors, there may be carers who have not been identified in SDAC and as such the analysis may not be comprehensive.

Co-resident carers only

As already mentioned, a further limitation of the SDAC data is that the information about service use is confined to co-resident caring situations. There is no information on the service use of care recipients who do not live with their carers. Although co-resident carers comprised the majority of carers in SDAC – 80 per cent of the primary carers and 75 per cent of the carers – they were by no means the whole population of carers covered by that survey. The literature suggests that co-resident carers may have lower levels of service use due to the targeting of services to carers and care recipients who live apart (Parker, 1990; Bebbington and Davies, 1993).

Aboriginal and Torres Strait Islander (ATSI) carers and carers from culturally and linguistically diverse (CALD) backgrounds

Another important qualification is that the SDAC sample size is not large enough to allow a detailed analysis of Aboriginal and Torres Strait Islander (ATSI) carers or of carers from culturally and linguistically diverse backgrounds (CALD) backgrounds due to the small numbers of these groups in the sample. Moreover, the proxy for CALD background is 'born in Asia, Africa, the Americas and South-eastern Europe', i.e. in a country other than Australia or north-western Europe. Countries in the 'Australia' category are Australia, New Zealand and Oceania (and Antarctica). Countries included in the north-western Europe category are: UK, Ireland, Austria, Belgium, France, Germany, Liechtenstein, Luxembourg, Monaco, Netherlands, Switzerland, Denmark, Faeroe Islands, Finland, Greenland, Iceland, Norway and Sweden. It is assumed that people born in countries other than these are less likely to have English language skills. But given that it was not possible to separate out North from South America, this proxy has its limitations.

Quantities of services used

Another limitation with the data is that it is only possible to discern whether or not services were used. It is not possible to determine how often or for how long the services were used by carers and their care recipients.

2.2 Method

To conduct this analysis of the SDAC data it was first necessary to create a data set in which the information on carers was linked with the information on their care recipients. This involved the construction of 'care units', each of which comprised one household of carers and their care recipients. This was a complex process, as within a household there can be more than one person caring for a care recipient, and one carer might provide assistance to more than one other household member. Moreover, carers themselves might be recipients of care from others within the household. The resulting data set thus contained care dyads with comprehensive information about the characteristics of the carer and care recipient, as well as service use information.

In this analysis, logistic regression was used to identify the factors that had the strongest association with community service non-use. This technique enables the analyst to consider the impact on service non-use of a number of factors simultaneously, and to identify factors that have an independent effect on it.

Construction of the dependent variables

The dependent variables were dichotomous variables indicating whether the carer was 'isolated' or not from formal services. Thus, the variables were coded 'one' if the carer *did not* have any care recipients who used formal services, and zero if they did use formal services. In the case of primary carers, the non-use of respite services by the primary carer was also a factor included in the definition of 'isolation' from services.

Construction of independent variables

Bi-variate analyses were used to identify those factors (the independent variables) likely to have an influence on service use and non-use (the dependent variable), and hence those population subgroups who were more likely not to use formal services.

This produced a range of 23 potential variables for multivariate analysis (see Table 2.4).

As already mentioned in Section 1, one of the main reasons why carers do not use services is because they do not need them. In order to allow for that possibility, this analysis holds constant the 'need' characteristics of the care situation, while varying socio-demographic characteristics that could predispose or enable (or hinder) carers and their care recipients to make use of formal services. The characteristics of the care situation were classified according to a conceptual framework suggested by Andersen and Newman (1973) into 'predisposing', 'enabling' or 'need' variables. 'Predisposing' variables are socio-demographic characteristics existing prior to the onset of the care situation that may predispose the carer to use services, such as the age or sex of the carer. 'Enabling' variables are those characteristics that may facilitate or inhibit the use of services, e.g. income. 'Need' variables are characteristics specific to the care situation such as the degree of disability or the level of caregiver burden. The variables thus identified and potentially included in the multivariate analyses are shown in Table 2.4 below. Some of the variables were available only for primary carers (as indicated in Table 2.4), because only the primary carer respondents to SDAC filled in a separate written questionnaire about their experiences of the care situation, including their use of respite care.

Table 2.4 Potential independent variables for the multivariate analyses

Category	Variable
The predisposing variables (characteristics that exist prior to onset of caring relationship and may predispose the carer to use services) are:	1.Sex of carer 2.Age of carer 3.Marital status of carer 4.Household composition 5.Birthplace of carer 6.Highest educational qualification of carer 7.Disability status of carer 8.Whether carer has a long–term health condition 9.Relationship of carer to care recipient 10.Whether carer speaks to care recipient in English **
The enabling variables (characteristics that facilitate the use of services) are:	11.Personal income of the carer 12.Main source of cash income of the carer 13.ISRED of the carer's local area 14.Employment status of carer 15.Geographical location of carer
The need variables (characteristics that are specific to the care situation) are:	16.Sex of the care recipient 17.Age of the youngest care recipient 18.Highest disability level of care recipients in household 19.Number of care recipients 20.Hours spent actively caring** 21.Whether carer has a fall-back informal carer** 22.Whether carer reports a relatively high level of 'carer burden'** 23.Whether carer reports having relatively poor health (physical and emotional)**

Notes: Variables marked with ** are available for the primary carers only

'Carer burden' index

As well as providing extra variables for the analysis, the information in the questionnaire has been used to create a 'carer burden' index of the extent to which the carer is negatively affected by their caring role. There are five domains in which carers could find themselves burdened by their caring role: employment, finances, physical/emotional wellbeing, social life and time. The literature also distinguishes between objective and subjective aspects of burdens, objective in the sense of things that happen (stressors), and subjective in the sense of the ways in which people respond to what happens (appraisal).

The data collected by the questionnaire gave 18 potential indicators of care burden. Fifteen of these variables were highly related in a test for internal reliability (Cronbach's Alpha = 0.85), and carers were regarded as experiencing a relatively high burden if they reported five or more of these fifteen indicators. While this was an arbitrary decision, the sensitivity of this threshold was tested by using different thresholds in the regression models. The results were similar for thresholds ranging from 3 to 6 indicators, and thus the decision was considered relatively robust. Fifty per cent of primary carers scored five or more on the index. They are thus classified as experiencing a relatively high burden. The indicators are listed in Table 2.5 below.

Table 2.5 Carer burden indicators

Domain	Indicator (due to the caring role)
Emotional	1. The carer had been diagnosed with a stress-related illness.
	2. The carer frequently felt weary or lacked energy.
	3. The carer frequently felt worried or depressed.
	4. The carer frequently felt angry or resentful.
	5. The carer did not feel satisfied.
Social/Time	6. The carer had lost touch or was losing touch with friends.
	7. The relationship between carer and care recipient had become strained.
	8. The carer had less time for relationships with co-resident family members or the relationships with family members had become strained.
	9. The carer had less time for relationships with spouse/partner or the relationship with spouse/partner had become strained.
Financial	10. The carer's income had decreased or the carer had extra expenses.
	11. The carer had difficulty with everyday living costs.
Physical/emotional	12. The carer's physical or emotional wellbeing had changed.
	13. The carer needed more support in caring role.
	14. The carer had sleep interrupted by caring role (frequently, occasionally or frequency not stated)
	15. Sleep interrupted interfered with normal daily activities frequently or occasionally
Variables considered but not included after assessment were:	• Carer had difficulty or was unable to take public transport when accompanied by care recipient.
	• Carer regularly paid a significant part of the recipient's living costs.
	• The caring role was the main reason carer was not working.

'Poor health' index

An index of 'poor health' was also included in the analysis. It was compiled from the responses to the twelve questions in a self-assessment health questionnaire (SF-12) completed by primary carers. The physical and mental component summary scores in SDAC have also been included in the index. Cronbach's alpha for this group of

indicators is 0.88. Carers were considered to have relatively poor health if they reported three or more of the indicators. (The sensitivity of this decision was tested as described for the 'carer burden' index and found to be robust for thresholds ranging from 2 to 4 indicators). Around 60 per cent of primary carers scored three or more on the index.

Table 2.6 Poor health indicators

Self-assessment indicators were:	1. General health assessment – health fair to poor 2. Limited a lot in moderate activities 3. Limited a lot in climbing stairs 4. Accomplished less than would have liked to, due to physical problems in the last four weeks 5. Limited in work/regular activities due to physical health 6. Accomplished less than would have liked to, due to emotional problems in the last four weeks 7. Work/activities not as careful as usual due to emotional problems 8. Pain interfered with work moderately, quite a bit or extremely in the last four weeks 9. Felt down a good bit of the time, most of the time or all of the time in the last four weeks 10. Felt calm some of the time, a little of the time or none of the time in the last four weeks 11. Had a lot of energy some of the time, a little of the time or none of the time in the last four weeks 12. Physical/emotional problems interfered with social life a good bit of the time, most of the time or all of the time in the last four weeks 13. Physical health score (pcs) is less than 50 (median for this group) 14. Mental health score (mcs) is less than 50 (median for this group

2.3 Overall level of formal service use

Carers' service use

Figure 2.2 shows the percentages of co-resident carers who had care recipients needing assistance, and of those whose care recipients *did* use community services. They are grouped within each of the nine activities (listed in Table 2.1) for which information was collected in SDAC. The first bar in each activity group indicates the percentage of carers with care recipients who actually needed assistance for that activity, and the second bar shows the percentage who used formal services.

It is clear that, for all activities except for 'communication', the majority of care recipients who needed assistance for each activity did not use formal services. In the case of assistance with 'communication', 15 per cent of carers had care recipients who needed assistance for this activity, and over half of these used formal support services, but this was the exception.

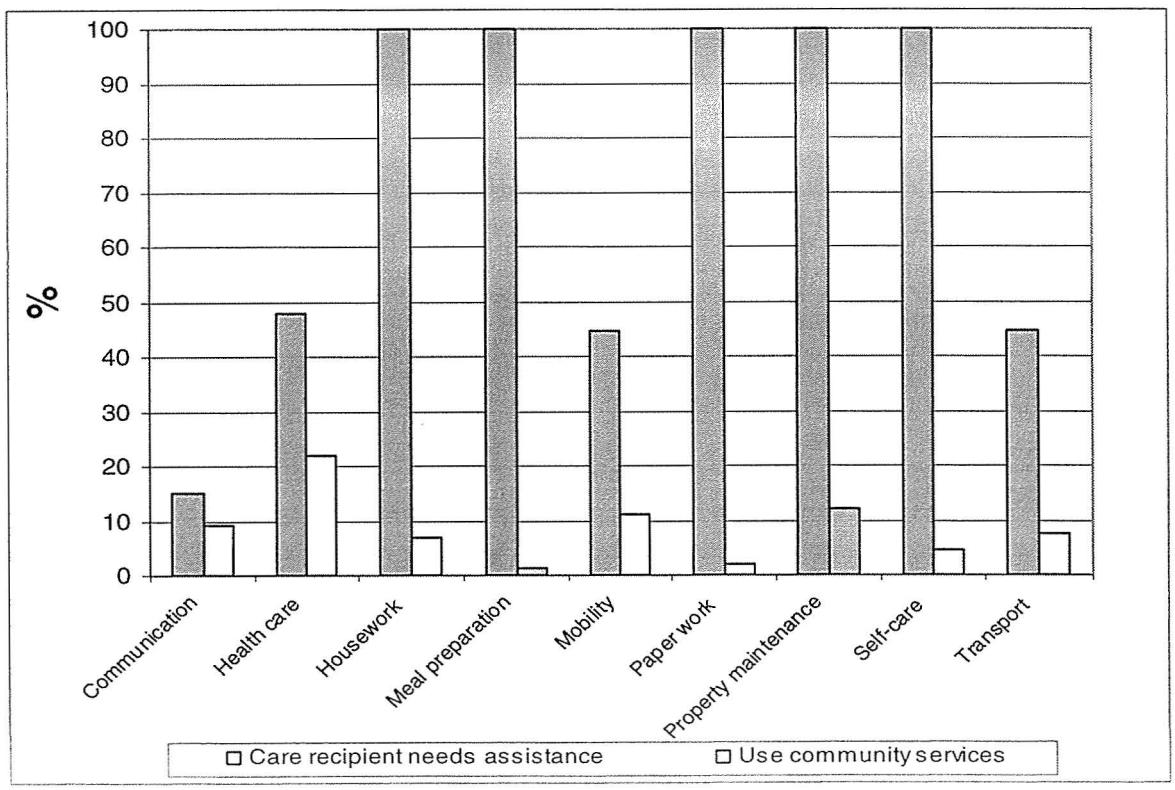
The activity for which most care recipients used formal services was 'health care' – this included such tasks as taking medications, dressing wounds or using medical machinery. Around 48 per cent of all carers had care recipients who need help for this task and nearly half of this group used formal services. This finding is not unexpected,

given that health care is the activity most likely to require professional assistance (Bass and Noelker 1987: 186).

For the 'five activities' (for which all carers had care recipients who needed assistance), the care recipients of fewer than 15 per cent of carers accessed formal services. In the case of 'meal preparation' and 'paperwork', the proportions were very low – less than five per cent. Once again, these findings are only to be expected, given that these carers were co-resident, and hence unlikely to ask for assistance for tasks considered to be normal domestic duties within their own homes.

Around 45 per cent of carers had care recipients who needed assistance for 'mobility' –getting in or out of bed, moving about the house – and for 'transport' – travel to places away from one's home. Still, less than a quarter of those who actually needed services for these activities used formal services for support.

Figure 2.1: Carers with care recipients needing assistance who used formal services



Primary carers' service use

According to SDAC approximately half of all primary carers spend more than 40 hour per week caring for someone with the two highest levels of handicap, those rated 'profound' or 'severe'. Figure 2.2 below describes the community service use of primary carers. As in Figure 2.1, the first bar in each group shows the proportion of primary carers with care recipients who needed assistance for that activity, and the second bar shows the proportion of primary carers who had care recipients who used formal services. The third bar in Figure 2.2 shows the proportion of primary carers

who either used respite care themselves or had a care recipient who used formal services, and hence shows the total community service use for the care situation.

Figure 2.2 shows that primary carers had care recipients with higher levels of need than did carers as a whole. They were nearly twice as likely as carers to have care recipients who needed assistance for 'communication', 'health care', 'mobility' and 'transport'. They were also more likely to have care recipients who used formal services for these activities. However, in the case of the 'five activities', only for 'self-care' were primary carers more likely than carers to have a carer recipient who received support from formal community services. In the other four tasks – 'housework', 'meal preparation', 'paperwork' and 'property maintenance' – they did not receive more support from community services than did carers.

Figure 2.2: Primary carers with care recipients needing assistance who used formal services and/or respite

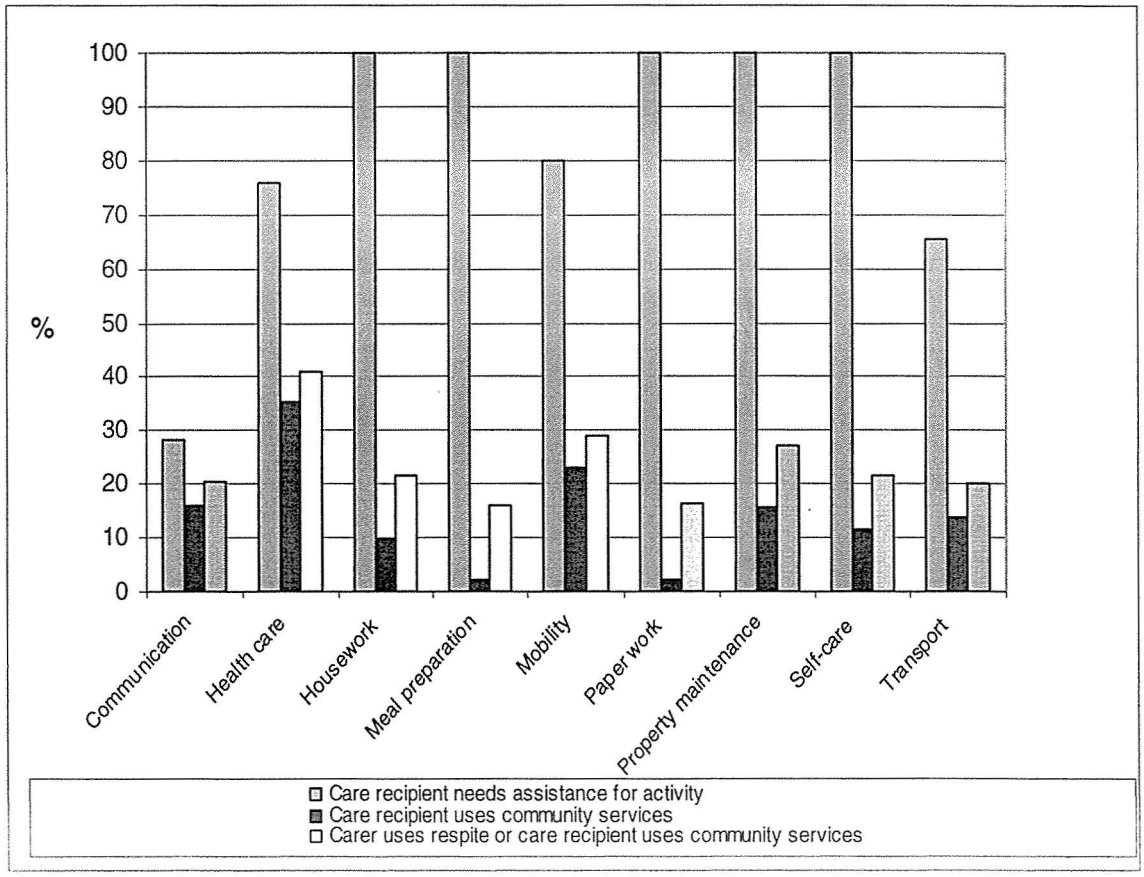


Figure 2.2 also shows that, even with respite added to the other community services (the third bar in each group), the majority of primary carers did not seek formal assistance for most activities, with the exception of 'communication' and 'health care'. Overall, only 13 per cent of primary carers had ever used respite care. For the 'five activities', adding the use of respite to the other community services increased the proportion of carers using formal support in their care situation, although for the rest of the activities the increase was relatively minor.

2.4 Results from the multivariate analysis

Factors relating to community service non-use

The variables considered as potential influences on the use of community services are listed in Table 2.4. As previously stated, the purpose of the multivariate analysis was to identify the socio-demographic characteristics, or the predisposing and enabling characteristics, that were strongly associated with service non-use after controlling for need characteristics in the care situation. The following discussion first describes which need factors showed strong associations with service use and non-use, and then the socio-demographic characteristics that were significantly associated with service non-use. The discussion in this section focuses on carers and primary carers in general; the service use and non-use of carers with special needs, such as young carers and carers with poor health, are considered in Section 4.

Table 2.7 and Table 2.8 report the predisposing, enabling and need factors, for primary carers and carers respectively, identified in the multivariate analysis as significantly associated with service non-use. The complete logistic regression results can be found in Appendix A. Table 2.7 provides an overview of the characteristics associated with service non-use by the care recipients of primary carers, as well as the use of respite services by the primary carer. It was found that there were relatively few 'predisposing' and 'enabling' factors associated with service non-use once controls for the 'need' characteristics of the care situation were included.

Table 2.8 provides an overview of the characteristics associated with service non-use by the care recipients of carers. There was less information available on the care situations of carers than of primary carers because primary carers filled in the questionnaire and carers did not, so it was not possible to control for a number of factors, including the number of hours spent caring, the 'carer burden' level reported by the carer, the carer's self-assessed health status, whether there was a fall-back carer available, and whether the language spoken to the care recipient was English. The results for carers must be interpreted with that limitation in mind.

There are four columns in each table, one column each for the 'five activities', 'health care', 'mobility' and 'transport'. The increases or decreases in the probabilities discussed below refer to average marginal probabilities, that is, the change in probability induced by each factor at the average point in the sample, and provide an indication of the strength of the effect of the variable on service utilisation.

Table 2.7 Primary carers and service non-use

Factors	Five activities[(a)] and respite	Health care and respite	Mobility and respite	Transport and respite
Predisposing	Carer under 45	Carer has CALD background (born in country other than Australia or North Western Europe) Carer does not have long term health condition	Carer is a spouse, other relative or friend of care recipient	Carer is a spouse, parent or other relative of the care recipient
Enabling	Lives in a more socio-economically disadvantaged area	Carer's main source of income is government pension or benefit	Lives in a more socio-economically disadvantaged area	
Need	Care recipient has a severe or a moderate disability Carer cares for less than 40 hours per week Carer has relatively low 'carer burden' levels Fall-back carer available Carer has relatively good health	Youngest care recipient is 25-64 Carer cares for less than 20 hours per week One care recipient	Youngest care recipient is over 45 Carer cares for less than 40 hours per week One care recipient Fall-back carer available Carer has relatively low 'carer burden' levels	Youngest care recipient is over 45 years Cares for less than 20 hours One care recipient Fall-back carer available

(a) Housework, meal preparation, paperwork, property maintenance and self-care

Table 2.8 Carers and service non-use

Factors	Five activities[(a)]	Health care	Mobility	Transport
Predisposing	Carer is male Carer under 65 years Carer does not live in a lone parent household Carer has CALD background (born in country other than Australia or north western Europe) Carer has year 10 or less vocational qualifications Carer does not have a long-term health condition	Carer has CALD background (born in country other than Australia or north western Europe) Carer does not have vocational qualification	Carer is female	Lives in couple or lone parent household
Enabling	Carer's personal income level is not in the top quintile Lives in a more socio-economically disadvantaged area Lives in a capital city	Lives in a more socio-economically disadvantaged area Carer's main source of income is government pension or benefit	Lives outside a capital city	Carer's main source of income is wage/salary or private income
Need	Youngest care recipient under 25 Care recipient has a severe or a lower level of disability	Care recipient is female Youngest care recipient under 65 Care recipient has mild or lower level of disability One care recipient.	Care recipient is female Care recipient is 45-64 Care recipient has severe disability One care recipient	Care recipient is over 25 Care recipient has moderate disability One care recipient

(a) Housework, meal preparation, paperwork, property maintenance and self-care

Need factors

Need factors are those characteristics specific to the care situation such as the degree of disability or the level of caregiver stress. For both carers and primary carers, the results show that the higher the need the more likely it was that services would be accessed to assist in the caring situation. Both carers and primary carers were more likely to use formal community services when they had a care recipient with a higher level of disability, or were caring for more than one care recipient. Both carers and primary carers caring for individuals with a 'profound' level of disability were 10 to 20 percentage points more likely to use services than those caring for people with 'severe' and lower levels of disability. Those caring for more than one care recipient were around 15 to 35 percentage points more likely to use services than those caring for only one care recipient.

In the case of primary carers, because additional information was collected about them, it was possible to identify other need factors significantly associated with the use of community services. These factors included:

- caring for more hours per week,
- not having a fall-back carer available,
- reporting relatively high levels of carer burden, and
- reporting relatively poor health.

The time reported spent caring each week was the one consistently significant predictor of the use of services by primary carers across services for all the activities. Primary carers caring for 40 hours per week were 15 to 30 percentage points more likely to use services than those caring for 20 hours per week or less. Having a fall-back carer available was also a fairly consistent predictor of service non-use for all activities apart from 'health care'. This suggests that support in health care activities may need to be provided by trained professionals rather than informally. For the other activities apart from health care, the availability of someone else to provide informal care decreased the probability of using services by between 10 and 18 percentage points.

From this analysis, it is clear that there was an overall pattern that carers who had greater need for services were more likely to access them

The variables used in this analysis to identify 'carer burden' and poor health (and thus a higher need for support) also showed significant although weaker associations with higher levels of service use, primarily for the 'five activities'. In these cases, primary carers who reported relatively higher levels of burden and relatively poorer health were 10 percentage points more likely to use services. It would seem that carers who experience greater difficulty in their care situations are only slightly more likely to access services than carers who do not, and only services for activities that may be considered to be domestic tasks.

One need factor not found to be significant in any of the results was whether primary carers spoke to their care recipients in a language other than English. This is perhaps a surprising result, as it might be expected that care situations where English was not the first language would have

limited access to information about services. This will be discussed further below when considering the effect of the country of birth of the carer on the probability of using services.

Predisposing factors

Predisposing factors are factors that exist prior to the onset of the care situation, such as age, sex, country of birth, and which may predispose carers to access community services. When need factors were controlled for, it was found that there were a number of factors that tended to be strongly associated with the non-use of community services. These are listed in the top rows of Table 2.7 and Table 2.8. The predisposing factors with significant effects on the probability of carers using services have a smaller average marginal effect than the need factors. This indicates that predisposing factors are weaker predictors of service non-use than need factors. Those factors that do have effects on the use of the majority of services are listed below.

Age of carer

Younger carers were less likely on the whole to use services than older carers were. Carers under 65, and primary carers under 45, were respectively 10 and 14 percentage points less likely to use services to support their care situation than older carers. This may be because services are targeted to carers who are older and have poor health.

Sex of carer

Male carers were slightly less likely than female carers to access services for the 'five activities'. There may be a number of reasons for this: they may have fewer sources of information about the availability of services through informal networks than women do; their spouses may not wish to have services for these activities; or they may not perceive that they need services.

Carers from Culturally and Linguistically Diverse (CALD) backgrounds

The most consistent predisposing factor predicting service non-use was a CALD background (born in Africa, the Americas, Asia, or South-eastern Europe). Being from a CALD background meant that a carer was 4 percentage points less likely to access services for the 'five activities' than an Australian-born carer, but a much more significant 17 percentage points for 'health care'. In the case of primary carers, being from a CALD background meant they were 19 percentage points less likely to use health care services than the Australian-born. This suggests that carers and primary carers from CALD backgrounds either lack knowledge of health care services, or find them inaccessible or culturally inappropriate. As noted above, the language spoken at home was not a key predictor of service non-use, thus suggesting that it is immigrant status rather than language spoken that is the decisive influence here, particularly in relation to the use of health care services.

Low education

Carers with relatively low levels of education (year 10 or less or vocational qualifications) were less likely to use services for the 'five activities'. Low levels of education may be associated with other factors such as lower income and fewer resources to draw on to access support.

Other factors

Other factors with small but significant effects on the probability of not accessing services for the 'five activities' in the case of carers (but not primary carers) were the absence of a long-term health condition, and not living in a lone parent household. Carers who did not have a long-term health condition were 4 percentage points less likely to use services than those who did; and carers not in lone parent households were 10 percentage points less likely to use services for the 'five activities' than carers in lone parent households.

Predisposing factors not significant

There were two predisposing factors that were not significant in any of the service non-use analyses: marital status and disability status of the carer.

Enabling factors

Enabling factors are those factors, such as income or employment status, that can facilitate or impede the use of community services. When the need factors were controlled for, there were some clear findings relating to enabling factors. These are outlined below.

Relatively socio-economically disadvantaged areas

Carers who lived in relatively disadvantaged socio-economic areas were less likely to use community services for the majority of activities. This finding held across all groups of carers analysed – carers, primary carers, primary carers in poor health, and young carers. It was those living in areas ranked in the bottom 40 per cent by the 1996 ABS Index of Relative Socio-Economic Disadvantage (IRSED) who were least likely to use community services. Whether this was because carers in these areas could not afford services, or whether there were fewer services available in these areas, is not known. Carers and primary carers living in areas ranked in the top 20 per cent of the IRSED were between 13 to 22 percentage points more likely to use services than those in the bottom 40 per cent.

Carers' personal income

Personal income showed an association with service use for carers, but not for primary carers. Carers who had personal incomes in the top quintile were 8 percentage points more likely to use services for the 'five activities' than carers in other income brackets. This may indicate that these carers are more able to pay for services such as housework or property maintenance.

Carers receiving government benefits and health care services.

Both carers and primary carers whose main source of income was government benefits were less likely to access support from formal services for 'health care' than were carers whose income was wages, salaries or a private income. Carers receiving government benefits were 9 percentage points less likely to use health care services than wage earners were; while primary carers who were beneficiaries were 23 percentage points less likely. The large gap for primary carers suggests that those who are receiving benefits (perhaps carer pensions) are disadvantaged in terms of access to support from health care services. On the other hand, in the case of 'transport', carers who were beneficiaries were slightly more likely than wage earners to use services.

Living in a capital city or the rest of the state

Carers (and young carers – see Section 4.2) were less likely to access formal services for the 'five activities' if they lived in a capital city than if they lived elsewhere in the state, although this factor was not significant for primary carers. This lesser service use in the cities compared to the rest of the state may indicate that there is greater pressure on resources in the capital cities, or it may be an artefact of the limited categories of the variable that were available in the data set. Other research has suggested that a more useful distinction would be between cities, regions and remote areas, but it was not possible to investigate this from the information contained in SDAC.

Summary of community service use results

There are two strong general conclusions that can be drawn from this analysis.

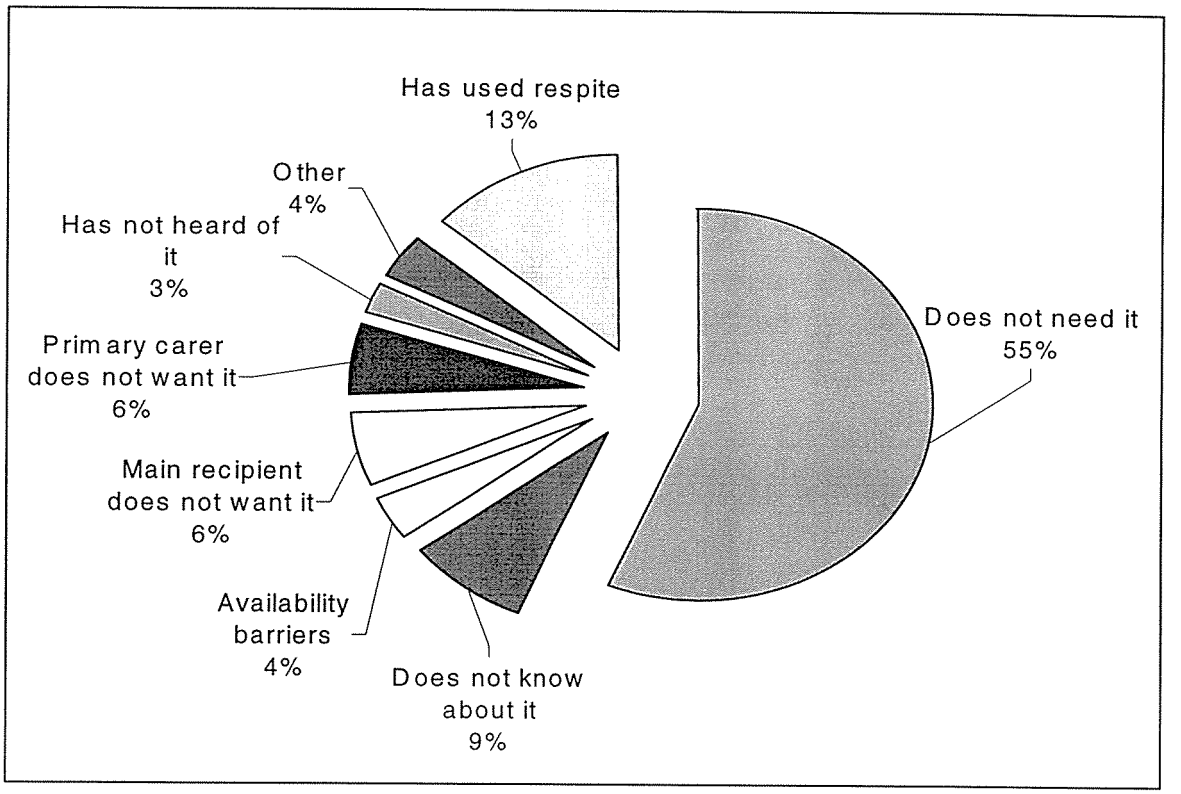
The first is that community services are more likely to be used in care situations with higher needs. The second is that factors associated with disadvantage are also associated with service non-use. In particular, carers from CALD backgrounds, and those living in relatively more socio-economically disadvantaged areas, are less likely to use community services.

2.5 Reasons for not using services

There is relatively little information in SDAC on why it is that the majority of carers do not use formal community services to support them in their caring role. However, there is information about the reasons why primary carers do not use respite services.

Figure 2.3 shows that the majority of primary carers (55 per cent) said they did not use respite care because they did not need to. Only 13 per cent had ever used it. There were 6 per cent who said they did not use it because they did not want to, and another 6 per cent who said their care recipient did not want it. A further 12 per cent said they either 'did not know about it' or 'had not heard of it', while 4 per cent reported availability barriers. On this information it does not appear that the majority of primary carers consider that they experience an unmet need for services. Nonetheless, efforts could be made to address information and accessibility issues for the small proportion of primary carers (16 per cent) who gave these factors as reasons for not accessing respite care.

Figure 2.3: Reasons why primary carers do not use respite services



Source: 1998 ABS Survey of Disability, Ageing and Carers

Is there an unmet need?

There is no information in SDAC from the carers' perspective as to why their care recipients did not use formal community services. However, care *recipients* were all asked if they needed more help for each of the activities for which they needed assistance. If they reported that they did, then they were asked what was the main reason that they did not receive more help from formal services.

For all the activities except 'communication', fewer than 20 per cent of those care recipients who needed assistance for a task reported an unmet need. In the case of communication activities, 30 per cent of care recipients reported an unmet need.

The most common reasons given were:

- not knowing of the existence of the service,
- the service costs too much,
- wouldn't ask because of pride,
- need not important enough, and
- other non-specified reasons.

2.6 Maps based on the SDAC results

The first two maps (Figures 2.4 and 2.5) provide an overview of the prevalence of carers in NSW, while the next two (Figures 2.6 and 2.7) combine the data on the prevalence of carers with the findings from SDAC that socio-economic status (SES) was associated with service non-use.

Prevalence of carers

The figures on the prevalence of carers in NSW are based on weighted estimates of the numbers of carers in each region from the SDAC results provided by the ABS. The proportion of carers in each region is indicated by the blue shading, the darker the shade the higher the proportion of carers in that region.

Figure 2.4 describes the distribution of carers in the Department of Ageing, Disability and Home Care (DADHC) Local Planning Areas (LPA) for NSW. Those areas with the highest proportion of carers are the Hunter, Illawarra, Inner West and Southern Highlands. In these areas, carers comprised between 15.5 and 16.8 per cent of the population. As some areas were not sufficiently sampled by SDAC to provide reliable estimates, some caution should be used in interpreting the results displayed in this map. In particular, the estimates for Central West, New England, Orana/Far West, Riverina/Murray and Southern Highlands were based on samples in a small number of Local Government Areas (LGA) and thus may not be reliable.

Figure 2.5 maps the prevalence of carers for the LGAs in metropolitan Sydney. This map shows that Ashfield, Drummoyne, Holroyd, Penrith, Strathfield and Wollondilly are the LGAs with the highest proportion of carers in their population (between 19.0 and 27.0 per cent).

Prevalence of carers and socio-economic status of areas

Figures 2.6 and 2.7 provide *an indicative guide only* to those areas where carers who are not using formal services are most likely to be located. The SES of the carer's local area is only one of the important factors in predicting service non-use among carers. The maps provide a general guide only and should be compared against other data for validation.

Colour legend

There are three main colours in the maps: purple, blue and grey. Purple indicates those LGAs and DADHC Local Planning Areas with a higher than average (for NSW) proportion of carers in the population. These are areas that have 12.5 per cent of the population, or more, reporting they are carers, based on the weighted estimates provided by the ABS. Blue indicates those areas estimated to have fewer than 12.5 per cent of the population who are carers. Grey indicates those areas where estimates of the proportion of carers in the population are not reliable due to the limitations of sampling in SDAC.

Shade legend

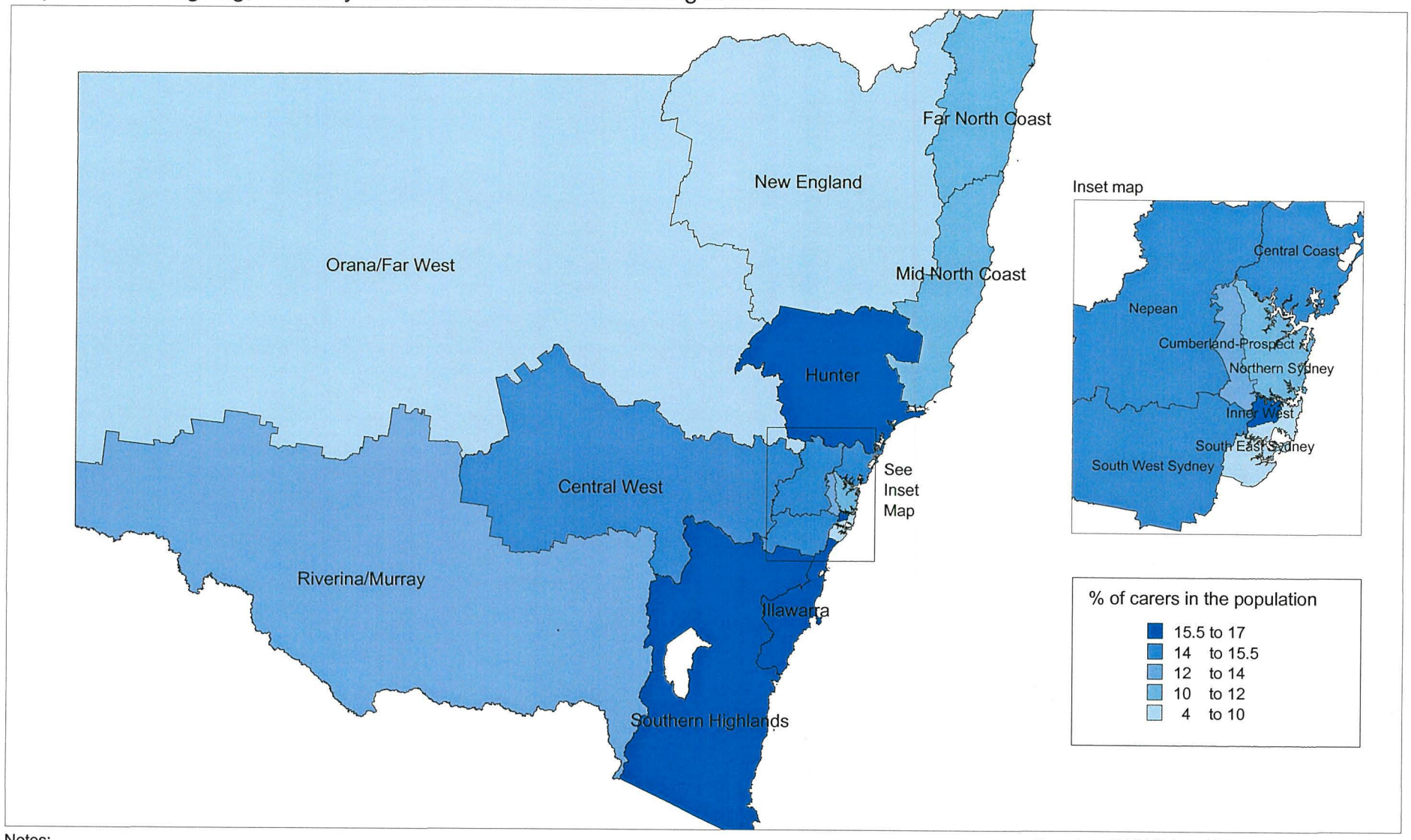
Both the purple and the blue have three shades – dark, medium and light. The dark shades indicate areas that score in the lowest 40 per cent of the IRSED; medium indicates areas within the 40^{th} to 80^{th} percentile; and the lightest shade indicates areas in the top 20 per cent. The areas defined as 'low SES' are those with a score below 986 on the IRSED; those defined as 'mid SES'

scored between 987 and 1082; and those defined as 'high SES' scored over 1082 (Australian Bureau of Statistics, 2002). These IRSED scores are based the 1996 Census. They are calculated on the proportion of people in each area with low income, low education, in low-level occupations, having low levels of English, and so on. An area that is more disadvantaged has a lower score and appears as a darker shade on the map.

Figure 2.6 shows the areas with high proportions of carers (12.5 per cent or more) and those with low proportions of carers (12.5 per cent or less), combined with either a low, mid or high SES, for the DADHC LPAs for NSW. The areas where carers who are not using services are more likely to be found are Cumberland/Prospect, Hunter, Illawarra and South West Sydney. Figure 2.7 provides the same results for the LGAs of the metropolitan Sydney area. Bankstown, Canterbury, Fairfield, Holroyd and Marrickville are the LGAs in Sydney where carers who are not using formal services are more likely to be living.

Figure 2.4 Prevalence of Carers in New South Wales

Department of Ageing, Disability and Home Care Local Planning Areas



Notes:
Estimates of percentage of carers in the population based on SDAC 1998.
Estimates for Central West, New England, Orana/Far West, Riverina/Murray, and Southern Highlands are based on small samples and may be unreliable.

Based on DADHC Local Planning Area Boundaries
Source: ABS Survey of Disability, Ageing and Carers 1998 and IRSED 1996
Produced by: Social Policy Research Centre
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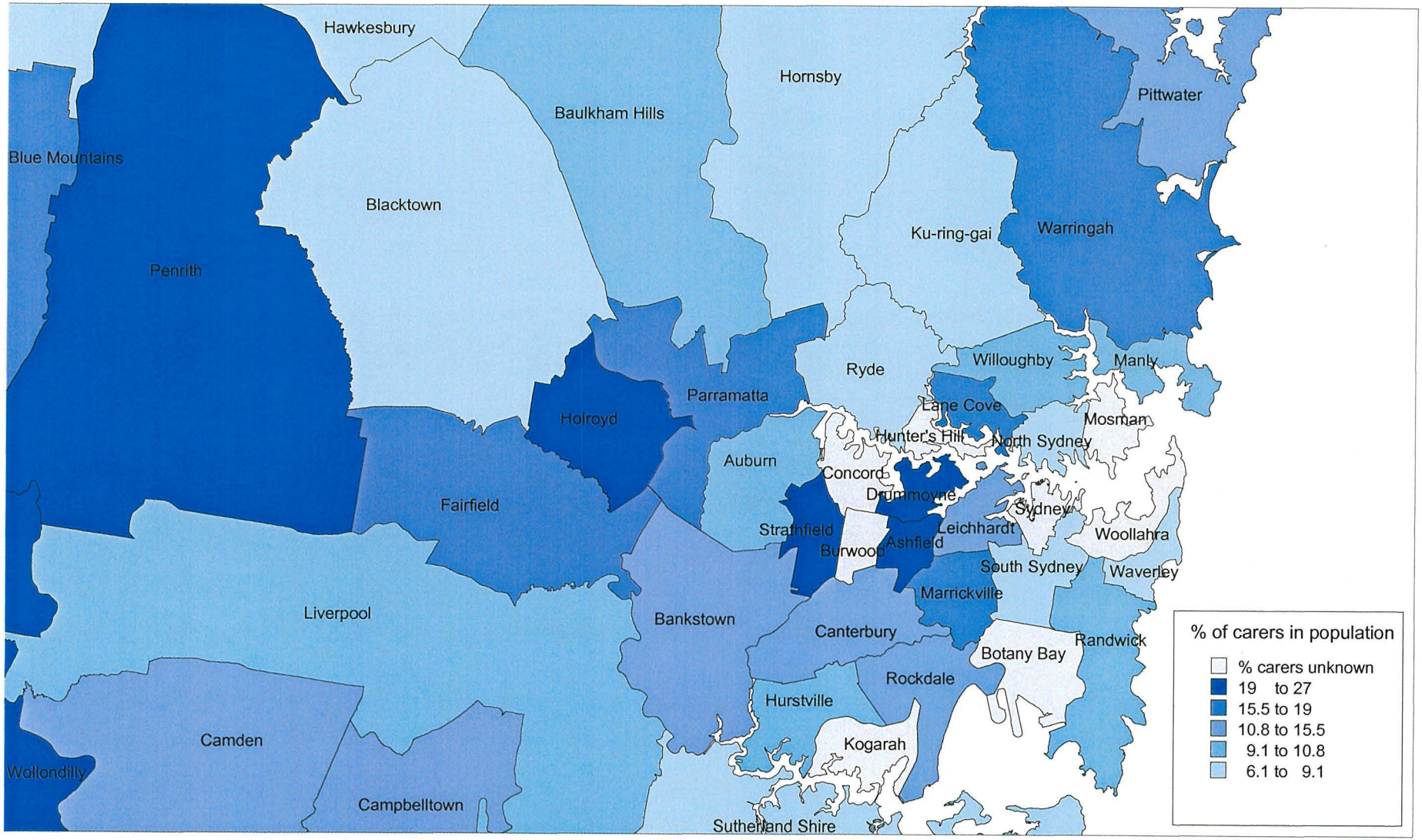
Figure 2.5 Prevalence of Carers in Population

Sydney Metropolitan Area Local Government Areas



Notes:
Estimates of percentage of carers in population based on SDAC 1998.

Based on 2001 Local Government Area Boundaries
Source: ABS Survey of Disability, Ageing and Carers 1998
Produced by: Social Policy Research Centre
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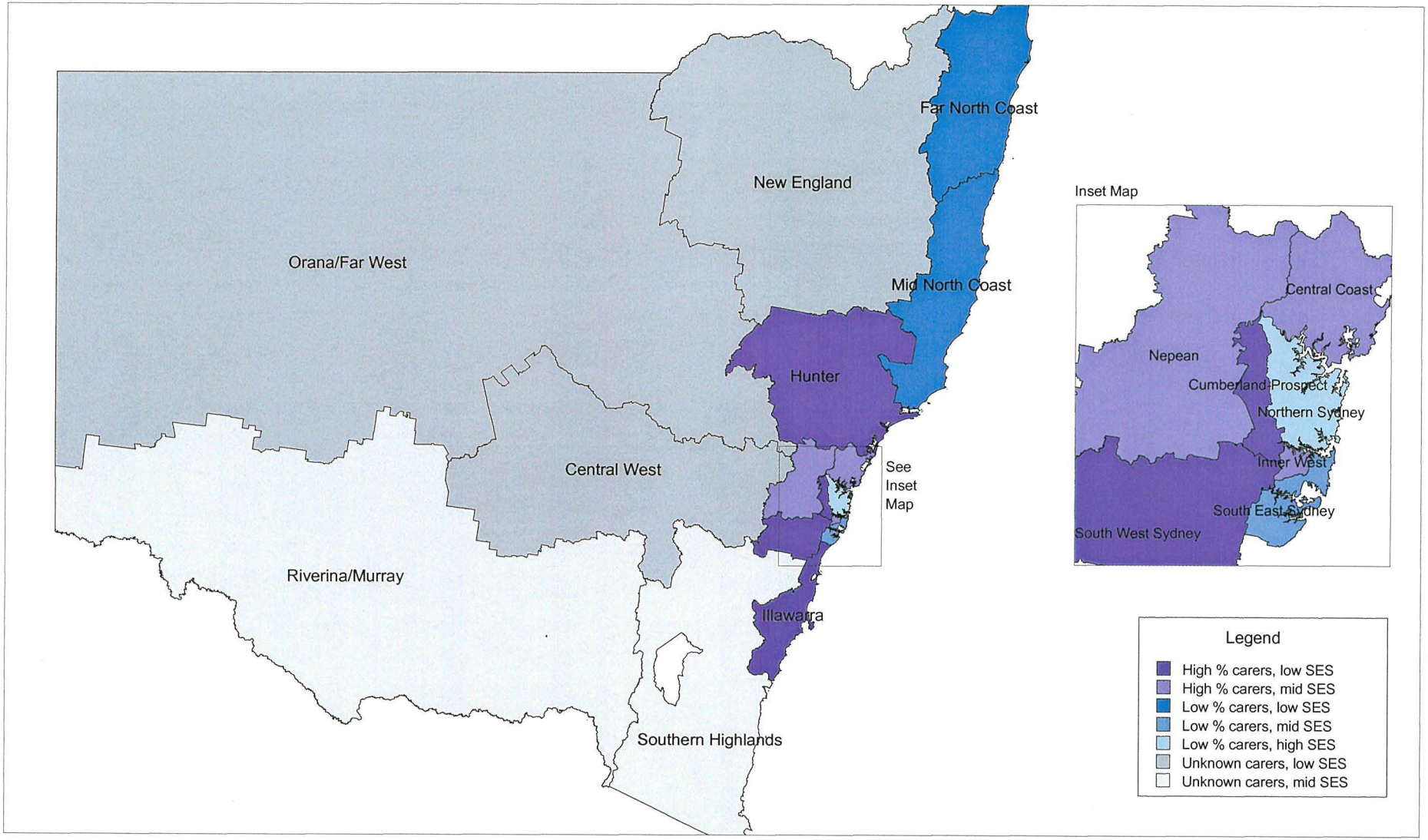
Figure 2.6 Prevalence of Carers and Socio-economic Status of Areas

Department of Ageing, Disability and Home Care Local Planning Areas



Notes:
Estimates of proportion of carers in the population based on SDAC 1998.
Socio-economic status (SES) is associated with community service use.
Carers living in areas of lower SES are less likely to use services.

Based on DADHC Local Planning Areas Boundaries
Source: ABS Survey of Disability, Ageing and Carers 1998 and IRSED 1996
Produced by: Social Policy Research Centre
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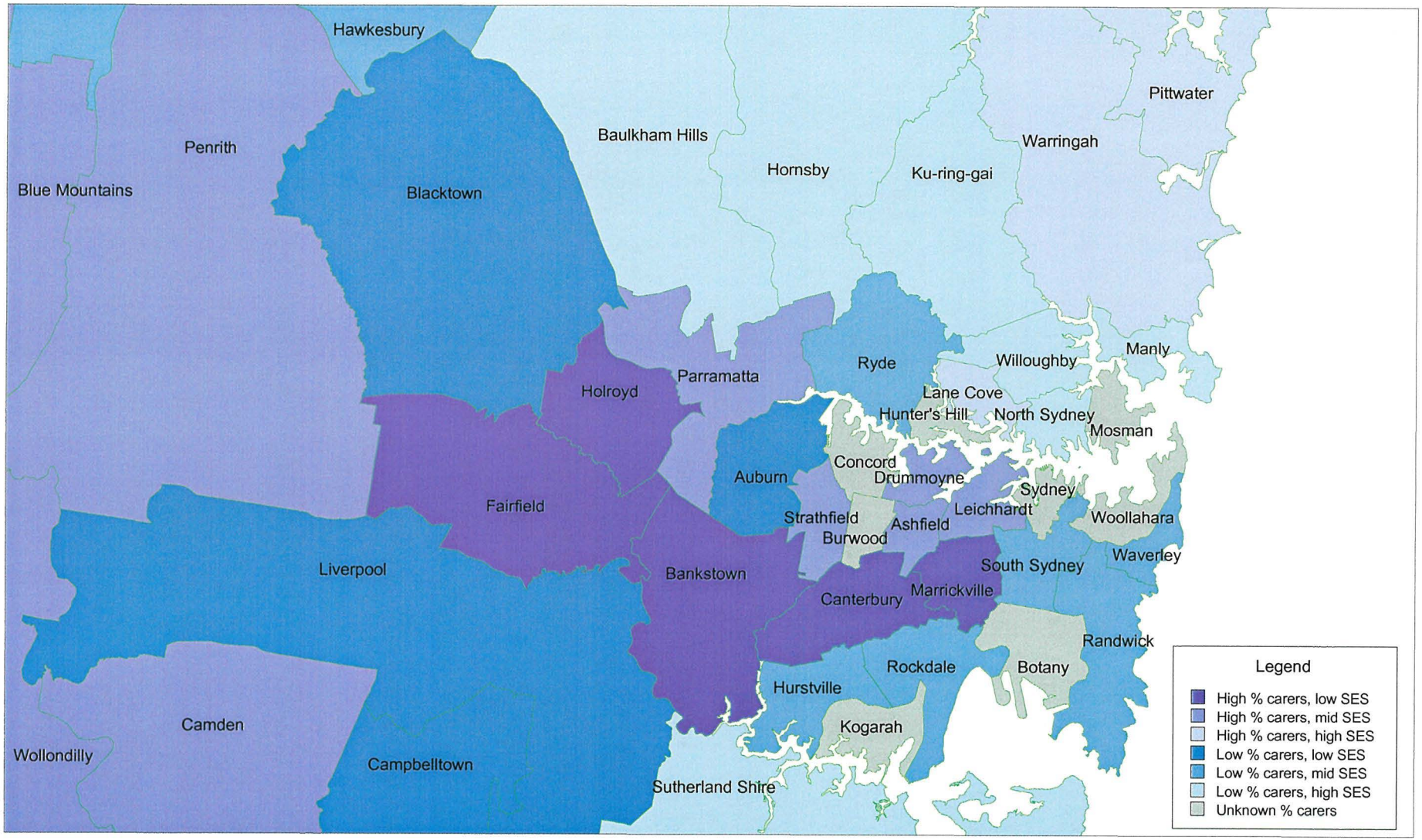
Figure 2.7 Prevalence of Carers and Socio-economic Status of Areas

Sydney Metropolitan Area Local Government Areas



Notes:
Estimates of proportion of carers in the population based on SDAC 1998
Socio-economic status (SES) of local area is associated with community service use.
Carers living in areas of lower SES are less likely to use services.

Based on 2001 Local Government Area Boundaries
Source: ABS Survey of Disability, Ageing and Carers 1998 and IRSED 1996
Produced by: Social Policy Research Centre
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3 Profiling identified and non-identified carers

The SDAC results relied on information gathered from people who were clearly carers (whether primary or not) and identified as such. The analysis of SDAC described above in Section 2 traced likely dimensions of unmet need among carers who were not 'isolated' to the extent that they failed to recognised their own status as carers (although any failure to access needed services on the part of particular groups does qualify as 'isolation' in the sense in which the term is being used here). SDAC respondents identified themselves as carers, or at the very least, were identified by a 'responsible adult' in the same household.

The second major aspect of this present research involved analysing the most recent (1997) ABS national-sample Time Use Survey for a potential solution to the problem of finding a means for objectively locating carers that does not rely on answers to self-reported status questions. Moreover, the non-identified carers usually uncovered by qualitative research have tended to be identified as carers by other people who came into contact with the research project. But it is possible that some non-self-identified carers do not have the social networks that might permit their identification in qualitative research. The Time Use Survey offers a unique opportunity to attempt to calculate an important dimension of the informal carer population.

The Time Use Survey asks all household members aged 15 and above to keep a diary of their activities over two consecutive 24-hour days beginning at midnight. Diarists note the starting and finishing times of activities and indicate the main focus of their attention, any other activities they undertook at the same time, for whom they performed each activity, who else was present, and where they were while they performed the activity. Information from the 1997 survey was used to profile the daily activity patterns, or 'time signatures', of people who identified themselves as carers. The records of other diarists were then searched for those exhibiting similar time signatures. By this means, it has been possible to estimate the size of the non-self-identified carer population.

Section 3.1 details the definitions of identified and non-identified carers based on the information in the 1997 Time Use Survey. Section 3.2 discusses the processes by which the time signatures of carers were uncovered. Section 3.3 explains how time signatures were used to locate people who were likely to be providers of adult care, and the strategies used for validating these results. As a result of this procedure, the size of the carer population in Australia is estimated to be two-thirds again as large as that suggested by carer surveys such as SDAC. Finally, Section 3.4 profiles the populations of identified and non-self-identified carers, before profiling the households in which carers reside.

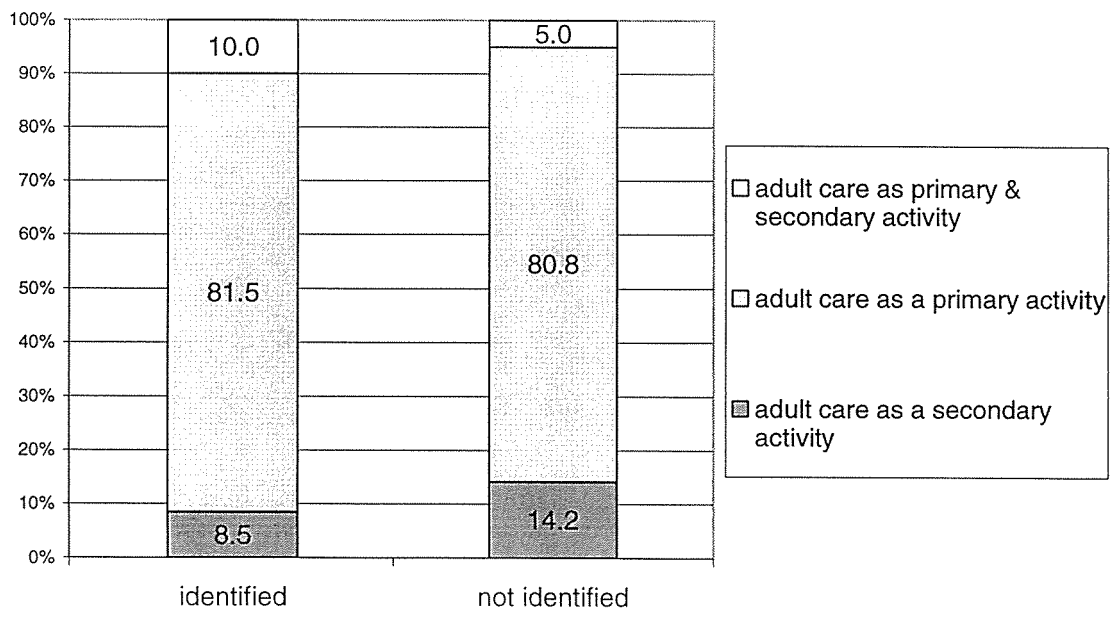
3.1 Defining identified and non-identified carers in the Time Use Survey

It is possible to distinguish four groups of carers from the Time Use Survey, two of which are self-identified carers, and two of which are non-self-identified carers. Five variables from the individual questionnaire from the Time Use Survey were used to locate self-identified carers: main economic activity status (including 'not working or seeking work on account of providing care to an adult'), together with four carer variables: one flagging people supplying the majority of care for an adult in their own household; one marking whether someone provided care to an adult living in another household; another marking whether the diarist provided the *main* source of care to an adult from another household; and one marking whether the diarist helped an adult

with a disability. People caring for adults in their own or in other households and who were the main source of care for that person were defined as self-identified 'primary carers'. All other diarists answering 'yes' to any of the other carer-variable questions were coded as self-identified 'other carers'. This yielded a sample of 262 primary carers and 627 other carers – making a total of 889 self-identified carers.

In the case of non-identified carers, there were 240 diarists whose economic activity status was not 'out of the labour market to provide care', and who answered 'no' to the four carer questions in the individual questionnaire, but who nonetheless recorded an activity coded as 'adult care' in one or both of their time diaries (such as helping their elderly father get out of bed and get dressed, or assisting a grandparent getting into and out of the bath and taking medication). These people who performed adult care but did not claim to be carers were categorised as 'non-identified carers'. These three groups of carers whose designation is straightforward – self-identified primary carers, self-identified other carers, and non-identified carers – were the basis on which the variations between the time-use patterns of carers and the rest of the survey population were calculated. Then there were 1263 diarists in the remaining population who exhibited similar behaviour patterns to carers, and whose behaviour could best be explained as arising from adult care. These diarists were grouped into a category of 'possible adult carers' – the second of the two categories of non-identified carers.

Figure 3.1 The recording of adult care activities by self-identified and non-identified carers



Source: 1997 Australian Bureau of Statistics Time Use Survey

Only a minority of these carers actually reported adult care activities. In total, only 370 diarists reported care activity – and the majority of those who did were non-identified carers. Only 130 self-identified carers (14.6 per cent) reported care on their diary days. That so few self-identified adult carers reported care activity is not entirely surprising. Focus groups conducted as part of an earlier study indicated that carers often did not recognise some of their care-related activities as

care, and viewed these activities merely as a part of the continuum of routine domestic work (Bittman and Thomson, 2000). Additionally, most adult care recipients prefer to do as much as they can for themselves. While some care relationships are very intensive, others are not. Many adult care relations may involve periodic rather than daily help, and thus not all carers will be engaged in care on any random day. There are also difficulties using diaries to measure actual time spent caring (an issue taken up in more detail in Section 5 of this report). That greater numbers of non-identified carers than identified carers are captured in the diaries at this level suggests that the population of non-identified carers is very large.

Even at this basic definitional level, we observe some differences in how carers report adult care in their diaries. Over 80 per cent of adult care is recorded as a main activity when the carer undertook no secondary activity.[2] Nevertheless, as Figure 3.1 shows, self-identified carers were twice as likely to record adult care as both a main activity and a simultaneous activity taking place during other activities, while non-identified carers are nearly twice as likely to record adult care as a secondary activity only.

3.2 Profiling the time signatures of carers

Not all the diaries completed for the Time Use Survey were of sufficient quality to include in this present investigation. Diaries were defined as being of poor quality if they had more than 1 hour and 30 minutes of missing information, if they contained fewer than 15 recorded activities, or if they omitted one or more of the common activities we would expect people to perform on a daily basis – including sleep or rest, eating or drinking, going to the toilet or engaging in related forms of basic personal care and hygiene. Such diaries are highly likely to differ from the diaries of carers, and this dimension of difference due to data quality needed to be removed from the profiling process.

Initial testing for impact of the caring role on daily activities

In an earlier research project undertaken by SPRC and Carers NSW in May 2000, six focus groups were conducted with carers to discuss how they fitted care needs into their days. Carers NSW recruited participants using their Carer Contact Database. Carers of people with cognitive and physical disabilities and mental illnesses of varying degrees of severity were represented in the groups. A total of 19 carers participated in the focus groups, most of whom were co-residential carers and 78 per cent of whom were women. Carers were asked to complete a time diary the day before the focus group in order to focus their thoughts on caring activities and the impact of being a carer on their daily lives.

These focus groups revealed a number of impacts that carers perceived their role imposed on their daily routines, including disrupting their sleeping patterns and interfering with their free time and leisure pursuits. These impacts clustered into six themes, perceptions that carers:

- spend more time doing care activities and voluntary work than other people;
- spend more time doing domestic work than other people;

[2] In this respect the reporting of adult care differs from the reporting of child care as people often record child care activities as secondary activities, or as a main activity overlayed by another activity, rather than as a primary activity without simultaneous activities (Ironmonger 2002).

- spend less time on paid work (and related activities), and on personal care;
- have very full or busy days;
- have more restricted leisure time and are more likely to be confined to home; and
- give more time to other people and have less time for themselves

These themes were operationalised into items measuring the time (minutes per day) spent:

- in various activities (with main activity time considered separately from the time of simultaneous activities);
- in various locations;
- alone; and
- for the diarists themselves as opposed to for various other groups of people;
- together with
- the number of episodes of selected activities during the diary day; and
- two constructed concepts of 'interrupted sleep time' and 'interrupted leisure time'.

As the measurement of these themes is not straightforward, a number of measures were developed for each concept. For example, there were six measures of interrupted sleep: the number of episodes indicating the main sleep of the day; the number of episodes of sleep while doing another activity (such as listening for crying or movement from a child or an adult for whose care they were responsible); the time spent in minutes per day sleeping; the time spent in minutes per day worrying or being unable to sleep; the number of episodes of any kind between 00:00 and 06:00 am; and number of episodes taking place in the home between 00:00 and 06:00 am.

There were also a number of measures of interrupted leisure. First there was the time spent in 'overlaid' leisure – that is, engaged in a free-time activity while simultaneously engaged in paid work, unpaid work, personal care, or adult or child care (such as preparing a special meal for a care recipient while watching television, or reading while waiting in a doctor's surgery for an appointment). Then there was the time spent in various leisure or free time activities, the number of episodes of free time activity, the total time spent in all leisure activities, and the average time of a leisure episode per diary day (summing main activity leisure time and time where the main activity is not leisure but the secondary activity is leisure, divided by the total number of leisure episodes on that day). It was speculated that carers might overall have less leisure time, that what leisure they had would be more likely to be interrupted, and that the time constraints of care might force carers to spend less time in leisure when they did get the opportunity, compared to people who did not have care responsibilities.

Table 3.1 shows the 73 operationalised items for the six themes. It runs over six pages, grouped into three sets of two pages each. Each set of two pages contains information on two of the six themes, and both pages relate to both themes. The first page indicates which items under each of the two themes were incorporated into the carer-profile scale (strong time signature for carers), which items were weakly associated with carers, and which items were not included in any further analysis. The second page in each two-page set displays the differences for those two

themes between the mean time carers spent in each of these activities and the time spent by all other diarists, as well as the β coefficients and levels of significance for the dummy variable marking whether the diarist was one of the three kinds of carers already defined at this stage of the research.[3] These results were constructed from an Ordinary Least Squares Regression modelling[4] of time spent on, or number of occurrences of, an activity on the diary day, for each of the 73 operationalised items. The second page also contains the One-Way Anova level of significance for the bivariate difference of mean time between carers and other diarists, as well as the level of significance from the non-parametric comparison of time or number of activities using the Mann-Whitney U test. In addition, given that full information from the procedures was summarised in these tables, the total difference in median scores for each operationalised variable between the three carer groups and the other diarists could be examined.

There was strong evidence that all six themes had an impact on carers' daily activity patterns, and in the general direction indicated in the focus group interviews. There was one exception – most carers were found not to be confined to the home, although confinement is a common complaint of people looking after adults with considerable care needs and all groups of carers did show restrictions on their leisure activities.

Of the 73 items, 58 proved significant in a consistent fashion across the majority of the tests. Of these, six were excluded from further analysis because they were either a matter of definition or identical to other, more robust measures. Because the activity of 'adult care' was part of the definition of 'carer', people not already defined as carers did not report any episodes in their diaries. So three of the variables that did not contribute to the time signature exercise were: time spent in 'adult care' as either a main or a secondary activity, and total episodes of 'adult care'. Six other variables clustered into three sets of two variables measuring the same concept: 'total time being sleepless and worrying' and 'episodes of sleepless or worry time'; 'total in-home episodes between 00:00 and 06:00 am' and 'total episodes between 00:00 and 06:00 am'; and 'total time in education or work away from home' and 'total time at a school or workplace'. In each of these cases the first measure proved more robust than the second, so only one of each of these pairs of measures was used in the subsequent analysis. Thus, the next phase of the time signature profiling involved working with 52 variables.

These 52 variables were further subdivided into two groups, a 24-item carer-profile scale where the distinctive behaviour of carers emerged particularly strongly, plus a 28-item set of factors with weaker associations with carers. Summarised, the carer-profile scale items indicate that carers spend more time engaged in voluntary activities, more time in a range of main activity and

[3] 'Self-identified primary carers', 'self-identified other carers', and 'non-identified carers'. For the defining of 'possible carers', see below p.47.

[4] The comparison group for these models was: men (as most research suggests that women bare a disproportionate share of adult care responsibilities), not coded as carers, born in Australia, who speak English at home, are aged 30 to 49, living in a married or cohabiting couple, do not live with children aged less than five, live in an urban area but not in a state or territory capital city, whose household falls within the middle 60 per cent of the income range, who work full-time, hold less than a university level education, and completed their diary on a normal Spring or an Autumn weekday. Additional employment variables were also tested, as well as three time-pressure variables, but the inclusion of an extra variable made no difference to the general results and weakened the R^2 scores of the models, so these additional background variables were not included in the final model.

secondary activity unpaid housework tasks, more time doing things for people with disabilities, more time with people with disabilities, and more time in other people's homes, than do people who do not provide care. Carers also have less time for themselves, spend less time listening to the radio, watching TV or using the internet, and get less sleep, than people who do not provide care. Carers have busier days (defined both in terms of doing more different activities during the day, and in terms of spending more time doing more than one thing at once). Carers have more episodes of free-time than non-carers, but on average they spend less time doing free-time activities when they get the chance to relax, and also spend more time simultaneously performing work (paid and unpaid) or personal care activities during their time to relax. The only surprising finding is that carers spend more time engaged in total activities outside the home than do non-carers.

Constructing a carer activity pattern scale

While many common elements of carers' daily experiences have already been identified, the task of constructing a profile of a carer's day is more difficult as there are considerable variations. In order to simplify that task, only the 24 items most strongly associated with carers were used to construct an ordinal scale of the degree to which a carer's time signature is exhibited. The first step was to determine the median, 40 percentile and 60 percentile scores for each of these 24 items for men and women, and for four age ranges: 15 to 34; 35 to 54; 55 to 74; and 75 or more. A scale score of zero was then set for all cases. For those variables where carers spent less time in, or did fewer episodes of, an activity compared to the rest of the population, the value of one was added to the scale score for all diarists scoring at or below the 40 percentile for their age group and sex. For those variables where carers spent more time in, or did more episodes of, an activity, the value of one was added to the scale score for all diarists scoring at or above the 60 percentile score for their age group and sex. For variables where the median and the relevant percentile were zero minutes or episodes, and the number of cases of carers in the sex and age group who did the activity exceeded six people, a score of one was added to the scale for diarists whose time or episodes exceeded or fell below (depending on how carer's time differed from the population on that variable) the median score of people who performed the activity. For those limited cases where the number of carers in the sex and age group was smaller than six, and carers did more of the activity, one was added to the scale score for any score above zero.

The resulting scale produced actual scores ranging from zero to 20. The scale did not produce clear-cut results as a limited number of all three types of carer identified thus far scored zero (less than 1 per cent of each of the carer types, compared to 2 per cent of people not identified as carers). Moreover, similar percentages of the three carer types scored between 17 and 20, as did some people not identified as carers. Nonetheless, differences do emerge. The non-carer median score of 5 represents the 25 percentile for 'self-identified primary carers' and 'non-identified carers' and the 30 percentile for 'self-identified other carers'. The 'self-identified carer' and 'non-identified carer' median score of 8 represents the 72 percentile score for non-carers, and the median score of 7 for 'self-identified other carers' represents the 64 percentile for non-identified carers.

Table 3.1 Time use categories tested for carer-distinctive time signatures

Categories of time use where carers may exhibit a distinctive time signature	Scale Items	Weak Items	Dropped
Perception that carers spend more time doing care and voluntary work			
performing adult care as a main activity	not used		
performing adult care as a secondary activity	not used		
total episodes of adult care (as either main or secondary activity)	not used		
performing child care as a main activity		x	
performing child care as a secondary activity		x	
performing pet and domestic animal care as a main activity		x	
performing pet and domestic animal care as a secondary activity			x
engaging in formal voluntary work as a main activity		x	
doing favours for others as a main activity			x
travel and communication related to voluntary work/help/adult care as a main activity	x		
total episodes of voluntary work and informal help (as either main or secondary activity)	x		
Perception that carers spend more time on domestic work			
shopping and service use as a main activity		x	
travel and communication related to shopping and services as a main activity		x	
total episodes shopping or using services (as either main or secondary activity)	x		
food preparation or clean-up as a main activity	x		
food preparation or clean-up as a secondary activity	x		
total food preparation or clean-up episodes (as either main or secondary activity)	x		
cleaning as a main activity		x	
total episodes of cleaning (as either main or secondary activity)	x		
textile care, laundry, or ironing as a main activity	x		
total episodes textile care, laundry, or ironing (as either main or secondary activity)	x		
home maintenance and repair as a main activity		x	
care of ground, yards, and gardens as a main activity		x	
household management as a main activity	x		
total episodes other housework (as either main or secondary activity)	x		
travel and communication related to domestic work as a main activity		x	

Table 3.1: Time use categories tested for carer-distinctive time signatures - Continued

Time signature variables	Mean score (in hours and minutes)		Identified primary carers		Identified other carers		Non-identified carers		1-Way Anova	Mann-Whitney U
	carer	not carer	β	Sig	β	Sig	β	Sig	Sig	Asymp
main activity adult care	13 min	0 min	13.70	**0.000**	3.53	**0.000**	34.82	**0.000**	**0.000**	**0.000**
secondary adult care	4 min	0 min	4.86	**0.000**	0.92	**0.035**	9.55	**0.000**	**0.000**	**0.000**
adult care episodes	0 epis	0 epis	0.70	**0.000**	0.10	**0.000**	0.87	**0.000**	**0.000**	**0.000**
main activity child care	35 min	33 min	-6.79	**0.036**	-1.91	0.377	1.75	0.602	0.744	**0.016**
secondary child care	1hr 31mn	1hr 30mn	-21.66	**0.023**	-12.02	0.058	-5.57	0.571	0.975	**0.029**
main activity pet care	10 min	7 min	3.11	**0.004**	1.00	0.165	0.02	0.987	**0.000**	**0.000**
secondary pet care	2 min	2 min	0.81	0.103	-0.35	0.294	-0.72	0.164	0.144	**0.005**
formal voluntary work	4 min	3 min	1.83	0.126	-1.04	0.190	2.53	**0.041**	**0.001**	**0.000**
doing favours for others	1 min	1 min	0.12	0.843	0.33	0.392	0.44	0.462	0.396	**0.000**
voluntary/care travel/communication	10 min	3 min	4.30	**0.000**	4.78	**0.000**	12.95	**0.000**	**0.000**	**0.000**
voluntary and help episodes	1 epi	0 epis	0.33	**0.000**	0.28	**0.000**	0.86	**0.000**	**0.000**	**0.000**
shopping and service use	32 min	26 min	1.03	0.637	1.72	0.238	3.15	0.164	**0.000**	**0.000**
shop/service travel/communication	17 min	16 min	1.54	0.264	-0.93	0.309	-1.31	0.356	**0.034**	**0.000**
shopping and service episodes	2 epis	2 epis	0.25	**0.037**	0.12	0.119	0.29	**0.020**	**0.000**	**0.000**
main activity food preparation/clean-up	1hr 4min	48 min	15.00	**0.000**	1.60	0.301	4.91	**0.040**	**0.000**	**0.000**
secondary food preparation/clean-up	4 min	2 min	1.01	**0.049**	0.27	0.424	3.22	**0.000**	**0.000**	**0.000**
food preparation/clean-up episodes	4 epis	3 epis	0.74	**0.000**	0.11	0.153	0.39	**0.001**	**0.000**	**0.000**
main activity cleaning	33 min	24 min	2.04	0.330	3.39	**0.015**	3.03	0.162	**0.000**	**0.000**
cleaning episodes	1 epi	1 epi	0.39	**0.000**	0.16	**0.000**	0.24	**0.000**	**0.000**	**0.000**
textile care, laundry, ironing	28 min	19 min	5.74	**0.001**	2.53	**0.032**	3.95	**0.031**	**0.000**	**0.000**
textile care, laundry, ironing episodes	2 epis	1 epi	0.31	**0.000**	0.12	**0.032**	0.35	**0.000**	**0.000**	**0.000**
home maintenance and repair	15 min	12 min	1.13	0.611	1.66	0.262	1.96	0.392	**0.040**	**0.000**
care of ground, yards, and gardens	24 min	18 min	-0.56	0.801	1.49	0.317	4.81	**0.037**	**0.000**	**0.000**
household management	12 min	8 min	4.13	**0.001**	1.96	**0.015**	0.63	0.615	**0.000**	**0.000**
other housework episodes	2 epis	2 epis	0.66	**0.000**	0.27	**0.000**	0.46	**0.000**	**0.000**	**0.000**
domestic work travel/communication	4 min	3 min	1.60	**0.019**	0.59	0.199	-0.80	0.260	**0.002**	**0.000**

Table 3.1: Time use categories tested for carer-distinctive time signatures - Continued

Categories of time use where carers may exhibit a distinctive time signature	Scale Items	Weak Items	**Dropped**
Perception that carers spend less time on other work and personal care			
time main daily sleeping	x		
total episodes of main daily sleeping			x
total overlayed sleep episodes (reporting doing something else while being asleep)			x
resting, napping, or thinking as a main activity			x
resting, napping, or thinking as a secondary activity			x
time worrying, being unable to sleep as a main activity		x	
total episodes of worrying or being unable to sleep		not used	
total episodes in the home between 00:00 and 06:00		x	
total episodes between 00:00 and 06:00		not used	
personal care as a main activity		x	
receiving medical services as a main activity		x	
total episodes of receiving medical services		x	
eat, drink, or smoke as a main activity			x
eat, drink, or smoke as a secondary activity			x
smoke as a main or a secondary activity			x
undertaking sports and exercise as a main activity			x
paid work or related activities as a main activity		x	
education, training, or related activities as a main activity		x	
Perception that carers have very busy days			
time where no main activity was recorded (bad diaries already excluded)			x
time with only a main activity and no secondary activity reported (no multi-tasking)	x		
other combinations of secondary activities not already listed elsewhere in this table		x	
total number of activities listed in the diary	x		

Table 3.1: Time use categories tested for carer-distinctive time signatures - Continued

Time signature variables	Mean score (in hours & minutes or number)		Identified primary carers		Identified other carers		Non-identified carers		1-Way Anova	Mann-Whitney U
	carer	not carer	β	Sig	β	Sig	β	Sig	Sig	Asymp
main daily sleeping	8hr 17mn	8hr 35mn	-10.77	**0.019**	-10.65	**0.001**	-16.74	**0.000**	**0.000**	**0.000**
main sleeping episodes	2 epis	2 epis	0.04	0.323	-0.02	0.432	-0.05	0.217	**0.029**	0.142
overlayed sleep episodes	0 epis	0 epis	-0.02	0.468	-0.04	**0.042**	-0.02	0.426	0.844	0.862
main activity rest/nap/think	20 min	19 min	-1.75	0.514	-2.31	0.197	-3.66	0.186	0.839	0.238
secondary rest/nap/think	5 min	5 min	0.07	0.958	-0.89	0.307	2.55	0.058	0.094	**0.010**
worry, unable to sleep	2 min	1 min	-0.72	0.232	0.43	0.287	1.00	0.109	**0.045**	**0.000**
worry episodes	0 epis	0 epis	-0.01	0.429	0.01	0.107	0.02	**0.012**	**0.001**	**0.000**
in-home episodes 00:00 to 06:00	2 epis	2 epis	0.19	**0.012**	0.07	0.145	0.09	0.242	**0.000**	**0.000**
total episodes 00:00 to 06:00	2 epis	2 epis	0.20	**0.021**	0.09	0.138	0.07	0.435	**0.008**	**0.003**
personal care	49 min	50 min	0.53	0.771	-3.41	**0.005**	-1.82	0.333	**0.036**	0.077
receiving medical services	3 min	2 min	1.39	**0.029**	-0.49	0.248	-0.40	0.544	**0.014**	**0.000**
medical services episodes	0 epis	0 epi	0.06	**0.000**	0.00	0.870	0.01	0.610	**0.000**	**0.000**
main activity eat/drink/smoke	1hr 43mn	1hr 40mn	-5.19	0.095	1.12	0.589	-1.15	0.720	0.080	**0.000**
secondary eat/drink/smoke	15 min	15 min	1.78	0.373	0.58	0.662	0.66	0.751	0.998	0.099
any smoking	1 min	2 min	-0.06	0.940	0.10	0.845	-0.21	0.791	0.383	0.603
sports and exercise	25 min	28 min	-4.74	0.141	-3.04	0.157	-5.02	0.132	0.186	0.919
paid work/related	2hr 42mn	3hr 32mn	-6.05	0.479	0.56	0.922	-26.24	**0.003**	**0.000**	**0.000**
education/training	13 min	26 min	-8.02	0.059	4.60	0.104	-11.15	**0.011**	**0.000**	**0.000**
no recorded main activity	1 min	1 min	0.74	**0.012**	0.18	0.367	0.26	0.395	0.119	0.113
no recorded secondary activity	17h 50m	18h 15m	1.28	0.920	1.13	0.894	-14.46	0.272	**0.005**	**0.000**
other secondary combinations	18 min	15 min	-2.16	0.299	0.80	0.563	4.80	**0.025**	**0.002**	**0.000**
number of activities in diary	33 acts	28 min	3.41	**0.000**	1.44	**0.000**	3.75	**0.000**	**0.000**	**0.000**

Table 3.1: Time use categories tested for carer-distinctive time signatures - Continued

Categories of time use where carers may exhibit a distinctive time signature	Scale Items	Weak Items	**Dropped**
Perception that carers have more restricted leisure and are confined to the home			
socialising as a main activity			x
reading as a main activity		x	
electronic media use as a main activity	x		
read or use electronic media as a secondary activity			x
other in-home leisure activities as a main activity		x	
other out-of-home activities as a main activity	x		
leisure communication as a secondary activity		x	
total episodes of leisure activities (as main or secondary activity)	x		
overlayed leisure (leisure during something else/something else during leisure time)	x		
out-of-home leisure time 17:00 to 24:00		x	
in-home leisure time 17:00 to 24:00			x
average time of a leisure episode	x		
time at own home		x	
time at other people's home	x		
time at school or work		not used	
time at shops or services		x	
time at leisure facilities or public locations		x	
time at other or unknown locations			x
Perception that carers give more time to others and have less time for themselves			
time alone		x	
time for self	x		
time around people with disabilities	x		
time for people with disabilities	x		
time for household members	x		
time for friends or work colleagues		x	
time for pets		x	

Table 3.1: Time use categories tested for carer-distinctive time signatures - Continued

Time Signature Variables	Mean score (in hours and minutes)		Identified primary carers		Identified other carers		Non-identified carers		1-Way Anova	Mann-Whitney U
	carer	not carer	β	Sig	β	Sig	β	Sig	Sig	Asymp
main activity socialising	11 min	11 min	1.33	0.517	1.73	0.206	-1.07	0.612	0.805	0.300
main activity reading	28 min	25 min	0.73	0.741	-1.14	0.438	-1.97	0.384	0.020	0.000
main activity electronic media	1hr 50mn	2hr 12mn	-18.93	0.000	-22.91	0.000	-21.96	0.000	0.000	0.000
secondary read/electronic media	2hr 22mn	2hr 18mn	5.42	0.444	-0.09	0.986	-0.01	0.999	0.587	0.000
other main activity in-home leisure	1hr 3min	55 min	0.73	0.844	4.21	0.090	9.07	0.018	0.000	0.000
other main activity out-of-home activity	53 min	43 min	2.86	0.423	10.46	0.000	8.02	0.029	0.000	0.000
secondary leisure communication	1hr 30mn	1hr 20mn	8.59	0.128	9.63	0.010	-0.02	0.997	0.006	0.000
total leisure episodes	14 epis	12 epis	1.32	0.000	0.81	0.001	1.03	0.005	0.000	0.000
overlayed leisure time	8 epis	7 epis	1.15	0.000	0.52	0.004	0.59	0.034	0.000	0.000
out-of-home leisure time 17:00 to 24:00	54 min	56 min	0.33	0.941	9.31	0.002	-3.58	0.441	0.010	0.977
in-home leisure time 17:00 to 24:00	2hr 48mn	2hr 47mn	-3.06	0.527	-7.92	0.014	-0.12	0.981	0.167	0.536
average leisure episode length	41 min	48 min	-5.34	0.000	-4.33	0.000	-5.51	0.000	0.000	0.000
time at own home	17hr 20m	17hr 8mn	-6.13	0.610	-29.40	0.000	10.74	0.387	0.000	0.000
time at other people's home	1hr 2min	49 min	12.92	0.046	15.40	0.000	11.28	0.092	0.003	0.000
time at school or work	2hr 25mn	3hr 20mn	-13.01	0.123	2.28	0.685	-25.70	0.003	0.000	0.000
time at shops or services	48 min	38 min	1.56	0.681	2.99	0.237	9.72	0.013	0.000	0.000
time at leisure facilities/public locations	2hr 22mn	2hr 17mn	3.59	0.614	9.55	0.044	-4.81	0.512	0.162	0.003
time at other or unknown locations	4 min	4 min	1.07	0.472	-0.83	0.405	-1.23	0.423	0.723	0.530
time alone	4hr 12mn	4hr 3mn	-42.89	0.002	28.06	0.003	-2.79	0.846	0.000	0.022
time for self	17hr 45m	18h 47m	-52.43	0.000	-34.76	0.000	-55.98	0.000	0.000	0.000
time around people with disabilities	7hr 56mn	5hr 19mn	444.49	0.000	17.24	0.245	55.32	0.016	0.000	0.000
time for people with disabilities	10 min	1 min	10.16	0.000	5.78	0.000	17.44	0.000	0.000	0.000
time for household members	3hr 52mn	2hr 50mn	47.52	0.000	10.93	0.057	31.83	0.000	0.000	0.000
time for friends or work colleagues	2hr 1min	2hr 21mn	-8.60	0.315	14.92	0.009	-2.95	0.738	0.000	0.372
time for pets	3 min	3 min	1.33	0.026	-0.25	0.538	0.42	0.493	0.011	0.000

Source: Australian Bureau of Statistics 1997 Time Use Survey

Defining possible carers

The concept of 'possible carer' was introduced to make allowances for the imperfections of the scale scores. 'Possible carers' were defined as diarists not already defined as carers on the criteria used for the other three types but who, at or above the carer 75 percentile score of 11 on either of their diary days, scored at or above the carer 40 percentile of 7, and either spent long periods with a person with a disability or did things for a person with impairments.

But the estimate of 3682 diaries of 'possible carers' this produced is probably too high and not all these people were carers. The obvious answer to the question of why some people may have gained such scores if they were not adult carers is that they may be providing another form of care. The 'possible carer' identification was clearly appropriate in all cases where the diarist had recorded doing an activity for a person with impairments or spending seven or more hours around a person with impairments. But for the other cases, diarists were coded separately from the category of 'possible carers' if they: lived in a household with a child aged less than 5; lived in a household with a child aged 5 to 14; did not live in a household with dependent children but recorded childcare activities in at least one of the diaries (most of these people were women nearing retirement age); and finally, did not live with a dependent child or perform childcare but did live in a household with a member with a temporary injury or illness. All cases remaining once these categories of diarists were excluded were coded as 'possible carers', leaving 1263 possible adult carers, 398 carers of children under 5 who were not also adult carers, 154 carers of older children who did not also have a younger child or care for an adult, 512 people who did not live with a child but performed childcare and did not care for an adult, and 102 people who did not live with a child or care for an adult, but who lived with a person with a temporary illness or injury.

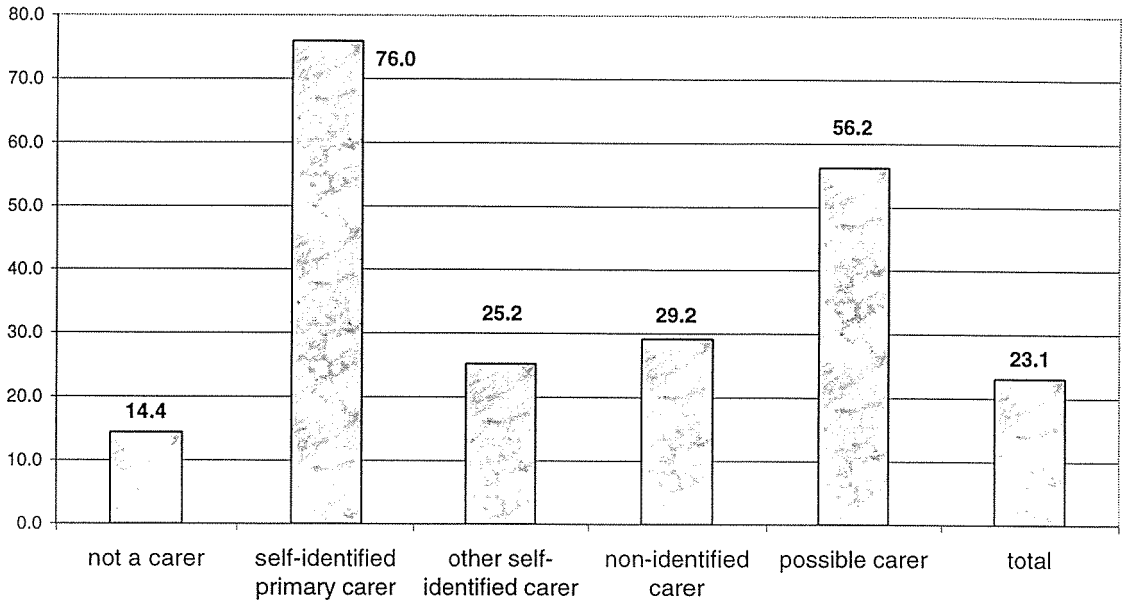
Some simple tests of the validity of the coding of 'possible carers' were then performed. Appendix B shows the dendrogram from a binary data between-groups linkage hierarchical cluster analysis. The included binary variables cover all the items used in the carer-profile scale, the remaining 28 items where carers differed from non-carers, and marker variables for the non-carers with 0 to the median non-carer scores, non-carers with scores above the non-carer media, non-carers who look after children from other households, non-carers with older children, non-carers with younger children, non-carers living with a person with a temporary illness or injury, 'possible carers', 'non-identified carers', 'self-identified primary carers', and 'self-identified other carers'. On this dendrogram, the shorter the lines connecting any two elements the more similar the coding pattern for those two elements – that is, the more likely they are to be coded 1 (the carer time signature score) on the same items or coded 0 (for not exhibiting a carer time signature for that item).

Non-carers with lower scores show no pattern similarities with other groups, and even high scoring non-carers have only very distantly related patterns. These orderings lend credibility to the validity of the categorisation of 'possible carer'. 'Possible carers' and 'self-identified other carers' show distinctive patterns. 'Self-identified primary carers' and 'non-identified carers' show similar patterns, as do non-carers living with a child aged less than five and those caring for children from other households, and non-carers living with older dependent children and those living with a person with a temporary illness or injury.

Figure 3.2 shows the percentage of people in the different carer categories who live in a household with an adult with impairments needing care. It is not surprising that over three-quarters of 'self-identified primary carers' live with an adult with impairments needing care. Over half the 'possible carers' also live with an adult with impairments needing care – a

reassuring result. Around one-quarter of 'self-identified other carers' and 'non-identified carers' also live with an adult with impairments – with both percentages above the population average of just under a quarter, and well above the non-carer average of 14 per cent.

Figure 3.2 The percentage of people in living in households with an adult with impairments needing care



Source: Australian Bureau of Statistics 1997 Time Use Survey

3.3 Profiles of the four types of adult carers

This section considers which groups of people in Time Use Survey took up which types of carer roles, and which groups did not provide care for adults. First, there are simple breakdowns by age and sex for each of the carer types, and then an examination of the differences that emerge in a binary logistic regression model of who works in each care type.

Age and sex profiles of adult carers

'Possible carers' constituted the largest group of carers, and 'self identified other carers' the second largest group, among both men and women of all age groups, as shown in Table 3.2. Among men, the proportion of 'possible carers' stood around 14 per cent from the age of 15 through 54, rising to 20 per cent between ages 55 and 64, and rising again to 24 per cent from the age of 65. Among women, only 10 per cent of those aged 15 to 25 were 'possible carers', but from 25 to 44 the percentage of women slightly exceeded the percentage for men, rose to 20 per cent among women aged 45 to 54, then increased again to 30 per cent from age 55. Below the age of 25 women and men provided care in equal proportions. From the age of 25 on, women were consistently more likely to be carers than men, although the gender gap declined after carers reached the age of 65.

Women aged 15 to 24, and men aged 15 to 34, were twice as likely to be 'non-identified carers' as they were to be 'self-identified primary carers'. Women aged 25 to 44 were equally likely to be 'self-identified primary carers' and 'non-identified carers'. Between the ages of 45 and 64 more women were 'self-identified primary carers' than 'non-identified carers', while from the age of 65 on more women were 'non-identified carers' than 'self-identified

primary carers'. Men aged 35 to 44 were equally likely to be 'self-identified primary carers' and 'non-identified carers', and from age 45 men were more likely to be 'self-identified primary carers' than 'non-identified carers'.

Table 3.2 consistently shows the prominence of 'non-identified' and 'possible' carers among the carer population. Moreover, it is likely that even this level of prominence is an underestimate. Given that a relatively low percentage of self-identified carers performed any care activities on their diary day, categorising non-identified carers through their reporting of adult care on a diary day is likely to have missed the majority of those who perform care activities but do not identify themselves as carers. Some people among the 'possible carer' population might have been classified as 'non-identified carers' if they had completed diaries on different days, though it is not easy to estimate what percentage of the non-identified population fits into this category. Nevertheless, Table 3.2 suggests that the non-identified carers might represent as much as 63 per cent of the total carer population for both women and men.

Logistic regression modelling of the four carer populations

We now turn to multivariate profiling of the four carer types using binary logistic regression modelling of the four types of carers as well as of people who did not provide care. The model covers marker variables for:

- the receipt of formal services
- whether the household pays for formal services
- whether the household receives income support
- whether the household is in a capital city or in a rural area (with non-capital urban areas held constant)
- whether the household possesses a car
- whether the diarist herself or himself has a disability
- whether the household is situated in the 20 per cent most socio-economically disadvantaged areas or the 20 per cent least socio-economically disadvantaged areas (with the middle 60 per cent of areas held constant)
- whether the diarist is female
- whether the diarist is aged 15 to 29, 50 to 64, 65 to 74, or 75 or more
- whether the diarist is single and does not have a cohabiting partner or has lost a partner through divorce, separation or death
- whether the diarist was born outside Australia
- whether the diarist does not speak English at home
- whether the diarist has completed some university level education
- whether the diarist is employed part-time, or is neither working nor seeking work (full-time workers and the unemployed are held constant)
- whether the diarist holds more than one job
- whether the diarist is a student

Table 3.2 The age and sex profile of the four carer types, non-adult-carers with other care responsibilities, and non-carers

Men	Aged 15 to 24		Aged 25 to 34		Aged 35 to 44		Aged 45 to 54		Aged 55 to 64		Aged 65 or more	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Self-identified primary adult carer	2	0.3	7	1.1	16	2.3	28	4.7	21	4.8	21	4.7
Other self-identified adult carer	20	3.3	46	7.0	58	8.5	68	11.3	56	12.8	32	7.1
Non-identified adult carer	8	1.3	16	2.4	15	2.2	17	2.8	16	3.7	17	3.8
Possible adult or child carer	86	14.2	95	14.4	94	13.7	86	14.3	89	20.4	108	24.1
Non-adult-carer, but other possible care responsibilities	40	6.6	143	21.6	181	26.4	66	10.9	28	6.5	11	2.5
Not a carer of any kind	451	74.3	353	53.5	322	46.9	337	56.0	227	51.9	259	57.8
Total	607	100.0	660	100.0	686	100.0	602	100.0	437	100.0	448	100.0

Women	Aged 15 to 24		Aged 25 to 34		Aged 35 to 44		Aged 45 to 54		Aged 55 to 64		Aged 65 or more	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Self-identified primary adult carer	6	1.0	22	2.9	42	5.5	52	7.9	29	6.9	16	3.1
Other self-identified adult carer	25	4.0	49	6.4	78	10.3	90	13.6	66	15.6	39	7.6
Non-identified adult carer	13	2.1	21	2.8	42	5.5	24	3.6	21	5.0	30	5.8
Possible adult or child carer	64	10.2	118	15.5	114	15.0	134	20.2	123	29.1	152	29.6
Non-adult-carer, but other possible care responsibilities	48	7.5	256	33.6	264	34.8	75	11.3	35	8.3	19	3.7
Not a carer or any kind	474	75.2	295	38.8	220	28.9	287	43.4	148	35.1	258	50.2
Total	630	100.0	761	100.0	760	100.0	662	100.0	422	100.0	514	100.0

- whether the diarist is a manager or professional, an own-account worker, or an unpaid family worker (with non-managerial/professional employees held constant)
- whether the diarist reports feeling time pressured
- whether the diary was completed in the summer or the winter (spring and autumn days are held constant)
- whether the diary was completed on an unusual day or on a weekend day (with usual weekdays held constant).

Table 3.3 shows the exponential β coefficients and levels of significance attached to variables where the four groups of adult carers differ from the rest of the Australian population, while Appendix C provides the complete breakdown of the regression results for carers and non-carers.

A number of common elements emerge across at least three, and possibly all, of the four carer types. 'Self-identified primary carers' and both groups of non-identified carers were more likely to be women. Women and men were equally likely to provide occasional assistance as 'self-identified other carers'. Self-identified carers and 'non-identified carers' were less likely to be aged under 30 but more likely to feel time pressured (while non-carers are significantly less likely to feel time pressured than carers – see Appendix C). Both groups of self-identified carers, as well as 'possible carers', were more likely to have a disability themselves. All four groups of carers were less likely than the general population to hold a job or be seeking one, or to work part-time if they were in the labour force. Each of these findings is consistent with previous research published about carers, both in Australia and in other OECD countries (Bittman et al., (in press); Neysmith 2000; Jacobzone 1999; Braithwaite 1990).

All four carer types also were more likely to have completed their diary on an unusual day (while non-carers are significantly less likely to report completing their diary on an unusual day – see Appendix C). The coefficient is highest for 'non-identified carers' than for the other three carer types, all of whom have similar coefficients for this variable. That 'non-identified carers' should score higher than other carers is not surprising, since it is likely that many of the carers in this group supply care only on occasional days, and at least one of their diary days coincides with a care day That all carers should identify a diary day as unusual while the majority of diaries days for the rest of the Australian population were ordinary, may suggest that carers generally have more varied days, though the precise implication of this finding is unclear.

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Table 3. 3 Profiles of adult carers based on binary logistic regression output (blank cells represent non-significant results)

Independent variable	Self-identified primary carers	Self-identified other carers	Non-identified carers	Possible carers
	Exp β and sig	Exp β and sig	Exp β and sig	Exp β and sig
diarist is a woman	1.41 (.001)		1.40 (.002)	1.21 (.001)
aged 15 to 29	0.21 (.000)	0.52 (.000)	0.62 (.004)	
aged 50 to 64		1.59 (.000)	1.32 (.031)	
aged 65 to 74	0.45 (.000)		1.60 (.012)	
aged 75 or more	0.55 (.010)	0.50 (.001)	1.76 (.014)	1.29 (.031)
single, never had partner	0.70 (.045)	0.59 (.000)		
divorced, widowed, separated	0.52 (.000)	1.28 (.008)	0.73 (.047)	
diarist has a disability	1.53 (.000)	1.28 (.000)		1.98 (.000)
born outside Australia		0.74 (.000)		
not speak English at home		0.44 (.000)		0.76 (.018)
has university level education	1.38 (.009)			1.40 (.000)
diarist feels time pressured	1.93 (.000)	1.34 (.000)	1.87 (.000)	
person lives in capital city		1.17 (.051)		0.87 (.023)
household does not have a car		0.38 (.000)		0.74 (.005)
household income in highest 20%			0.65 (.003)	
household receives services	1.87 (.015)			1.54 (.004)
household pays for services				0.64 (.004)
household receives benefits	2.43 (.000)			1.25 (.001)
works part-time	1.40 (.021)	1.22 (.030)	1.38 (.023)	1.26 (.004)
neither working nor unemployed	1.58 (.001)	1.29 (.007)	1.38 (.029)	1.59 (.000)
manager or professionals		1.27 (.011)	1.42 (.019)	
own account worker	0.47 (.006)			
diarist is a student		1.23 (.053)		0.72 (.001)
diary completed in summer		1.25 (.001)		1.15 (.021)
diary completed in winter		0.76 (.001)		
diary complete on unusual day	1.30 (.007)	1.24 (.001)	2.12 (.000)	1.27 (.000)
diary completed on weekend day				0.88 (.027)
number of diaries (unweighted)	513	1232	475	1932

Source: 1997 Australian Bureau of Statistics Time Use Survey

Carers are more likely than other Australians to live in couples. 'Self-identified primary carers' and 'non-identified carers' are less likely to have lost a partner through divorce, separation or death, and 'self-identified primary carers' and 'self-identified other carers' are less likely to be single. In curious contrast, though, 'self-identified other carers' are more likely to have lost a partner than other Australians.

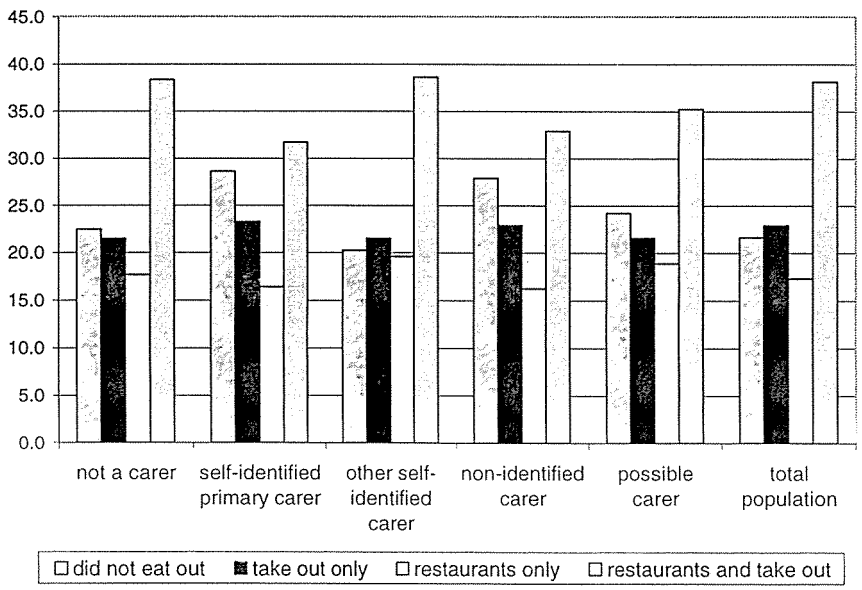
Some clear age differences divided the carer groups. 'Self-identified primary carers' were most likely to be aged 30 to 49, and significantly less likely to be aged 65 or more. 'Self-identified other carers' were more likely to be aged 50 to 64, but less likely to be aged 75 or more. 'Non-identified carers' were more likely to be aged 50 or older, and both 'non-identified' and 'possible' carers were more likely to be aged 75 or more. The clustering in the older age groups of carers who do not report themselves to be carers may indicate a policy need to target information about services for carers at the older sections of the population, particularly as care needs among the elderly will rise as the population ages.

Table 3.3 also suggests that carers do have access to some resources. 'Possible carers' and 'self-identified other carers' were more likely than the general population to live in households with a car. 'Possible carers' and 'self-identified primary carers' were more likely to have some university education and to live in households that made use of external domestic services and that received income support payments. 'Possible carers' were less likely to pay for domestic services which their households received. Other differences were specific to one or to two types of carers and do not readily inform carer policy.

Other impacts of being a carer

A limited number of other questions from the main questionnaire of the Time Use Survey further illuminated the impact of assuming the caring role. First, the questionnaire asked household members how often over a month they purchased food made outside the home, and whether they tended to frequent restaurants, purchase take-away meals, or both. Figure 3.3 shows the distribution of answers for the four carer types, non-carers and the total population. 'Self-identified primary carers' and 'non-identified carers' were least likely to purchase meals made outside the home and eat out in restaurants. Though this relationship is weak (Cramer's V score 0.073),[5] it is nonetheless statistically significant (Pearson's Chi Squared significance p<.000). Figure 3.3 thus reinforces the belief of the focus group participants that carers are more likely to experience restrictions on their leisure activities and somewhat more confined to their homes than are non-carers.

Figure 3.3 Percentage of diarists by monthly patterns of eating out and carer type

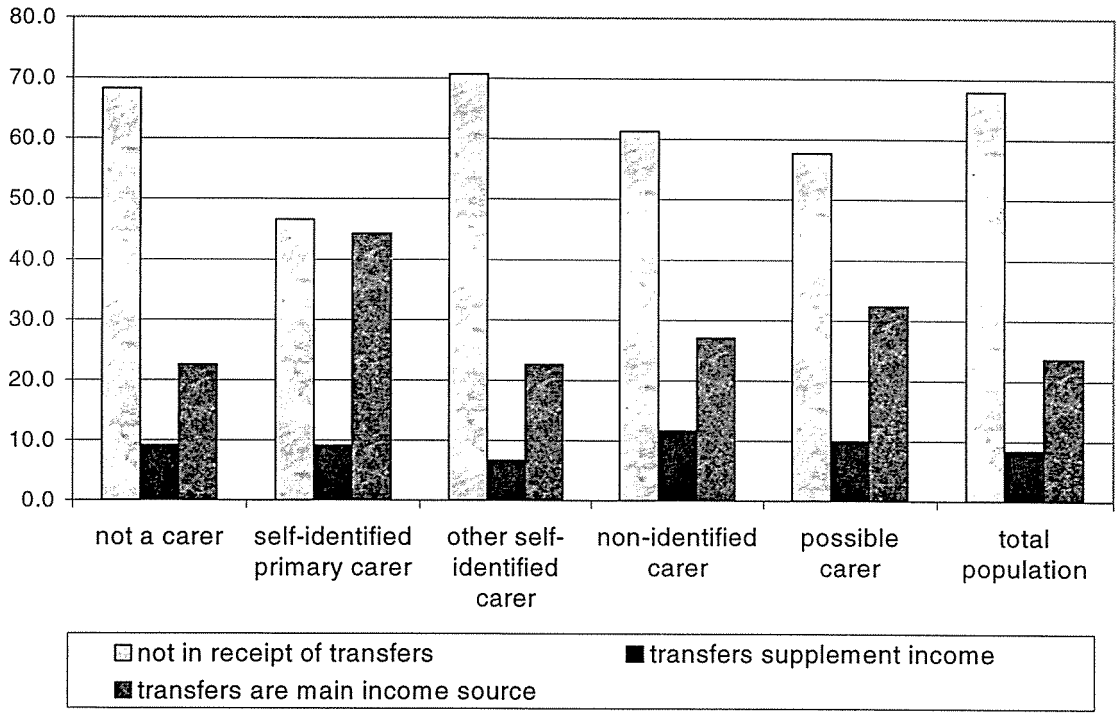


Source: 1997 Australian Bureau of Statistics Time Use Survey

[5] Cramer's V scores measure the strength of the relationship between two categoric variables (that is, variables which are categories and not real numbers) where at least one variable is nominal – that is does not have any implied order between the categories. The closer the Cramer's V score is to 0, the weaker the relationship, while the closer the score is to 1, the stronger the relationship. A Cramer's V score of 0.300 represents a moderate strength relationship between the two variables.

Figure 3.4 provides part of the explanation for why some groups of carers eat out in restaurants less than the rest of the Australian population. 'Self-identified primary carers', followed by 'possible carers' then 'non-identified carers', were more likely than the general population and non-carers to rely on income support payments and family transfers as their main source of income. Curiously, though, 'self-identified other carers', followed by 'non-identified carers' then 'possible carers', were less likely than non-carers and the general population to receive any form of benefits payments or family income transfers. While again this relationship is a loose one (Cramer's V = .139), the strength of the relationship is stronger than for eating out and again statistically significant (Pearson's Chi Squared significance p<.000).

Figure 3.4 Carer type by relevance of income support and family income transfers



Source: 1997 Australian Bureau of Statistics Time Use Survey

Table 3.4 The activities which account for half of all activity episodes by adult carer type and non-carers

	percentage of episodes	cumulative percentage
not a carer		
personal care with no secondary activity	9.4	9.4
main sleep, no secondary activity	9.2	18.6
paid work with no secondary activity	8.0	26.6
eat, drink, or smoke with no secondary activity	7.0	33.6
use electronic media with no secondary activity	7.0	40.6
food preparation or clean-up with no secondary activity	4.1	44.7
eat, drink, or smoke with reading or media use	4.0	48.7
in-home leisure with no secondary activity	3.9	52.6
self-identified primary adult carer		
personal care with no secondary activity	7.5	7.5
main sleep with no secondary activity	6.2	13.7
food preparation or clean-up with no secondary activity	5.5	19.2
eat, drink, or smoke with no secondary activity	4.5	23.7
use electronic media with no secondary activity	4.3	28.0
in home leisure with no secondary activity	4.0	32.0
paid work with no secondary activity	3.1	35.1
eat, drink, or smoke with reading or media use	3.1	38.2
out-of-home leisure with no secondary activity	2.9	41.1
shopping/service travel & communication, no secondary	2.8	43.9
food preparation or clean-up with reading or media use	2.8	46.7
cleaning with no secondary activity	2.7	49.4
clothing care with no secondary activity	2.6	52.0
self-identified other adult carer		
personal care with no secondary activity	7.2	7.2
main sleep with no secondary activity	6.5	13.7
paid work with no secondary activity	4.9	18.6
eat, drink, or smoke with no secondary activity	4.7	23.3
in-home leisure with no secondary activity	4.4	27.7
use electronic media with no secondary activity	4.4	32.1
food preparation or clean-up with no secondary activity	4.4	36.5
out-of-home leisure with no secondary activity	3.7	40.2
eat, drink, or smoke with reading or media use	3.4	43.6
shopping/service travel & communication, no secondary	2.7	46.4
food preparation or clean-up with reading or media use	2.6	49.0
child care with no secondary activity	2.6	51.5

Table 3.4 The activities which account for half of all activity episodes by adult carer type and non-carers (continued)

	percentage of episodes	cumulative percentage
non-identified adult carer		
personal care with no secondary activity	7.6	7.6
main sleep, no secondary activity	6.0	13.6
in-home leisure with no secondary activity	4.9	18.4
food preparation or clean-up with no secondary activity	4.7	23.2
eat, drink, or smoke with no secondary activity	4.5	27.7
use electronic media with no secondary activity	4.1	31.9
out-of-home leisure with no secondary activity	3.6	35.5
paid work with no secondary activity	3.4	38.8
eat, drink, or smoke with reading or media use	3.2	42.0
shopping/service travel & communication, no secondary	2.8	44.9
textile and clothing care with no secondary activity	2.7	47.6
cleaning with no secondary activity	2.5	50.1
possible adult carers or child carer		
personal care with no secondary activity	7.4	7.4
main sleep with no secondary activity	5.2	12.7
food preparation or clean-up with no secondary activity	4.6	17.3
in home leisure with no secondary activity	4.4	21.7
use electronic media with no secondary activity	4.1	25.8
eat, drink, or smoke with reading or media use	3.8	29.5
food preparation or clean-up with reading or media use	3.4	32.9
eat, drink, or smoke with no secondary activity	3.3	36.2
out-of-home leisure with no secondary activity	3.0	39.2
paid work with no secondary activity	2.9	42.1
shopping/service travel & communication, no secondary	2.8	44.9
textile and clothing care with no secondary activity	2.6	47.5
eat, drink or smoke with leisure communication	2.6	50.1

Source: 1997 Australian Bureau of Statistics Time Use Survey

This section concludes by considering the impact of being a carer on the most common activities people perform. Table 3.4 shows the activities that comprise half of all activity episodes for each of the four carer types and non-carers. Only eight core activities account for half the daily activities of people who do not provide adult care. The most frequently performed activity is personal care and hygiene, followed by main night sleeping. The order of the next six activities varies by the carer and non-carer groups, but five of the next six most frequently undertaken activities for all Australian are: eating, drinking or smoking; paid work; watching or listening to electronic media; food preparation and clean-up; and other in-home leisure pursuits – all performed without secondary activity. The only simultaneous activity most frequently performed across the population is eating, drinking or smoking while watching or listening to electronic media.

Adult carers are distinguished from people who do not provide adult care by including four ('self-identified other carers' and 'non-identified carers') or five ('self-identified primary carers' and 'possible carers') additional activities among those they perform most frequently. For all types of carers, these additional activities include two main activities without secondary activity: out-of-home leisure and shopping-related travel or communication. Both groups of self-identified carers and 'possible carers' also perform one simultaneous activity frequently: food preparation or clean-up while watching or listening to electronic media. 'Possible carers' also regularly perform a third simultaneous activity: eating, drinking or smoking while engaged in leisure-related communication. 'Self-identified primary carers', 'non-identified carers' and 'possible carers' also frequently engage in clothing repair, ironing and laundry activities; and 'self-identified primary carers' and 'non-identified carers' also regularly engage in episodes of cleaning. 'Self-identified other carers', in contrast, most frequently engage in childcare activities as one of their most common behaviours.

3.4 Profiles of carer households

The household circumstances of carers of adults provide an important piece of the puzzle for policy makers. People who do not self-identify as carers may well be less informed about sources of support and services assisting both themselves and the people to whom they provide care. The potential impact of not identifying as a carer will be greatly reduced, however, if the non-self-identified carer lives with a self-identified carer. For this reason, it is important to know the likely percentage of the non-identified carer population that does not live with an identified carer.

Table 3.5 indicates that just under half the diarists and slightly more than half of Australian households from the Time Use Survey include no members who provide adult care. This means that a considerable proportion of Australians have some connection to adult care – nearly half of all households include at least one member who provides some form of assistance to a person with impairments.

The next largest cluster of households are those which include no self-identified adult carers (27.3 per cent), the majority of which are households with possible carers only. Households where all adult carers self-identify as carers represent 14.2 per cent of households, followed more distantly by the 5.9 per cent of households containing both self-identified and non-identified carers. Consequently, people who do not identify as carers are more likely to live in a household where no-one self-identifies as a carer, than to live with a self-identified carer.

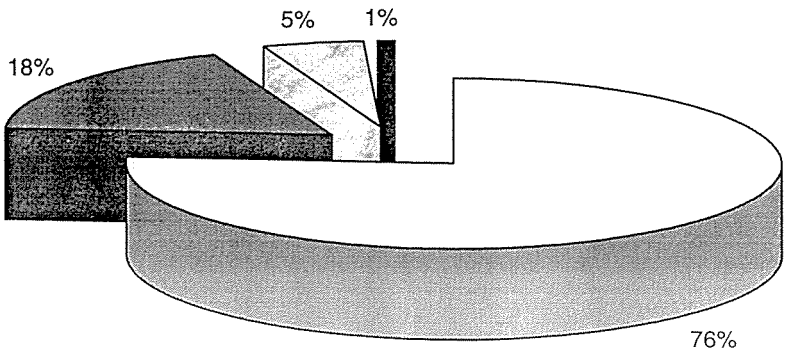
Table 3.5 The distribution of households by the combinations of carer residents

	number of diarists		number of households	
household includes no adult carers	3511	48.8%	1923	52.6%
household includes possible adult carers only	1700	23.6%	818	22.4%
household includes non-identified carers only	273	3.8%	138	3.8%
household includes self-identified carers only	1022	14.2%	519	14.2%
household includes identified and non-identified carers only	74	1.0%	28	0.7%
household includes identified and possible carers only	475	6.6%	182	5.0%
household includes non-identified and possible carers only	112	1.6%	42	1.1%
household includes identified, non-identified and possible carers	22	0.3%	6	0.2%

Source: 1997 Australian Bureau of Statistics Time Use Survey

Figures 3.5 and 3.6 show the living arrangements of male and female 'possible carers'. More women than men live either with no other carer or with only another 'possible carer', while more men than women live with a self-identified carer. Nevertheless, male possible carers also are more likely than female possible carers to live with a non-identified carer and with no self-identified carer (a statistically significant though weak relationship – Pearson's Chi^2 significance $p<0.013$; Cramer's $V=0.055$).

Figure 3.5 Living arrangements of male possible carers



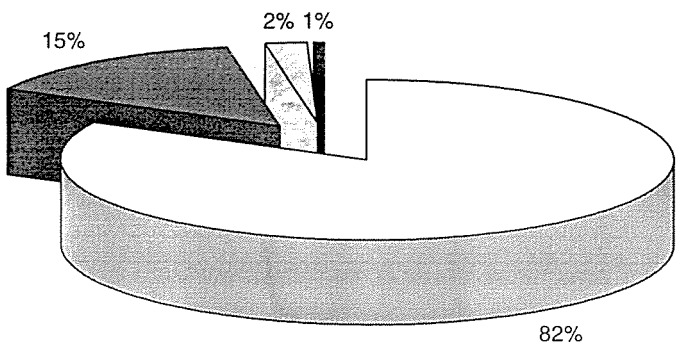
Source: 1997 Australian Bureau of Statistics Time Use Survey

As the households where no adult carers self-identify are potentially at greater risk of difficulties than households containing self-identified carers, binary logistic regression was employed to profile households with either non-identified or possible carers. (See Table 3.6). In this model, the constant category includes households:

- where at least one adult member is in the labour force
- where at least one member possesses a car
- where no dependent children reside
- where no member has reached retirement age
- where no member needs adult care
- which do not use outside domestic services
- which does not receive income support
- which are located in an urban area but not in a state or territory capital city
- which have at least one adult member who is a woman
- where no member holds a university education
- where all adult members speak English at home
- where all adult members were born in Australia.

Only five of the tested variables proved statistically significant. Households where no carer identified as such were more likely to have a retired member, to possess a car, to include a member needing care, to include an adult woman member, and to include an adult with a university level education.

Figure 3.6 Living arrangements of female possible carers



Source: 1997 Australian Bureau of Statistics Time Use Survey

Table 3.6 Binary logistic regression profile of households with only non-identified carers

	Exponential B	Significance
no adult household members are in the labour force	1.03	0.812
household does not possess a car	0.64	**0.002**
children aged 0 to 14 are in the household	0.89	0.180
at least one person in the household is aged 65+	1.47	**0.002**
at least one household member needs or receives care	3.05	**0.000**
the household makes use of outside housework services	1.03	0.709
household receives benefits of some kind	0.91	0.373
lives in a capital city	0.89	0.230
lives in a rural area	0.96	0.721
household has no adult women members	0.78	**0.043**
at least one household member has a university degree	1.23	**0.018**
English is not the main language spoken in the home	0.74	0.076
at least one member born outside Australia	0.98	0.788
constant	0.30	**0.000**

Source: 1997 Australian Bureau of Statistics Time Use Survey

4 Carers with special needs

This section of the report examines the characteristics of carers with special needs including carers with poor health, young carers and carers from CALD or ATSI backgrounds using where possible data from both the SDAC and the Time Use Survey.

4.1 Primary carers with poor health

Information on the health status of those caring for persons with disabilities or the frail elderly is available only for *primary* carers, not carers, since only primary carers completed the health self-assessment questionnaire (SF-12) included in SDAC. This section therefore investigates the characteristics of primary carers who reported having poor health, and who were not using respite services and lived with care recipients who did not use formal services.

This group may be of particular concern to policy makers as they are potentially vulnerable to being unable to continue in their caring role due to ill health or physical restrictions. The provision of services either to the carer or to the care recipient may be especially effective in supporting these carers.

Poor health and service non-use

Table 4.1, reports the percentage of primary carers in poor health who had care recipients needing assistance for each of the activities plus respite care. Column one shows the percentages of all primary carers who had care recipients who needed help in that particular task (compare Table 2.3). Column two shows the percentages of primary carers in poor health whose care recipients needed assistance for each task and did not use formal services. Column three shows the percentages of primary carers in poor health whose care recipients needed assistance for each task and did not use formal services, and who themselves did not use respite care. This analysis aims to identify the characteristics of the primary carers in the final column.

Table 4.1 Need for services, carer health and service non-use

Activity	Care recipients need assistance for task[a] %	Carer has poor health and care recipient does not use services %	Carer has poor health, does not use respite and care recipient does not use services %
Five activities[b]	100	40.8	34.9
Health care	74.4	25.6	21.4
Mobility	76.0	36.0	31.4
Transport	65.3	31.5	27.5
Communication	28.3	8.2	4.5

Source: Unpublished data, ABS *Survey of Disability, Ageing and Carers,* 1998

a Percentage of co-resident primary carers who have care recipients who need assistance

b Five activities include housework, meal preparation, paperwork, property maintenance, self-care

All percentage estimates are weighted by primary carer weights

The results for the bivariate analysis of the service use of carers with poor health is reported in Appendix D. The multivariate analysis is reported below.

Multivariate analysis

Figure 4.1 summarises the findings from the logistic regressions. Results for the 'health care' variable need to be interpreted with caution due to the low predictive capacity of the model. (Although the model predicts around 70 per cent of all the cases correctly, it only correctly predicts 6.7 per cent of the cases where carers have poor health and care recipient who do not use services). The models for the other variables all report a higher sensitivity (see tables in Appendix D), but they should be considered suitable only for identifying factors associated with the dependent variable, and not for prediction. Bearing that caveat in mind the results show that:

- The only factor consistently associated with a greater likelihood of non-use of services by care recipients of primary carers in poor health is 'born in a country other than Australia and north-western Europe', the proxy for CALD background.
- Reporting a relatively high score on the 'carer burden' index was significant for 'health care', 'mobility' and 'transport', although not for the use of services for the 'five activities'. Further analysis of this group of primary carers with poor health and a high level of 'carer burden' showed that they comprised around 38 per cent of all primary carers. Women were over-represented, making up 75 per cent although they were only 68 per cent of all primary carers. However, the men in this group were less likely than women to be using services in their care situation for all the activities except 'health care'. Service use by this high 'carer burden' group was found not to be associated with age, country of birth, educational qualification, labour force status or socio-economic status of local area.
- Another factor significantly associated with poor health and service non-use among primary carers was the presence of a care recipient whose level of disability was less than the highest level of 'profound' disability. This was significant for all activities except for 'transport'. This is not surprising as carers of individuals with a 'profound' level of disability are more likely to use services than others.

Other factors that were significant for particular services were:

- *for 'mobility' and 'transport'* – primary carer is a spouse of the care recipient; primary carer lives in an area classified in the 3rd quintile of the index of socio-economic disadvantage (further analysis showed that primary carers who lived in the 3rd quintile areas were more likely to live in the city than in the country);
- *for the 'five activities'* (self-care, housework, meal preparation, paperwork and property maintenance) – primary carers living in more socio-economically disadvantaged areas; primary carers of care recipients under 25;
- *for 'health care' and 'mobility'* – primary carers with relatively low personal incomes;
- *for 'mobility'* – primary carers living outside capital cities.

Figure 4.1: Primary carers – Poor health and service non-use

Factors	Five services and respite	Health care services and respite [a]	Mobility services and respite	Transport services and respite
Predisposing	Carer born in country other than Australia or north western Europe	Carer born in country other than Australia or north western Europe	Carer born in country other than Australia or north western Europe	Carer born in country other than Australia or north western Europe
	Carer has vocational qualification		Carer lives in couple household (is spouse of care recipient)	Carer is spouse or other relative of care recipient
Enabling	Lives in relatively more socio-economically disadvantaged area (quintiles 1-4)	Carer's personal income level is relatively low (in the 1st or 2nd quintile)	Carer's personal income level is relatively low (in the 1st or 2nd quintile)	Carer is not in the labour force
	Carer is unemployed or not in the labour force		Lives in average socio-economic area (quintile 3)	Lives in average socio-economic area (quintile 3)
			Lives outside a capital city	
Need	Care recipient is aged under 65 years (especially under 25 years)	Care recipient has severe or less disability	Carer recipient has severe disability or less	Carer reports relatively high 'carer burden' levels
	Care recipient has severe or less disability	Carer reports relatively high 'carer burden' levels	Carer reports relatively high 'carer burden' levels	

Source: Unpublished data, ABS Survey of Disability, Ageing and Carers
Notes: (a) Results of the health care analysis need to be interpreted with caution as the model has low predictive power.

4.2 Young carers

Previous research has identified young carers as a particularly vulnerable and disadvantaged group, noting that they may have greater difficulty accessing appropriate support from formal services than older carers. These difficulties include a lack of awareness on the part of service providers about the existence and needs of young carers, as well as young carers' more limited financial resources and access to information and transport, and their mistrust of services and reluctance to use them. There may be additional barriers for young carers in rural or remote regions, or for those from CALD or ATSI backgrounds (Commonwealth Department of Family and Community Services, 2002).

SDAC

This section analyses the SDAC data on carers aged 10 to 24 years (see Section 2.1 for the decision to exclude from the analysis carers below the age of 10). The analysis refers to the whole sample of young carers in the survey. It was not possible to examine young primary carers separately from young carers in general as their numbers were too small. (There were only 28 young primary carers in the SDAC sample). As was the case with the overall sample of carers, it was not possible to consider the young carers who did not live with their care recipients as SDAC collects no information about the service use of care recipients who do not live with their carers.

Characteristics of young carers

There were 625 co-resident carers under the age of 25 in the SDAC sample. Fifty-four were excluded from this analysis because they were under the age of 10, along with four others for whose care recipients there was no information on service use in the disability level file. This left a sample of 567 co-resident carers aged between 10 and 24 years. This figure represents a weighted estimate of 292 573 young co-resident carers throughout Australia.

Of the final sample of 567 young co-resident carers,

- slightly over half (51 per cent) were male;
- 35 per cent were sons (58 per cent caring for mothers and 42 per cent for fathers);
- 31 per cent were daughters (73 per cent caring for mothers and 26 per cent caring for fathers);
- 10 per cent were other female relatives; and
- 10 per cent were other male relatives.

All of these young carers were significantly more likely than other young people in their age group:

- to live in lone parent household; and
- to live in more socio-economically disadvantaged area (two lowest IRSED quintiles).

Like older carers, they were also more likely than others in their age group:

- to have a disability or long-term health condition themselves;[6]
- to receive a government pension or benefit
- to be unemployed (for those in the 15-24 age group, particularly those aged 20-24)

Support needed and service use by care recipients of young carers

Table 4.2 indicates that the care recipients of young carers have similar needs for assistance for the various activities as do the care recipients of older carers. A chi-squared test found no significant differences in the proportion of young carers who lived with care recipients who use formal services for the various activities compared to co-resident carers who are aged 25 years and over.

Table 4.2 Support needed and service use by care recipients of carers by age group

Service Type	Young carers		Carers aged 25 and over	
	Per cent who live with care recipients who need assistance for that activity	Per cent who use formal services	Per cent who live with care recipients who need assistance for that activity	Per cent who use formal services
Five services[(a)]	100	18.5	100	21.4
Communication	10.5	7.2	15.3	9.4
Health care	46.4	19.2	49.1	22.4
Mobility	44.6	9.7	44.6	11.3
Transport	42.1	6.7	45.2	7.6

Source: *ABS Survey of Disability, Ageing and Carers* 1998

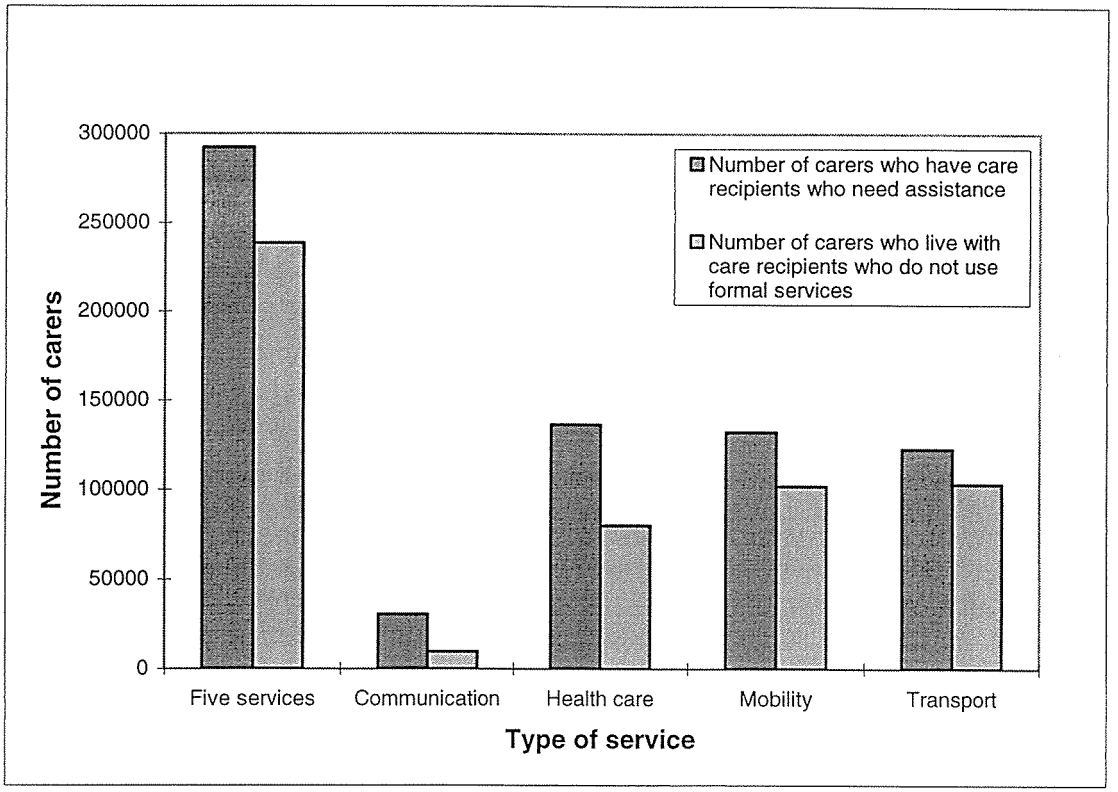
Notes: (a) Five services include housework, meal preparation, paper work, property maintenance, and self-care.
All percentages weighted by carer level weights.

Service non-use by care recipients of young carers

Figure 4.2 below illustrates the extent of service non-use for the various activities among care recipients of young carers. The first bar in each group indicates the weighted estimate of the number of young carers who have care recipients needing assistance for each activity. The second bar indicates the weighted estimate of the number of young carers living with care recipients who need assistance but who do not use formal services for that particular activity. Except in the case of communication activities, the majority of young carers whose care recipients needed assistance did not use formal services. Stated in terms of the estimated 292 573 young carers throughout Australia, 238 557 young carers used no formal assistance for the 'five activities', 9560 used none for 'communication' assistance, 80 308 used none for 'health care', 102 198 used none for 'mobility', and 103 461 used none for 'transport'.

[6] Just over 16 and a half per cent of young carers had a disability compared with 8.2 per cent of that age group in the general population, while 29 per cent of young carers had a long-term health condition compared with 17.5 per cent of young people in general. But these rates are half those of people over 25 years of age.

Figure 4.2: Young resident carers and service non-use



Source: *ABS Survey of Disability, Ageing and Carers* 1998
Notes: Five services include housework, meal preparation, paper work, property maintenance, and self-care.
All estimated numbers weighted by carer level weights.

Appendix E reports the results of the bivariate analysis of the service use of different groups of young carers and the multivariate analysis is reported in the following section.

Multivariate analysis

Because of the small numbers of young carers, it was only possible to analyse their service use in relation to the 'five activities'. All predisposing, enabling and need factors except for personal income were considered as having potential strong associations with service non-use. Personal income was not included as a potential variable as 35 per cent of young carers in the sample had not provide that information. Table 4.3 reports the results of the logistic regression analysis. The factors with the strongest association with service non-use in the case of the 'five activities' were the age of the care recipient, the household type of the carer, and the relative socio-economic status of the carer's local area. Young carers were less likely to use formal services if:

- their youngest care recipient was under 45 years;
- they did *not* live in a lone parent household; or

Table 4.3: Logistic regression: young carers and service non-use (five services)

Parameter	sig	Estimate	Standard Error	Chi-square	Probabilities
					Baseline probability
					0.8765
					Average marginal probabilities
Intercept	***	1.959	0.433	20.479	
Geographical location					
Lives outside a capital city	*	-0.487	0.260	3.499	-0.0679
Socio-economic status					
2nd Quintile		-0.017	0.397	0.002	-0.0023
3rd Quintile	**	-0.803	0.368	4.774	-0.1227
4th Quintile	***	-0.996	0.372	7.180	-0.1602
5th Quinitile	***	-1.159	0.422	7.529	-0.1970
Employment status					
Full-time	**	0.680	0.331	4.233	0.0780
Part-time		0.277	0.302	0.842	0.0345
Unemployed		0.477	0.418	1.301	0.0555
Household type					
Lone parent household	***	-1.031	0.294	12.261	-0.1673
Other household		0.389	0.360	1.169	0.0474
Sex of care recipient					
Male care recipient		0.148	0.261	0.321	0.0194
Age of care recipient					
Under 24 years	***	1.793	0.432	17.269	0.1713
25-44 years	**	0.514	0.261	3.878	0.0647
65 and over		0.069	0.550	0.016	0.0089
Disability level					
Profound	***	-0.949	0.353	7.231	-0.1509
Moderate		0.149	0.348	0.184	0.0191
Mild		-0.406	0.299	1.840	-0.0575
Number of care recipients					
More than one care recipient		-0.389	0.399	0.950	-0.0571
					Average probability of sample
McFadden's pseudo r^2=0.010					0.8432

- they lived in relatively socio-economically disadvantaged areas (quintiles one and two).

The young carers were also less likely to use formal services if:

- they worked fulltime;
- they lived in a capital city;
- their care recipient had a lesser level of disability than the highest, i.e. 'profound', level.

These findings were very similar to the findings for all carers, with the following exceptions:

- gender – whereas among carers in general males were less likely to use services, this was not the case for young carers;
- country of birth, education level, and carer's long-term health condition – these were significantly associated with service non-use among carers in general, but not for young carers; and
- employment status – this was significant for young carers, but not for carers in general.

The following analysis examines the characteristics of different groups of young carers using data from the Time Use Survey.

Time Use Survey

It is important to note that the age range of the young carer respondents to the Time Use Survey is different from the age range of young carers in SDAC, which included carers as young as 10. The information from the ABS *1997 Time Use Survey* (ABS, 1998) relevant for this analysis is that collected from young people aged 15 to 24. There is no information on time-use for persons under the age of 15 because the survey does not collect it.

Moreover, whereas the carers in SDAC were all self-identified, the Time Use Survey data can be used to identify young carers who do not self-identify. In fact, the Time Use data provide the only evidence-based picture of young non-self-identified carers.

That picture of the characteristics of young non-self-identified carers was filled out by means of a binary logistic regression modelling of four mutually exclusive young carer profiles on a number of marker variables (listed below). In the first place, and as a starting point, there are those young people who answered any of the background questions in the questionnaire accompanying the Time Use Survey indicating they were primary carers. This group comprises the 'self-identified primary carers' profile for the purposes of the model. Next, there was a group of young people who did not self-identify as primary carers but who answered other questions in the questionnaire marking them as carers. This group is the 'self-identified other carer' profile. Then there were the young people who did not admit to being carers on the questionnaire but who recorded care activities in their time diaries. This group is the 'non-identified carer' profile. Finally, young people who neither identified as carers nor recorded care

activities in their time diaries, but who did have a daily activity pattern similar to the daily patterns of carers, were modelled as 'possible carers'.

The model covers marker variables for:

- the receipt of formal services
- whether the household pays for formal services
- whether the household receives income support
- whether the household is in a capital city or in a rural area (with non-capital urban areas held constant)
- whether the household possesses a car
- whether the diarist herself or himself has a disability
- whether the household is situated in the 20 per cent most socio-economically disadvantaged areas or the 20 per cent least socio-economically disadvantaged areas (with the middle 60 per cent of areas held constant)
- whether the diarist is female
- whether the diarist is single and does not have a cohabiting partner
- whether the diarist was born outside Australia
- whether the diarist does not speak English at home
- whether the diarist is employed part-time, unemployed, or neither working nor seeking work (full-time workers are held constant)
- whether the diarist holds more than one job
- whether the diarist is a student
- whether the diarist is a manager or professional, an own-account worker, or an unpaid family worker (with non-managerial/professional employees held constant)
- whether the diarist reports feeling time pressured
- whether the diary was completed in the summer or the winter (spring and autumn days are held constant)
- whether the diary was completed on an unusual day or on a weekend day (with usual weekdays held constant).

Table 4.4 shows the exponential β coefficients and levels of significance attached to those variables where the four groups of young carers differed from the rest of the Australian population aged 15-24 in the time-use data.[7] Some caution must be exercised interpreting the results because the number of cases of each the four types of young carers is small, ranging from 188 'possible carers' to a mere 16 'self-identified primary carers'.

[7] Separate models were run for young people with childcare responsibilities, those living with a person with a temporary illness or injury, and those who had no care responsibilities. Appendix F contains the regression results for these non-carers, as well as the complete breakdown of the results for the four groups of carers.

Table 4.4: Profiles of young carers aged 15-24 based on binary logistic regression output (blank cells represent non-significant results)

Independent variable	Self-identified primary carers	Self-identified other carers	Non-identified carers	Possible carers
	Exp β and sig	Exp β and sig	Exp β and sig	Exp β and sig
diarist is a woman				0.70 (.036)
single, never had partner		0.47 (.015)		
diarist has a disability				2.20 (.000)
born outside Australia				1.60 (.046)
not speak English at home	15.30 (.016)			
person lives in capital city				1.90 (.007)
person lives in a rural area				2.00 (.020)
household receives services				5.30 (.000)
household pays for services				0.22 (.001)
household receives benefits	29.74 (.000)			1.87 (.001)
works part-time		2.15 (.034)		
neither working nor unemployed		5.16 (.000)		
works more than one job		2.55 (.016)	2.94 (.018)	
diarist is unemployed				0.53 (.038)
diarist is a student	0.17 (.044)			
diary completed in summer				1.58 (.011)
diary completed on unusual day			2.00 (.035)	
diary completed on weekend day			2.31 (.011)	1.42 (.036)
number of cases (unweighted)	16	85	41	188

Source: 1997 Australian Bureau of Statistics Time Use Survey

Table 4.4 suggests that young carers, unlike those aged 25 or more, are equally likely to be men or women – and 'possible carers' are more likely to be men. 'Self-identified other carers' are more likely than the general population in that age group to have a partner currently or to have lost a partner through divorce, widowhood or separation, although there is no significant effect from marital status for the other groups of young carers. There is some indication that young people from minority groups are more likely to be carers. The 'self-identified primary carers' are significantly more likely not to speak English at home, while the 'possible carers' are more likely to have been born outside Australia. That being said, the young people in the diary population who are not carers also are more likely to not speak English at home (exponential β 3.07, significance 0.007), though there is no significant relationship for this group for the dummy variable marking being born outside Australia (see Appendix F). 'Possible carers' are more likely to have a disability themselves, and to live in capital cities or in rural areas

Both the 'self-identified primary carers' and the 'possible carers' are more likely to live in households in receipt of income support, with 'possible carer' households also more likely to receive services but not to pay for these services. The population of young non-carers, in contrast, is less likely to live in households receiving either services or income support, and to pay privately for the services they do receive (see Appendix F)

The 'self-identified other carers' are more likely to work part-time than full-time, and even more likely to have no job and seek no job. 'Self-identified primary carers' are less likely to be students, and 'possible carers' are less likely to be unemployed. When

they work, both the 'self-identified other carers' and the 'non-identified carers' are more likely to hold more than one job.

The day the diary was completed does not matter for the' self-identified carers'. 'Non-identified carers' were more likely to perform care on unusual days as well as on weekends. The 'possible carers' were more likely to have completed diaries in the summer and on weekend days.

4.3 Aboriginal carers and carers from CALD backgrounds

Neither SDAC nor the time-use data provide sufficient information about the caring situations of Aboriginal and Torres Strait Islander (ATSI) carers or of carers from CALD backgrounds. Neither of these groups appears in either sample in sufficient numbers to be analysed separately, nor to be combined into a single dummy variable in regression models. ATSI respondents in particular appear in these surveys in very low numbers, and those who live in remote regions tend not to be sampled at all, as is the case with many other large-scale studies in Australia. Moreover, people who do not speak English are rarely included in large-scale studies because of the costs of translation.

However, two separate projects commissioned by project partner, Carers NSW, in Western Sydney in the mid-1990s do illuminate some of the particular issues relevant to these two groups, and indicate that they may face additional challenges. One of these projects investigated the needs of Koori carers in Blacktown in 1994 (Orcher 1995), while the other surveyed carers of CALD in Western Sydney in 1995 (Misic 1996). In each study, Carers NSW employed a worker from the community to administer the project, and participants reported that they found that having researchers who shared their experiences as minority group carers increased their sense of the value of the research.

While many of the issues facing each group were different, there were also some common elements. Carers in both groups had had bad experiences with services, with the effect of decreasing their willingness to consider using services again. In the case of CALD carers, the information pamphlets were a major cause of dissatisfaction. The study found that many agencies tended to use up all the pamphlets translated into another language because of the expense of printing costs and translation services, even though the information in these pamphlets was out-of-date and hence incorrect. Outdated information yielded counter-productive consequences for some carers, especially those who received these unhelpful pamphlets at their first contact with formal services (Misic 1996: 44). Both ATSI and CALD carers reported finding mainstream services for carers culturally inappropriate. ATSI carers and care recipients in particular reported a need for specialised nursing homes and respite care centres staffed by Aboriginal professionals (Orcher 1995).

As in Australia generally, it is the women in ATSI and NESB communities who are more likely to provide care than the men. These women carers find themselves relatively isolated, despite stereotypes of both communities in the mainstream culture and in the disability support agencies that assume that female carers in these communities can draw on extended family networks. In practice, only one or two people are likely to assume responsibility for providing care, rather than a wider family network or community (Misic 1996; Orcher 1995). In the case of many CALD

cultures, the presumption that care is a woman's role can also mean that the few men who do provide care find themselves unsupported (Misic 1996: 45).

Focus groups conducted with carers in both communities found that face-to-face contact and the opportunity to converse with informed professionals emerged as a significant need. Carers preferred active exchanges with service providers to passively receiving information through pamphlets or media campaigns (Orcher 1995; Misic 1996: 38). And yet, as both projects found, service providers tended to emphasise pamphlets and media campaigns as the primary way of transmitting information about their services. Media campaigns could have the effect of informing the wider community, making it more likely that carers might receive valuable advice from friends. But there was also a need for more resources to be devoted to hiring care workers who could communicate in carers' own languages (Orcher 1995; Misic 1996). The CALD project also found a need for information campaigns to target doctors, as half of the carers surveyed indicated that they relied primarily on doctors for their main source of information (Misic 1996: 35).

Each community in Western Sydney also had specific needs not shared by the other. CALD carers from some communities felt that, in admitting a need for help from formal services, they were admitting to failing in their role as a carer (Misic 1996). Carers of people with mental illnesses also were more likely to face strain as many CALD communities have less sympathy for or understanding of mental illness, compared with their reaction to people with physical impairments (Misic 1996).

Many carers in the Blacktown Koori community found contact with the health care system intimidating, and thus they were reluctant to use formal services (Orcher 1995). Aboriginal Australians also have a shorter life span on average than other Australians, which often means that issues of age-related impairment can manifest much earlier in this community than among other groups. In consequence, some ATSI carers find some formal services inappropriate, as they do not properly reflect this age difference. They can also find that their care recipient is excluded from some services on the grounds that they do not meet age requirements to qualify for assistance (Orcher 1995). In addition, many members of the Koori community live in geographically isolated areas not well serviced by public transport – and in some cases not serviced at all. Orcher (1995) also found that many ATSI carers had difficulty affording driving lessons or the fees needed to obtain a driving license, and recommended that financial assistance to carers to obtain driving licenses would enhance the ability of some Koori carers to access services. Orcher stressed a need to emphasise driving licenses over increased public transport links on several grounds. Private driving licenses allowed greater flexibility in transporting the person needing care, and many Koori carers did have access to a car they could use, but simply lacked the driving license. Further, many Aboriginal people in this area found riding on public transport intimidating when Aboriginal people were a minority of the passengers. Carers in mainstream Australia can find the process of travelling with a person with severe needs on public transport uncomfortable, and combining the two stresses for Aboriginal carers acted as a strong disincentive to some to use public transport to access services. Orcher (1995) also found that the stress of unsupported caring had encouraged some Koori carers to turn to drug or alcohol abuse.

4.4 Summary

This section of report examined the characteristics of carers who are potentially vulnerable including carers with poor health, young carers and carers from CALD and ATSI backgrounds. Targeting the provision of services to these particular carers or their care recipient may be especially effective in supporting these carers to continue providing assistance.

Overall the findings of the multivariate analysis of carers with poor health indicated a number of key points.

- The only factor that emerges as consistently associated with being a primary carer in poor health with a care recipient who is not using any support services is *being born in a country other than Australia or north-western Europe.*
- However, there is a strong association between the experience of 'carer burden' among primary carers with poor health, and the non-use of services by their care recipients.
- There is also a strong association between the care recipient's level of disability and service non-use among the care recipients of primary carers reporting poor health. Among primary carers with poor health, those whose care recipients have less severe levels of disability are less likely to make use of formal services than those whose care recipients have a 'profound' disability.
- Low income and living in a socio-economically disadvantaged area are also associated with less use of services among primary carers in poor health, although to a less consistent degree than the above three factors.

In terms of young carers the analysis found that they were less likely to use formal services if:

- their youngest care recipient was under 45 years;
- they did not live in a lone parent household;
- they lived in relatively socio-economically disadvantaged areas
- they worked fulltime;
- they lived in a capital city; and
- their care recipient did not have a profound disability.

Young carers in the Time Use Survey are equally likely to be men or women. There is some indication that young people from minority groups are more likely to be carers and more likely to live in households in receipt of income support. The 'self-identified other carers' are more likely to work part-time or to be unemployed and not seeking work. 'Self-identified primary carers' are less likely to be students, and 'possible carers' are less likely to be unemployed.

Analysis of the characteristics of carers from CALD and ATSI backgrounds was not possible using data from SDAC or the Time Use Survey because the sample size of each of these groups was too small. However other qualitative research into barriers to accessing services found that there were many common issues facing these carers. Many were unwilling to use services after having had a bad experience while others

found that mainstream services were culturally inappropriate. Further quantitative research on the characteristics of carers from CALD and ATSI backgrounds is required.

5 Time spent caring

One aspect of the experience of being a carer involves the time requirements different groups of carers typically commit to this role. While the focus groups in the previous project dealt with the issue of how caring affects daily activities, participants were not asked to estimate the time they spent caring. In part this was because there were other essential topics to be covered with the participants, and in part it was because of the difficulties of generalising from the time commitments of such a small number of people. SDAC and the Time Use Survey, however, were national data sets, and they included two different types of time estimates. SDAC asked primary carers if their typical weekly care commitment required fewer than 20 hours, 20 to 39 hours, or 40 or more hours of work, while the information recorded in the time diaries allows the summation of the time actually recorded as care. Moreover, information gained from the patterns of carers' daily activities can be used to build more precise estimates of the average time different groups of carers spend daily doing care-related activities. Section 5.1 discusses the information yielded by the time-use data, Section 5.2 compares the time estimates from the two surveys, Section 5.3 considers the time worked in care at the household level estimated as hours per week from the time diary data, and Section 5.4 concludes this part of the report.

5.1 The Time Use Survey estimates

Using the time-use diary data to calculate time spent caring requires caution to avoid double-counting the time slots where care activities are recorded. Although this was not a problem in that majority of cases where adult care was coded as the main activity, 12 per cent of diarists recorded adult care as a secondary activity only, while for a further 7 per cent both primary and secondary activities were care tasks. Even when overlaid with another activity, such as socialising with the care recipient or listening to the radio while undertaking care, secondary care time imposes constraints on the range of activities in which the carer can engage and, like main activity care time, tends to cover a significant need for the care recipient. Hence, secondary care time counts equally with main activity care time in terms of summing the time commitment from care, provided that periods where both the main activity and secondary activity are care are not double-counted.

The Time Use Survey collected additional information which may also reflect adult care – a 'For whom' column. This column identifies activities done for 'a person with a disability on account of that person's disability'. This time also properly fits into the domain of care time, with the proviso that it not be included if the main or secondary activity is already recorded as adult care.

However, even with the inclusion of the broadest of these definitions of care time (main activity recorded as care + secondary activity recorded as care when main activity is not care + time spent for people with a disability when neither the main nor the secondary activity is recorded as care), the Time Use Survey yields very low estimates of time spent caring. The 80 percentile carer score (where the time spent caring by the 20 per cent of carers reporting the longest time is at this level or higher, and the time spent caring by all other carers is lower) is 23 minutes per day – and the median time spent caring by all four types of carers is no time spent caring.

Thus, restricting the definition of care time to minutes spent in activities carers themselves recognised as caring time misses out a significant proportion of the total commitment carers make to the people they assist. There are good reasons why this might be so. As already noted in this report, some aspects of care are closely related to domestic activities. A household where there is a person who has continence problems, or who regularly spills drinks and food on account of a hand tremor, or who sweats profusely, for example, likely spends more time in laundry than a household with members similar in terms of sex and age but without those problems. It is highly unlikely that a carer in such a position could accurately estimate how much of the time spent doing these tasks is simply part of their routine domestic needs, and how much is extra time generated by their caring role. The time-use diaries enable us to work out what that difference is likely to be, by working out the average laundry time of households where no care takes place. In this case, extra time in the activities associated with carers was defined as time spent in excess of the 60 percentile score for non-care households composed of people of the same age and sex as the equivalent care households.

Even so, it is not possible simply to add the extra time spent doing laundry or other activities to the time already identified as caring time. People who are not carers can also spend long periods performing those activities that dominate the days of carers (cleaning the house after the visit of many guests or before a large celebration, for example). Similarly, carers themselves will sometimes spend longer periods on activities for reasons entirely unrelated to their role as carers. It is important to exclude as much time not related to care as possible. In order to do this, we experimented with the effect of including 30 per cent, 40 per cent, 50 per cent, and 75 per cent of the extra time expended by carers in care-related activities minus the mean score non-carers spent in extra time in these same activities, and found that the 75 per cent score was sufficiently robust for use in the estimate.

Table 5.1 shows the estimates of care time yielded by this procedure. The first feature to note about this table is that some residual caring time remains for some non-carers, but this is considerably lower than the time invested by all types of adult carers and by people with other kinds of care responsibilities. The next striking feature is the similarity between the care times of 'self-identified primary carers' and those of 'self-identified other carers'. Although primary carers recorded marginally higher care times, the difference is not significant. Equally striking is the similarity between the scores of the adult care groups and those of people who were likely to have other kinds of care responsibilities: people who did not live with a person with a disability but who did live with a child or children under five or with one or more dependent children aged five to fourteen, people who did not live with children but who did provide care to one or more dependent children on their diary day, and people who did not live with children but who did live in a household where someone had a temporary illness or injury.

Another notable feature of Table 5.1 is that the average time spent undertaking care by both 'non-identified carers' and 'possible carers' is markedly higher than the care time reported by both types of identified carers. The diary data gives no indication of why this might be so. One reason may be that the diary data is picking up a disproportionate number of non-identified carers on the days when they undertake care. Another may be that they are failing to identify an element of the non-identified

carer population that performs less intensive care as these individuals did not complete a diary on a care day. It is also possible that non-identified carers do spend more time caring, or that a combination of these reasons accounts for the higher time estimates for the 'non-identified carer' and 'possible' carer populations.

Table 5.1 Estimates of average daily time ranges spent in care (in hours and minutes per day) by the carer types

Carer Type	20 percentile	median time	80 percentile
Self-identified primary carers	2 minutes	1 hour 19 min	3 hours 16 min
Self-identified other carers	0 minutes	1 hour 14 min	3 hours 8 min
Non-identified carers	37 minutes	1 hour 59 min	4 hours 29 min
Possible carers	12 minutes	1 hour 27 min	3 hours 33 min
All carer types	10 minutes	1 hour 27 min	3 hours 31 min
Non-carers living with a child aged <5	11 minutes	1 hour 57 min	5 hours 25 min
Non-carers living with a child aged 5-14	49 minutes	2 hours 59 min	6 hours 11 min
Non-carers looking after a child from another household	4 minutes	1 hour 24 min	3 hours 51 min
Non-carers living with a person with a temporary illness or injury	0 minutes	1 hour 10 min	4 hours 8 min
Non-carers with no other care responsibilities	0 minutes	10 minutes	1 hour 39 min

Source: Australian Bureau of Statistics 1997 Time Use Survey

Table 5.1 suggests that the care needs of a household can have a similar impact on the daily routines of household members, whatever the nature of the care needed. Nevertheless, as Valerie Braithwaite (1990) has observed, caring for children or for people with temporary illnesses differs fundamentally from the care of the elderly and of people with long-term disabilities. People with temporary medical conditions recover and children develop into independent adults. Parents and temporary carers can look forward to milestones of achievement for the care recipients and decreased needs of the person for whom they provide aid. In contrast, carers of adults with permanent incapacities or declining basic functions do not have milestones marking decreased dependence to which they can look forward. Indeed, some will face the reverse experience of the increased dependency of the person whom they aid. Moreover, governments, religious institutions, and businesses contribute to the care of children and people with temporary conditions by providing services for those whose care needs are temporary – public education, temporary leave and pay provisions to aid recovery from injury, special meals and activity packs for children, baby changing facilities in public toilets. But the number of facilities and services available to providers of adult care are few compared to support for raising children or helping people with temporary injuries and illnesses (Braithwaite 1990; Bittman and Fisher 2003).

Table 5.1 also suggests that the care time of those caring for adults, whether temporarily or in the long term, differs from the care time for people looking after children. While children, especially young children, have certain basic levels of need that are the same for all households, the care needs of adult care recipients are more varied and, for a large number of them, the care process will not be as intense and encompassing as it is for children. Some adults may require only limited help with a single activity, such as getting out of bed or into and out of the shower, but otherwise be relatively independent. Some conditions require intermittent assistance but not

daily commitment. Most adult care recipients will have at least some capacity to look after themselves, as well as the desire to do so.

The time-use data do not supply a clear means of separating the carers who look after people with minimal needs from those who look after people with more profound needs. However, the information in Table 5.1 does show that people living with dependent children spend more time in care activities than people caring for adults. However, the reader should bear in mind that carers of adults are far more likely than carers of children to devote time to employment-related activities. And when total work load, including paid employment, domestic work, voluntary work, child care, adult care and personal care, is considered, adult carers frequently enjoy less discretionary time than people whose care responsibilities extend only to children, and considerably less discretionary time than people who do not provide care.

The time-use data also show that people living with children aged five to fourteen are more than twice as likely as the carers of younger children or of adults (either temporarily or long term) to hold no job and to not be seeking work. While all carers are significantly more likely to have no current labour force attachment (with the exception of people living with a person with a temporary illness of injury, for whom this variable is not significant), the exponential β scores for the four groups of carers as well as people performing child care who do not live with a dependent child range from 1.29 (significance 0.007) for 'self-identified other carers' to 1.59 (significance 0.000) for 'possible carers'. In contrast, people living with a child aged less than five have an exponential β score for not working or seeking work of 3.20 (significance 0.000), and the score for people with living with older children is 3.72 (significance 0.000). People who do not exhibit a carer time signature and who do not live with a person needing care are significantly more likely to participate in the labour force, with their exponential β score at 0.43 (significance 0.000). Thus while the care time for many carers may appear lower than the time devoted to child care – and some adult carers also care for children as well. As previously discussed in this report,

5.2 Comparing the time estimates of the 1998 SDAC and the 1997 TUS

Unfortunately, the SDAC only asked primary carers to estimate their weekly care commitments. Also, in addition to limiting the hours estimates to a three point range, the age categories in the SDAC are limited to four age groups: under 25; 25-39; 40-64; and 65 or more. Consequently, this section offers more limited analysis to permit comparison.

Some general trends emerge in the SDAC data. For co-resident female primary carers, the proportion indicating that their care time consumes 40 or more hours per week increases with age. Among all female primary carers, the proportion spending 40 or more hours per week in care is lowest in the under 25 age group 19.7 per cent), plateaus in the middle age groups (34.6 per cent and 33.8 per cent respectively), and rises among women aged 65 or more (60.6 per cent). The youngest male primary carers did not report spending full time hours in care, and two-thirds of both co-resident male primary carers and all male primary carers indicated that they spent fewer than 20 hours per week providing care. Around one-third of both male and female primary carers performing 20 to 39 hours of care work per week are in the youngest age group – and the young carers are the modal category among the age groups for this middle care time variable.

Figure 5.1 compares the time estimates of the two data sets for women and men by the four age categories available in the 1998 SDAC data. A similar picture emerges for primary co-resident carers. These comparisons suggest that women of all ages and men and 25 or more over-estimate their hours of care time, though men aged 25 to 39 appear to make smaller over-estimates than female carers or older male carers, while women aged 65 or more appear to make the highest over-estimates. Nonetheless, Figure 5.1 also suggests that male carers aged less than 25 may be significantly underestimating their care time, compared to the SDAC estimations.

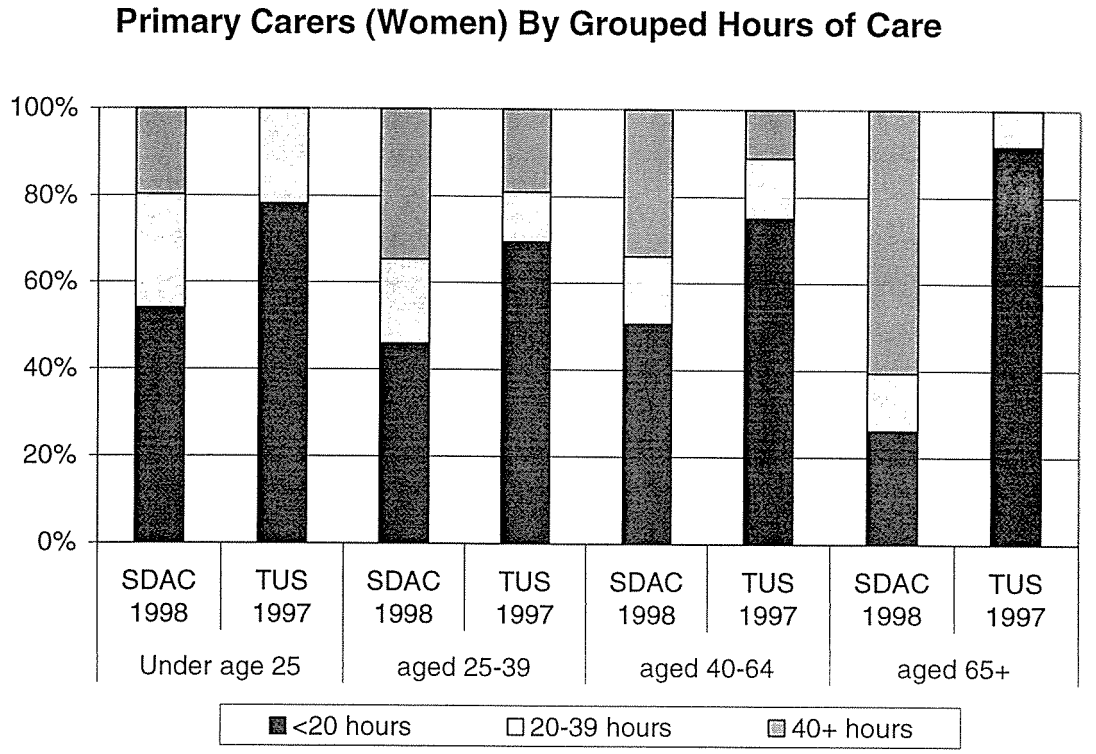
The time-use data is not picking up some supervisory time nor is the time-use data necessarily reflecting time when carers rearrange their schedules to be nearby to the care recipient in case they are needed, and it is possible that the weekly estimates carers provide to the SDAC includes such rearranged schedule time. It may also be the case that the carers covered in the SDAC survey look after people with more profound disabilities, and consequently these respondents have a higher average time commitment to care than the total primary carers population in the time-use data. It may also be the case that primary carers are lumping in some hours of care actually provided by other household members when they make their estimates. As we shall see in the next section, the people living in over one-fifth of households where an adult needs care collectively put in the equivalent of forty or more hours of care per week. Even if the SDAC data are reflecting over-estimates of the time individual carers spend in care, the average care median time of ten hours per week of care is not an inconsequential commitment of personal resources on the part of a considerable number of Australian adult carers.

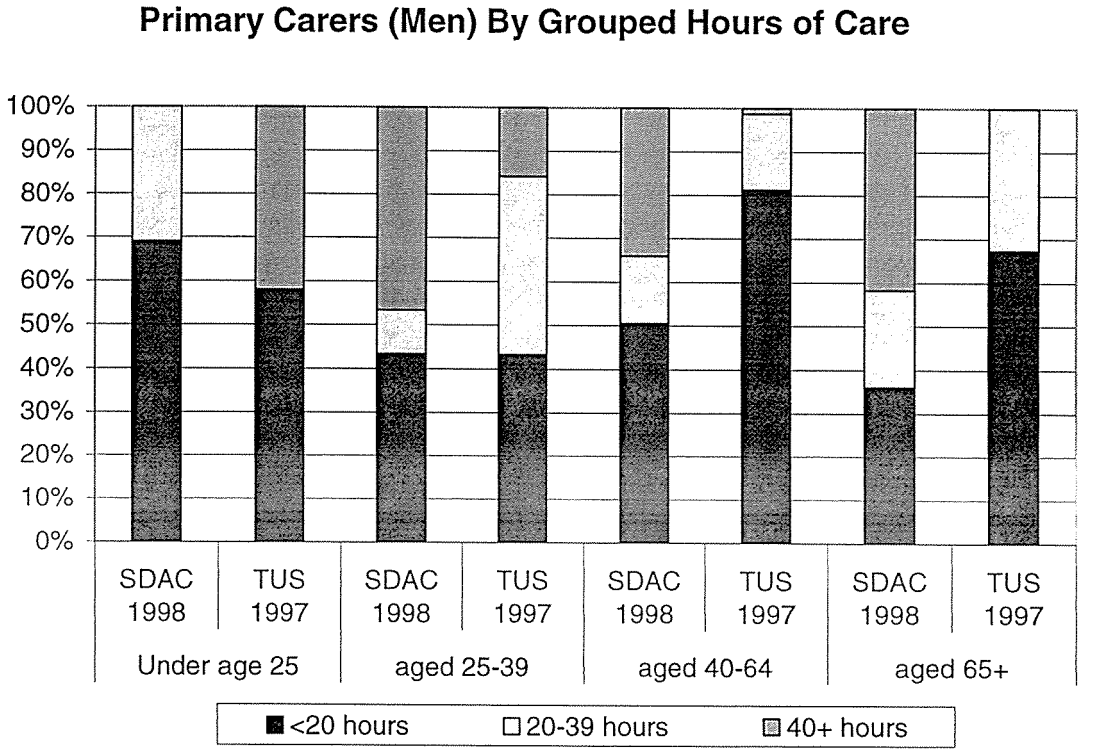
5.3 Hours of care provided at the household level

As the 1997 Time Use Survey collected diaries from all adult household members, we now can consider the total weekly hours of adult care provided by all carers in households where at least one person provides care. The level of care provided at the household level does not differ greatly by the number of carers in the household. The 1053 households in the 1997 Time Use Survey where we identified one carer, 520 households where we identified two carers, and 74 households where we identified three carers each undertook a median weekly time of over 13 hours of care work. The 18 households with four carers performed a median of nine weekly hours of care, and the one household with five carers reported an estimated 2 hours and twenty minutes of care time, though the numbers of households in these latter groups is too small for more meaningful examination.

\Figure 5.2 shows the breakdown of grouped weekly hours of care provided at the household level in Australia in 1997. Just under one quarter of carer households provide 40 or more hours of adult care per week, while another nearly quarter of carer households perform between 20 and 39 hours of care per week. This means that roughly half of all carer households in Australia perform a minimum equivalent of a part-time or a full-time job when they look after one or more adults.

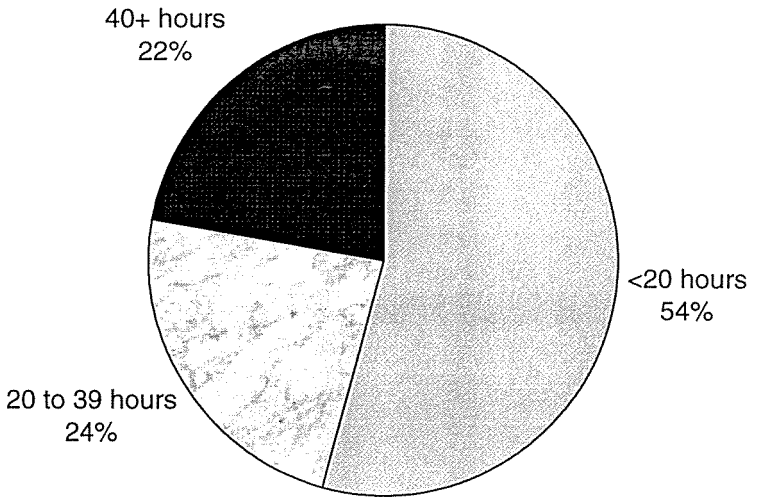
Figure 5.1 Time spent by women and men performing care from the 1998 SDAC





Source: 1997 Australian Bureau of Statistics Time Use Survey

\Figure 5.2 Percentage of carer households by grouped weekly hours of care provided by all carers living in the same household



Source: 1997 Australian Bureau of Statistics Time Use Survey

5.4 Conclusions

The estimates of the weekly hours devoted to care differ considerably between the two surveys. These differences may in part arise from the different sample populations and the different means of data collection, or they may reflect limitations in either or both of the data sets. In particular, the level of hours in the three categories offered to respondents in the SDAC may have skewed results. Carers who perform around 13 or more hours of care per week may recognise that their caring responsibilities make a considerable impact on their week, and feel reluctant to choose the smallest category of time on offer. Time diary researchers often argue that diary-based estimates of most activities are more reliable than direct questions asking people to estimate the time they spend performing activities (Gershuny 2000; Niemi 1993); however, time diary data has been shown to significantly underestimate time spent performing child care (Ironmonger, 2002). It may well be that time diaries also under-report adult care – especially by not capturing supervisory time or time where carers rearrange their schedules to be nearby to their care recipient in case their services are needed.

These limitations aside, this section demonstrates that the caring role makes a significant impact on the daily lives of carers, as carers commit a median time of over an hour of care each day. Nearly half of all carer households perform the equivalent of part-time or full-time working hours to look after their friends and family members. Thus the costs to public service providers to replace such informal present care arrangements at the same standard of care would be considerable.

6 Conclusions and Policy Implications

6.1 Summary of Analysis of Survey of Disability, Ageing and Carers

It is well documented that the use of appropriate support services by carers can assist them to maintain their caring role. One of the key aims of this project is to identify the demographic characteristics of carers who may be not be accessing services despite their evident need. Identifying these carers can assist policy makers to design and target services more effectively. There are two clear findings from the analysis of community service use in Australia. First is that community services are more likely to be used by carers and care recipients who have high needs such as high levels of disability, carers reporting high levels of burden and those providing more intensive amounts of care. This may reflect the current targeting of services to carers who have higher needs or may suggest that carers themselves only seek help when their level of need is relatively high and perhaps at a crisis point. Second factors associated with low service use were also associated with disadvantage including youth, CALD background, low levels of education, low income, receipt of government benefit and living in relatively socio-economically disadvantaged areas.

6.2 Summary of Analysis of Time Use Survey

Policymakers working in the field of health and welfare have a vested interest in protecting the needs of informal adult carers and the recipients of this care, but to effectively target policies designed to assist carers, policymakers need relatively accurate estimates of the size and composition of the adult carer population. People who do not recognise their role as adult carers are not likely to emerge in the survey data that have served as the basis for policy on adult care to date. This report has revealed that the total carer population is large – with a person who provides at least some limited assistance to an adult with impairments in nearly half of Australian households. The self-identified adult carer population is likely to represent only one-third of all adult carers. Non-identified adult carers are more likely not to live with another carer or to live with another non-identified adult carer. As a result, current policies aimed at carers do not effectively target the full population of carers, and may miss some carers with high needs.

Time diary data offer two possibilities for locating non-identified carers: noting people who answer that they are not adult carers to individual questionnaire items but who record adult care activities in their time diaries; profiling the time signatures of carers, then identifying other diarists who do not claim to be carers, who do not record adult care directly in their diaries, and who have no other obvious care responsibilities. Though these possibilities produce less than ideal estimates, they nonetheless give some glimpse of the profile of non-identified carers, and initial testing of the results suggests that the coding of non-identified carers is largely valid.

The development of the time signature profile of carers confirmed six themes about the impact of care on the daily activities of carers which emerged in focus groups with carers conducted as part of a previous research project:

- Adult carers spend more time undertaking all forms of care activities and voluntary work than adult who were not carers;

- Adult carers engage in more episodes of domestic work and also spend more time performing domestic chores;
- Adult carers spend less time in paid work and personal care activities (particularly sleep);
- Adult carers have particularly busy days;
- Adult carers have less time for leisure activities, and tend to enjoy their free time in more frequent but shorter episodes than the rest of the Australian population. Self-identified primary carers and non-identified carers additionally are less likely to be able to eat out in restaurants;
- Adult carers give more of their time to others and have less time for themselves than other Australians.

Adult care responsibilities even change the range of activities which people most frequently perform on a daily basis.

When diarists recorded adult care in their time diaries, they most often reported concentrating only on this care rather than performing adult care in conjunction with other activities. For the nearly 20 per cent of adult care time that did include secondary activities, however, identified carers were more likely to report adult care as both a main activity and a secondary activity. Non-identified carers, in contrast, were more likely to record adult care only as a secondary activity done at the same time as they focussed on another activity.

Relatively few people aged less than 30 provide adult care, and young carers tend to differ markedly from older adult carers. Older carers are more likely to be women, to live in couples, to feel time pressured, to have a disability themselves, and either to not work or to work part-time. Self-identified primary cares and non-identified carers (both those who record adult care in their time diaries and possible carers) are more likely to rely on income support and family financial transfers as their main source of income.

Non-identified carers are more likely to be older, to live in households with a member needing care, and, curiously, also to live in households where a member has some university level education. The key issue may be education about services for carers – particularly for older carers, rather than a problem of general education.

6.3 Policy Implications

There are a few key policy implications that follow from this analysis.

- Further investigation of why carers are not using community services is needed. This investigation should focus on three groups of carers who are less likely to be accessing community services:
  - younger carers (under 45 years of age);
  - carers from CALD backgrounds; and
  - carers who live in relatively more socio-economically disadvantaged areas.

- More information about respite and other community services needs to be disseminated, as there is a small but not insignificant group of carers and care recipients who are unaware of these services.
- Access to, and affordability of, community services needs to be addressed. Further analysis might be able to reveal which groups of carers find access and affordability a particular problem.
- There needs to be a general effort to encourage care recipients to view community services as appropriate forms of support.
- The need to raise awareness and understanding about the issues involved in caring to assist carers to self-identify.

6.4 Future research

Given the limitations in the ABS data encountered in the course of this analysis using, it is clear there are gaps in the data on carers. In particular, there is a need for:

- more data on the service use of carers who do not live with the people they care for,
- more direct data on carers' perceptions of their need for services (and not just respite services) in their care situation,
- more data on Indigenous carers and carers from CALD backgrounds, and
- more data on the regional distribution of carers.

One way of gaining greater insight into the extent and distribution of caring in the community, and of the situation of carers from smaller population groups, is to go beyond sample surveys such as SDAC and include a question identifying carers in the Census.

Appendix A: Logistic regressions for non-use of services by primary carers and carers

Table A.1: Primary carers' non-use of services for the 'five activities' and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability 0.5908
					Average marginal probability
Intercept		0.367	0.276	1.773	
Age of carer					
Aged under 45	***	0.627	0.201	9.774	0.1375
Aged 65 and over		-0.266	0.215	1.529	-0.0616
Socio-economic status of carer's local area					
2nd quintile		-0.139	0.241	0.332	-0.0320
3rd quintile		-0.039	0.250	0.024	-0.0089
4th quintile		-0.252	0.259	0.946	-0.0585
5th quintile	***	-0.919	0.275	11.189	-0.2213
Care recipient's level of disability					
Severe	**	0.439	0.190	5.362	0.0977
Moderate or less	***	1.280	0.485	6.974	0.2281
Hours spent actively caring					
Hours not stated		0.353	0.396	0.794	0.0759
Less than 20 hours	***	0.769	0.222	12.022	0.1660
Between 20 and 39 hours	***	0.691	0.239	8.382	0.1443
Burden index score >5	***	-0.515	0.192	7.229	-0.1164
Health index score .>3	**	-0.428	0.186	5.325	-0.0956
Has fall-back carer available	**	0.396	0.173	5.275	0.0902
					Average probability of sample 0.6505
Predicted correct 67.2					
Sensitivity 82.3					
Specificity 41.9					
McFadden's pseudo r^2= 0.12					

Table A.2: Primary carers' non-use of services for health care and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability 0.4736
					Average marginal probability
Intercept		-0.106	0.253	0.176	
Country of birth					
North Western Europe		0.315	0.278	1.286	0.0784
Other country	***	0.780	0.291	7.177	0.1923
Has long term health condition	**	-0.439	0.201	4.778	-0.1085
Main source of income is private	***	-0.970	0.214	20.526	-0.2305
Age of youngest care recipient					
Under 25 years		0.428	0.270	2.516	0.1063
25 to 44 years	**	0.690	0.296	5.431	0.1707
45 to 64 years	***	0.657	0.246	7.112	0.1626
Number of care recipients					
More than one care recipient	***	-1.025	0.254	16.237	-0.2361
Hours spent actively caring					
Hours not stated		0.233	0.420	0.308	0.0579
Less than 20 hours	***	0.634	0.228	7.722	0.1569
Between 20 and 39 hours		0.149	0.263	0.318	0.0369
					Average probability of sample 0.4451
Predicted correct 62.6					
Sensitivity 53.1					
Specificity 70.5					
McFadden's pseudo r^2= 0.08					

Table A.3: Primary carers' non-use of services for mobility and respite

Parameter	*sig*	*Estimate*	*Standard Error*	*Chi-Square*	*Probabilities*
					Baseline probability 0.7787
					Average marginal probability
Intercept	***	1.258	0.307	16.760	
Relationship of carer to care recipient					
Parent	**	-0.665	0.382	3.028	-0.1492
Child	***	-0.973	0.308	9.977	-0.2266
Other relative		-0.308	0.455	0.457	-0.0686
Socio-economic status of carer's area					
2nd quintile		-0.185	0.296	0.390	-0.0401
3rd quintile	*	0.561	0.329	2.912	0.1108
4th quintile		-0.109	0.328	0.110	-0.0235
5th quintile	***	-0.891	0.340	6.875	-0.2071
Age of youngest care recipient					
Under 25 years	***	-1.708	0.439	15.147	-0.3914
25 to 44 years	**	-0.746	0.345	4.668	-0.1710
45 to 64 years		0.449	0.322	1.952	0.0913
Care recipient's level of disability					
Severe or moderate	*	0.479	0.261	3.374	0.0992
Number of care recipients					
More than one care recipient	***	-0.759	0.269	7.968	-0.1723
Hours spent actively caring					
Hours not stated	*	-0.839	0.472	3.165	-0.1978
Less than 20	***	1.043	0.299	12.138	0.2020
Between 20 and 39	**	0.668	0.300	4.970	0.1291
Has fall-back carer available	**	0.475	0.229	4.296	0.1014
Burden index score>5	**	-0.517	0.230	5.047	-0.1087
					Average probability of sample 0.6923
Predicted correct 75.7					
Sensitivity 87.5					
Specificity 54.6					
McFadden's pseudo r^2= 0.26					

Table A.4: Primary carers' non-use of services for transport and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability 0.7548
Intercept	***	1.124	0.246	20.892	*Average marginal probability*
Relationship of carer to care recipient					
Parent		-0.445	0.400	1.240	-0.1104
Child	***	-1.206	0.327	13.635	-0.2816
Other relative		0.110	0.564	0.038	0.0274
Age of care recipient					
Aged less than 25 years	***	-1.306	0.472	7.668	-0.3050
Between 25 and 44 years	***	-0.956	0.369	6.703	-0.2289
Between 45 and 65 years		0.042	0.336	0.015	0.0104
Number of care recipients					
More than one care recipient	***	-0.830	0.282	8.675	-0.2017
Hours spent actively caring					
Hours not stated		-0.377	0.486	0.602	-0.0934
Less than 20 hours	***	1.352	0.331	16.678	0.3178
Between 20 and 39 hours		0.495	0.301	2.702	0.1223
Has fall-back carer available	***	0.727	0.240	9.143	0.1797
					Average probability of sample 0.7358
Predicted correct 74.3					
Sensitivity 88.8					
Specificity 41.5					
McFadden's pseudo r^2= 0.17					

Table A.5: Carers' non-use of services for the 'five activities'

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability
					0.9013
					Average marginal probability
Intercept	***	2.211	0.206	115.527	
Male	***	0.272	0.093	8.546	0.0414
Carer aged 15 to 24		0.093	0.178	0.275	0.0139
Carer aged 25 to 44	*	0.244	0.131	3.494	0.0362
Carer aged 65 and over	***	-0.590	0.141	17.624	-0.1004
Couple household		-0.143	0.134	1.140	-0.0223
Lone parent household	***	-0.579	0.151	14.593	-0.1011
Other household		0.140	0.141	0.975	0.0207
Country of birth					
North Western Europe		0.067	0.140	0.227	0.0100
Other country	**	0.293	0.137	4.573	0.0418
Highest educational qualification					
Bachelor degree	***	-0.623	0.169	13.541	-0.1108
Diploma	***	-0.512	0.172	8.861	-0.0889
Vocational qualification		-0.130	0.115	1.275	-0.0202
Year 11 or 12	***	-0.520	0.149	12.188	-0.0895
Has long term health condition	***	-0.272	0.101	7.234	-0.0412
Carer's personal income					
Quintile unknown	***	-0.538	0.162	11.027	-0.0929
1st quintile		-0.204	0.144	2.002	-0.0324
3rd quintile		-0.180	0.138	1.709	-0.0285
4th quintile		-0.081	0.158	0.265	-0.0126
5th quintile	**	-0.449	0.181	6.151	-0.0762
Socio-economic status of carer's local area					
2nd quintile		0.108	0.144	0.563	0.0162
3rd quintile	**	-0.300	0.138	4.746	-0.0483
4th qiuintile	***	-0.418	0.141	8.767	-0.0689
5th quintile	***	-0.718	0.151	22.498	-0.1261
Geographical location					
Lives in rest of state	***	-0.290	0.100	8.395	-0.0455
Age of youngest care recipient					
Less than 25 years	***	0.972	0.164	35.191	0.1238
25 to 44 years		0.094	0.136	0.477	0.0141
65 years and over		-0.059	0.131	0.204	-0.0091
Highest level of disability in household					
Profound	***	-0.901	0.119	57.587	-0.1568
Moderate		0.043	0.138	0.097	0.0065
Mild/or employment /schooling restriction/or no restriction		0.170	0.123	1.910	0.0253
					Average probability of sample
Predicted correct 78.9					0.8118
Sensitivity 97.8					
Specificity 10.0					
McFadden's pseudo r2=0.09					

Table A.6: Carers' non-use of services for health care

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability
					0.7495
					Average marginal probability
Intercept	***	1.096	0.176	38.708	
Highest educational qualifications					
Bachelor degree		-0.232	0.216	1.159	-0.0580
Diploma		-0.142	0.224	0.401	-0.0354
Vocational qualification	***	-0.435	0.135	10.372	-0.1083
Year 11 or 12		-0.144	0.178	0.652	-0.0359
Country of birth					
North Western Europe		0.168	0.176	0.906	0.0416
Other country	***	0.692	0.165	17.543	0.1659
Socio-economic status of carer's local area					
2nd Quintile		-0.039	0.163	0.056	-0.0096
3rd quintile		-0.131	0.160	0.670	-0.0327
4th quintile		-0.236	0.163	2.093	-0.0589
5th quintile	***	-0.541	0.183	8.784	-0.1342
Main source of income					
Wages/salaries or private income	***	-0.364	0.116	9.900	-0.0904
Sex of first care recipient					
Female	***	-0.490	0.108	20.513	-0.1215
Age of youngest care recipient					
Less than 25 years	*	0.289	0.160	3.273	0.0714
25 to 44 years		0.093	0.162	0.326	0.0230
65 years and over	***	-0.685	0.146	22.058	-0.1697
Highest level of disability of care recipients					
Profound		0.028	0.129	0.047	0.0070
Moderate		-0.251	0.174	2.092	-0.0628
Mild/employment schooling restriction/ No restriction	**	0.388	0.182	4.558	0.0950
Number of care recipients					
Two care recipients	***	-1.601	0.166	92.675	-0.3643
Three care recipients	***	-1.630	0.341	22.861	-0.3532
					Average probability of sample
Predicted correct 65.0					
Sensitivity 71.9					0.5286
Specificity 57.2					
McFadden's pseudo r^2=0.10					

Table A.7: Carers' non-use of services for mobility

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline Probabilities
					0.9444
					Average marginal probability
Intercept	***	2.832	0.216	172.154	
Sex of carer					
Male	**	-0.347	0.152	5.244	-0.0533
Geographical residence of carer					
Does not live in capital city	***	0.632	0.157	16.201	0.0911
Sex of care recipient					
Female care recipient	**	0.323	0.151	4.554	0.0495
Age of care recipient					
Under 25 years	***	-2.129	0.206	106.333	-0.4168
25 to 44 years	***	-0.809	0.231	12.332	-0.1425
65 years and over	**	-0.564	0.222	6.481	-0.0933
Disability level of care recipient					
Profound	***	-1.042	0.152	47.316	-0.1612
Number of care recipients					
Two care recipients	***	-1.725	0.172	100.511	-0.3475
Three care recipients	**	-0.706	0.345	4.186	-0.1297
					Average probability of sample
Predicted correct 80.4					
Sensitivity 91.3					0.8125
Specificity 47.9					
McFadden's pseudo r^2=0.29					

Table A.8: Carers' non-use of services for transport

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Baseline probability
					0.8992
					Average marginal probability
Intercept	***	2.189	0.249	77.418	
Household type					
Couple	***	0.780	0.261	8.931	0.0702
Lone parent	**	0.602	0.287	4.396	0.0510
Other household		0.282	0.218	1.675	0.0270
Main source of income					
Wages, salary or other private income	**	0.384	0.163	5.529	0.0394
Age of youngest care recipient					
Under 25 years	***	-0.996	0.238	17.569	-0.1307
25 to 44 years		-0.144	0.248	0.336	-0.0151
65 years and over		-0.225	0.235	0.920	-0.0236
Highest disability level of care recipients					
Profound	***	-0.893	0.184	23.641	-0.0986
Moderate	**	0.885	0.402	4.841	0.0699
Mild/employment or schooling Restriction/or no restriction		0.534	0.344	2.406	0.0469
Number of care recipients					
Two care recipients	***	-1.718	0.181	90.122	-0.2687
Three care recipients		-0.489	0.414	1.399	-0.0593
					Average probability of sample
Predicted correct 85.3%					
Sensitivity 96.3%					
Specificity 29.6%					
McFadden's pseudo r^2=0.21					0.8852

Hierarchical cluster analysis output including the 24 binary items used to create the carer-profile scale, the further 28 items with weaker associations with carers, the four adult carer types, the other four possible carer groups, and higher scoring and lower scoring non-carers

Appendix B: Dendrogram

Appendix B

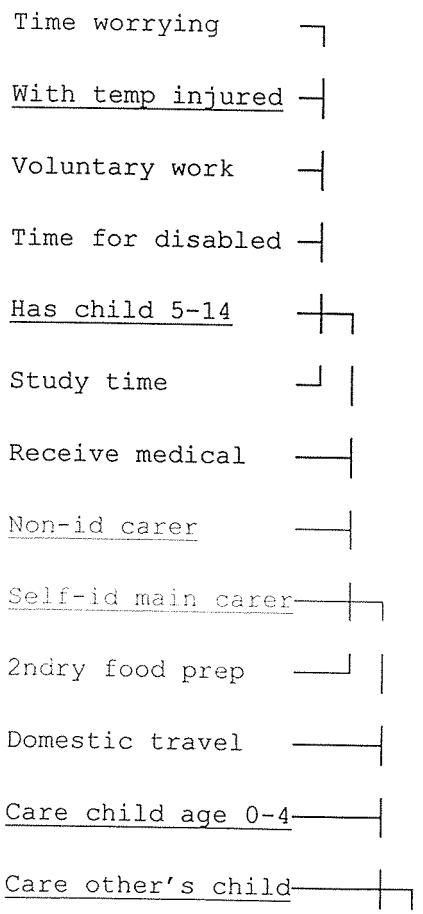
Hierarchical cluster analysis output including the 24 binary items used to create the carer profile scale, the further 28 items with weaker associations with carers, the four adult carer types, the other four possible carer groups, and higher scoring and lower scoring non-carers

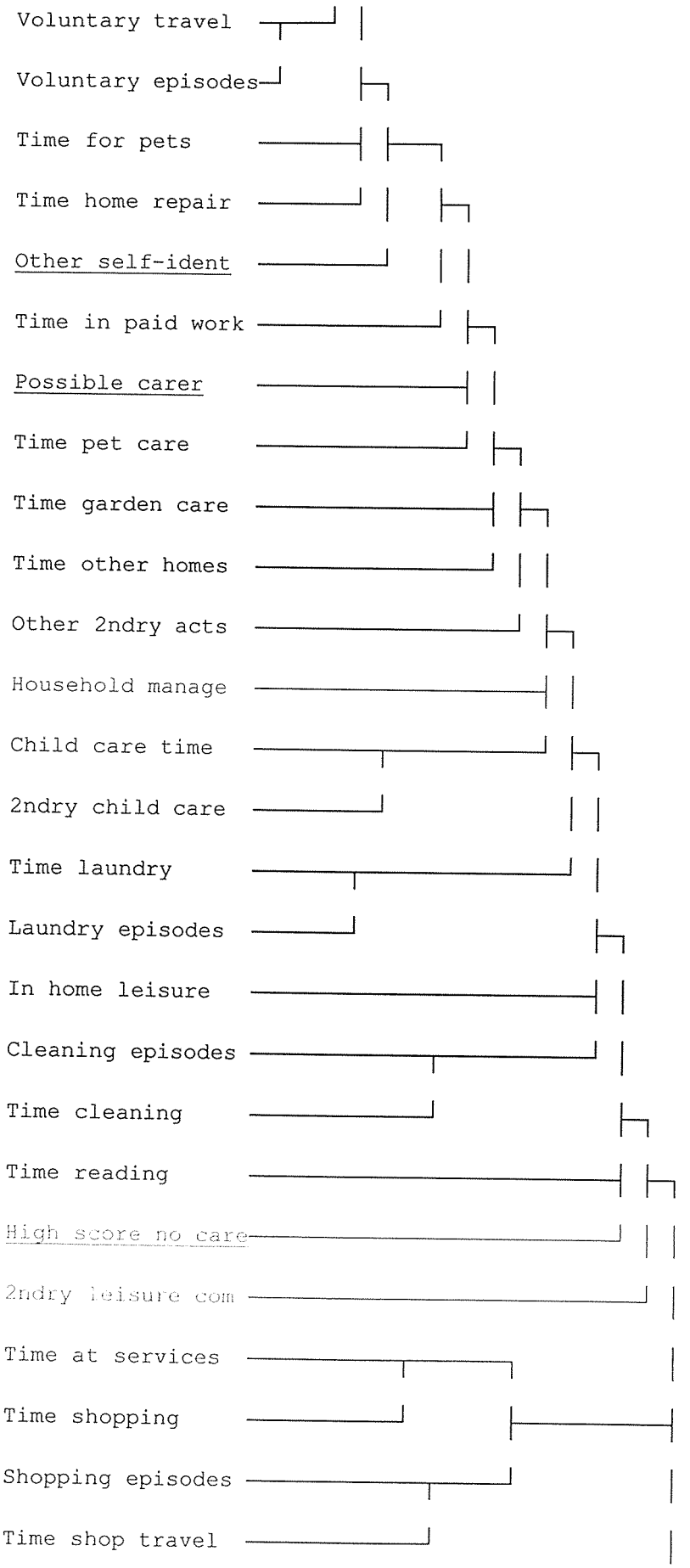
* * * * * * H I E R A R C H I C A L C L U S T E R A N A L Y S I S
* * * * * *

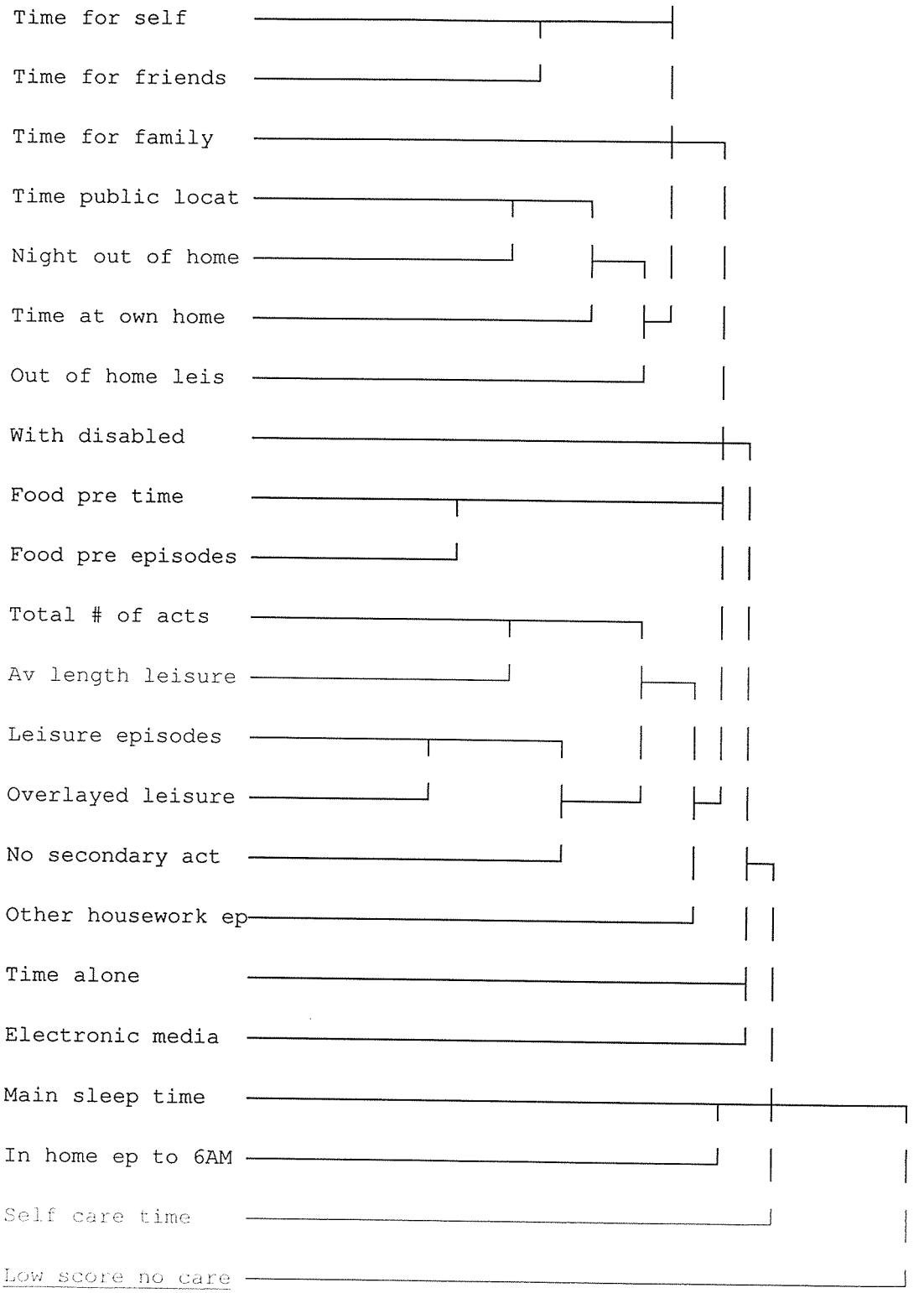
Dendrogram using Average Linkage (Between Groups)

Rescaled Distance Cluster Combine

C A S E		0	5	10	15	20	25
Label	Num	+---------+---------+---------+---------+---------+					




Voluntary travel
Voluntary episodes
Time for pets
Time home repair
Other self-ident
Time in paid work
Possible carer
Time pet care
Time garden care
Time other homes
Other 2ndry acts
Household manage
Child care time
2ndry child care
Time laundry
Laundry episodes
In home leisure
Cleaning episodes
Time cleaning
Time reading
High score no care
2ndry leisure com
Time at services
Time shopping
Shopping episodes
Time shop travel


Time for self
Time for friends
Time for family
Time public locat
Night out of home
Time at own home
Out of home leis
With disabled
Food pre time
Food pre episodes
Total # of acts
Av length leisure
Leisure episodes
Overlayed leisure
No secondary act
Other housework ep
Time alone
Electronic media
Main sleep time
In home ep to 6AM
Self care time
Low score no care

Appendix C: Logistic regression results of the four carer populations

Appendix C All carers

whole population	self-identified primary carers		self-identified other adult carers		non-identified adult carers		possible adult carers	
	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig
number of cases (unweighted)	513		1232		475		1932	
household recieves services	1.87	**0.015**	0.78	0.259	1.00	0.995	1.54	**0.004**
household pays for services	0.69	0.167	1.10	0.685	0.91	0.768	0.64	**0.004**
household receives benefits	2.43	**0.000**	0.92	0.307	1.26	0.060	1.25	**0.001**
person lives in capital city	0.96	0.699	1.17	**0.051**	1.00	0.987	0.87	**0.023**
person lives in a rural area	1.03	0.832	1.12	0.266	1.06	0.687	0.90	0.221
household not have a car	1.36	0.088	0.38	**0.000**	1.32	0.131	0.74	**0.005**
diarist has a disability	1.53	**0.000**	1.28	**0.000**	0.97	0.785	1.98	**0.000**
lowest 20% of income range	1.14	0.272	1.14	0.135	0.99	0.949	0.87	0.059
highest 20% of income range	0.97	0.824	1.03	0.683	0.65	**0.003**	1.07	0.361
diarist is a woman	1.41	**0.001**	1.05	0.457	1.40	**0.002**	1.21	**0.001**
diarist aged 15 to 29	0.21	**0.000**	0.52	**0.000**	0.62	**0.004**	0.85	0.067
diarist aged 50 to 64	1.20	0.111	1.59	**0.000**	1.32	**0.031**	1.10	0.164
diarist aged 65 to 74	0.45	**0.000**	0.95	0.718	1.60	**0.012**	0.97	0.728
diarist aged 75+	0.55	**0.010**	0.50	**0.001**	1.76	**0.014**	1.29	**0.031**
divorced, widowed, separated	0.52	**0.000**	1.28	**0.008**	0.73	**0.047**	0.87	0.079
single, never had partner	0.70	**0.045**	0.59	**0.000**	1.04	0.796	0.92	0.339
born outside Australia	0.82	0.098	0.74	**0.000**	0.97	0.780	1.00	0.945
not speak English at home	1.41	0.060	0.44	**0.000**	0.78	0.270	0.76	**0.018**
has a university degree	1.38	**0.009**	0.93	0.420	1.26	0.069	1.40	**0.000**
works part-time	1.40	**0.021**	1.22	**0.030**	1.38	**0.023**	1.26	**0.004**
neither working nor unemploye	1.58	**0.001**	1.29	**0.007**	1.38	**0.029**	1.59	**0.000**
works more than one job	0.88	0.582	1.03	0.799	0.95	0.826	1.24	0.055
diarist is a student	0.82	0.295	1.23	**0.053**	0.85	0.339	0.72	**0.001**
diarist is a manager/profession	1.02	0.881	1.27	**0.011**	1.42	**0.019**	0.90	0.248
diarist is an own-account worke	0.47	**0.006**	1.07	0.589	0.83	0.409	1.02	0.881
diarist is an unpaid family work	1.20	0.737	0.88	0.746	1.90	0.149	1.42	0.225
diarist is time pressured	1.93	**0.000**	1.34	**0.000**	1.87	**0.000**	1.04	0.505
diary completed in summer	1.09	0.457	1.25	**0.001**	0.85	0.147	1.15	**0.021**
diary completed in winter	1.03	0.783	0.76	**0.001**	0.84	0.149	0.91	0.153
diary completed on unusual da	1.30	**0.007**	1.24	**0.001**	2.12	**0.000**	1.27	**0.000**
diary completed on weekend d	0.95	0.597	1.00	0.964	1.08	0.449	0.88	**0.027**
constant	0.01	**0.000**	0.06	**0.000**	0.01	**0.000**	0.09	**0.000**

control group: men aged 30 to 49; born Australia and speaking English at home; employees in one job working full-time who feel r
pressure; in a couple; not disabled; less than university level education; living in an urban area that is not a capital city;
in a household in the middle 60% of the income range that does not receive services or pay for services and that does not receiv
or family transfers; that owns a car; completed the diary on a spring or autumn day, on a normal day and on a week day

Appendix C All carers

whole population	non-adult carer with child aged<5		non-adult carer with child aged 5 to 14		non-adult carer, looks after non-resident child		non-adult carer with temp injured		rest of population	
	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig
number of cases (unweighted)	621		336		651		142		8177	
household recieves services	1.07	0.815	1.16	0.719	0.12	**0.003**	0.01	0.407	0.90	0.434
household pays for services	0.80	0.477	0.97	0.941	7.30	**0.005**	120.00	0.387	1.14	0.361
household receives benefits	1.12	0.405	0.40	**0.000**	0.75	**0.026**	0.74	0.231	0.99	0.786
person lives in capital city	0.92	0.418	0.85	0.256	0.83	0.066	1.17	0.487	1.19	**0.000**
person lives in a rural area	0.78	0.073	0.90	0.564	0.87	0.279	1.30	0.344	1.18	**0.011**
household not have a car	1.03	0.887	1.46	0.277	1.29	0.223	0.41	0.138	1.16	0.102
diarist has a disability	0.40	**0.000**	0.42	**0.000**	0.55	**0.000**	1.31	0.170	0.86	**0.001**
lowest 20% of income range	1.28	**0.045**	1.04	0.842	0.73	**0.025**	1.09	0.737	1.10	0.098
highest 20% of income range	1.26	**0.048**	1.19	0.236	1.31	**0.010**	1.07	0.750	0.84	**0.001**
diarist is a woman	0.70	**0.001**	1.12	0.444	1.26	**0.016**	0.84	0.366	0.87	**0.003**
diarist aged 15 to 29	1.24	**0.050**	0.67	**0.016**	0.64	**0.000**	1.10	0.708	1.24	**0.001**
diarist aged 50 to 64	0.05	**0.000**	0.11	**0.000**	0.42	**0.000**	0.83	0.436	2.30	**0.000**
diarist aged 65 to 74	0.03	**0.000**	0.00	0.299	0.26	**0.000**	0.31	**0.033**	2.94	**0.000**
diarist aged 75+	0.04	**0.000**	0.00	0.454	0.09	**0.000**	0.14	0.057	2.25	**0.000**
divorced, widowed, separated	0.60	**0.008**	0.45	**0.010**	0.94	0.691	1.29	0.383	1.32	**0.000**
single, never had partner	0.11	**0.000**	0.05	**0.000**	0.21	**0.000**	0.82	0.476	2.77	**0.000**
born outside Australia	0.79	**0.048**	0.96	0.755	1.02	0.876	1.61	**0.016**	1.03	0.620
not speak English at home	0.70	0.108	0.31	**0.003**	0.59	**0.012**	0.48	0.095	1.60	**0.000**
has a university degree	1.07	0.537	1.23	0.154	1.21	0.077	0.78	0.288	0.74	**0.000**
works part-time	2.21	**0.000**	1.83	**0.000**	1.33	**0.012**	1.08	0.743	0.61	**0.000**
neither working nor unemployed	3.20	**0.000**	3.72	**0.000**	1.41	**0.005**	1.05	0.855	0.43	**0.000**
works more than one job	0.91	0.604	0.75	0.295	0.82	0.285	1.52	0.178	0.95	0.599
diarist is a student	0.65	**0.005**	0.84	0.398	1.00	0.992	0.82	0.473	1.52	**0.000**
diarist is a manager/professional	1.54	**0.001**	1.44	**0.030**	0.92	0.489	1.54	0.086	0.88	**0.046**
diarist is an own-account worker	0.59	**0.013**	0.62	0.101	1.21	0.224	0.69	0.327	1.12	0.212
diarist is an unpaid family worker	1.02	0.972	0.95	0.942	0.94	0.909	0.01	0.671	0.81	0.417
diarist is time pressured	2.43	**0.000**	2.07	**0.002**	1.08	0.521	0.91	0.682	0.81	**0.000**
diary completed in summer	1.09	0.415	1.54	**0.001**	0.83	0.071	1.29	0.210	0.88	**0.010**
diary completed in winter	1.13	0.261	1.48	**0.007**	1.07	0.498	1.31	0.202	0.95	0.356
diary completed on unusual day	0.86	0.118	1.37	**0.009**	1.04	0.670	2.93	**0.000**	0.79	**0.000**
diary completed on weekend day	1.12	0.212	1.02	0.871	1.10	0.287	1.55	**0.013**	1.00	0.959
constant	0.04	**0.000**	0.02	**0.000**	0.09	**0.000**	0.00	**0.000**	3.07	**0.000**

control group: men aged 30 to 49; born Australia and speaking English at home; employees in one job working full-time who feel no time pressure; in a couple; not disabled; less than university level education; living in an urban area that is not a capital city; in a household in the middle 60% of the income range that does not receive services or pay for services and that does not receive welfare or family transfers; that owns a car; completed the diary on a spring or autumn day, on a normal day and on a week day

Appendix D: Bivariate and multivariate results for service non-use for primary carers with poor health

Bivariate analysis of carers with poor health

Tables D1, D2 and D3 report the percentages of primary carers in each subgroup of 'predisposing', 'enabling' and 'need' characteristics, who reported that they had poor health and that no services were being used by their care recipients. A higher number indicates a higher rate of poor health and service non-use. The shaded areas denote groups of variables where the differences between the subgroups are statistically significant at the 0.05 level.

There are two subgroups of primary carers who report significantly higher rates of poor health and service non-use across all activities. These are:

- those who receive a government pension or benefit as their main source of income; and
- those who are unemployed.

There are other groups of primary carers where the results are significantly different for all but one type of service, indicating a clear trend towards higher rates of poor health and service non-use. These are:

- primary carers in the 'born in another country' category, the CALD proxy in this analysis;[8]
- primary carers with personal income levels in the 2nd quintile;
- primary carers who live in relatively disadvantaged areas (in the first to third quintiles of the index of relative socio-economic disadvantage); and
- primary carers who report a relatively high 'carer burden' score.

[8] Those who speak to their care recipient in a language other than English also report a consistently higher rate of both poor health and service non-use, but the results are not statistically significant except for health care services.

Table D.1: Bi-variate analysis. Percentage of primary carers who have poor health and who do not use services – predisposing characteristics

	Services not used			
	Five activities and respite	Health care and respite	Mobility and respite	Transport and respite
Sex of carer				
Males	38.3	**18.5**	**39.4**	33.0
Females	33.3	**22.8**	**27.5**	24.9
Age of carer				
Age 15-24	**26.5**	11.5	**30.6**	**16.5**
Age 25-44	**42.0**	18.5	**21.2**	**16.8**
Age 45-64	**35.5**	23.8	**34.3**	**29.5**
Age 65 +	**26.8**	22.7	**39.4**	**39.4**
Marital status				
Married/defacto	35.3	22.1	33.6	28.2
S/W/D	31.2	20.7	18.6	27.5
Single	37.1	17.0	30.4	22.0
Household composition				
Couple	33.2	24.3	**43.5**	**35.4**
Couple and children	38.7	17.8	**25.0**	**19.8**
Lone parent	29.0	16.1	**19.7**	**21.6**
Other households	37.1	27.4	**28.8**	**31.3**
Country of birth				
Australia	34.5	**18.7**	31.0	**27.4**
North-Western Europe	28.3	**26.2**	25.9	**19.6**
Other country	43.3	**33.1**	38.4	**35.6**
Educational qualifications				
Bachelor degree or above	29.4	19.0	25.0	24.0
Diploma	38.4	26.2	29.4	25.7
Vocational qualification	39.2	21.8	36.7	35.5
Year 11 or 12	37.2	16.2	35.1	25.2
Year 10 or less	33.0	21.6	29.7	25.2
Whether carer has long-term health condition				
Has long-term health condition	**40.1**	22.4	**37.6**	**33.1**
Does not have long-term health condition.	**26.4**	19.7	**21.1**	**18.4**
Carer – disability status				
Has disability	**45.8**	**23.7**	**42.3**	**38.3**
Does not have a disability	**27.2**	**19.8**	**23.6**	**19.8**
Relationship of carer to care recipient				
Partner/spouse	33.8	23.1	**39.1**	**33.6**
Parent	37.5	17.8	**15.9**	**15.4**
Child	32.0	16.8	**27.0**	**21.3**
Other relative /friend	42.3	33.4	**39.7**	**40.2**
Whether carer speaks to the care recipient in English				
Speaks English	34.5	**20.4**	34.3	26.7
Does not speak English	39.1	**30.8**	31.1	35.2

Notes: Figures in bold indicate statistically significant differences between the group of variables at the 0.05 level using a chi-squared test.

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Table D.2: Bi-variate analysis – primary carers who have poor health and do not use services – enabling characteristics

	Five services and respite	Health care and respite	Mobility and respite	Transport and respite
Personal income of carer				
1st quintile	35.1	**20.2**	**29.1**	**23.8**
2nd quintile	36.8	**28.2**	**41.7**	**38.3**
3rd quintile	34.5	**18.6**	**22.1**	**20.5**
4th quintile	37.2	**12.6**	**27.4**	**25.3**
5th quintile	23.6	**11.6**	**14.2**	**9.8**
Refused/Unknown	31.3	**19.6**	**31.6**	**18.5**
Main source of cash income of primary carer				
Private income	**32.2**	**16.0**	**25.9**	**20.6**
Government pension or benefit	**36.6**	**24.5**	**34.5**	**31.5**
Index of relative socio-economic disadvantage (local area)				
1st quintile	**35.6**	22.3	**34.1**	26.4
2nd quintile	**39.6**	19.6	**30.8**	29.2
3rd quintile	**42.7**	27.1	**41.5**	34.7
4th quintile	**30.0**	17.4	**21.3**	22.4
5th quintile	**21.7**	19.2	**24.6**	23.2
Employment status of carer				
Employed full-time	**30.0**	**14.9**	**25.6**	**17.2**
Employed part-time	**30.3**	**16.6**	**22.6**	**17.3**
Unemployed	**63.1**	**27.3**	**45.8**	**27.3**
Not in the labour force	**35.2**	**23.5**	**33.7**	**32.2**
Whether carer lives in capital city or balance of state				
Capital city	33.3	20.8	30.1	27.0
Balance of state	37.8	22.5	33.2	28.3

Notes: Figures in bold indicate statistically significant differences between the group of variables at the 0.05 level using a chi-squared test.

Table D.3: Bi-variate analysis – primary carers who have poor health and do not use services – need characteristics

	Five services and respite %	Health care and respite	Mobility and respite	Transport and respite
Sex of care recipient 1				
Male	33.5	**24.4**	28.2	25.3
Female	36.5	**18.3**	34.7	29.8
Age of youngest care recipient in household				
Under 25 years	**41.3**	18.0	**15.8**	**15.7**
25-44 years	**33.4**	19.4	**28.3**	**19.7**
45-64 years	**37.5**	25.3	**37.6**	**33.2**
65 years and over	**29.8**	21.7	**38.3**	**34.6**
Highest disability level of care recipients in household				
Profound	**30.0**	21.7	**30.5**	29.1
Severe	**42.4**	22.2	**37.5**	27.0
Moderate/mild/employment or schooling restriction/LTHC	**38.5**	13.2	**2.8**	15.4
Number of care recipients				
One care recipient	**33.4**	22.2	32.4	28.2
More than one care recipient	**41.3**	18.1	27.4	24.7
Hours spent actively caring				
Less than 20 hours	42.1	16.9	29.8	**18.6**
20 to 39 hours	34.5	22.0	35.5	**34.7**
40 hours or more	43.5	23.8	32.0	**32.2**
Not stated	31.0	27.7	23.8	**22.3**
Whether has fall-back informal carer				
Has fall-back informal carer	37.5	20.3	28.7	26.9
Does not have fall-back informal carer or does not know whether has fall back informal carer	32.1	22.7	34.3	28.2
'Carer burden' index				
Burden index score 5 or more	38.0	**26.2**	**36.0**	**32.4**
Burden index score less than 5	31.8	**16.5**	**26.6**	**22.5**

Notes: Figures in bold indicate statistically significant differences between the group of variables at the 0.05 level using a chi-squared test.

One other notable result was that primary carers aged over 45, and those with care recipients aged over 45, were more likely to be in poor health and less likely to use formal services for 'mobility' and 'transport activities' than other age groups.

Although the bi-variate analysis also shows that primary carers who have long-term health conditions and disabilities are more likely to fall into the category of poor health and service non-use than those who don't have such conditions, this is only to be expected given the definition of the variable under analysis

Regression results for service non-use of primary carers with poor health

Table D.4: The 'five activities' and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Base-line probability 0.2015
Intercept	***	-1.377	0.230	35.972	***Average marginal probability***
Country of birth					
North western Europe		-0.365	0.272	1.791	-0.0720
Other country	**	0.640	0.253	6.403	0.1451
Educational qualifications					
Bachelor degree		0.128	0.359	0.128	0.0275
Diploma		0.469	0.315	2.220	0.1053
Vocational qualification	***	0.566	0.210	7.274	0.1250
Year 11 or 12		0.322	0.303	1.130	0.0709
Index of relative socio-economic disadvantage					
2nd quintile		0.025	0.231	0.012	0.0053
3rd quintile		0.290	0.238	1.488	0.0629
4th quintile		-0.294	0.259	1.291	-0.0592
5th quintile	**	-0.725	0.307	5.591	-0.1347
Employment status					
Employed full-time	**	-0.677	0.266	6.498	-0.1270
Employed part-time	***	-0.685	0.262	6.822	-0.1286
Unemployed		0.338	0.380	0.791	0.0749
Age of youngest care recipient					
Aged under 25 years	***	0.932	0.235	15.723	0.2128
25 to 44 years	*	0.457	0.271	2.840	0.1029
45 to 64 years	**	0.478	0.227	4.453	0.1061
Highest disability level of care recipients					
Severe	***	0.705	0.186	14.396	0.1523
Moderate or less		0.386	0.352	1.199	0.0860
Predicted correct 66.3%					***Average probability of sample***
Sensitivity 22.5					
Specificity 89.8					
McFadden's pseudo r^2= 0.07					0.2996

Notes: Significance column ***p<0.01, **p<0.05, *p<0.1

Factors that were found to increase the probability that a primary carer with poor health will not use respite, and will have a care recipient who does not use formal services for the 'five activities', are:

- that the care recipient is under 65, especially under 25;[9]
- that the care recipient has a 'severe' level of disability, rather than either a 'profound' or a 'moderate' level;
- that the carer was born in another country (as defined in section 2.1);
- that the carer has a vocational qualification;
- that the carer lives in an area that is relatively socio-economically disadvantaged (IRSED quintiles 1-4);
- that the carer is not in the labour force or is unemployed.

Hours spent actively caring, and having a fallback informal carer, were not found to be significant.

[9] Primary carers of care recipients under 25 are significantly more likely to be female than male, so there is gender issue here. They are also more likely than other carers to be separated, widowed or divorced, and to be the parents of the care recipients.

Table D.5: Health care and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Base-line probability
					0.2605
					Average marginal probability
Intercept	***	-1.043	0.233	20.131	
Country of birth					
North Western Europe		0.303	0.296	1.051	0.0620
Other country	***	0.927	0.286	10.471	0.2047
Personal income of carer					
Quintile unknown		-0.504	0.429	1.382	-0.0875
1st quintile		-0.447	0.285	2.458	-0.0807
3rd quintile	*	-0.502	0.268	3.521	-0.0910
4th quintile	***	-1.013	0.371	7.465	-0.1597
5th quintile	*	-1.134	0.583	3.781	-0.1667
Sex of care recipient one					
Female		-0.334	0.207	2.597	-0.0645
Carer burden index					
Burden score>=5	**	0.476	0.206	5.319	0.0914
Highest disability level of care recipients					
Severe disability or less	**	0.449	0.216	4.331	0.0898
Predicted correct 71.4%					*Average probability*
Sensitivity 6.7 %					
Specificity 96.4 %					*of sample*
McFadden's pseudo r^2= 0.05					0.2642

Notes: Significance column ***p<0.01, **p<0.05, *p<0.1

Factors that were found to increase the probability that a primary carer with poor health will not use respite, and will have a care recipient who does not use formal services for 'health care', are:

- that the carer was born in another country (as defined in section 2.1);
- that the carer has relatively low personal income (1st and 2nd quintiles);
- that the care recipient has a lesser level of disability than the highest, i.e. 'profound', level; and
- that the carer reports relatively high levels of 'burden' due to the caring role.

The predictive capacity of this model is fairly low and so the results must be interpreted with caution.

Table D.6: Mobility and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Base-line probability 0.3862
Intercept	*	-0.463	0.279	*2.752*	*Average marginal probability*
Household type					
Couple with children	***	-0.932	0.233	15.988	-0.2045
Lone parent	***	-1.010	0.309	10.674	-0.2062
Other household	***	-0.866	0.283	9.372	-0.1814
Country of birth					
North Western Europe		-0.297	0.311	0.914	-0.0668
Other country	***	0.849	0.296	8.249	0.2068
Personal income of carer					
Quintile unknown		-0.451	0.398	1.287	-0.0986
1st quintile		-0.203	0.278	0.532	-0.0463
3rd quintile	**	-0.560	0.267	4.404	-0.1238
4th quintile	*	-0.562	0.320	3.081	-0.1217
5th quintile	***	-1.707	0.551	9.605	-0.2872
Index of relative socio-economic disadvantage					
2nd quintile		0.169	0.262	0.414	0.0397
3rd quintile	***	0.795	0.280	8.080	0.1922
4th quintile		-0.307	0.306	1.004	-0.0691
5th quintile		-0.355	0.335	1.123	-0.0795
Capital city or rest of state					
Rest of state	*	0.345	0.208	2.755	0.0811
Highest disability level of care recipients					
Severe disability or less	***	0.699	0.201	12.066	0.1650
Carer burden index					
Burden score>=5	***	0.600	0.195	9.438	0.1379
Predicted correct 68.4 % Sensitivity 44.1 % Specificity 83.7%					*Average probability of sample*
McFadden's pseudo r^2= 0.11					0.3687

Notes: Significance column ***p<0.01, **p<0.05, *p<0.1

Factors that were found to increase the probability that a primary carer with poor health will not use respite, and will have a care recipient who does not use formal services for 'mobility', are:

- that the carer is the care recipient's spouse;
- that the carer was born in another country (as defined in section 2.1);
- that the carer lives in an area in the 3rd quintile on the index of relative socio-economic disadvantage;
- that the carer lives outside a capital city;

- that the care recipient has a lesser level of disability than the highest, i.e. 'profound', level; and
- that the carer reports relatively high levels of 'burden' due to the caring role.

Table D.7: Transport and respite

Parameter	sig	Estimate	Standard Error	Chi-Square	Probabilities
					Base-line probability 0.3940
Intercept	*	-0.431	0.253	2.903	*Average marginal probability*
Country of birth					
North western Europe		-0.473	0.336	1.982	-0.1088
Other country	***	0.810	0.310	6.846	0.1994
Relationship of carer to care recipient					
Parent	***	-0.835	0.260	10.295	-0.1885
Child	***	-0.826	0.303	7.413	-0.1834
Other relative		0.320	0.428	0.560	0.0787
Labour force status					
In the labour force	***	-0.722	0.235	9.485	-0.1670
Index of relative socio-economic disadvantage					
2nd quintile		0.278	0.285	0.949	0.0678
3rd quintile	**	0.764	0.300	6.490	0.1877
4th quintile		-0.381	0.317	1.448	-0.0892
5th quintile		-0.050	0.351	0.020	-0.0120
Carer burden index					
Burden score>=5	***	0.694	0.211	10.857	0.1648
Predicted correct 66.3 % Sensitivity 45.6% Specificity 81.1%					*Average probability of sample*
McFadden's pseudo r^2= 0.09					0.4054

Notes: Significance column ***p<0.01, **p<0.05, *p<0.1

Factors that were found to increase the probability that a primary carer with poor health will not use respite, and will have a care recipient who does not use formal services for 'transport', are:

- that the carer was born in another country (as defined in section 2.1);
- that the carer is a spouse or other relative of the care recipient;
- that the carer is not in the labour force;
- that the carer lives in an area in the 3rd quintile on the index of relative socio-economic disadvantage; and
- that the carer reports relatively high levels of 'burden' due to the caring role.

Appendix E: Summary of bi-variate results for non-use of services for all activities by young primary carers

Figure E1 summarises the findings from the bi-variate analysis of young primary carers. It shows that the care recipients of young primary carers were most likely to use formal services for the activity of 'health care', and least likely to use formal services for 'transport'. This finding is similar to the analysis of all carers. Tables E1 to E3 report the detailed figures for the bi-variate analysis. They show that need factors, rather than predisposing or enabling factors, were most often associated with formal service use for young carers. The relatively small numbers of young carers meant the analysis was limited and it was not possible to consider the effects of CALD background or personal income on the use of services for 'health care', 'mobility' and 'transport'.

Given that these results are only bi-variate and do not control for the need factors in the care situation which, as noted above, were the most common predictors of service use, some findings of note are:

- that care recipients with young carers living in relatively socio-economically disadvantaged areas are less likely to use formal services for all activities except 'health care' and 'transport', than those who live in less disadvantaged areas;
- that care recipients with young carers living outside capital cities are much less likely to use formal services for 'mobility' than those who live in the capital cities; and
- that care recipients with young female carers are less likely to use formal services for 'mobility' than those with male carers.

Figure E.1: Young co-resident carers – Service non-use – Bi-variate summary

Factors	Five Services [(a)]	Health Care	Mobility	Transport
Predisposing	Young carers who are living in 'other' households		Young carers who are female	
Enabling	Living in relatively socio-economically disadvantaged areas (quintiles one and two)		Living in relatively socio-economically disadvantaged areas (quintiles one and two) Living outside of a capital city	
Need	Care recipient is aged under 25 years	Young carers caring for male care recipients Caring for one care recipient	Care recipients are aged over 25 years Care recipient is female Care recipient has severe rather than profound disability Caring for one care recipient	Young carers who have care recipients who are aged over 25 years Care recipient is female Care recipient has a severe or less disability rather than a profound disability

Source: *ABS Survey of Disability, Ageing and Carers* 1998
Notes: (a) Five services include housework, meal preparation, paper work, property maintenance, and self-care.

Table E.1: Bi-variate analysis: Young carers who do not use formal services – predisposing characteristics.

	Services not used			
	Five services	Health care	Mobility	Transport
Sex of carer				
Male	82.3	57.7	70.4	82.0
Female	80.7	60.1	85.6	86.3
Marital status				
Married/defacto	87.1	67.0	*	*
Separated/Widowed/Divorced	*	-	-	-
Single	81.3	58.2	77.2	84.1
Household composition				
Couple	*	*	*	*
Couple and children	82.2	61.1	78.7	82.5
Lone Parent	71.3	57.7	76.7	87.5
Other Households	87.3	53.6	77.1	84.8
Country of Birth				
Australia and North-Western Europe	81.2	58.0	79.7	83.8
Other Country (CALD proxy)	85.6	*	*	
Educational qualifications				
Post-secondary qualifications	86.5	55.7	80.5	78.6
Year 12 or less	80.7	59.4	78.0	85.0
Whether has long-term health condition				
Has long-term health condition	82.8	56.6	82.2	86.7
Does not have long-term health condition	81.1	59.6	76.7	83.2
Disability status				
Has Disability	84.6	51.3	79.8	89.9
No Disability	81.0	60.2	78.1	83.1
Relationship of carer to care recipient				
Spouse /parent	88.3	*	*	*
Child	79.4	58.2	82.0	85.2
Other relative	84.8	57.1	64.9	78.3
Friend/Not stated	87.0	61.1	*	*

Source: *ABS Survey of Disability, Ageing and Carers* 1998

Notes: Shaded groups of variables indicate that the differences are significant at the 0.05 level.
* indicates that the sample size was too small to give reliable estimates

Table E.2: Bi-variate analysis: Young carers who do not use formal services – enabling characteristics

	Services not used			
	Five services	Health care	Mobility	Transport
Personal income of carer				
1st quintile	83.0	60.2	81.7	82.5
2nd quintile	80.4	64.1	*	*
3rd quintile	84.0	55.3	*	*
4th quintile	85.5	*	*	*
5th quintile	*	*	*	*
Unknown/Refused	77.1	58.2 (a)	71.3 (a)	80.5(a)
Main source of cash income of carer				
Private income	81.1	57.0	78.0	85.1
Government pension or benefit	83.0	66.5	79.9	78.9
Index of relative socio-economic disadvantage (local area)				
1st quintile	86.5	60.3	80.4	73.6
2nd quintile	88.2	51.2	89.3	91.8
3rd quintile	80.5	61.2	76.3	88.0
4th quintile	74.4	45.0	77.9	84.1
5th quintile	75.0	54.0	62.3	79.9
Employment status of carer				
Employed full-time	86.8	53.1	84.6	86.4
Employed part-time	80.9	56.4	79.7	83.4
Unemployed	88.2	60.0	75.3	*
Not in the labour force	77.4	53.8	76.2	86.2
Whether lives in capital city or rest of state				
Capital city	81.2	58.1	71.4	82.6
Balance of state.	82.3	60.3	91.6	87.5

Source: *ABS Survey of Disability, Ageing and Carers* 1998

Notes: (a) Around 40 per cent of young carers who had care recipients requiring 'health care', 'mobility' and 'transport' assistance did not state their personal income levels.

Shaded groups of variables indicate that the differences are significant at the 0.05 level.

* indicates that the sample size was too small to give reliable estimates

Table E.3: Bi-variate analysis: Young carers who do not use formal services – need characteristics.

	Five services	Services not used: Health care	Mobility	Transport
Sex of care recipient 1				
Male	84.8	63.0	67.1	73.9
Female	79.3	54.6	86.5	91.6
Age of youngest care recipient in household				
Under 25 years	90.1	60.5	55.0	75.8
25-44 years	81.9	62.4	85.8	92.2
45-64 years	76.8	57.2	86.5	81.0
65 years and over	80.6	*	*	*
Highest disability level of care recipients in household				
Profound	76.3	58.2	61.9	71.5
Severe	82.5	62.4	89.5	88.0
Moderate	82.1	31.3	-	96.1
Mild	81.0	*	-	*
Employment restriction/long term health condition or no restriction	90.7	*	-	*
Number of care recipients				
One care recipient	82.3	64.4	85.0	89.0
Two or more care recipients	74.4	28.9	43.7	53.4

Source: *ABS Survey of Disability, Ageing and Carers* 1998

Notes: Shaded groups of variables indicate that the differences are significant at the 0.05 level.
* indicates that the sample size was too small to give reliable estimates

Appendix F: Logistic regression results for the four young carer populations

Appendix F Young carers
People Aged 15 to 24

	self-identified primary carers		self-identified other carers		non-identified carers		possible carers	
	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig	Exp Beta	sig
number of cases (unweighted)	16		85		41		188	
household receives services	0.00	0.966	0.01	0.641	0.00	0.808	5.03	**0.000**
household pays for services	14586.25	0.959	72.91	0.681	611.01	0.817	0.22	**0.001**
household receives benefits	29.74	**0.000**	0.88	0.695	0.99	0.985	1.87	**0.001**
person lives in capital city	0.46	0.241	1.02	0.951	2.02	0.165	1.90	**0.007**
person lives in a rural area	0.00	0.856	1.58	0.218	2.34	0.175	2.00	**0.020**
household not have a car	0.55	0.541	0.33	0.136	0.81	0.778	1.38	0.276
diarist has a disability	0.86	0.856	0.81	0.543	0.76	0.615	2.20	**0.000**
lowest 20% of income range	1.72	0.407	0.93	0.824	0.61	0.371	0.70	0.169
highest 20% of income range	0.00	0.863	1.03	0.920	0.42	0.063	1.07	0.753
diarist is a woman	2.84	0.116	0.91	0.695	1.52	0.230	0.70	**0.036**
single, never had partner	0.46	0.283	0.47	**0.015**	1.11	0.838	0.84	0.449
born outside Australia	0.00	0.856	1.01	0.975	1.18	0.751	1.60	**0.046**
not speak English at home	15.30	**0.016**	0.32	0.134	0.58	0.493	0.49	0.112
works part-time	1.48	0.622	2.15	**0.034**	1.09	0.845	0.97	0.885
neither working nor unemployed	0.41	0.395	5.16	**0.000**	0.77	0.626	0.72	0.185
works more than one job	1.90	0.525	2.55	**0.016**	2.94	**0.018**	0.62	0.178
diarist is unemployed	0.61	0.617	2.19	0.106	0.55	0.449	0.53	**0.038**
diarist is a student	0.17	**0.044**	0.67	0.170	1.53	0.319	0.86	0.425
diarist is a manager/professional	1.78	0.559	1.85	0.160	1.49	0.501	1.57	0.132
diarist is an own-account worker	0.00	0.960	2.77	0.088	0.00	0.772	1.14	0.818
diarist is an unpaid family worker	0.00	0.963	2.68	0.221	0.00	0.839	0.88	0.872
diarist is time pressured	2.55	0.289	1.54	0.177	1.28	0.601	0.98	0.917
diary completed in summer	1.00	0.999	1.33	0.254	0.83	0.621	1.58	**0.011**
diary completed in winter	0.77	0.732	0.50	0.072	0.54	0.194	1.07	0.752
diary complete on unusual day	1.42	0.556	0.95	0.839	2.00	**0.035**	1.33	0.084
diary completed on weekend day	1.49	0.525	0.94	0.816	2.31	**0.011**	1.42	**0.036**
constant	0.00	**0.000**	0.03	**0.000**	0.00	**0.000**	0.04	**0.000**

control group: men born Australia and speaking English at home; employees in one job working full-time, who feel no time pressure; not disabled; living in an urban area that is not a capital city; in a household that owns a car; in a household that does not receive se for services; does not receive welfare or family transfers; in a household that falls into the middle 60% of the income range; completed the diary on a spring or autumn day, on a normal day and on a week day

Appendix F Young carers
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