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Young carers in Australia: understanding the advantages and disadvantages of their care giving

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Executive summary

This report presents the findings from a multi-stage study on young carers undertaken by the Social Policy Research Centre for the Department of Families, Housing, Community Services and Indigenous Affairs.

‘Young carers’ is the term used in Australia and the United Kingdom (‘young care givers’ in the United States) to refer to children and young adults with informal caring responsibilities for other people—usually, but not always co-resident family members, who have a chronic illness, physical or mental disability or are frail aged. It is evident that increased recognition has been accorded to young carers, most likely because of increased research and policy emphasis on informal care provision as a consequence of the move away from provision of care in residential settings to care in the home and community (Jenkins et al. 2003). Also salient has been recognition of the personal costs of informal care, including direct costs and opportunity costs, relating to impacts on education, employment, income, health and wellbeing, over the short and longer-term.

The study consisted of a number of stages:

- a literature review of what is known about the socioeconomic, demographic and sociocultural determinants of children and young people who become young carers, drawing on literature from Australia, the United Kingdom and North America
- quantitative analysis of existing national data sets, involving the *Census of Population and Housing 2006*, the *ABS Survey of Disability, Ageing and Carers (SDAC) 2003* and the Household Income and Labour Dynamics in Australia (HILDA) survey 2005
- qualitative analysis of focus groups with young carers
- analysis of findings from focus groups and interviews undertaken with Australian Government policy makers and service providers in the non-government sector.

Literature review and overview of the issues

The survey of the published research in Australia, the United Kingdom and the United States reveals that children and young people become carers in two interconnected circumstances: through individual and family decisions opting for informal care within the family, and because other adult carers are not available within the kin network (for example, in lone-parent families); and through lack of appropriate, accessible and affordable formal services.

The social care theoretical framework (Daly & Lewis 2000) provides a useful conceptual basis through which to understand the lives of young carers. The extant literature indicates that for young carers:

- **care is labour** that may occupy time that would otherwise be available for participation in education, training, employment and social and/or friendship activities
- **care is located in a normative framework** within which young people may not identify themselves as carers but as family members carrying out their responsibilities and obligations
- **caring incurs costs** that may include strains on or interruptions to completion of education, reduced labour force participation and labour force attachment, which may have long-term implications for future secure employment and adequate income; and caring may also incur costs to emotional wellbeing and mental health
- **there are benefits as well as costs**: profound contributions to the wellbeing of the care receiver and the family, and acquisition by the carer of valuable skills and a deep sense of achievement.

The literature strongly suggests young carers tend to be located in identifiable socioeconomic–cultural circumstances, often in low-income families, and in families of migrant and/or culturally and linguistically

diverse backgrounds where care giving is central to mobilisation of intergenerational resources and strengths. The Australian and United Kingdom literature also emphasises the issue of recognising and making contact with ‘hidden young carers’, so they are in a position to access the services and supports available to them.

The most frequently cited policy issues in the literature included young carers’ wish to receive:

- recognition, understanding and respect, especially from service providers and in the education system
- age-appropriate information on illness and disability
- assistance with education in terms of flexible schooling practices and recognition by the school and by teachers of their caring responsibilities
- assistance with entering and remaining in employment with their caring responsibilities recognised through flexible work practices
- access to appropriate, flexible and affordable services, and appropriate, adequate forms of financial support.

Many studies in Australia and the United Kingdom suggest that young people and service providers in this field see supports for young people who provide care, and supports for family members with disability or chronic illness who require care, as closely related and needing to be addressed simultaneously. This points to the importance of a whole-of-family approach to service development and delivery.

Quantitative analysis derived from Census of Population and Housing 2006, ABS Survey of Disability Ageing and Carers 2003 and the HILDA survey 2005

The analysis in this section explored three nationally representative data sources on young carers to describe their socioeconomic–demographic and care situation characteristics, participation in education and employment, income circumstances and health. Analysis of the Census 2006, HILDA 2005 and SDAC 2003 data sets revealed great variation in estimates of the number of young carers. Examining only young people aged 15 to 24 years providing care, the numbers identified in the Census are around 119,000, those estimated in SDAC are around 240,000 and in the HILDA survey (2005) the weighted population estimate of the number of young carers aged 15 to 24 years is around 140,000. In effect, the SDAC estimates are slightly more than twice the numbers identified in the Census and much higher than the number in HILDA. There are several reasons for these differences, encompassing variation in the definition of carers and in the methods of survey administration. The methodological reasons for the differences in these data sources are discussed in Section 3.

The sex and age dimensions of care giving identified in the literature review are apparent in the prevalence statistics from all data sources. In the Census, while a similar proportion of young men and women aged 15 to 19 years report care giving responsibilities, it is evident that young women aged 20 to 24 years are more likely to be carers than their male counterparts. Data from the SDAC show an overrepresentation of young women among primary carers, or those having main responsibility for care, while HILDA showed that young women comprised a higher proportion of those caring for someone outside their own household. According to the Census data, caring is also more prevalent among Indigenous young people, with young Indigenous women aged 20 to 24 years reporting the highest rates of care provision of all young people. Other analyses of the Census report that caring is also more prevalent among those from culturally and linguistically diverse backgrounds (Hill et al. 2009).

Data in SDAC 2003, which provide the most comprehensive count of young carers, show that carers are more likely than non-carers to live in lone-parent families and that young carers, like older carers, are more likely than non-carers to have a disability themselves. The obligations and responsibilities of young carers are evident in the SDAC data on provision of assistance by young primary carers. Primary carers are defined in this data set as those individuals who are the main providers of care. One-quarter of young primary carers are providing care for more than one care recipient and over half of all young carers are providing care to a person with a profound or severe disability. These care recipients require assistance either all or some of the time for

self-care, communication or mobility. Young carers in the SDAC data were most likely to be caring for a person with a physical restriction or chronic pain. The low proportion of young carers identified in SDAC as providing care for a person with mental illness are at odds with literature on young carers who are being supported by specialist projects in the United Kingdom (Dearden and Becker 2004). More research is needed to gain a more complete picture of the circumstances of young people who provide care for a person with a mental illness in Australia.

Previous research analysing SDAC 1998 data suggested that young primary carers were significantly less likely to participate in education and employment. In all data sources examined here, it appears that young primary carers and young carers are still disadvantaged with respect to participation in employment; however, their rates of participation in education, as recorded in SDAC and HILDA, are possibly now closer to that of their non-carer peers. These findings are, however, not reiterated in the lower rates of completion of Year 12 for young people identified in the whole population survey of the Census (Hill et al. 2009). Nor do they reflect the qualitative studies outlined in the literature review and the primary qualitative data collected for this study that indicate that young carers face many challenges in maintaining their participation at school.

The finding of lower participation of young carers in employment is much more consistent and reiterated in the multivariate analysis. Controlling for a number of factors, young primary carers were significantly less likely to participate in employment than other young people. As a corollary, all young carers and young primary carers in particular were more likely to be receiving a government pension or benefit compared with non-carers. These circumstances of employment disadvantage and receipt of income support are reflected in the data on household equivalised income distribution, which show that of all young carers (primary carers and carers), nearly 40 per cent live in households in the bottom two income quintiles compared with only 25 per cent of young people who are not carers. Further evidence of the economic disadvantage of young people who are carers is found in the higher poverty and deprivation rates of young carers compared with non-carers in the HILDA data. These findings corroborate the conclusions of the review of the national and international literature that low income is very likely to frame the socioeconomic circumstances of young carers. In addition, there are mental health dimensions to these findings. While all groups of young people reported similar scores on self-reported physical health, young carers had significantly lower scores on self-reported mental health scales than other young people, indicating that care is associated with emotional and mental health costs for these young people.

The HILDA data provide a new and rich data source for analysing the circumstances of young carers. Responding to concerns about the existence of ‘hidden carers’, particularly among young people, the analysis explored the circumstances of identified and ‘potential’ young carers. In this study, potential carers are defined as those young people living in a household with a child or adult with a long-term health condition, disability or impairment. It is not suggested that all of these young people are currently undertaking caring responsibilities, but it is hypothesised that they may be unrecorded, unrecognised carers, or that under some circumstances they may undertake caring responsibilities in the future. The results suggest there may well be a significant group of young people whose caring responsibilities go undocumented and unrecognised. In this case, it may be that their care responsibilities are so embedded in familial relationships and obligations that they consider unremarkable any additional domestic work undertaken on behalf of, or assistance given to, a care recipient. Analysis of the HILDA data shows that this group is significantly larger than the group of self-identified young carers. Young men are overrepresented in this group, as are young people aged 15 to 19 years. The analysis here does not intend to imply that all these young people have care responsibilities at a level that requires policy responses or intervention. Rather it aims to highlight the extent to which the experience of disability and illness in another family member may form part of young people’s everyday lives and how it may affect their lives.

The analysis also explored any similarities in education and employment participation, economic circumstances, and health between these potential young carers and other self-identified young carers. Overall, it found that potential young carers aged less than 19 years were more likely to be still at school than other young people; however, among the 19 to 24 year age group, they appeared to have achieved lower levels

of education. The employment profiles of potential young carers had similarities to those of young carers, with a lower proportion of potential carers in full-time employment and more were unemployed, marginally attached or not in the labour force than non-carers. Potential carers also showed similarities to young carers with respect to their economic circumstances, with higher rates of income poverty and deprivation than young people who were not carers.

Overall, the evidence suggests the costs of care are in terms of lower levels of completion of all years of education, lower rates of employment participation, lower levels of household economic resources and lower scores on self-reported mental health for young carers. While the evidence presented here on whether potential carers have similar profiles to young self-identified carers is somewhat mixed, future research should still consider this group when exploring other aspects of the lives of young people.

Qualitative analysis: focus groups with young carers

The very rich sources of evidence and understanding emerging from the focus group research is illustrative and illuminative of the findings of the analyses of the national data sets. It was evident from listening to the voices of young carers who participated in this project that young care giving is constituted by a diverse set of experiences and circumstances, affected by the age of the carer, their relationship to the person/s for whom they provide care; the intensity of their care giving responsibilities; the period of time over which they have been carers; and the extent to which they receive support from family members and are able to draw upon close friendships, in particular from other young carers. What is overwhelmingly apparent from these focus groups is that despite the diversity of experiences, young carers show levels of commitment, courage, generosity and understanding well beyond what might be expected at their ages, and well beyond what general community perceptions hold of young people and their expected contributions to family life.

Indeed young carers' perceptions of care correlate with Daly and Lewis's (2000) theoretical framework of social care:

- **Care is labour:** the areas of young people's lives generally most affected by care giving include their schooling and for older carers their employment, and for many young carers their opportunities for friendship and social life. However, the diversity of young carers' responsibilities and the continuum of intensity of the care they provide must be recognised, in that age and intensity of care interact to determine the impacts of care on other life domains.
- **Care is located in a normative framework** of familial obligations within which young people may not identify themselves as carers. This is the context in which many young carers expressed the view that despite the evident strains of care giving they are able to identify, they nevertheless wish to continue their responsibilities so as to protect the strength and integrity of their families and contribute to the health and wellbeing of the person for whom they care. However, when they do identify themselves as carers, and do become aware of the range of supports and services that may benefit their care recipient and themselves, they are able to identify those that would enable a genuine private–public sharing of the responsibilities of care in their own families.
- **Caring incurs costs:** participants in the young carer focus groups reported strains with respect to their efforts to combine school education and care, enter further education and training, and combine employment and caring. Caring often incurs costs to friendships and social life, and costs to emotional and mental health. Most significantly, the evidence of these focus groups is strongly suggestive of the financial strains imposed by both care giving and disability or long-term ill health within the family. This is especially important with respect to perceived access to services, and to participation in social and friendship activities that may alleviate the burden of care giving.
- **There are benefits as well as costs.** The young people perceive profound contributions to the wellbeing of the care receiver and the whole family; they see their caring responsibilities contributing to the wellbeing and integrity of the whole family. Young carers also perceive that they acquire valuable skills, including a sense of maturity, independence and a deep sense of achievement, which they believe should be much better recognised and more widely valued and respected.

Formal services young carers and their families received and appreciated and that they and service providers would like to see more widely available are:

- adequate financial support given the costs of ill health and disability and the constraints imposed on their parents' employment
- respite care for longer hours to benefit both the care recipient and the young carer so they can complete their education with less strain and participate in friendship and social activities.

Assistance with domestic activities, especially with transport, was often emphasised. To help relieve the strain of balancing education and care, and employment and care, focus group participants spoke of the need for schools, TAFE colleges, universities and workplaces to institute much more flexible arrangements to fully and appropriately accommodate their care giving responsibilities.

Qualitative analysis: focus groups with policy makers and service providers

Analysis of the interviews and focus groups with policy makers, service providers and carer advocacy organisations revealed three key themes: the importance of recognising young carers and identifying hidden young carers; the centrality of education as a site for identifying and supporting young carers; and the need for expanded provision of age-appropriate and culturally-sensitive support services, and appropriate forms of financial support.

All service providers and policy makers observed that the greatest difficulty for young carers in accessing support was a lack of recognition of their responsibilities, either on the part of the young people and their families or on the part of the organisations and institutions with which young carers come into contact. Organisations are often not aware that young people provide any kind of care, since the cultural expectation is often that young people **receive** care, they do not **give** care. Services that support carers might have age-based eligibility criteria that exclude young people. The service providers who participated in the research overwhelmingly agreed there was a great need to inform organisations about the existence of young carers and their needs, and to promote support for young people who might be carers in a way that does not require them to identify as 'young carers'.

Policy makers, service providers and carer advocacy organisations believe schools are central to increasing recognition of young carers. Service providers reported that young carers are keen to receive academic assistance so they can complete their secondary education, to which they are deeply committed; that schools are important for maintaining social connectedness; and that young carers, through schools, might learn about the existence of other young carers and the support for which they might be eligible. However, schools that do not recognise the responsibilities of young carers or are not sensitive to young carers' needs may deny them support and understanding. A lack of support from school staff and/or bullying from other students might lead young carers to resort to home schooling, where they face extreme isolation. Turning all schools into a supportive environment for young carers, through a whole-of-school commitment is a key priority of policy makers, service providers and carer advocacy organisations.

All parts of the research raise the issue of the need to enable young carers to receive appropriate forms of income support for which they might be eligible, given the strains imposed by low income and high household costs, both while at school and upon leaving education. This is an important issue because a significant proportion of young carers are in low-income households subject to the financial strains of disability or illness, in addition to the costs of caring.

Finally, young carer service providers felt their services played an important role in the support of young carers. Their flexible and creative approaches to giving young carers educational and social opportunities were seen to be in greater demand than they could provide. Participants identified groups of young carers with specific supports needs that are not always adequately or appropriately met by support services. These include young people of Indigenous and culturally and linguistically diverse backgrounds, those in remote areas and young carers who are home schooled. Participants recommended that these subgroups

of young carers be carefully considered in future policy development. In this context, it should be noted that the quantitative analysis showed that young carers of Indigenous and culturally and linguistically diverse backgrounds are overrepresented among identified young carers. Further research is needed to explore in greater depth the circumstances of young carers of culturally and linguistically diverse and Indigenous backgrounds and young carers in rural and remote areas.

Conclusions

Development of policies and services for young carers and their families is relevant to a number of Australian Government and state and territory portfolios and programs within a number of departments. It is also of great significance for non-government community service organisations and carers associations across Australia. Thus comprehensive and cohesive policy and program development across government portfolios and coordination between levels of government and the community sector is very important.

The research identified the following issues for policy development:

- raising awareness of young carers in a range of institutional settings, including schools, the health care system, and mainstream family and young people's services
- recognising the centrality of education as a site for identifying and supporting young carers through whole-of-school commitments
- taking a whole-of-family approach to service development and provision that recognises the close connections between support for young carers and support for the family members for whom they provide care
- providing appropriate and timely information about available services and supports to young carers and their families
- recognising the importance of age-appropriate and culturally-appropriate services and supports
- addressing unmet support needs for domestic help, respite, transport assistance and counselling
- providing appropriate and adequate financial assistance to young carers and their families
- providing help with entry into post-school training and further education
- providing help with seeking and entering employment
- recognising the specific support needs of young carers whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous background, culturally and linguistically diverse backgrounds and those in rural and remote areas.

1 Introduction

‘Young carers’ is the term used in Australia and the United Kingdom (‘young care givers’ in the United States) to refer to children and young adults with informal caring responsibilities for other people, usually, but not always, co-resident family members, who have a chronic illness, physical or mental disability or are frail aged. In these countries over the last 15 years, researchers, policy makers, social welfare agencies and advocates and service providers in health care and education have taken a growing interest in the extent, nature and outcomes of children and young people’s informal care giving within the family (Becker 2007). Young carers are not a new phenomenon. Children and young adults have always provided care for younger siblings, frail elderly grandparents, sick or disabled parents and other household members (Aldridge & Becker 1993), but the naming and identification of ‘young carers’ as a category in public discourse and policy development is relatively recent. While it is difficult to establish that the prevalence of young carers has increased, due to the absence of baseline data, it is evident that increased recognition has been accorded to young carers. This is likely due to increased emphasis on informal care provision in general as a consequence of the move away from provision of care in residential settings to care in the home and community (Jenkins et al. 2003). Also salient is recognition of the personal costs of care, including both direct costs to health and wellbeing, and opportunity costs to labour force participation and earned income over the short and longer-term as outlined in the general care literature (Daly & Lewis 2000).

It is only over the last two decades in the United Kingdom, in Australia since the latter part of the 1990s, and much more recently in the United States, that the concept of a ‘young carer’ has been identified as a social category. In Australia and the United Kingdom this identification or recognition occurred through a combination of non-government organisations’ research, advocacy and representation, government policy makers’ establishment of formal reviews, and the growth of academic research. In Australia, it can be argued that identification of ‘young carers’ as a category was initiated by non-government sector advocacy giving carers and young carers a voice through the efforts of national and state and territory carers associations. These efforts inspired research partnerships with government policy makers and university researchers, generating a small number of Australian studies on the characteristics, circumstances and needs of young carers, and the people for whom they care, and the policy environments in which their care giving is located (Carers Association of Australia 1996, 1997; Gays 2000; Moore 2005a, 2005b, 2005c; Moore & McArthur 2007; Morrow 2005; Noble-Carr & DFACS 2002a, 2002b; Price 1996; Thomson et al. 2005).

This report builds on and develops existing research to present the findings from a multistage study on young carers undertaken for the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. The multistudy provides new insights into the circumstances and needs of young Australians who provide care for sick or disabled family members or friends. The study includes a review and analysis of the dominant themes identified in the national and international literature on young carers; comprehensive quantitative analysis of three nationally-representative data sources—the Australian Bureau of Statistics (ABS) *Census of Population and Housing 2006*, the ABS *Survey of Disability Ageing and Carers* (SDAC) 2003 and Wave 5 of the Household Income and Labour Dynamics in Australia (HILDA) survey; and qualitative research through focus groups with young carers and with service providers and policy makers. The value of combining quantitative and qualitative methods is that it allows for the triangulation of data (Denzin 1970).¹ A further advantage is that it allows for exploration of different facets of a phenomenon in order to generate a wide-ranging understanding of the topic under study (Bryman 2001).

Section 2 of the report presents a review of the existing published research on young carers’ experiences, circumstances and the impacts of their care giving in Australia, the United Kingdom and North America—predominantly the United States, with some reference to Canada. ‘Young carer’ is the term used in the Australian and United Kingdom literature; ‘young care giver’ is used in the United States (Becker 2007; Hunt, Levine & Naiditch 2005). Young carers in this literature review include children and teenagers up to 17 years of age and also young adult carers aged 18 to 24 years who provide ‘any informal

assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people (aged 60 and over)' (ABS 2004). The review covers what is known about the socioeconomic, demographic and sociocultural determinants of children and young people becoming and continuing to be informal carers. It also examines the experiences and outcomes of caring including the impacts on education, employment participation and income, physical and mental health, interactions with friendship groups and participation in social activities. The review identifies the positive impacts of caring, which include acquisition of caring skills and strengthening of intrafamilial and interfamilial bonds of reciprocity with the people receiving care and other family members. The review identifies key domains of policies, programs and services that the literature indicates to be of importance in supporting young carers, and care recipients and their families. The literature surveyed covers Australian, United Kingdom and North American published books, book chapters and journal articles, and reports produced by government departments and non-government community service agencies.

Section 3 of the report is an analysis of three nationally-representative data sets: the ABS SDAC 2003; the *Census of Population and Housing 2006*; and Wave 5 of the HILDA survey (2005). The analysis explores the socioeconomic–demographic circumstances of young carers; the intensity and nature of their caring responsibilities; their participation in education, training, and employment; their income; their own perceived health status; and their family and household circumstances, including the health and disability status of the people for whom they care. The issue of hidden young carers (as discussed in the literature) is explored in the analysis of the HILDA data and a concept of 'potential' young carer is coined to identify young people living in a household with a child or adult with a long-term health condition, disability or impairment. The characteristics of potential young carers are compared with those of young people identified in the data sources as young carers. The findings suggest that there may well be a significant group of young people whose caring responsibilities go undocumented in public discourse and where the young people themselves do not recognise the term as applicable to themselves.

Section 4 presents a qualitative analysis of primary research that was undertaken through focus groups held with young carers aged 11 to 25 years, carried out in New South Wales, South Australia and the Australian Capital Territory in 2007. This age range was chosen in order to work within the guidelines of the Human Research Ethics Committee at the University of New South Wales, which gave approval for this project and the focus groups to proceed.

Eleven focus groups were held at three Young Carer Camps in Sydney, Adelaide and Canberra with a total of 68 participants who were recruited through consultation with Carers NSW and Carers South Australia. Both associations have well-developed young carers websites, provide services and links to services, and hold camps for young carers to provide respite and recreation, as well as information about services. The focus groups explored young carers' experiences; the intensity and dimensions of care giving and level of responsibility; their health, patterns of education, training and employment; family composition; the circumstances and needs of the person being cared for; the networks of relatives and friends and interactions with them; access to recreational, sporting, and other social activities; and usage of formal services, and supports and reasons for non-usage.

Section 5 of the report presents findings from focus groups and interviews undertaken with Australian Government policy makers who provide programs and services for young carers and their families; and also with service providers in all carers associations across the country whose responsibilities focus on support for young carers, as well as with other non-government community services providing services and programs for young carers. The purpose of these focus groups and interviews was to identify the policies and services that currently support young carers' educational retention, entry into post-secondary school education and training, labour force entry and maintaining labour force participation, and participation in social and friendship networks. The research was designed to identify any gaps in services, how the gaps might be addressed and the ways in which current effective services might be enhanced to the benefit of both young carers and the people for whom they care.

Section 6 draws together the four phases of the project: literature review and analysis of the issues, quantitative analyses, the findings of qualitative research with young carers, policy makers and service providers. The concluding section indicates how new, significant information and insights about young carers in their family, community, education, employment, social networks and service provision contexts may be used to identify issues for policy development and suggest areas for further research.

2 Literature review and overview of the issues

2.1 Introduction

This section reviews existing knowledge about young carers in Australia, the United Kingdom and the United States in order to set out the context of the project, framing it conceptually before examining the research on young carers and setting the policy scene. It will do so by first situating young carers within the social care framework. It then presents the research on the numbers and characteristics of young carers, who they provide care for and what that care entails. It then explores some of the reasons that lead to young carers assuming a care giving role and the impacts of this role—both positive and negative—on the young carers' lives. Finally, it reviews the literature on the service responses to the needs of young carers and their families and sets out the policy context.

2.2 Placing young carers within the social care theoretical framework

Much of the literature on care—both paid care and unpaid care (often provided by family members within households and kin networks)—constructs dichotomies of formal or informal, paid or unpaid care. There is, however, a more thoughtful and nuanced literature that rejects these dichotomies, developing a conceptualisation of social care in which the interconnections of paid and unpaid care are mapped through the life course. One influential contribution to this literature (Daly & Lewis 2000) focuses on three interconnected aspects of care:

- **Care is labour**, requiring consideration of whether care is paid or unpaid, formal or informal and the social policy determination of these boundaries. These are not fixed but blurred and changing boundaries framed and shaped by public policies and may be subject to significant policy shifts. Becker (2007, p. 24) notes that conceptualising unpaid care giving as labour is to make public 'the activities, roles, value and outcomes that characterise unpaid and family-hidden care giving'.
- **Care is embedded within a normative framework of obligation and responsibility**. Informal care tends to be provided under conditions of social, usually familial relationships and responsibilities, making it inappropriate to consider the labour aspects of care alone. With respect to young carers, for example, the bonds of intrafamilial love and reciprocity between care giver and care recipient may act to hide, even isolate young carers, and to reduce their use of appropriate levels of support (Bittman et al. 2004; Moore & McArthur 2007).
- **Care is an activity that incurs costs** that extend across public–private boundaries. These costs include direct costs with respect to expenditure and costs to physical and mental health; and opportunity costs, concerned with possible disruption to education, training, labour force participation, income earning, and participation in social and friendship networks. The key question surrounds how the costs of providing care should be shared among individuals, within families and across society at large. Moreover, what is the most appropriate balance between formal and informal care, and to what extent will informal care be assisted by formal support?

Other influential contributors to the social care framework have also developed multidimensional approaches to understanding the caring relationship. Fisher and Tronto's (1990) typology of care distinguishes between different modalities of care provision:

- **caring about**—paying attention to the factors that determine wellbeing and establishing the need for care
- **caring for**—taking the initiative for concrete caring activities and taking responsibility to ensure they are carried out
- **taking care of**—actually carrying out the daily tasks of care giving work
- **care receiving**—signifying that caring is a reciprocal relationship.

Fine's (2004) typology encapsulates similar relational dimensions:

- **care as a mental disposition**, an emotional engagement with and concern for the wellbeing of others
- **care as an activity**, a form of work concerned with personal maintenance, assistance or support
- **care as an interpersonal relationship** between individuals with the emphasis on development of ongoing personal ties through attending to the needs of the other.

However, the theoretical frameworks on care giving and analysis of the policy settings in which care giving is situated rarely consider the case of young carers, focusing instead on parental care of children, and adult care for disabled or chronically ill offspring, spouses or older relatives. This may be because children and young people are not expected to take on substantial caring responsibilities. While adult carers are seen as conforming to familial and societal norms, the image of children and young people as unpaid carers appears to transgress the norms that envisage them as care recipients, as dependent. Becker (2007, p. 25) notes that in western constructions of childhood, children are not expected or encouraged to take on substantial or regular care giving responsibilities. Yet it is apparent both from official statistics and from qualitative research in Australia, the United Kingdom and the United States (ABS 1999, 2004; Becker 2005, 2007; Hunt, Levine & Naiditch 2005; Moore 2005a, 2005b, 2005c; Moore & McArthur 2007; Morrow 2005; Noble-Carr & DFACS 2002a, 2002b) that children and young people are providing informal care for family members, in ways which go beyond the household tasks usually associated with children's family responsibilities (Warren 2007).

Placing young carers within the 'social care' framework is to perceive them as active agents engaged in reciprocal relationships of care and contributing substantially to family wellbeing, particularly the wellbeing of their care recipient. Much of the literature on care giving tends to emphasise the concepts of 'stress' and 'burden', and fails to capture the complexity and worth of the diverse experiences of care (Burack-Weiss 2006). Focusing on children and young people as active carers making profound contributions to their families and communities, while incurring personal costs (Noble-Carr & DFACS 2002a, 2002b), is consistent with a framework that sees children and young people as active participants within their families and communities (NSW Commission for Children and Young People 2005; Prior 2002, 2005; Ridge 2002, 2007).

The concept of social care therefore provides a useful framework for analysing the research on young carers, exploring the socioeconomic-cultural circumstances of young carers' labour; their sense of normative obligation and responsibility; and identifying the current and longer-term costs, as well as the benefits, of their care (Cass 2007).

2.3 Who are they?

Defining 'young carers'

The ABS SDAC defines a carer as 'a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people (aged 60 years and over)'. This assistance has to be ongoing, or likely to be ongoing, for at least six months. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: cognition or emotion, communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self care and/or transport. Assistance for a person in a different household relates to 'everyday types of activities',

without specific information on the activities (ABS 2004, p. 71). A 'primary carer' is defined as 'a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities'. This 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 of communication, mobility and self care (ABS 2004, p. 77).

'Young carer' is the term used in Australia and the United Kingdom, 'young care giver' in the United States, to refer to children and young people (in the United Kingdom up to the age of 17 years, in Australia up to the age of 24 years, in the United States up to the age of 18 years) who undertake informal caring responsibilities for other people, usually family members, who have a chronic illness, physical or mental disability or are frail aged. Becker (2007) argues that the definition of young carers should be restricted to those under 18 years of age, because carers over the age of 18 years are no longer children and many are caring for partners or their own disabled children. This perspective is also adopted in Australian research by Moore (2005a, 2006b, 2005c). However, this perspective is disputed by advocacy organisations and other researchers in the field in Australia for whom the term 'young carers' is used to refer to young people under 25 years of age. The rationale for including young people up to the age of 25 years in the definition of 'young carer' is driven largely by the fact that the transition into adulthood (from education into employment, moving out of the family home) has been extended over the last two decades (Noble-Carr & DFACS 2002a, 2002b). In the research for this report the age range up to 24 years was adopted, but age differences within this range were also considered, especially as the nationally representative data sources permitted.

The responsibilities of young carers cover a range of care tasks, both practical tasks such as mobility assistance or help with medication, and emotional support, including providing company, supervision and paying close attention to the emotional and psychological state of the person with care needs (Warren 2007). It can also involve supporting adult carers, looking after other children in the family, and 'looking after yourself' (Morgan 2006; Noble-Carr & DFACS 2002a, 2002b). These informal caring tasks and responsibilities go beyond not only what adults would normally expect of children but also what most children would expect routinely to do within the family (Becker 2007; Early, Cushway & Cassidy 2006, p. 170; Warren 2007).²

Numbers of young carers

This study of young carers in Australia covers children and teenagers up to age 17 years and young adults aged 18 to 24 years. According to the ABS SDAC data for 2003 (ABS 2004), there were 170,600 carers up to age 17 years, comprising 3.6 per cent of all children and young people in this age range; and 178,000 carers aged 18 to 24 years, comprising 9.1 per cent of young people in this age range (Table 1). Thus 348,600 children and young people were undertaking caring responsibilities for people with disabilities or long-term conditions, or older people, for at least six months, or were likely to be doing so for at least six months. The data on young primary carers, or those who provide the most caring assistance, showed that 4,700 young people aged 15 to 17 years and 15,600 aged 18 to 24 years identified as a primary carer (although they are likely to have been undercounted in the survey, for reasons described in more detail later in this report).

Table 1: Status of young carers, by age and gender

Carer status		Primary carer ^(a)	Carer not a primary carer	Total carers	Not a carer	Total
Males						
Up to 17 years	n ('000)	2.4	85.1	87.6	2,345.0	2,432.6
	%	0.1	3.5	3.6	96.4	100
18–24 years	n ('000)	3.0	87.8	90.8	907.4	998.2
	%	0.3	8.8	9.1	90.9	100
Females						
Up to 17 years	n ('000)	2.3	80.8	83.1	2,224.2	2,307.3
	%	0.1	3.5	3.6	96.4	100
18–24 years	n ('000)	12.6	74.6	87.2	881.6	968.8
	%	1.3	7.7	9.0	91.0	100
Total						
Up to 17 years	n ('000)	4.7	165.9	170.6	4,569.3	4,739.9
	%	0.1	3.5	3.6	96.4	100
18–24 years	n ('000)	15.6	162.4	178.0	1,789.0	1,967.0
	%	0.8	8.3	9.1	91.0	100

(a) Primary carers only include persons aged 15 years and over for whom a personal interview was conducted. Persons aged 15 to 17 years were only interviewed if parental permission was granted.

Note: Due to rounding, percentages may not add to 100 per cent.

Source: ABS 2004.

Comparisons with the United Kingdom and United States statistics are difficult to make because of differences in survey methodologies and age bands. Nevertheless, the statistical evidence shows a degree of uniformity in the proportion of children who are young carers (Becker 2007). Secondary analysis of the United Kingdom 2001 Census shows that 2.1 per cent of all children aged 5 to 17 years were providing informal care (Becker 2004). The only available United States survey of young care givers³ estimated that there were approximately 1.3 to 1.4 million child care givers in the United States, comprising 3.2 per cent of all United States households with a child in them aged 8 to 18 years, evenly balanced by gender (Hunt, Levine & Naiditch 2005; Kornblum 2005a, 2005b). A comparison of these figures with the data from the ABS SDAC for 2003 (ABS 2004) for young carers up to age 17 years shows that the young carers in these comparable age bands comprise from 2.1 per cent to 3.6 per cent of all children in Australia, the United Kingdom and the United States. Despite the attempt to make the statistical comparison, it must be emphasised that the figures in each country are likely to be an underestimate, because of the largely hidden nature of young people's care giving, demonstrated in the literature reviewed below. No comparable figures in the three countries are yet available for young adult carers aged from 18 to 24 years. Nor are figures available for 'primary carers', a concept not used in the United Kingdom and United States literature.

Characteristics of young carers

Analysing data from the ABS SDAC (ABS 1999), Bittman and colleagues (2004) found that young carers were more likely than their peers to be in a lone-parent family. Bittman and colleagues also found that young carers were more likely to live in socioeconomically disadvantaged areas; to have a disability or long-term health condition themselves; to be in receipt of government income support; and be from a non-English speaking background.

Research evidence from the United Kingdom suggests that young carers share many of the socioeconomic and demographic characteristics of their Australian counterparts. United Kingdom studies show that young carers are more likely than their peers to be in single-parent families; their families are likely to receive little support from the extended family; and their parents are likely to be unemployed or outside the labour market, and have low incomes. The United Kingdom research shows that in two-parent families, a young carer's responsibilities may involve looking after siblings rather than a parent. The presence of a second parent who is not disabled or ill does not necessarily mean that a child will not have caring responsibilities because the second parent needs to remain employed (SCIE 2005). A study by Dearden and Becker (1998) found that one-quarter of young carers and their families had no outside support, except for their contact with a young carers project. A study of young care givers in the United States reached similar conclusions: young care givers are more likely to live in households with lower incomes than are non-care givers, and they are more likely to live in a one-parent household (Hunt, Levine & Naiditch 2005).

In Australia, females comprise 49 per cent of carers aged up to 17 years and 49 per cent of carers aged 18 to 24 years. They also comprise 49 per cent of primary carers aged up to 17 years. However, gender parity is no longer evident when considering primary carers aged over 18 years. Among primary carers, or those providing the most informal assistance to a person with one or more disabilities, 81 per cent are female. This suggests that among young adults there are gender-differentiated practices influencing primary care responsibilities, which may be related to different emphases placed on continuing education and training and on labour force participation, drawing considerably more young women than young men aged 18 to 24 years into the responsibilities of primary care.

Eley (2004) in a study on young caring, gender and education in the United Kingdom, found that girls were more likely to be involved in all aspects of care, especially domestic tasks and personal care, and were considered more 'available' for care within the family. Eley suggests that this reflects wider societal expectations that are placed on women to adopt caring roles, with the expectation in some families that not only will young women 'naturally' possess the skills and knowledge to carry out caring work, but that they will also want to do it. Compared to girls, boys had different pressures within the family, such as an expectation that they would discipline siblings, and respond positively to crises as they arise. The issue of gender-differentiated patterns of care giving has not been explored comprehensively in the Australian literature on young carers. However, this issue is important in understanding the familial, sociocultural and socioeconomic processes that influence young people to take up primary carer responsibilities and the level at which those responsibilities are undertaken.

'Hidden' young carers

While the body of data on the numbers and characteristics of young carers is growing, researchers are concerned that many young people performing a caring role are not being picked up in the statistics. These young people are known as 'hidden' young carers. These young people often remain 'hidden' because they do not identify themselves as 'carers' and consequently do not use or make contact with formal services.

In Australia, research shows that a large proportion of carers under the age of 25 years do not use formal services (Bittman et al. 2004; Moore 2005a, 2005b, 2005c; Thomson et al. 2005). In the Noble-Carr and DFACS (2002a, 2002b) study of young carers some participants said they did not perceive the need for formal services because they did not identify as 'carers'. In this case, the normative relationships of familial care giving are at the heart of their sense of identity. In the United Kingdom, this perception is particularly evident among young people from minority ethnic or immigrant backgrounds, among whom the term 'carer' is often meaningless and ignores the complexity of family relationships and obligations (Halpenny & Gilligan 2004, p. 28). Australian studies show that many carers in Indigenous communities also perceive care giving as part of a moral order of kinship obligation, in which the giving and receiving of care are an integral part of everyday life (Henry & Daly 2001; Henry & Smith 2002; Jenkins & Seith 2004; Rowse 1998).

In the United Kingdom, Becker (2004, 2007) notes that while national census figures provide the most comprehensive estimates of young carers, it is widely accepted that they do not capture the full extent of young people's care giving responsibilities. Census figures are likely to underestimate the prevalence of children's unpaid care work because they rely on parents reporting their children's caring roles and the data are not likely to adequately identify or count children in some caring situations; for example, parents who misuse drugs or alcohol or where there is persisting parental mental illness or HIV/AIDS. Consequently, many young carers remain 'hidden', because they are not recognised or identified as young carers and are not in touch with services (SCIE 2005). A United Kingdom study by Warren (2007) found that around one-tenth of her randomly selected group of children (not defined as 'young carers') had considerable caring responsibilities, sometimes as substantial as the self-identified young carers in her study. This suggests that there is a hidden group of young carers in the general United Kingdom population who are unlikely to be in receipt of formal support or services (Becker 2007).

In both Australia and Britain, studies have also raised other reasons for young carers not accessing formal services, residing in the characteristics of the services. For example, even when young carers do identify themselves as being a carer and seek assistance, some indicated that the targeting of services bypasses their particular needs; services are not available, accessible or affordable; and that service providers lack awareness about the specific needs of young carers (Morgan 2006; Noble-Carr & DFACs 2002a, 2002b). Other young people attributed their reluctance to use services to a mistrust of services in general, and some young carers had not received support because they challenged the services' conception of who a 'carer' should be, with respect to their age (Moore 2005a, 2005b).

2.4 Who do they care for?

Relationship to care recipient

Analysis of data in the SDAC 1998 shows that two-thirds of young carers aged 10 to 24 years provided care for a parent, with 43 per cent caring for their mother, and 23 per cent for their father. A further 10 per cent provided care for a female relative and 10 per cent for a male relative other than their parents and 14 per cent cared for other persons, a category which includes friends and neighbours (Bittman et al. 2004, p. 64; Thomson et al. 2005).

In the United Kingdom, a 2004 study of young carers by Dearden and Becker found that parents were also the most common recipients of care. In the study, young carer support services in Britain were asked to complete a survey providing information about each of the young carers accessing the service, resulting in collection of information from about 6,178 young carers (Dearden & Becker 2004, p. 4). The study revealed that 66 per cent of people receiving care were parents of the young carers and that 52 per cent of these were mothers (or stepmothers). In addition, 34 per cent of people receiving care were siblings (31 per cent) or grandparents (3 per cent). In lone-parent families, the care recipient was much more likely to be the mother (70 per cent) than the father (7 per cent) (Dearden & Becker 2004, p. 5). As well, a 2008 study of young carers aged 16 to 24 years found that the most common recipient of care was the mother (Becker & Becker 2008, p. 23).

In the United States, a report by Hunt, Levine and Naiditch in 2005 revealed slightly different results. The report was based on the results of two studies that set out to discover the prevalence and experiences of young care givers in the United States: a survey sent to a random sample of households; and a series of telephone interviews with 213 young care givers (and 250 non-care giving children) between the ages of 8 and 18 years (Hunt, Levine & Naiditch 2005, p. 3). The authors found that 34 per cent of young care givers were caring for a parent (usually the mother), 38 per cent—a much greater proportion than in Australia or the United Kingdom—were caring for a grandparent (usually the grandmother), and 11 per cent were caring for a sibling. In addition, young care givers in minority households were more likely to be caring for their mother (42 per cent) than those in non-minority households (25 per cent) (Hunt, Levine & Naiditch 2005, p. 12).

Characteristics of care recipients

In Australia, data derived from the SDAC show that the intensity of the care needs of the care recipient varies. The data show that in 1998, 20 per cent of young carers were caring for a person who was profoundly limited in their core activity (self-care, communication or mobility), and 36 per cent for a person who was severely limited (Hill et al. 2009, p. 147). This compares with 26 per cent and 63 per cent respectively for young primary carers. In 2003, the figures for young carers were reasonably unchanged, with 18 per cent caring for a person with profound limitations to their core activity and 34 per cent for those who were severely limited. However, by 2003, young primary carers were more likely to be caring for someone with profound limitations, with the percentage rising to 37 per cent—twice as likely as non-primary carers (Hill et al. 2009, p. 147). During the same period, the proportion of young primary carers caring for a person with severe limitations fell to 49 per cent.

In Britain, young carers participating in Dearden and Becker's 2004 study were caring for people with a range of conditions: 50 per cent were caring for a person with a physical health problem or disability, 29 per cent for someone with a mental health problem (including problems with drug and alcohol use), 17 per cent for someone with a learning difficulty, and 3 per cent for someone with a sensory impairment (Dearden & Becker 2004, p. 6). The distribution of conditions varied depending on the relationship of the care recipient to the young carer. For example, 50 per cent of mothers and 43 per cent of fathers had care needs because of a mental health problem. Physical health problems were the most common conditions resulting in the need for care among grandparents (88 per cent), and 63 per cent of siblings requiring care did so because of learning difficulties (Dearden & Becker 2004, p. 7).

In the United States, those requiring care had a range of conditions (Hunt, Levine & Naiditch 2005). The most common conditions resulting in the need for care were Alzheimer's disease and dementia (18 per cent); disease of the heart, lungs, or kidneys (16 per cent); arthritis (14 per cent); and diabetes (14 per cent). The report indicates that 'depression, mental health' accounted for only a small percentage of the conditions requiring care (3 per cent) (Hunt, Levine & Naiditch 2005, p. 14).

The perspective of parents of young carers

Although young carers may provide care for younger siblings who have a disability, frail elderly grandparents and, in the case of young adult carers, their spouse or their own children with a disability, in Australia most (62 per cent) provide care for sick or disabled parents (ABS 2004). Newman (2002) in the United Kingdom suggests that as an 'unintended consequence of the rise of young carers', many disabled parents feel disempowered and 'pathologised', believing that researchers and official authorities have the perception that their disabilities are seriously affecting the immediate and long-term welfare of their children. Aldridge and Becker (1994) investigated the perspective of parents receiving care and found a tendency to 'keep it in the family' and for families not to involve friends and neighbours in caring routines. Few members of the extended family, neighbours or friends offered support. Mothers in this study indicated a lack of support from male partners. Half of those interviewed had a partner but they were no longer living in the family home, had refused to take part in any caring commitments, or had left when the diagnosis occurred. All the parents agreed that children should not have to provide care, yet none wanted their children replaced entirely by an informal or formal professional carer. All the parents/care receivers interviewed said their children were better carers than the professionals who were paid to provide care, and they preferred to be cared for by their children, illustrative of the bond between care recipient and care provider. Many of the parents, similar to the young carers themselves, found it difficult to recognise that their children had specific needs as carers, which is indicative of the complex, normative, familial relationships entailed in care giving (Aldridge & Becker 1994).

In a Canadian study, McKeever et al. (2003) found that mothers with a physical disability were likely to experience inner turmoil and guilt associated with accepting care from their children. This study found strong indications that accepting assistance from children was not the mothers' preferred option, because it contradicted their conceptions of 'good mothering'. Similarly, Aldridge and Becker (1994) found that parents held fears that other people may disapprove of their children's care giving.

It is of great importance to explore these issues in Australia, given the importance of young carers within the normative relations of care provision and care receipt, and in considering the policies and services that might alleviate the intensity of their care provision, through adopting a whole-of-family perspective. A whole-of-family perspective is one in which the needs of both the young person providing care and the person for whom they provide care and support are the focus of policy development and service provision (Aldridge & Becker 1996; Becker 2005, 2007; Becker, Aldridge & Dearden 1998; Moore & McArthur 2007).

2.5 What do they do?

Caring tasks (intensity, hours and type of care)

Studies in Australia, the United Kingdom and the United States show that the responsibilities of young carers, in terms of the types of tasks and levels of responsibility, differ from the household tasks their peers carry out (Gays 2000; Hunt, Levine & Naiditch 2005; Moore 2005a; Morrow 2005; Warren 2007). Warren's study in the United Kingdom found that young carers perform a wider range of domestic, emotional, nursing and intimate care tasks and they spend longer on these responsibilities than other children.

In Australia, the results are similar, with the responsibilities of young carers covering a range of care tasks, both practical and emotional. The practical tasks can involve giving 24-hour personal support including washing, showering and bathing, dressing and undressing, using the toilet, mobility assistance, help with medication (including administering injections), housework, shopping and meal preparation. It can also include making regular telephone calls, supporting adult carers in the household, looking after other children in the family, and 'looking after yourself' (Morgan 2006; Noble-Carr & DFACS 2002a, 2002b). Of major importance is provision of emotional support, including providing company, supervision and paying close attention to the emotional and psychological state of the person with care needs (Warren 2007).

Moore's studies of young carers in the Australian Capital Territory (Moore 2005a, 2005b, 2005c; Moore & McArthur 2007), which included in-depth face-to-face interviews, focus groups and workshops with young carers and other key informants, corroborated the findings reported above and highlighted the intensity of the work young carers undertake. Many cared for significant periods of time (an average of 6.4 hours per day) for a substantial duration (an average of 6 years). They were responsible for tasks around the home, caring for other relatives, providing emotional support, helping financially, and protecting the family. These responsibilities were more intense than those undertaken by their non-caring peers and were often provided without adult supervision and support. In the United Kingdom, Becker drew on census data to reveal that 83 per cent of young people providing informal care do so for between one and 19 hours per week, and 17 per cent provide care for 20 hours per week or more, with roughly half of these providing at least 50 hours of care per week (Becker 2007).

2.6 Why do they care?

The family circumstances and policy settings in which children and young people become carers

The Australian, United Kingdom and United States research suggests that children and young people participate in informal care giving as a result of two interconnected circumstances: as part of the family network of obligation and responsibility; and through lack of appropriate, accessible and affordable formal services. Moreover, family decisions tend to be bounded both by socioeconomic factors and the accessibility and perceived appropriateness of formal services.

In Australia and the United Kingdom, the intrafamilial factors that 'push' young carers into providing informal care include systems of family obligation and expectation, absence of other appropriate and/or available informal care givers within the family and kin network (especially in lone-parent families), and the nature and intensity of the illness or health condition of the care recipient. In Australia, Noble-Carr and DFACS

(2002a, 2002b) provide a significant contribution to the literature on young carers. The methodology employed in the study included an analysis of SDAC (ABS 1999) and focus groups with three groups of young primary carers (aged under 12 years, 13 to 18 years and 19 to 25 years). Noble-Carr and DFACS note that the young people in the study were caring because they were the only ones available to provide care, resulting from demographic trends in family size and composition (in particular the increase in lone-parent families), the diminution in the number and availability of other informal family supports, and government policy shifts towards deinstitutionalisation with respect to mental illness.

In the United Kingdom, Becker, Aldridge and Dearden (1998) provide a framework for understanding the ‘push and pull’ of interrelated factors prompting children to become young carers, including the nature of the illness or condition of the care recipient, love and attachment, co-residency, family structure, gender, socialisation into caring roles, low income, and lack of other care alternatives. The sense of responsibility to provide care within the kin network is particularly strong in cultural circumstances where kin reciprocity is paramount in family functioning (such as in families of migrant and/or ethnic minority background). Research in Australia shows that many young carers are so embedded in the acceptance of familial obligation that they do not identify as carers; the relationships of familial care giving frame their sense of identity (Bittman et al. 2004; Moore 2005a, 2005b, 2005c; Thomson et al. 2005). This leads to reluctance to access formal services. This is especially pertinent to young carers from culturally and linguistically diverse backgrounds (Misic 1996), and Aboriginal and Torres Strait Islander backgrounds (Orcher 1995).

Canadian research by McKeever and colleagues (2003) found it was often the perceived unsuitability of the home and community care services, rather than the nature of the parent’s disability, which influenced provision of care by children. In the United Kingdom, the disability rights movement has argued that it is the lack of sufficient, accessible and affordable services for people with chronic illness, particularly mental illness or physical disability, that leads adults to rely on their own children for care, and that if appropriate and sufficient resources and services were available, the need for reliance on young carers would be mitigated (Keith 1992; Keith & Morris 1995; Newman 2002; Prilleltensky 2004).

Hence, the literature suggests that young carers tend to be located in identifiable socioeconomic–cultural circumstances, often in low-income families where care giving is central to mobilising intergenerational resources and strengths. However, these familial care giving relationships must be analysed in the context of the system of formal services that frames the extent to which informal care by children and young people is needed and the extent to which formal care is sought, accessed and found relevant and appropriate.

2.7 The impact of caring on young carers

Caring is an activity that may incur both direct and opportunity costs, in addition to providing great benefits. The literature suggests that the cost for young carers may include an adverse effect on school retention, as well as on entry into post-secondary education and training. This may have an adverse impact on their employment opportunities. Young carers also tend to live in households that experience financial hardship. In addition, depending on their regularity and intensity, caring responsibilities may constrain participation in friendship networks, social, sporting and other recreational activities, with resultant impacts on social connectedness and personal health and wellbeing (Morrow 2005; Noble-Carr & DFACS 2002a, 2002b; Price 1996; SCIE 2005). At the same time, family members and other relatives reap significant benefits from young people’s contributions to informal care. Such benefits include maintaining ‘at home’ care for disabled or seriously ill adults and children; reducing the costs of either out-of-home residential care or purchase of formal domiciliary care services; and most importantly, contributing to the integrity and resilience of families (Banks et al. 2002; Moore 2005a, 2005b, 2005c).

Participation in education

The Australian, United Kingdom and United States evidence demonstrates that care giving responsibilities may sometimes impose constraints on continuing participation in school education and post-secondary education

and training (Becker 2005, 2007; Hunt, Levine & Naiditch 2005; Moore 2005a, 2005b, 2005c; Noble-Carr & DFACS 2002a, 2002b). In Australia, Noble-Carr and DFACS (2002a, 2002b) found that young carers are more likely than their age peers to have low participation rates in education, training and consequently in employment. Many frequently missed school, had less time to complete homework, felt worried and distracted when they were at school and experienced limited connectedness with the school community (Noble-Carr & DFACS 2002b).

The literature identifies young primary carers in particular as being at risk of leaving school early. ABS data for 1998 indicate that only 4 per cent of young primary carers aged 15 to 25 years were in education compared to 23 per cent of the general population in this age group (Noble-Carr & DFACS 2002a). Moore's (2005a, 2005b, 2005c) study of young carers in the Australian Capital Territory found that young carers were often discriminated against within the education system because of lack of awareness by teachers and other students of what caring entails, stigma surrounding disability, and inflexible teaching practices.

The state and territory and Australian governments have, however, provided respite care and established programs in schools that recognise and support vulnerable young people at risk of leaving school early or struggling with their dual caring–school responsibilities.

In the United Kingdom literature, young carers have reported feeling stigmatised by teachers and their peers and feel that little support is forthcoming from schools (SCIE 2005). Eley (2004) found that while young carers' schoolwork did not appear to suffer unduly from carrying out caring duties, the young people stated that balancing school attendance, homework and caring obligations could be tiring. Young carers felt that teachers and schools should have a greater awareness of their circumstances, including how their caring responsibilities might affect their school attendance and their capacity to meet assignment deadlines. They also believed that schools could do more to support young carers. Many young carers had plans to pursue higher education and were critical of the circumstances that they perceived compromised their performance at school. Based on their personal experiences, the children and young people reported that some teachers were, at times, insensitive and hard on them (Eley 2004). Similarly, Thomas and colleagues (2003) found that young carers experienced a negative impact on their education if schools were unaware of their caring responsibilities or, conversely, if school staff were overly intrusive into their family circumstances.

Participation in employment

Analysing data from the SDAC (ABS 1999), Bittman and colleagues (2004) found that young carers aged 15 to 24 years, especially those aged 20 to 24 years, were more likely than their peers to be unemployed or not in the labour force; if employed, they were more likely to be working part-time; and consequently were more likely to be in receipt of government income support. Noble-Carr and DFACS (2002b) found that approximately 60 per cent of primary carers aged 15 to 25 years were unemployed or not in the labour force, compared with 38 per cent of their age peers.

In the United Kingdom, Young, Grundy & Jitlal (2006) examined the household and family characteristics of young adult carers (20 to 29 years) providing 20 hours or more of care per week. They chose to focus on this age group because most people in this group have completed all or most of their education and have entered the labour market, making differences between carers and non-carers more clear. The research found that young adult carers had lower levels of education and were less likely to be in employment compared with non-carers of the same age, circumstances likely to have consequences for their quality of life and future opportunities. Researchers in the United States have found that care giving as a young adult may create career possibilities in the health and social service professions, although higher education, which is required for professional care giving occupations that attract higher income, may be less accessible to young adult care givers (Levine et al. 2005).

The recent interest in estimating the costs of care in Australia has not considered, as a special instance, the case of young carers. Access Economics (2005) has estimated the economic value of informal care using two models: the **opportunity cost model** and the **replacement of services model**. The opportunity cost model

estimates the income carers forego because they are unable to enter employment, or they leave employment or reduce their hours of employment. The replacement of services model estimates the cost of replacing informal care with formal care provision. Using the opportunity costs model, Access Economics conservatively estimated the time devoted to informal care in 2005—measured as reduction in paid employment—at \$4.9 billion, based on the fact that rates of labour force participation are substantially lower for carers than for other population groups of similar ages. Using the replacement of services model, it further estimated a replacement value of \$30.5 billion, which would be the cost if all hours of informal care were to be replaced by formal care providers. Not taken into account in the opportunity cost model are the circumstances and needs of young carers, whose caring responsibilities may reduce their participation in education, training and employment and reduce their income, not only at the time of caring, but these effects may have life-course impacts. There is a clear need to develop a longer-term opportunity cost model which estimates the life-course impacts of caring at younger ages, potentially affecting educational achievement, workforce opportunities and earnings.

Financial impacts

Comparing research in the United Kingdom, Australia and the United States, Becker emphasises the extent to which 'low income distinguishes most of the families where children are known to be care givers' (2007, p. 34). As a result, these families lack the resources to access good quality care alternatives that might prevent children from having to undertake care giving, or that might reduce the amount of care giving they need to provide.

In Australia, research by Bittman and colleagues (2004) and Noble-Carr and DFACS (2002a, 2002b) about young carers' relatively high levels of unemployment, low rates of labour force participation, and higher rates of receipt of government income support, compared with their age peers, are indicative of low personal income. In addition, the illness or disability of their care recipient is likely to be accompanied by, or be a contributing factor to, low family income. Further, young carers in the focus groups organised by the Noble-Carr and DFACS study (2002a, 2002b) reported that many struggled with what they described as inadequate financial support. Moore's study of young carers in the Australian Capital Territory (Moore 2005a, 2005b) reported that no young carers in the sample received either a Carer Payment or Carer Allowance, which may be an indication of lack of information and advice, or lack of willingness to apply to official authorities for carer support, or because young carers in full-time education are unlikely to meet the criteria for receipt of Carer Payment. These findings show the financial costs of informal care giving, because the difficulties young carers experience accessing and maintaining employment reduce their personal income; and the additional—direct and indirect (opportunity)—costs of illness and disability affect the income and living standards of the whole family (Saunders 2005).

Similarly, in the United Kingdom, Butler and Astbury (2005) found that inappropriate levels of government income support, in proportion to the amount of caring they performed, often made young carers feel that recognition, praise or respect for their contribution was lacking. Young carers felt the strain of having to contribute to the family's finances and, in some cases, felt responsible for paying the mortgage and the household bills because existing financial support for their parents was inadequate. Similarly, Cree (2003) found that half of the young carers studied worried about money, and while this may be a familiar teenage complaint, it may be compounded by financial difficulties in the family. These difficulties are highly likely to be caused by parents' inability to retain employment because of their illness or disability. A study of young care givers in the United States reached similar conclusions about financial constraints: young care givers tend to live in households with lower incomes than do non-care givers (Hunt, Levine & Naiditch 2005).

Social exclusion and isolation

The demands of caring may constrain young people's opportunities for social, sporting and other recreational activities and participation in friendship networks, leading to feelings of isolation and social exclusion. In the United Kingdom, Butler and Astbury (2005) found that isolation, social exclusion and stigmatisation were major issues for young carers. Young carers reported that their role as carer restricted opportunities

to socialise with their peers and resulted in carers having to ‘steal’ an hour here or there for social activities. The young carers felt that their friends and peers did not understand what it meant to be a young carer and reported that their friends were sometimes cruel. Thomas and colleagues (2003) suggest that young carers are ‘doubly disadvantaged’ in terms of their social life since they are less able to go out due to their caring responsibilities and also more likely to have low incomes and limited resources for travel and socialising. The young people Banks and colleagues (2002) studied were aware that their care giving was necessary for their family and accepted it as part of their daily routine. However, although most of the young people talked about having friends at school, some were unable to bring friends home, which in conjunction with their inability to exchange confidences about their circumstances, hindered development of friendships.

Research in Australia reports similar findings, where caring responsibilities have been found to place constraints on participation in friendship networks, and recreational activities (Moore 2005a, 2005b, 2005c; Noble-Carr & DFACS, 2002a, 2002b; Price 1996). The *Families Caring for a Person with a Disability Study*, for example, drew on a random sample of 5,000 carers who were recipients of Carer Payment and/or Carer Allowance (accessed through Centrelink’s records), to analyse the experiences of a sample of informal care givers. The study found that the young adult carers in their sample had lower levels of face-to-face social contact outside the household, compared with the general population, controlling for demographic circumstances (Edwards, Higgins & Zmijewski 2007). Noble-Carr and DFACS reported similar findings, stating that young carers had to forego personal relationships and leisure activities. Many participants in their study felt they could not trust others enough to discuss their caring role with them and were concerned about the social stigma and misunderstanding associated with illness and disability (Noble-Carr & DFACS 2002a, 2002b). Moore (2005a, 2005b, 2005c) found this was a particular issue faced by young people caring for a relative with an alcohol or drug problem. Aldridge and Becker (1994, p. 9) aptly use the term ‘the silent children’, to describe young carers who do not talk to anyone about their caring responsibilities or their fears and pressures related to their caring roles. The fear of an official welfare authority response—that telling might lead to separation of family members—was especially important. For Moore and McArthur (2007), concerns of this nature prompted the sense among young carers and their parents that their care giving should remain hidden.

In both Australia and Britain, lack of access to transport was identified as a major factor contributing to social isolation (Butler & Astbury 2005; Noble-Carr & DFACS 2002b). British research found that young carers were frustrated by a lack of self-sufficiency with respect to transport, compounded by the fact that they were not legally licensed to drive even though circumstances forced them to play adult roles within their families (Butler & Astbury 2005).

Physical and mental health and wellbeing

In the Australian literature, Bittman and colleagues (2004) found that young carers were more likely than their peers to have a disability or long-term health condition themselves. However, since the ABS SDAC data are point-in-time and not longitudinal, it is not possible to determine whether these conditions are a consequence of, or coexistent with, their care giving responsibilities. Moore (2005a, 2005b, 2005c) notes that young carers tend to report fatigue, injury and greater levels of stress and anxiety as a result of their care giving and Noble-Carr and DFACS found that ‘young carers are an extremely vulnerable and disadvantaged group who are often at risk of experiencing poor physical or mental health’ (Noble-Carr & DFACS 2002b, p. 15). Morrow (2005) found that many young carers whom she surveyed in Western Australia indicated negative aspects of caring on their psychological wellbeing.

United Kingdom researchers have found that young carers may experience fatigue, have problems sleeping and generally have poor health. They may experience pain and discomfort as a result of the physical strain of caring for a parent with a physical disability (Aldridge & Becker 1993; Doran, Drever & Whitehead 2003). They may also experience a negative effect on their mental and emotional health. Some studies have estimated that one-third of children who have parents with mental health problems will experience emotional and behavioural difficulties and a further one-third will develop psychological problems (Leason 2004; Sloman 2004). Cree (2003), in exploring the experiences of young carers in Edinburgh, found that young carers speak of significant worries and problems in relation to their wellbeing, over and above any ‘normal’ adolescent difficulties.

Children and young people who are caring for a parent with a mental illness may have fears that they may inherit some of the psychological problems experienced by their parent. Bauman et al. (2006) found that when children take on significant caring responsibilities, the possible outcomes may include depression and low self-esteem. The negative impact that caring may have on young carers' mental health has also been recorded in the United States (Hunt, Levine & Naiditch 2005).

Loss of childhood

In Australia, Harrison and Seith (2004) state that caring responsibilities may reduce young carers' access to parental support, guidance and control since the socially expected relationship between parent and child is changed, and the normally expected experiences of childhood may be compromised. As Aldridge and Becker (1993, p. 76) note 'we have seen that children who care are denied the rights and the opportunities that other children enjoy—the right to play, social interaction and friendships, education, autonomy—the opportunities to be children'. Aldridge has claimed that children's development and childhood experiences may be adversely affected when caring becomes long term and disproportionate, and when the onset of responsibility is not congruent with a child's age and level of maturity and understanding (Aldridge 2006, p. 83). Bancroft and colleagues (2004) found, when exploring the experiences of young people caring for a parent with a drug or alcohol problem, that most study participants reported their parent had diminished capacity to provide practical and emotional care, although some distinguished between their parent's capacity to care **for** them and their parents continuing to care **about** them. About half, mostly young women, reported that they had to take on parenting roles, caring for siblings and/or parents. Research such as this demonstrates that in taking on early responsibilities for their own and others' care, young carers may feel as though they have experienced a shortened childhood, compared with their peers. On the other hand, Morgan's 2006 study in the United Kingdom found that while young carers thought that being a carer involved doing much more work and taking on much more responsibility than other children of the same age, and giving up part of their childhood, they nevertheless saw being a young carer as 'something you just get on with'.

'Parentification': a contested proposition

As an extension of the concept of 'loss of childhood', the difficult (indeed tortuous) term 'parentification' has been coined. This is a contested concept with contradictory evidence adduced to support or reject the argument that young carers are being inducted into the role of parent. Early and Cushway (2002) outline the notion of the 'parentified child', a notion which is primarily concerned with establishing how care giving as a child affects their later adult functioning. They claim that identity development and personality, interpersonal relationships and relationships with an individual's own children could be affected when children have the responsibility for the welfare of others and become 'parentified'. Parentification is defined as assuming responsibilities performed more appropriately by an adult, including providing health and personal care, emotional support, caring for siblings and maintaining the household.

Providing a contrary argument, Aldridge (2006) emphasises that young caring is not indicative of role transference between children and parents or the contested notion of parentification, because parents continue to retain the status of and recognition as parent, if not always the physical capacity to carry out household activities in practical terms. Responsiveness to parents' needs by children and young people is not inherently problematic and may help children to develop sensitivities and reciprocity with others. Parentification may become problematic, however, when there is a lack of acknowledgement and reciprocity between parent and children, or when expectations exceed the child's capacities (Halpenny & Gilligan 2004, p. 26). It is apparent, however, from the work of Prilleltensky (2004) that the premise of young carers taking on parenting roles for their own parents and siblings is deeply contested and problematic. Providing care is not equivalent to becoming a quasi-parent, and in most cases the parents remain as parents, emotionally, psychologically and in the recognition and respect of their children.

One main source of criticism of the concept of parentification comes from the disability rights movement in the United Kingdom (Keith & Morris 1995; Morris 1997a, 1997b, 2001). Proponents of this approach argue that while there is much evidence that children undertake practical and personal care tasks due to a lack of

alternative formal services, there is little evidence to support the view that children are ‘parenting’. They go further to argue vigorously that the representation of children as carers defines parents with disabilities as inadequate and undermines their role as parents. In response, Aldridge and Becker (1996) argue that although the debate between young carer researchers and disability rights advocates takes place within two different philosophical perspectives (young carer researchers embrace a children’s rights perspective, while challenges to this stem from a disability rights perspective), these perspectives should not be positioned in conflict with each other, or set up as zero-sum positions with respect to policy and service provision. Instead Aldridge and Becker (1996) agree with the disability rights perspective that it is policies and service provision that must be investigated in order to determine the extent of recognition and responsiveness to the needs of both young carers and the family member/s requiring care. Becker (2005, 2007) notes that the way to resolve these apparently contradictory perspectives is to adopt, in both research and policy development, a whole-of-family approach by identifying, understanding and meeting the needs of young carers and the needs of the people for whom they care. It must be emphasised that in the Australian context, Moore and McArthur’s study (2007) revealed that young carers felt the best way services could support them was to better support their relative with care needs.

Acquisition of caring skills and self-development

Much of the research on young carers acknowledges the positive benefits they receive by providing care. The existing research in Australia, the United Kingdom and the United States shows that many young carers are committed to their caring role, often indicate that they are proud of what they do, and expect to receive recognition and respect for their caring. They usually come from strong, close-knit families and manage well with the additional responsibilities of care (Aldridge & Becker 1998; Hunt, Levine & Naiditch 2005; Noble-Carr & DFACS 2002a, 2002b). In Australia, Moore (2005a, 2005b, 2005c) found that caring can engender feelings of pride and worth, a sense of accomplishment, greater levels of fitness, greater resilience and a positive outlook on life. Noble-Carr and DFACS (2002b) also noted the acquisition of independence and skills that may bring future benefit. Similarly, a United Kingdom study reported that being a young carer imparted responsibility, opportunities to be ‘appreciated’, ‘needed’, accorded ‘importance’ and young carers expressed pride at learning skills at an earlier age than their peers (Lackey & Gates 2001). One of the key conceptual and methodological issues for young carer researchers and policy makers is to reconsider the dominant framework which conceptualises and estimates the ‘costs of care’, to reframe the issue as understanding and estimating both the costs and the ‘worth of care’, in their many interactions.

Strengthening family bonds

Informal caring is predominantly an interpersonal and reciprocal relationship between family members, embedded in a sense of normative obligation, which can strengthen family bonds. While the idea of child as carer and parent as care recipient may appear unidirectional, the parent, as care recipient, does not cease to be a parent, but continues to provide emotional, social and other forms of support and is perceived so by their child, demonstrating the reciprocity of care provision and receipt (Hunt, Levine & Naiditch 2005; Prilleltensky 2004).

Similarly, SCIE (2005) research found that young carers report feelings of maturity and a sense of closeness to their parents and family and also value their responsibilities and consider them to be a source of practical life skills. They report that young carers are often happy to perform their role and see it as providing support to the family. These findings corroborate earlier United Kingdom research by Aldridge and Becker (1993), which found that despite the often negative impacts on education, employment, and social and friendship participation, young carers demonstrated strong commitment to their parents and derived positive benefits from their caring roles. It is argued that by maintaining ‘at home’ care for disabled or seriously ill adults and children, young carers contribute to the integrity and resilience of families and to their own sense of worth (Banks et al. 2002).

2.8 Policy issues and service needs identified in the literature

The policy issues identified in the Australian, United Kingdom and United States literature on young carers are broadly similar. The importance of supporting young carers and their families through a whole-of-family approach and the most appropriate and effective ways in which this might be done are issues that receive attention. Moreover, it is recognised that supporting young carers will contribute to the wellbeing of the care recipient and the whole family, and conversely, that supporting the person requiring care will benefit the young carer. It is also acknowledged that young carers are not a homogeneous group and that culturally and linguistically diverse young carers, and in Australia Indigenous young carers, usually have specific needs, although there is, as yet, little research on these issues.

Noble-Carr and DFACS (2002b) set the policy scene in broad terms by outlining 10 indicative policy issues important for young people with caring responsibilities:

- programs and services specifically targeted to children and young people with caring responsibilities and to their families
- specification of children and young people with caring responsibilities and their families as key client target groups of relevant mainstream services
- appropriate and effective responses from key professionals to children and young people with caring responsibilities and to their families
- appropriate forms of income support for young carers and their families
- participation of children and young people with caring responsibilities in education, training and employment at rates similar to those of their peers who do not have caring responsibilities
- regular opportunities for social participation for young carers
- commitment to a whole-of-government approach to address the key issues for children and young people with caring responsibilities and for their families
- research funding for studies of young carers and their families to generate sound quantitative and qualitative research information
- improved understanding of the needs of children and young people with caring responsibilities within their own families
- increased community awareness of the needs of children and young people with caring responsibilities and of their families.

More recent Australian literature, based on research with service providers, has identified a range of policy issues and service needs for young carers and the people they care for. Some of the key issues include:

- lack of community-wide awareness of young carers and their significant responsibilities and contributions to the wellbeing of their care recipients
- perceived lack of appropriate levels of support for young carers
- lack of recognition of the diverse needs of Indigenous young carers and culturally and linguistically diverse young carers
- gaps in the provision of in-home services, especially respite care
- problems for young carers in the school system and for young adult carers in their transitions from school to post-school training, education and employment

- the need for appropriate recognition of the income support needs of young carers and their families, given the low-income circumstances of many families (Kroehn & Wheldrake 2006, pp. 58–68; Moore 2005a, 2005b, 2005c; Moore & McArthur 2007; Morrow 2005).

Evidence from Australian studies about income support and payments for young carers indicates that many young people providing care do not receive government income support payments (Kroehn & Wheldrake 2006; Moore 2005a, 2005b, 2005c). Kroehn and Wheldrake (2006) found perceptions that processes for applying for and receiving financial assistance, such as Carer Payment and Carer Allowance, are complex and that it is thought difficult for young people to get support through these payments. To qualify for a Carer Payment an individual must be providing constant care, which nevertheless permits 25 hours per week of education, training or employment. This is particularly difficult for young school-age carers whose educational responsibilities are usually greater than 25 hours per week, and who are unlikely to make known to any authority, federal or state, that they are taking time out of school to undertake caring work. Providing appropriate forms of income support for young people undertaking care, particularly those in low-income family circumstances, is a difficult issue that needs further research and policy deliberation.

The young carers in studies by Noble-Carr and DFACS (2002b) and Moore (2005a, 2005b, 2005c) identified a number of similar service needs that were important to them, including:

- age-appropriate information about disability and illness and about their rights as young people and carers
- provision of peer support
- young carer programs in their local areas
- community awareness, recognition, understanding and respect for the role of young carers, particularly from service providers
- community education about disability and illness to foster understanding and acceptance and reduce the effects of stigma
- more flexible schooling arrangements and study options based on an understanding of young carers' family responsibilities
- flexible employment environments
- targeted transition to employment and return to employment programs.

The participants in these studies also identified the importance of appropriate forms of income support, transport assistance, provision of appropriate respite care so they could continue their education and participate in social activities, and access to family-based rehabilitation and mediation and to counselling and medical services.

While some young carers in Moore's study did access formal support (including respite care, domiciliary services, emergency relief, family support, personal support, counselling and holiday camps) only a handful could identify a service for their family that they could access more than once a month and a service that was ongoing. Of considerable significance is the finding that 'young carers in the study felt the best way that services could support them was to better support their cared-for relatives' (Moore & McArthur 2007, p. 3). Young carers most often identified assistance with personal and intimate care tasks and support with mobility and transport as the services that would best assist with their care giving responsibilities. Where the person receiving care had an intellectual disability or mental health condition, young carers identified assistance with supervising and monitoring their family member, especially when the young carer was at school or needed to be outside the home (Moore & McArthur 2007). The young carers in this study were reluctant to speak of their own needs, but said that other young carers would benefit from services that helped them participate in education and in social/recreational activities.

Moore and McArthur (2007) found that many of their study participants and their families did not seek assistance from formal programs because:

- they felt the services were not appropriate to their needs as the service providers lacked awareness and recognition of young carers
- they had problems with transport
- they were concerned about affordability
- they were not aware of available programs and how to access them.

Further reasons participants proposed for not accessing services were negative community attitudes towards disability, illness, alcohol or other drug use, and towards care giving itself. They felt unable to speak with peers, teachers and service providers because they were concerned about the negative way in which their care giving and the illness or disability of their family member would be perceived. It is significant that the families in this study that were reluctant to seek or accept assistance felt they could cope within the family. Moreover, they did not want to feel judged or overscrutinised by the service system and run the deeply feared risk of child removal by child welfare and child protection authorities (Moore & McArthur 2007, p. 5).

United Kingdom research notes an apparent conflict of interest between the needs of care givers and of care recipients; this is, however, a service provider construct because they tend to regard either the care giver or the care recipient as their principal client (Banks et al. 2002). Some services are now tending to take a more family-centred approach and to seek innovative ways to develop a mutually beneficial form of service provision. Nonetheless, it continues to be the case that many young carers do not receive adequate information about their parents' condition or appropriate support (Rapaport et al. 2006). Aldridge (2006) notes that even when health and social care professionals visit parents, children's contributions and needs may be overlooked and/or discounted. Aldridge therefore proposes that monitoring and mapping the experiences of children and parents using a systematic approach would be advantageous to identifying, understanding and assessing the needs of both. This is an important issue that might be usefully explored in the Australian context, in order to take a whole-of-family approach.

2.9 Summary

Drawing on Daly and Lewis' (2000) social care theoretical framework, for young carers: care is labour which may occupy time which would otherwise be available for participation in education, training, employment and social/friendship activities; care is located in a normative framework within which young people may not identify themselves as carers but as family members carrying out their responsibilities and obligations; caring incurs costs, which may consist of interrupted education and labour force participation that may have long-term implications for future secure employment and adequate income, and caring may also incur costs to emotional and mental health. There are benefits as well as costs: profound contributions to the wellbeing of the care receiver and the family, and acquisition by the carer of valuable skills and a deep sense of achievement.

The literature strongly suggests that young carers tend to be located in identifiable socioeconomic and cultural circumstances, very often in low-income families, and in families of migrant and/or culturally and linguistically diverse backgrounds where care giving is central to mobilising intergenerational resources and strengths. A key finding from this analysis of the literature is that there is some knowledge internationally, especially in the United Kingdom, of the diverse socioeconomic and sociocultural factors that initiate and sustain caring responsibilities for children and young people, but more research is needed in the Australian context. Further, what is missing in the Australian research literature is knowledge of the geographic distribution of young carers, and their diversity, in particular taking into account culturally and linguistically diverse and Indigenous backgrounds. The Australian and United Kingdom literature also emphasises the issue of recognising and

making contact with ‘hidden young carers’, so they are in a position to access the services and supports available to them.

From the perspectives of young carers, and in some studies their parents and service providers, concerns are expressed about access to appropriate social supports and services designed to meet young people’s specific needs and the needs of the family member for whom they provide care. Overwhelmingly, research findings point to the importance of flexible education, training and employment conditions for young carers, so they are better able to meet their many obligations in ways that recognise and minimise the costs of their care giving. Issues of adequate income support are also consistently noted, given the low-income circumstances often associated with households where there is chronic illness, disability and informal care giving. Many studies in Australia and the United Kingdom suggest that young people and service providers in this field see support for young people who provide care, and support for family members with disability or chronic illness who require care, as closely related and needing to be addressed simultaneously. This points to the importance of a whole-of-family approach to service development and delivery.

It will be important to explore in future research the extent to which the age of carers, and their socioeconomic, linguistic and cultural differences, are taken into account in service provision. This study builds on the existing literature by combining comprehensive qualitative data with an analysis of the most up-to-date national quantitative data sets, conducting a range of focus groups and interviews with both young carers and service providers, and situating the study in a framework of social care and the policy implications of the findings.

Development of policies and services for young carers and their families is relevant to a number of federal, state and territory portfolios and programs within a number of departments. Thus comprehensive and cohesive policy and program development across Australian Government portfolios and coordination between federal, state and territory governments and the non-government sector is very important. **The major question is:** how might the needs of young carers and their care recipients be appropriately and satisfactorily addressed, preferably through a whole-of-family approach?

It is the objective of this project to produce policy-relevant research that will help policy makers and service providers at federal, state and territory levels, and across government and non-government community services sectors, to develop appropriate policies and services to enhance the wellbeing of young carers and the people they support and for whom they provide care.

3 Quantitative analysis: characteristics of identified and potential young carers in Australia

3.1 Introduction

In Australia, relatively few analyses of young carers in large-scale data sets have been undertaken, primarily due to limited data sources and small sample sizes in nationally representative household sample surveys. Noble-Carr and DFACS (2002a, 2002b) provide an analysis of the characteristics of young carers using the ABS SDAC 1998 and a recent study by Hill and colleagues (2009) considered the trends in the characteristics of young carers and the geographical distribution of young carers in Australia. This study examined three data sources in Australia that provide information about the circumstances of young carers: the *Census of Population and Housing 2006*, the ABS SDAC 2003 and the HILDA survey.

This section first outlines the different methods used by the three surveys to collect data and identify carers, and the range of information collected by the different surveys. It then analyses the characteristics of young carers identified in the different surveys, including demographic characteristics, their care situation, participation in education and employment, their financial circumstances and their health. The study then employs a novel method to identify young people who may be hidden or potential carers, by identifying those young people who live with a person with a disability, long-term chronic illness or impairment, but who do not indicate in the HILDA data that they are carers. The characteristics of these potential young carers are compared with those of young carers and non-carers.

3.2 Data sources and definitions of young carers

A number of nationally representative data sources on young carers exist in Australia. These include ABS surveys, such as the SDAC, the *Census of Population and Housing 2006*, the *General Social Survey 2006*, and the Time Use surveys. These surveys are all cross-sectional surveys that can describe the circumstances of young carers at a point in time; however, in some cases analyses are limited by the sample sizes in these data sources. In addition, since commencing in 2001, the HILDA survey, which is a panel survey, has collected data on whether respondents spent time providing informal care to an adult, and since 2005, a specific series of questions has sought to identify informal carers. The analysis in this section draws upon three of these data sources. Each survey has a different method of data collection and a different main purpose, which provides different opportunities for analysis, as outlined below.

Census of Population and Housing 2006

The fifteenth ABS Census of Population and Housing was conducted on Tuesday 8 August 2006, a survey of all people in Australia on that night with the exception of foreign diplomats and their families. The Census collects demographic data for all persons and socioeconomic data for persons aged 15 years and over. For the first time, the Census included questions about the need for assistance and unpaid care work; one of these questions related to care for a person with a disability (ABS 2006b). The question, 'In the last two weeks did the person spend time providing unpaid care, help or assistance to family members or others because of a disability, a long term illness or problems related to age?' was only asked of people aged 15 years or over. The 2006 Census was a self-completion form that could be submitted on paper or electronically. Respondents

who had questions about the Census or about the completion of the form could call a telephone enquiry service. The 2006 data counted around 119,000 young carers aged between 15 and 24 years (Table 8).⁴

Survey of Disability, Ageing and Carers 2003

The ABS SDAC is a nationally representative survey of households and cared accommodation, which aims to gather data on people with disabilities, people aged over 60 years and informal carers. The latest survey was conducted between June and November 2003. The reference population for the household component of the survey includes people in private and non-private dwellings (including hotels, motels and boarding houses, short-term caravan parks and self-care components, including retirement villages but excluding jails and correctional institutions), and in rural and urban areas, with the exception of remote and sparsely populated areas. The cared accommodation section of the survey covers residents of hospitals, nursing homes, hostels and other homes. The analysis in this study draws upon the sample of 35,704 people in the household component of the survey who were living in private dwellings. Individuals living in cared accommodation or special dwellings are not included in this sample.

The data for the SDAC survey are gathered through computer-assisted face-to-face interviews. Initial household composition screening questions are conducted with a responsible adult (aged over 15 years) to ascertain whether the household contains a person with a disability, a person aged over 60 years, or an informal carer. Personal interviews are then sought with any members of these populations aged over 15 years. Interviews with children aged 15 to 17 years are only conducted with the parent's permission. If the parent does not permit an interview with the young person, proxy interviews are conducted with the parent. Proxy interviews are also conducted for all children aged less than 15 years in the target population. Demographic and socioeconomic data for other members of the household are collected primarily from the responsible adult rather than through personal interviews. The interviews with carers collect information about their characteristics, the type and intensity of care provided, and some data on their care recipient. For individuals who are the main providers of care, defined as 'primary carers', additional information on the experience and impact of care on their lives and their attitudes to caring is collected on a self-enumeration form during the interview. The data for this analysis is based upon the SDAC Confidentialised Unit Record File (CURF). The CURF is a hierarchical data file with 10 levels of information. The analysis is conducted on information drawn from the household, family, income unit, person, and recipient levels of the CURF.

Of the 46 primary carers aged under 25 years in the SDAC, 31 completed a personal interview and the remaining 15 had proxy interviews (most of the latter were aged under 15 years) (see Table 2). Of the 580 young carers who were not identified as primary carers, 202 were aged under 15 years and in all of these cases proxy interviews were conducted. Among the 378 carers aged between 15 and 24 years, 49 per cent or 185 young carers had a personal interview and in the case of the remaining 193, proxy interviews were conducted. This analysis is based on information gathered in both types of interviews. As the sample size of primary carers is small in this survey all results for primary carers should be interpreted with caution.

Table 2 reports the overall sample size and weighted population estimates of young carers in the SDAC by age group and carer classification in this survey. A total of 626 respondents in this survey were identified as having care responsibilities. The weighted population estimate of the number of young carers based on this sample is 338,946 persons aged up to 24 years. This estimate differs slightly from the published figures by the ABS reported in Table 2, most likely due to confidentialising processes the ABS undertakes for the CURF data. The ABS indicate that, with respect to the SDAC 2003 data, confidentialising processes included changing some characteristics, such as age and sex and dropping some children and records, and that estimates based on the CURF will not exactly match published estimates (ABS 2005, p. 4).⁵

Table 2: Young carers in the SDAC data, sample size and weighted estimates

Age	Primary carers (confirmed and unconfirmed)	Carer, not a primary carer	Total
Sample size			
0–14 years	9	202	211
15–19 years	13	188	201
20–24 years	24	190	214
Total	46	580	626
Weighted population estimates			
0–14 years	3,240	95,562	98,802
15–19 years	7,371	102,028	109,399
20–24 years	13,927	116,818	130,745
Total	24,538	314,408	338,946

Notes: Unconfirmed primary carers are identified either by the responsible adult in the household or care recipients, but are not able to be self-confirmed in a personal interview.

Source: ABS 2003.

Household, Income and Labour Dynamics in Australia (HILDA) survey

The HILDA survey is a nationally representative panel survey that commenced in 2001. The first wave of the survey drew upon a stratified random sample of 7,682 Australian households (13,969 people) (Watson & Wooden 2002). As a panel survey, individuals in the original households are followed each year for repeated interviews, even if they changed households, and new members of their household are added to the panel each year, while they reside with original members of the sample. The survey collects much more detailed data about income, education, employment and family formation than SDAC and the Census, along with other general items. In 2005, the HILDA survey included for the first time specific questions on informal care, which provide an opportunity to examine the effects of informal care on a much greater range of life circumstances of young people. As all questions in the HILDA survey are also asked of all young people it is possible to compare the circumstances of young carers with other young people across a greater range of factors than in SDAC. The analysis below undertakes the first examination of the HILDA data on young carers in Australia.

The survey has three levels of instrument that are administered in face-to-face interviews (household form, household questionnaire, personal questionnaire) and one self-completion questionnaire form given to each person who completes a personal interview, which contains questions about health and other matters of a more private nature. The data for this analysis are taken from the household, person and self-completion questionnaires. The analysis below uses Wave 5 of the HILDA data for the year 2005, which is the first year in which specific questions about informal caring responsibilities were included in the person questionnaire.⁶

Young identified carers in this analysis are those who self-identify either on the direct questions (co-resident or ex-resident carers) and 'other carers'. The 'other carers' are young people who do not positively identify as carers on the direct questions about provision of informal care, but who do report time spent caring for an adult in a typical week. The questions identifying young carers in the HILDA data are outlined below.

Co-resident carers answered yes to this question:

I now have some questions about caring for others. By care I mean regular, informal help that is ongoing. Don't include any care that you might undertake as part of your paid employment. Is there anyone in the household who has a long-term health condition, who is elderly or who has a disability, and for whom you care or help on an ongoing basis with any of the types of activities listed on showcard K7 (self care, mobility or communication)?

Ex-resident carers answered yes to this question:

Is there anyone living elsewhere who has a long-term health condition, who is elderly or who has a disability, and for who you care or help on an ongoing basis with any of the types of activities listed on showcard K7 (self care, mobility or communication)?

Other carers could be identified through the following question in the self-completion questionnaire:

How much time would you spend on each of the following activities in a typical week? Caring for a disabled spouse or disabled adult relative, or caring for elderly parents or parent in law.

Analysis in the latter part of this section identifies the characteristics of a fourth group of young people: 'potential carers'. These are young people living in a household with a child or adult with a disability, long-term health condition or impairment, which is ongoing and restricts everyday activities, and hence, may be involved in the care or support of that person or may have more intangible responsibilities for monitoring a care recipient or assisting a carer. These young people may not have identified as a carer for two reasons: first, they may not have self-identified as carers themselves; or second, they may provide support and assistance for activities other than the core activities of self-care, communication and mobility.

Potential carers were other young people in the following living arrangements:

Living in a household with a child or an adult with a long-term health condition, disability, or impairment.

HILDA, like the SDAC, is a sample survey, and thus the sample size of identified young carers in the analysis of the HILDA data is relatively small (96 respondents) and all findings must be interpreted with that caveat in mind. The weighted population estimate of the number of identified young carers aged 15 to 24 years is around 140,000 young people and a potential carer population of around 717,000 young people (Table 3). Half of the co-resident carers were the main provider of care, whereas nearly all ex-resident carers shared the care with others. These data were not available for the other categories of carers.

Table 3: Sample size, weighted proportion and number of young carers aged 15 to 24 years in HILDA 2005

	Sample size	Weighted percentage of young people	Weighted population estimate
Co-resident carer	32	2.0	54,642
Ex-resident carer	32	1.6	45,757
Other carers	32	1.4	39,492
Total carers	96	5.0	139,891
Potential carers			
Living in a household with a child or adult with a long-term health condition, disability or impairment	556	25.7	717,079

Source: HILDA version 5.0, Wave 5, 2005.

Differences in survey methods and identification of identified and potential young carers

For purposes of comparison between the Census 2006, HILDA 2005 and SDAC 2003 figures: looking only at young people aged 15 to 24 years providing care, the numbers identified in the Census are around 119,000, while the numbers estimated in SDAC are around 240,000 and the numbers estimated in HILDA are close to 140,000. In effect, the SDAC estimates are slightly more than twice the numbers identified in the Census and much higher than the number in HILDA. There are several reasons for these differences, encompassing differences in the definition of carers and the methods of survey administration.⁷

First, the Census asked respondents about provision of care **in the previous two weeks**, which would have excluded many young people who provide ongoing support for a relative with intermittent care needs. People with mental illness, health problems or disability often have sporadic need for assistance so many of the young people providing such care may not have been counted. The HILDA survey asks questions about provision of regular, informal help, which is undertaken on **an ongoing basis**, but that help is restricted to the activities of self-care, mobility and communication, and excludes activities like shopping or domestic tasks. SDAC questions about care use a six-month timeframe and measure care provision looking backwards in time but also forwards; that is, care that has been ongoing or was likely to be ongoing for a period of at least six months. This allows the survey to include those who provided intermittent care within a half-year period. Also, while the Census asked about 'unpaid care, help or assistance', and HILDA asked about help with specific tasks, SDAC specifically defined assistance as including 'help or supervision'. As a result, SDAC may have incorporated more carers than the Census or HILDA, as Census or HILDA respondents whose primary care responsibility was supervision may not have believed this was or would be recognised as a form of care.

The second point relates to survey administration. The Census is a self-completion questionnaire with the possibility of telephone assistance for any enquiries. On the whole, however, respondents interpret the question themselves. Census prompts were limited to three on the form:

that 'recipients of Carers Allowance or Carer Payments should state that they provide unpaid care'; that ad hoc assistance with shopping or the like should 'only be included if the person needs this sort of assistance because of his/her condition'; and that work with voluntary organisations should not be included.

The HILDA survey asks questions about informal care in a face-to-face interview with trained interviewers, but the questions on carers are limited to providing help with core activities and prompts were limited to defining care as 'regular, informal help that is ongoing' and do not include any care undertaken as part of employment. In contrast, SDAC information is collected through personal interviews conducted by trained ABS interviewers and one of the main purposes of the survey is to identify carers. The SDAC uses two methods to identify carers:

- The responsible adult first answers questions in the household questionnaire and identifies household members who provide assistance to people within or outside the household in the tasks of mobility, self-care and communication. Individuals identified as potentially part of the carer population are then interviewed personally to confirm their status.
- Carers are also identified through information provided by the care recipients themselves about care and assistance received from household members and others for 10 activities, including mobility, self care, communication, transport, health care, cognitive or emotional support, household chores, home maintenance/gardening, meal preparation and reading and writing.

In the SDAC interview, individuals not identified by the responsible adult or care recipient are not able to self-identify as carers, whereas the Census and HILDA methodology may be more likely to locate only those carers who do self-identify.

These differences in question design and survey methodology suggest that young carers are likely to be substantially underrepresented in the 2006 Census and HILDA survey and that each survey may identify slightly different groups of carers. Given the approaches and methods used, it is likely that the SDAC provides a more accurate estimate of the number of young carers in Australia.

The analysis in the following sections draws upon these different data sources. As all people in Australia complete a Census form, the Census provides the most comprehensive basic data on the population and geographical location of some young carers. However, as noted, the restricted nature of the Census question on the provision of unpaid assistance will not identify many types of young carers. The SDAC has the most comprehensive data on aspects of the care situation for young carers, but limited information on their income, employment, family circumstances and other aspects of their life. The HILDA survey provides a new rich data source for analysing young carers, which is investigated for the first time here. In addition, HILDA and Census data provide the opportunity to distinguish between self-identified and 'potential' carers.⁸

3.3 Characteristics of identified young carers

Demographics

Age and gender

The findings about the age composition of young carers are fairly consistent across all three data sources in this analysis: caring is more prevalent among young adults (aged 20 to 24 years) than younger people (15 to 19 years). This is consistent with the literature. In the 2006 Census data, 6 per cent of young adults aged 20 to 24 years were carers compared with 5 per cent of young people aged 15 to 19 years (Table 4). Women aged 20 to 24 years were more likely than any other group to be carers: 7 per cent compared to 5 per cent of young women aged 15 to 19 years, compared to 5 per cent and 4 per cent of men aged 20 to 24 years and younger men aged 15 to 19 years respectively. In the SDAC CURF data, 9 per cent of young adults were carers compared with 8 per cent of those aged 15 to 19 years, although young men had a higher rate of providing care, in the young adult group (20 to 24 years) in this data. In the HILDA data, slightly more than 5 per cent of young adults aged 20 to 24 years were carers compared with slightly less than 5 per cent of young people (aged 15 to 19 years).

Table 4: Proportion of young people aged 15 to 24 years who are carers, by sex and age

	Census 2006 ^(a)	SDAC 2003 CURF ^(b)	HILDA Wave 5 2005 ^(c)
	per cent		
Males			
15–19 years	4.0	7.7	2.9
20–24 years	4.5	9.4	6.4
Females			
15–19 years	5.0	8.7	4.4
20–24 years	6.5	9.0	6.4
Persons			
15–19 years	4.5	8.2	4.6
20–24 years	5.5	9.2	5.4

Sources: (a) ABS 2006a. Note that individuals who did not respond to the carer question are excluded from the total when calculating percentages.

(b) ABS 2003, authors' calculations, includes primary carers and carers.

(c) HILDA version 5.0, Wave 5, 2005, authors' calculations, identified carers only.

The findings about gender composition of the young carer group are also fairly consistent across the data sources. The SDAC data show that the gender composition of young carers in Australia in the sample analysed is relatively evenly split: 53 per cent were male and 47 per cent were female (Table 5). This gender parity no longer remains, however, when primary carers are considered. Among young primary carers, 30 per cent were male and 70 per cent were female. This latter finding is significant as it suggests that younger women may have more intensive care responsibilities.

Table 5: Gender composition of young people aged less than 25 years, by carer status, SDAC 2003

	Primary carers	Carers, not primary carers	Non-carers
	per cent		
Male	30.3	53.1	51.0
Female	69.7	46.9	49.0
Total	100	100	100
Sample size	46	580	11,774

Notes: Authors' calculations, weighted percentages.

Source: ABS 2003.

HILDA data show that co-resident carers and 'other carers' aged 15 to 24 years comprised fairly equal proportions of males and females (Table 6). However, young men were less likely to be ex-resident carers than young women. Most ex-resident carers were female (61 per cent) and other analysis (not reported here) shows that nearly half (48 per cent) were women aged 20 to 24 years.

Table 6: Gender composition of young people aged 15 to 24 years, by carer status, HILDA 2005

	Co-resident carers	Ex-resident carers	Other carers	All identified carers	Non-carers
	per cent				
Males	53.0	38.9	49.0	47.2	51.4
Females	47.0	61.2	51.0	52.8	48.5
Total	100.0	100.1	100.0	100.0	99.9

Notes: Authors' calculations. Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Analysis of the Census has shown that young women comprise just over half of young carers aged 15 to 19 years but a higher proportion of young adult carers aged 20 to 24 years (Hill et al. 2009). Comparing all identified carers to non-carers in Table 7, it is apparent that males and females in the age group 20 to 24 years are overrepresented among young carers, comprising 32 per cent and 31 per cent of the young carers identified in the HILDA sample, respectively.

Table 7: Gender and age composition of young people aged 15 to 24 years, HILDA 2005

	Identified carers ^(a)	Non-carers
	per cent	
Males		
15–19 years	14.9	26.3
20–24 years	32.4	25.1
Total males	47.3	51.4
Females		
15–19 years	21.9	24.8
20–24 years	30.9	23.7
Total females	52.8	48.5
Total	100.1	99.9

(a) Identified carers include co-resident, ex-resident and other carers.

Note: Due to rounding, percentages may not add to 100 per cent. Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Geographical distribution

The Census data provide some indication of the geographical distribution of young carers. The data indicate that the largest group of young carers was in New South Wales (41,526 young carers), followed by Victoria (29,602). The smallest groups were in the Northern Territory (1,659) and the Australian Capital Territory (2,093) (Table 8). Examining the proportion, rather than the numbers, of young people who are carers presents a different picture (Figure 1). The largest proportion of young people who provide care support was in the Northern Territory, where 7 per cent of young people were carers, followed by New South Wales at 5 per cent. Western Australia and the Australian Capital Territory had the lowest proportion of young people who were carers. In the Northern Territory, 9 per cent of 20 to 24 year-old females were providing care. These findings point to the gendered nature of young adult care giving, as noted in the United Kingdom research. For a more detailed analysis of the geographical distribution of young carers, see Hill and colleagues (2009).

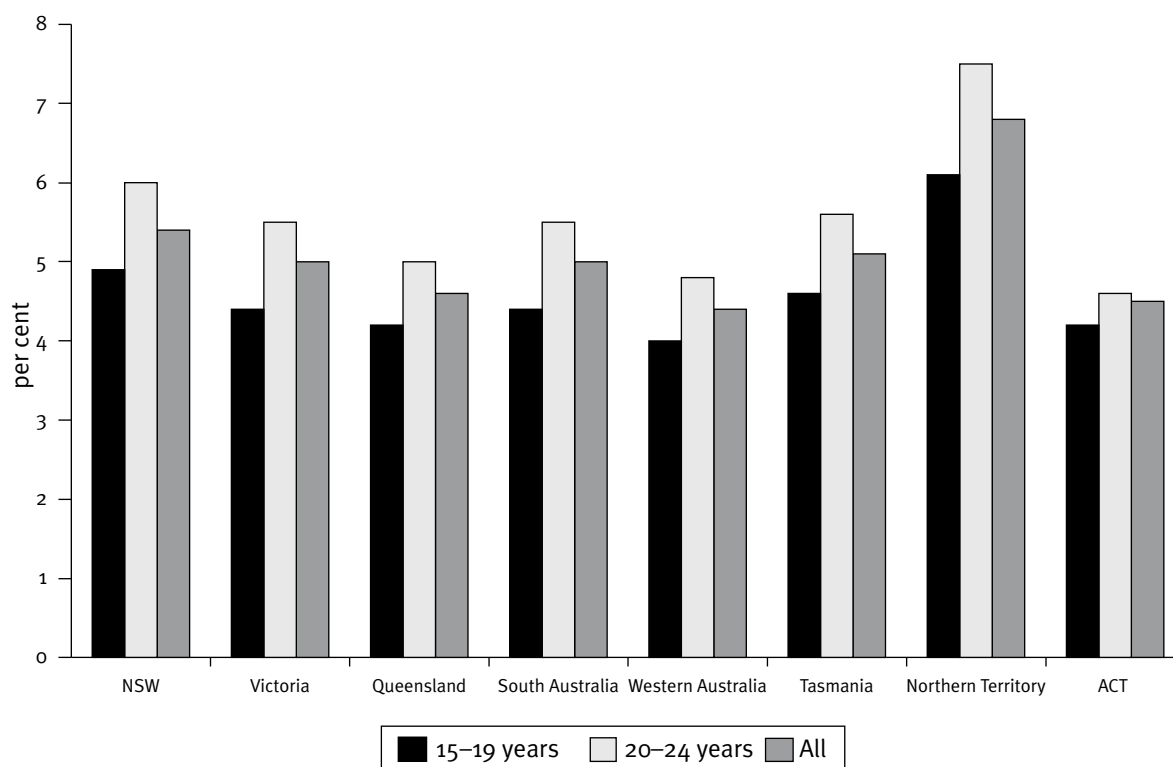
Table 8: Number of young people, aged 15 to 24 years, who provided 'unpaid assistance to a person with a disability', by state, age and sex, Census 2006

	Males		Females		Persons		All
	15–19 years	20–24 years	15–19 years	20–24 years	15–19 years	20–24 years	
NSW	8,354	9,562	10,069	13,541	18,423	23,103	41,526
Vic.	5,766	6,791	6,932	10,113	12,698	16,904	29,602
Qld	4,471	4,902	5,380	7,338	9,851	12,240	22,091
SA	1,770	2,091	2,113	3,051	3,883	5,142	9,025
WA	2,155	2,311	2,640	3,497	4,795	5,808	10,603
Tas.	604	600	717	905	1,321	1,505	2,826
NT	322	390	380	567	702	957	1,659
ACT	423	510	476	684	899	1,194	2,093
All ^(a)	23,861	27,161	28,710	39,709	52,571	66,870	119,441

(a) State and territory totals do not exactly sum to 'All' total due to randomisation of Census data at state and territory level. 'All' totals are based on ABS Census data for Australia.

Note: The 'unpaid assistance to a person with a disability' variable records people who, in the two weeks prior to Census Night, spent time providing unpaid care, help or assistance to family members, or others because of a disability, a long-term illness, or problems related to old age.

Source: ABS 2006a.

Figure 1: Proportion of all young people aged 15 to 24 years who are carers, by age and state, Census 2006

Note: Authors' calculations. Individuals who did not respond to the carer question are excluded from the total in the calculation of percentages.

Source: ABS 2006a.

Cultural background

Data on the cultural background of young carers are very limited in the SDAC and HILDA due to the small sample sizes. The SDAC data provide an indication of the country of birth for all young carers aged less than 25 years, but not the language spoken at home. In the SDAC data, most young carers aged under 25 years were Australian-born (87 per cent), as were their peers who were not carers (91 per cent).

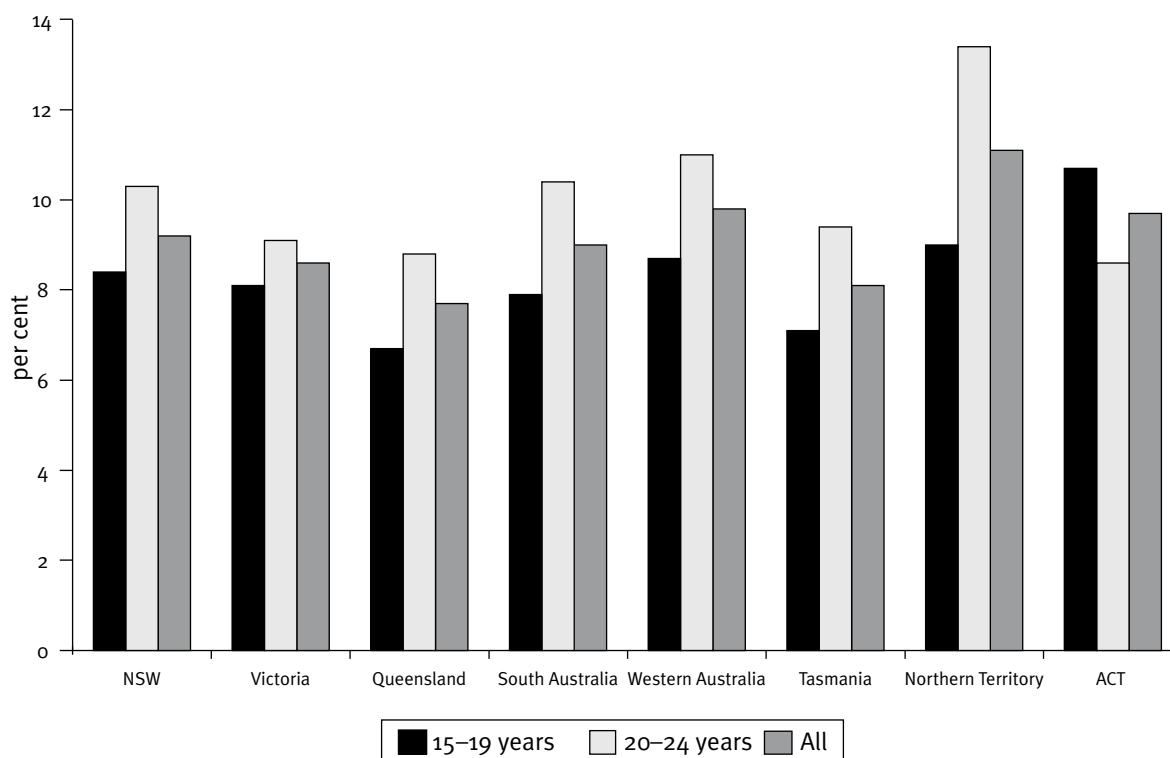
An alternative approach to identifying cultural and linguistic diversity status among young carers is to examine the proportion of young people who speak languages other than English at home. Analysis of the 2006 Census data shows that a higher proportion of young people who spoke languages other than English at home provided informal care than those from non-Indigenous English-speaking backgrounds (Hill et al. 2009).

Indigenous status

The 2006 Census data provides the first national data in Australia on the prevalence of caring among Indigenous young people. Care responsibilities are far more common among Indigenous young people than all young people: 9 per cent of Indigenous young people have caring responsibilities, compared to 5 per cent of all young people. The highest proportion of carers among young Indigenous people was in the Northern Territory where 11 per cent were carers (Figure 2). In the Northern Territory, 15 per cent of young Indigenous women between 20 and 24 years were providing care, and 10 per cent of young women between 15 and 19 years were young carers. The rates were lower among Indigenous young men in the Northern Territory compared with young women, but still higher than the rates for all young people: 12 per cent of young Indigenous men aged 20 to 24 years, and 8 per cent of those aged 15 to 19 years were carers.

The higher prevalence of informal care among Indigenous young people is not surprising, given the higher rates of disability and earlier onset of chronic illness among the Indigenous population compared with the non-Indigenous population (ABS 2008; ABS & AIHW 2008). Hill and colleagues (2009) provide further analysis of the characteristics of Indigenous young carers identified in the Census.

Figure 2: Proportion of young Indigenous people aged 15 to 24 years who are carers, by age and state, Census 2006



Note: Authors' calculations. Individuals who did not respond to the carer question are excluded from the total when calculating percentages.

Source: ABS 2006a.

Disability status

The SDAC data, which provide the most comprehensive and accurate data about disability, show that young people, both male and female, who provide care were nearly twice as likely as non-carers to have a disability themselves (Table 9). The higher prevalence of disability among young carers (and carers generally) has been noted in previous research (see, for example, Bittman et al. 2004; Noble-Carr & DFACS 2002a). As all analyses of young carers in Australia have been undertaken with cross-sectional data, it is not possible to determine whether informal care responsibilities are co-existent, a cause, or a consequence of the disability. Having a disability and less opportunity to participate in paid employment may be one factor influencing the decision to take on informal care responsibilities. Alternatively, the disability may have occurred as a consequence of the caring role and associated physical and mental stresses. As will be shown later in this section, young carers in the HILDA data report lower self-rated mental health than young people who are not carers.

Table 9: Disability status of all young people aged less than 25 years, by sex and carer status, SDAC 2003

	Males		Females	
	Primary carers and carers	Non-carers	Primary carers and carers	Non-carers
Has disability (%)	12.2	6.5	11.7	5.9
Sample size	196	2,170	219	2,108

Note: Disability is defined as having a profound, severe, moderate or mild disability or a schooling or employment restriction. Differences between carers and non-carers for males and females are statistically significant. Chi-square test, $p < 0.01$. Weighted percentages.

Source: ABS 2003.

Family type

As noted in Section 2, evidence on the family circumstances under which young people and children take on care responsibilities suggests that the absence of alternative adult carers is a key factor. Australian research using the Census data has shown that young carers were more likely than their non-carer peers to live in lone-parent households, particularly young carers aged 15 to 19 years, where around 25 per cent lived in lone-parent households (Hill et al. 2009). The Census data are not, however, able to distinguish between young people with differing levels of care responsibility. The SDAC data analysed (Table 10) show that young carers were considerably more likely to live in lone-parent families than non-carers, especially young carers with the main responsibility for care. Nearly half of all primary carers (47 per cent) and one-quarter of other carers lived in lone-parent households, compared to just 18 per cent among their peers. Just over one-quarter of primary carers lived in couple families, in contrast to over two-thirds of other carers and close to three-quarters of non-carers.

Table 10: Family type, all young people aged less than 25 years, by carer status, SDAC 2003

	Primary carers	Carers	Non-carers
		per cent	
Couple family with or without children	47.5 (8.6)	68.0 (2.6)	76.0 (0.7)
Lone-parent household	46.5 (7.9)	24.2 (2.2)	17.6 (0.6)
Other household	n.p.	7.8 (1.1)	6.4 (0.2)
Total	100.0	100.0	100.0
Sample size	46	580	11,774

Notes: 'n.p.' = not published, due to small sample size. Standard errors (in brackets) are calculated using SAS ABS Jack macro developed by Bruce Bradbury using replicate weights on SDAC CURF. Differences in family types between primary carers and other groups and carers and non-carers are statistically significant: Chi square test, $p < 0.01$. Weighted percentages.

Source: ABS 2003.

Care situation

Intensity and nature of caring responsibilities

The SDAC is the only data source that collects information about the care situation. Unfortunately the sample size of primary carers in the SDAC CURF means the amount of data that can be analysed is limited. Factors in the care situation are considered below.

Co-residency

The residential location and proximity of the care recipient to the carer is likely to have an impact on the intensity of care responsibilities and the consequent effects on participation in education and employment. The SDAC data show that a similar proportion of young primary carers and young carers cared for someone in their own home and someone outside the home. In both cases nearly all (89 per cent) lived in the same house as the care recipient. However, young women were more likely to be providing care to someone living outside their home than were young men (Table 11).

Table 11: Residency of carer of all young carers aged less than 25 years, by sex, SDAC 2003

	Male primary carers and carers	Female primary carers and carers	All primary carers and carers
	per cent		
Co-resident carer	91.0	86.4	88.8
Ex-resident carer only	9.0	13.6	11.2
Total	100.0	100.0	100.0
Sample size	315	311	626

Notes: Gender differences are statistically significant: Chi square statistic=5.0770, $p=0.0242$, Cramer's $V=0.0901$.

Co-resident carers may also care for an ex-resident recipient. Weighted percentages.

Source: ABS 2003.

Number of care recipients

The intensity of care will also be affected by the amount of care provided and the number of people for whom help and assistance is needed in a household or family. Most young carers who were not primary carers (90 per cent) provided care to only one recipient (Table 12). However, young primary carers were more likely than other carers to be caring for more than one recipient; this was the case for one-quarter of primary carers. Female carers providing primary or secondary care were slightly more likely than male carers to be caring for more than one care recipient, but this difference was not statistically significant (Table 13).

Table 12: Number of care recipients, all young carers aged less than 25 years, SDAC 2003

	Primary carers	Carers	Primary carers and carers
	per cent		
One care recipient	75.1 (6.4)	89.7 (1.8)	88.7 (0.1)
Two or more care recipients	*25.0 (6.4)	10.3 (1.8)	11.3 (0.2)
Total	100.1	100.0	100.0

Notes: Due to rounding, percentages may not add to 100 per cent. Standard errors are in brackets. *Denotes relative standard error of between 25 and 50 per cent and should be used with caution. Weighted percentages.

Source: ABS 2003.

Table 13: Number of care recipients, all young carers aged less than 25 years, by sex, SDAC 2003

	Primary carers and carers		Primary carers and carers	
	Male	Female	Male	Female
	per cent		weighted numbers	
One care recipient	90.7 (2.6)	86.6 (2.4)	158,165	142,405
Two or more care recipients	*9.4 (2.6)	13.4 (2.4)	*16,315	22,061
Total	100.1	100.0	174,480	164,466

Notes: Overall differences in number of recipients between males and females not statistically significant. Due to rounding, percentages may not add to 100 per cent. Standard errors are in brackets. *Denotes relative standard error of between 25 and 50 per cent and should be used with caution. Weighted percentages.

Source: ABS 2003.

Characteristics of the care situation

The SDAC contains data on the relationship of the carer to the first recipient of care for most co-resident carers. Most young people were caring for a parent (61 per cent), and 22 per cent of primary carers were providing care for their spouse (Table 14). More than half of all young carers cared for a person with a profound or severe limitation (Table 14). In cases of profound limitation, the care recipient always needed help with communication, self-care or mobility. Thirty-seven per cent of young primary carers and 19 per cent of other young carers were caring for someone with a profound limitation. Care recipients with severe limitation sometimes needed assistance with self-care or mobility and could have difficulty being understood by family or friends. Forty-eight per cent of young primary carers and 35 per cent of young carers were caring for a person with a severe limitation.

The most common condition of the first recipient of care for young carers was chronic or recurring pain or discomfort (27 per cent), or restriction in physical activities and work (22 per cent) (Table 14). Only 3 per cent of young carers were caring for a person with mental illness. This compares with the United Kingdom figure of 29 per cent of young carers caring for a person with mental health problems from the survey of young carers who were being supported by specialist projects (Dearden & Becker 2004). This data was collected directly from care recipients, which may have led to underreporting of mental illness as is often the case in self-reporting in surveys.

Table 14: Characteristics of care situation, young carers aged 15 to 24 years, SDAC 2003

	Primary carers	Carers per cent	All carers
Carer is:			
Partner	*21.9 (6.8)	*2.4 (0.1)	3.8 (0.7)
Son or daughter	58.4 (9.2)	60.9 (3.6)	60.7 (3.3)
Other ^(a)	*19.7 (6.9)	36.7 (3.4)	35.5 (3.2)
Has disability and is profoundly limited in core activities	*36.8 (9.4)	18.7 (2.4)	20.0 (2.6)
Has disability and is severely limited in core activities	47.5 (8.4)	34.7 (2.5)	35.7 (2.5)
Other	*15.7 (5.9)	46.5 (2.6)	44.4 (2.6)
Chronic or recurring pain or discomfort	*28.8 (7.9)	26.9 (2.6)	27.1 (2.3)
Slow at learning or understanding	n.a.	11.2 (2.2)	10.7 (2.0)
Restriction in physical activities or work	29.3 (6.4)	21.7 (2.4)	22.2 (2.4)
Mental illness		*3.2 (0.9)	*2.9 (0.8)
Other	42.0	35.4	35.6
Not applicable		1.6	1.5
Sample size			559

(a) Includes daughter-in-law, mother, other relative, friend and not determined.

Notes: For young carers caring for more than one person this is the recipient with the highest level of disability. Due to rounding, percentages may not add to 100 per cent. Standard errors are in brackets. *Denotes a relative standard error of between 25 and 50 per cent and should be used with caution. Weighted percentages.

Source: ABS 2003.

Caring and participation in education and employment

Participation in education

Existing research on young carers (reported in Section 2) described the challenges young carers face in remaining in school and undertaking higher education studies. Lower rates of participation in education may lead to long-term impacts on employment possibilities and career aspirations for young carers. This study's findings about education participation in SDAC and HILDA were somewhat mixed.

In the SDAC data (Table 15) no statistically significant differences between carers and non-carers aged 15 to 24 years were apparent in terms of their participation in education. Their patterns of enrolment, either full-time or part-time, were similar to their peers. This finding may be a result of different age composition of the carer and non-carer sample.

Table 15: Participation in education, all young people aged 15 to 24 years, by sex and carer status, SDAC 2003

	Studying full-time	Studying part-time	Still at school	Not studying	Total	n
	per cent					
Males						
Non-carers	17.5	12.0	27.5	43.1	100.1	2,170
Carers	19.5	14.6	24.2	41.6	99.9	196
Females						
Non-carers	22.1	8.6	27.6	41.8	100.1	2,108
Carers	23.7	6.1	27.7	42.4	99.9	219
All						
Non-carers	19.7	10.3	27.5	42.5	100	4,278
Carers	21.6	10.4	26.0	42.0	100	415

Notes: Carers include all primary carers and carers. Due to rounding, percentages may not add to 100 per cent. Weighted percentages.

Source: ABS 2003.

In HILDA it is possible to disaggregate data more closely concordant with school ages than in the SDAC CURF. Only 50 per cent of identified carers aged less than 19 years in this group were at school, compared to around two-thirds of non-carers (Table 16). However, this finding is not statistically significant, possibly due to the small sample size of young carers.

Table 16: Participation in secondary school, all young people aged less than 19 years, by carer status, 2005

	Carers	Non-carers
	per cent	
Still at school	50.4	63.0
Not at school	49.6	37.0
Total	100.0	100.0
n	34	968

Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

No statistically significant differences, in terms of highest education qualifications achieved for identified carers and non-carers, were apparent in the HILDA data (Table 17) although once again this may be due to small sample sizes. In Hill and colleagues' (2009) analysis of the Census data, young carers aged 15 to 24 years were found to have lower rates of completion of Year 12 than non-carers.

Table 17: Highest education qualification completed, all young people aged 19 to 24 years, by broad carer status, HILDA 2005

	Carers	Non-carers
	per cent	
Tertiary degree	20.7	13.2
Diploma	25.0	26.7
Year 12	36.6	34.7
Year 11 or below	17.8	25.4
Total	100.1	99.9
n	62	1,890

Note: Due to rounding, percentages may not add to 100 per cent. Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Participation in employment

Lower rates of completion of Year 12 as shown in the Census data (Hill et al. 2009) and the time constraints of caring may have effects on labour force status. In the data sources examined here, consistent findings showed that a lower proportion of young carers were employed full-time and a higher proportion were unemployed. Gender differences were also apparent.

In SDAC, there were some statistically significant differences by gender between young carers aged 15 to 24 years and young people who were not carers (Table 18). Male young carers were less likely to be employed full-time and more likely to be employed part-time compared with male non-carers aged 15 to 24 years. Male non-carers were more likely to be outside the labour force, which suggests they might be in education or training.⁹ Female young carers are less likely to be working full-time, somewhat more likely to be working part-time and considerably more likely to be unemployed, compared with female non-carers aged 15 to 24 years.¹⁰

Table 18: Labour force status, young people aged 15 to 24 years, by sex and carer status, SDAC 2003

	Males		Females		All	
	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers
	per cent					
Employed full-time	39.6	35.7	27.5	20.0	33.7	27.9
Employed part-time	23.9	34.9	32.9	34.7	28.3	34.8
Unemployed	8.4	9	7.8	14.1	8.1	11.6
Not in labour force	28.1	20.4	31.9	31.1	29.9	25.8
Total	100	100	100.1	100	100	100.1
n	2,170	196	2,108	219	4,278	415

Notes: Weighted percentages and numbers. Carers include all primary carers and carers. Due to rounding, percentages may not add to 100 per cent.

Source: ABS 2003.

In the HILDA data, sample size restrictions meant it was not possible to disaggregate by gender; however, overall, young carers were less likely to be employed full-time or part-time than non-carers (53 per cent were employed compared with 69 per cent of non-carers). In addition, a higher proportion of young carers were unemployed (14 per cent) than non-carers (7 per cent) (Table 19).¹¹

Lower levels of employment among carers were also evident in Hill and colleagues' (2009) analysis of the 2006 Census data, supporting these findings in the HILDA and SDAC data. It is evident from all three sources of data that the labour force circumstances of young carers show a level of relative disadvantage compared with their age peers who do not have caring responsibilities.

Table 19: Labour force status, all young people aged 15 to 24 years, by identified carer status, HILDA 2005

	Identified carers	Non-carers
	per cent	
Employed full-time	33.3	35.4
Employed part-time	19.9	33.1
Unemployed	13.6	7.3
Not in labour force—marginally attached	16.4	12.1
Not in labour force—not marginally attached	16.8	12.1
Total	100.0	100.0
n	96	2,252

Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

In the SDAC data, young women were more likely than young men not to participate in either education or employment and caring exacerbates this difference. Sixteen per cent of young female carers (primary carers and carers) were neither studying nor employed, compared with 12 per cent of other young women and a much smaller proportion of young men. This finding of gendered disadvantage in participation accords with Hill and colleagues' (2009) analysis of the 2006 Census, which found that 20 per cent of young female carers aged 15 to 24 years were not in employment or education, a rate that was around double that of female non-carers (11 per cent) and higher than young males, whether carers (14 per cent) or non-carers (9 per cent).

Multivariate analysis: does caring have an independent effect on the likelihood of participating in employment given other factors?

The SDAC data in Table 18 show labour force status for young carers and non-carers. Multivariate analysis permits investigation of whether the differing levels of employment are associated with the caring responsibilities themselves or with other characteristics of the young person that also affect participation in employment. The following analysis (Table 20) considers the factors that affect the probability of employment among all young people aged 15 to 24 years. Only the SDAC data are used in this analysis as they provide both an adequate sample size and the most comprehensive sample of young people with any form of caring responsibilities. The analytical strategy uses a probit model and proceeds in two stages.

The first model considers whether caring has an effect on the probability of participating in employment after controlling for age, educational qualifications, whether born in a non-English speaking country, whether the young person has a disability and whether the young person is still at school. Caring responsibilities are indicated by three variables: whether the young person is a primary carer, and whether they are a male or a female young carer who is not the primary carer.

The second model augments the first by adding in other variables that would affect the amount of time a young person has available for employment: care responsibilities for their own children and participation in further study. After initial exploration these variables were found to interact with caring status, and hence, interaction terms between caring and parenthood and caring and study have been included in the model. Table 20 reports on the parameter estimates, the statistical significance of the variable, and the marginal effect of the variable (calculated according to the method outlined in Pascale (1998)).

The reference group for the first model is non-carers aged 15 to 19 years with Year 10 or lower qualifications, Australian born, without a disability and no longer attending school. This group had a 60 per cent probability of employment. The reference group for the second model is all of the above characteristics with the addition of no children of their own and not currently studying. This group had a slightly higher probability of employment at 64 per cent.

The findings in Model 1 show that compared to young non-carers and holding all other factors in the model constant, being a young primary carer is associated with a significant 14 percentage point decrease in the probability of participating in employment. Conversely, being a male young carer (but not a primary carer) is associated with an increase in the likelihood of being in employment of 9 percentage points compared with the reference group of non-carers. Compared with non-carers, female young carers (not primary carers) were less likely to be employed, but this effect was smaller than for primary carers (6 percentage points) and only statistically significant at the 10 per cent level.

The other factors in the model show results that are standard in employment participation models more generally. Young people aged 20 to 24 years have higher employment rates than 15 to 19 year olds. Young people with education beyond high school have higher participation rates than their less qualified counterparts. All else being equal, young people with disabilities, or who were born in non-English speaking countries, or who are still at school, have lower employment participation rates than their counterparts without these characteristics.

Table 20: Probit regression, probability of participation in employment, young people aged 15 to 24 years, SDAC 2003

	Model 1		Model 2	
	Parameter estimate	Baseline probability	Parameter estimate	Baseline probability
Intercept	0.250***	0.60	0.371***	0.64
	Marginal effects		Marginal effects	
Primary carer	-0.438**	-0.14	-0.647***	-0.19
Male carer	0.268**	0.09	0.111	0.03
Female carer	-0.193*	-0.06	-0.092	-0.03
Aged 20–24 years	0.110**	0.04	0.218***	0.07
Has tertiary degree	0.872***	0.28	0.786***	0.24
Has diploma	0.692***	0.22	0.718***	0.22
Certificate	0.690***	0.22	0.717***	0.22
Year 11 or 12	0.407***	0.13	0.480***	0.14
Born in non-English speaking country	-0.705***	-0.23	-0.647***	-0.19
Has disability	-0.482***	-0.16	-0.546***	-0.16
Still at school	-0.728***	-0.23	-0.869***	-0.26
Non-carer, has child aged under 2 years			-1.150***	-0.35
Non-carer, has children aged between 2 and 10 years			-0.855***	-0.26
Is a carer and a parent			-1.841***	-0.55
Non-carer and full-time student			-0.600***	-0.18
Non-carer and part-time student			0.556***	0.17
Carer and full-time student			-0.243	-0.07
Carer and part-time student			0.496*	0.15
Sample size	4,693		4,693	

Notes: Sample includes all young persons less than 25 years. Dependent variable is 1 if the young person is in employment and zero otherwise. * $p < 0.1$, ** $p < 0.5$, *** $p < 0.01$. Marginal effects are estimated by calculating the first derivative for each observation, and then the mean of the standardisation factors for the entire sample, multiplied by the parameter estimates (Pascalle 1998).

Source: ABS 2003.

Model 2 includes controls for the parenting and study variables and this specification slightly complicates the story about caring roles and participation in employment. One factor that remains unchanged in both models is that, when all these other factors are controlled for, young primary carers are still significantly less likely to be employed than other young people. However, in Model 2, the male carer and female carer (not primary carer) variables are no longer statistically significant predictors of employment. The inclusion of the parenting variables removes the (almost) statistically significant negative effect on the female carer variable. The inclusion of children variables and an interaction term between the informal care and child care variables in the model shows that having parenting responsibilities lowers the probability of employment by 26 percentage points and that this negative effect is doubled (55 percentage points) if the young person

has the dual responsibility of child care and other forms of informal care. As this is a cross-sectional analysis it is not possible to determine the timing or sequence of the dual caring roles, that is, whether the young person (most likely a young woman) became a parent and then, as they were already at home caring for children, acquired informal caring responsibilities for another family member or friend, or whether the two caring roles commenced simultaneously, or whether the young person already had the informal care responsibilities before becoming a parent.

The inclusion of variables indicating current full-time or part-time study status for carers and non-carers shows that non-carers who are studying full-time are less likely to be employed than their non-studying counterparts, whereas those studying part-time are more likely to be in employment. The direction of effects is similar for carers who are studying, but the effects are not statistically significant except at the 10 per cent level for carers studying part-time. This suggests that young carers who are studying part-time are less able to combine employment with part-time study compared with their non-carer peers. It also suggests that the young carers who are studying full-time are also more likely to be in employment than their non-carer peers. The inclusion of study status variables removes the statistical significance on the male carer variable indicating that much of the positive effect on employment associated with the male caring role is also associated with undertaking part-time study. Overall, the findings are indicative of a tendency for young male carers to have greater participation in employment and study and to take on breadwinner roles and for young female carers to become more entrenched in care roles.

Financial circumstances

Lower levels of educational attainment (completion of 12 years of schooling) and participation in employment are likely to lead to lower levels of income for young carers.

Main source of income

SDAC data (Table 21) show that overall young primary carers were much more likely to be receiving a government pension or benefit compared with non-carers (60 per cent compared with 16 per cent) and less likely to be receiving wages as a main source of income (30 per cent compared with 56 per cent of non-carers). Other young carers have wages as their main source of income in a similar proportion to non-carers (55 per cent), but a higher proportion of young carers who do not have primary caring responsibilities are in receipt of government pensions and benefits than non-carers (21 per cent compared with 16 per cent).

Table 21: Main source of income, all young people aged 15 to 24 years, by carer status, SDAC 2003

	Primary carers	Carers	Non-carers
	per cent		
Wages	*30.4 (8.3)	55.2 (2.5)	55.5 (0.9)
Other private business income, superannuation, child support or workers compensation	0	*2.4 (0.8)	3.7 (0.4)
Government pension or benefit	59.5 (8.6)	21.1 (2.5)	15.7 (0.8)
No income, nil or negative income, not known	**10.2 (5.2)	21.3 (2.5)	25.1 (0.8)
Total	100.1	100.0	100.0
n	37	378	4,278

Notes: Weighted percentages and numbers. Due to rounding, percentages may not add to 100 per cent. Standard errors are in brackets. *Denotes a relative standard error of between 25 and 50 per cent and should be used with caution.

**Denotes a relative standard error of more than 50 per cent, which is considered an unreliable estimate.

Source: ABS 2003.

Analysis of sources of income by sex (Table 22) shows that female young carers (primary carers and carers) were least likely to have wages as their main source of income (46 per cent) compared with all male carers (60 per cent), male non-carers (57 per cent) and female non-carers (54 per cent). Thirty per cent of female young carers were in receipt of a government pension or benefit, a higher proportion than male carers (19 per cent) and male and female non-carers (12 per cent and 19 per cent respectively).

Table 22: Main source of income, all young people aged 15 to 24 years, by sex and carer status, SDAC 2003

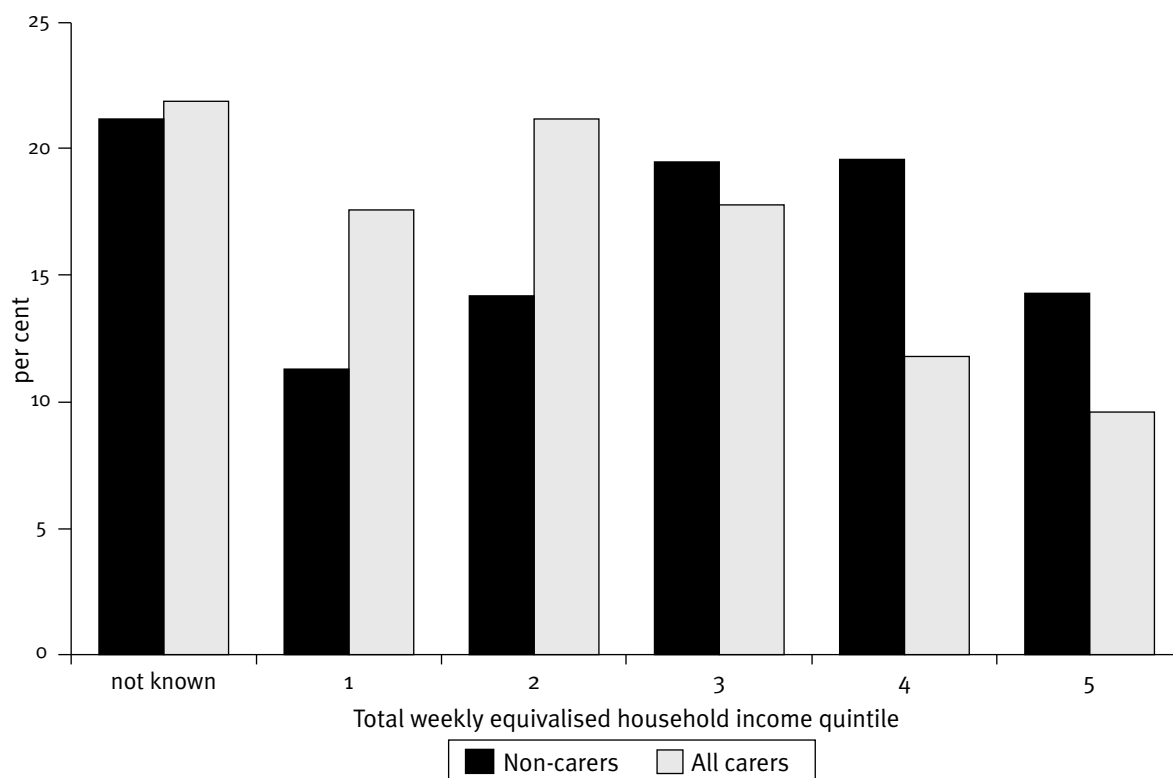
	Males		Females	
	Carers	Non-carers	Carers	Non-carers
	per cent			
Wages	59.6	56.8	46.3	54.2
Government pension or benefit	19.0	12.3	30.0	19.3
Other	21.4	30.9	23.7	26.5
Total	100	100	100	100
n	196	2,170	219	2,108

Note: Weighted percentages and numbers.

Source: ABS 2003.

Household income levels

Section 2 of this report indicated that low income was associated with the household circumstances of children and young adults who were carers. The SDAC provides information on household income distribution in the form of equivalised household income deciles. Figure 3 provides a graphical representation of the proportion of all young carers (primary carers and carers) and young people who are not carers in each weekly equivalised household income quintile. Nearly 40 per cent of young carers live in households in the bottom two income quintiles (equivalised household income of less than \$453 per week in 2003) compared with only 25 per cent of young people who are not carers. At the other end of the equivalised household income distribution, only 22 per cent of young carers live in households with income in the top two quintiles (equivalised household income above \$644 per week in 2003) compared with nearly 35 per cent of young people who are not carers. A similar proportion of carers and non-carers lived in households where the income could not be determined (the not known category).

Figure 3: Household income distribution for young people aged 15 to 24 years, by broad carer status, SDAC 2003

Note: Weighted percentages.

Source: ABS 2003.

The extent of economic disadvantage also appears to be exacerbated by the intensity of care provided by young carers. Table 23 describes the proportion of young primary carers, carers and non-carers aged 15 to 24 years who live in households in the bottom quintile of the household income distribution. Young primary carers are significantly more likely to live in households with income in the lowest quintile than young carers and non-carers. Among young people aged 15 to 24 years, 38 per cent of young primary carers, 14 per cent of young carers, and 11 per cent of young people who are not carers live in households in the bottom quintile. The finding that young carers were more likely to live in households characterised by low incomes than young people who were not carers is consistent with Hill and colleagues' 2009 analysis of the 2006 Census, where young carers, particularly those living in regional areas, were more likely to live in economically disadvantaged households.

Table 23: Proportion of young people aged 15 to 24 years living in households in the lowest income quintile, by carer status, SDAC 2003

	Primary carers	Carers	Non-carers
	per cent		
Lowest quintile	37.9 (8.5)	14.3 (2.2)	10.8 (0.7)
Quintiles 2 to 5	52.0 (8.6)	60.9 (3.0)	67.0 (1.2)
Income not known	*10.1	24.8	22.2
Total	100.0	100.0	100.0

Notes: Weighted percentages. Standard errors in brackets. *Denotes a relative standard error of between 25 and 50 per cent and should be used with caution.

Source: ABS 2003.

Income poverty and deprivation

The HILDA data provide more extensive information on income than the SDAC, so it is possible to use an alternative measure to identify the level of economic disadvantage experienced by the households in which young carers live. Two measures of economic disadvantage are considered in this analysis. The first measure is a conventional income poverty measure. To calculate income poverty, the poverty line was defined as 50 per cent of median household equivalised disposable annual income. Income in this case was defined as gross annual income minus annual taxes. Income was equivalised to enable comparison between households of different sizes using the modified OECD equivalence scales which allocate 1 to the first adult, 0.5 to each subsequent adult aged over 15 years and 0.3 to each child under 15 years.

Overall, young carers were more likely to live in a household in income poverty than non-carers (19 per cent compared with 15 per cent; Table 24). The subgroup of young co-resident carers were considerably more likely to live in a household with income below the poverty line than all other young people. Their household poverty rate was 30 per cent compared with 15 per cent for non-carers. There appears, therefore, to be income penalties associated with care giving, as noted by Becker (2007).

Table 24: Income poverty rates, all young people aged 15 to 24 years, by carer status, HILDA 2005

	All identified carers	Non-carers
	per cent	
Poor	18.8	15.1
Not poor	81.2	84.9
Total	100.0	100.0
n	96	2,252

Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

The second measure of economic disadvantage used in this analysis draws upon individual responses from young carers and other young people to questions about deprivation and financial stress in the self-completion component of the HILDA survey. A deprivation index range between zero and eight was constructed from positive responses to the following questions:

Since January 2005 did any of the following happen to you **because of a shortage of money**:

1. Could not pay electricity, gas or telephone bills on time?
2. Could not pay the mortgage or rent on time?
3. Pawned or sold something?
4. Went without meals?
5. Was unable to heat home?
6. Asked for financial help from friend or family?
7. Asked for help from welfare/community organisations?
8. And a response to a further question indicating that the young person could not raise \$2,000 in one week for an emergency.

Overall, identified young carers were significantly less likely than non-carers to report none of the eight items of deprivation (64 per cent compared with 68 per cent; Table 25). Just over one-third (36 per cent) of young identified carers reported one or more of the deprivations compared with 32 per cent of non-carers.

Table 25: Self-reported deprivation rates, all young people aged 15 to 24 years, by carer status

	All identified carers	Non-carers
	per cent	
One or more deprivations	36.3	31.9
No deprivations reported or not answered	63.7	68.1
Total	100.0	100.0
n	96	2,252

Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

3.4 Characteristics of ‘hidden’ carers: comparing identified and potential carers

Exploring the issue of hidden carers

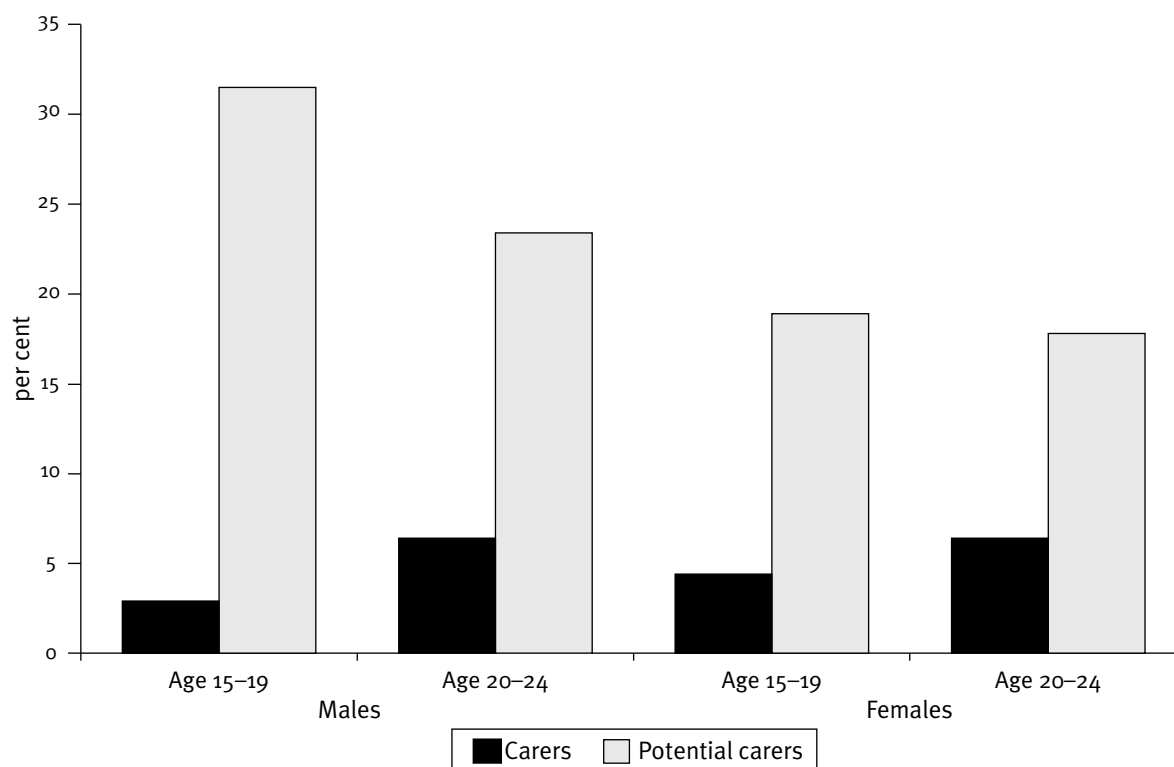
The research on young carers in the United Kingdom and Australia outlined in Section 2 suggests that many young people do not identify themselves as carers. As noted, the HILDA data and the Census data offer the opportunity to compare the circumstances of young people who identify as a carer either in an interview or on a self-completion form with those of young people who do not indicate that they are carers but who are living with a person with disability. The analysis below explores the characteristics of these hidden or potential carers in the HILDA data to examine possible similarities between the identified carer and potential carer characteristics. At the time of this study, 2006 Census data were not available to undertake such analysis. However, subsequent analysis by Hill and colleagues (2009) examined some of the characteristics of potential carers in the Census data and the relevant findings are reported here. This analysis does not assume that all young people living in households with a person with disability are providing care, but aims to explore the characteristics of this group to identify any similarities with young identified carers.

Age and sex

Overall, between 18 per cent and 32 per cent of young people were identified in the HILDA data as potential carers, or living in a household with a person with a disability (Figure 4). This represents a rate of potential caring that is much higher than that of the identified carers in the HILDA data. This rate of potential caring is also higher than that identified in the Census data, where the proportion of young people who could be regarded as potential carers was a little lower than of identified carers (Hill et al. 2009). The relatively large proportion of young people identified as potential carers in HILDA, compared with the Census, is likely to be

due to a broader definition of disability or illness in the HILDA data than the Census and possibly also due to differences in survey administration. In each age group, young men had higher rates of potential caring than young women in the HILDA data, a finding that accords with Hill and colleagues' 2009 analysis of the Census data. As noted in that report, it is possible that males are less likely to self-identify as carers due to stigma or specific notions of masculine roles within households, which are not identified with 'care'. Alternatively, gender differentiated roles within the household may imply that these young men do not assist in the caring if other household members are present.

Figure 4: Proportion of young people who are identified and potential carers, by sex and age, HILDA 2005



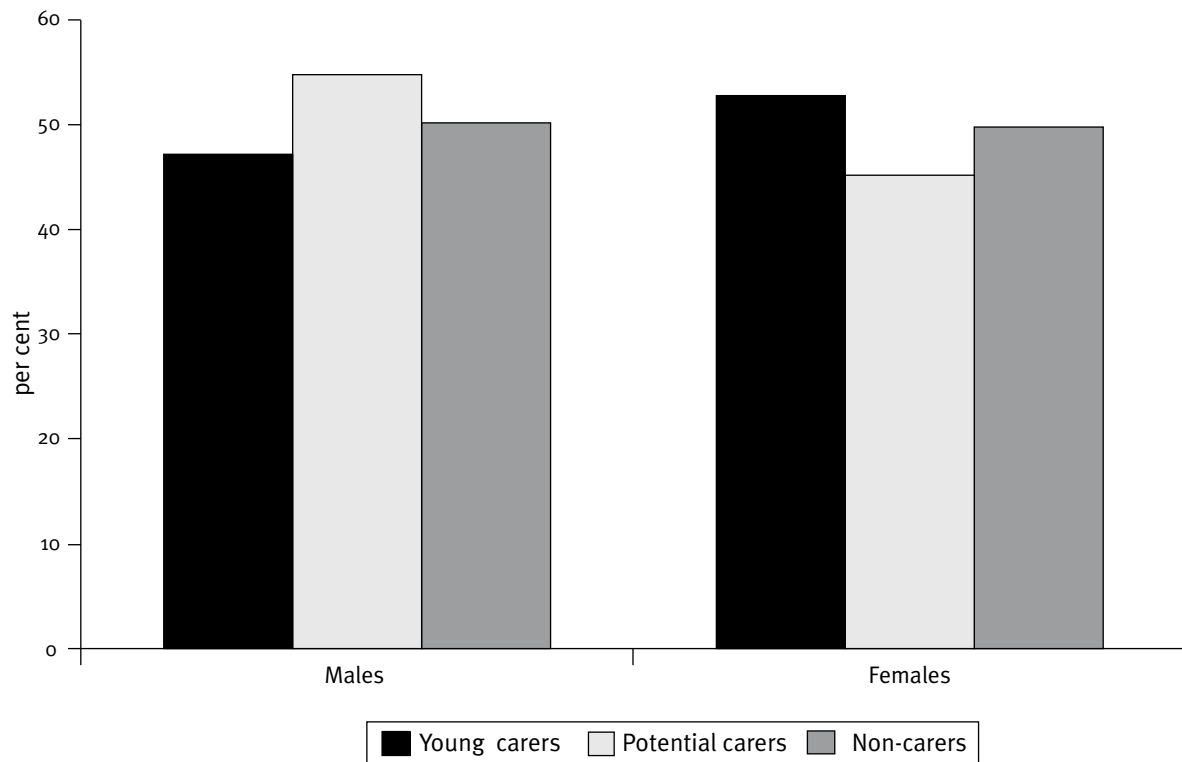
Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Gender composition

The higher prevalence of potential caring among young men results in a higher proportion of young men being potential young carers than young women. Figure 5 describes the gender composition of the different groups of young people by carer status. Around 55 per cent of the potential carer group was young men compared with 47 per cent of identified young carers and 50 per cent of non-carers.

Figure 5: Gender composition, all young people aged 15 to 24 years, by identified and potential carer status, HILDA 2005

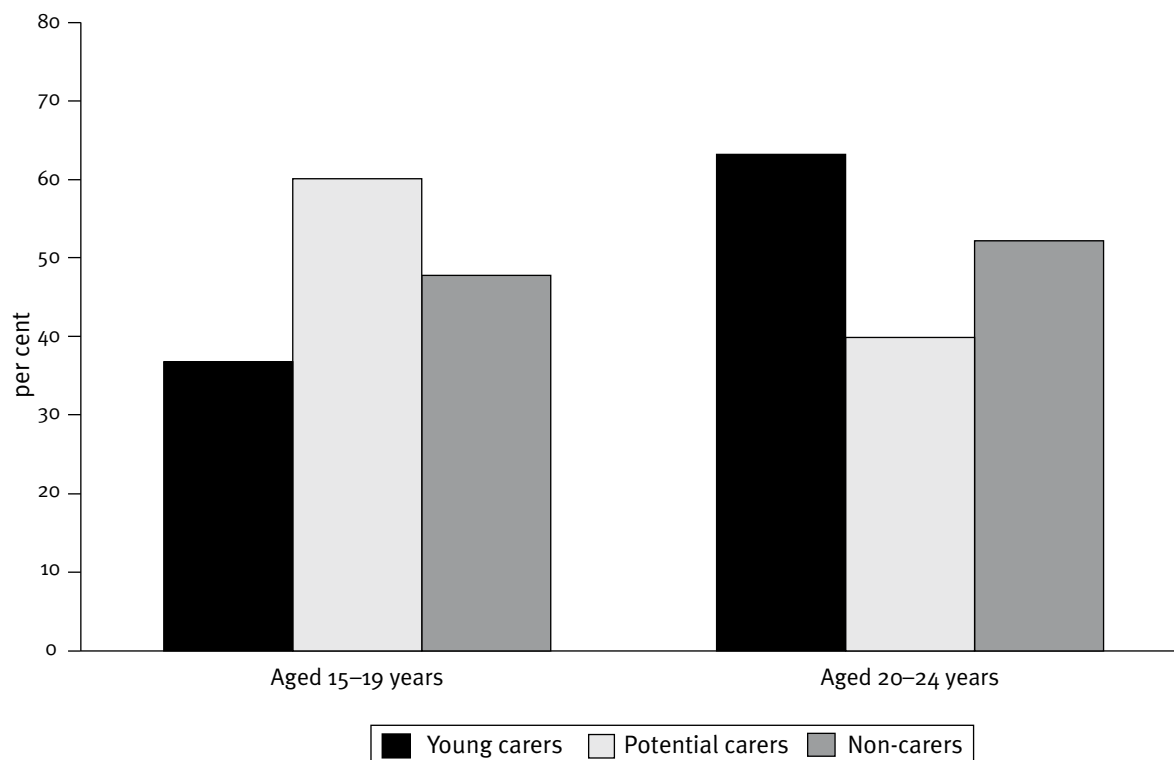


Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Figure 6 shows the age composition of the ‘potential’ and ‘identified’ young carer groups and indicates that young people aged 15 to 19 years are overrepresented in the potential carer group. This contrasts with identified carers who are more likely to be aged 20 to 24 years.

Figure 6: Age composition, all young people aged 15 to 24 years, by identified and potential carer status, HILDA 2005



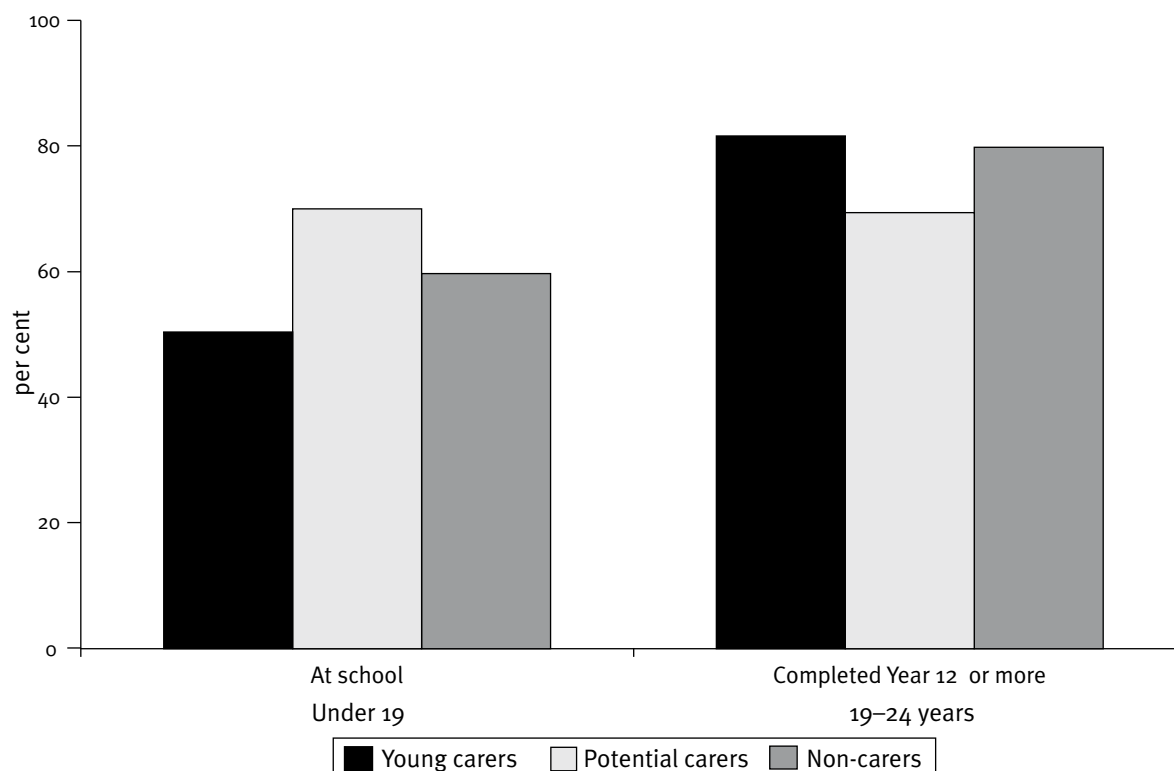
Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Participation in education

Young people who were potential carers and aged less than 19 years had higher rates of participation in school than their non-carer or identified carer peers (Figure 7). This finding suggests that, in this age group, any care responsibilities they may have are not currently interfering with their schooling. However, among young people aged 19 to 24 years, potential carers had lower rates of completion of Year 12 than non-carers and identified carers, indicating that among the young adult potential carers there may have been some negative effects on education (Figure 7).

Figure 7: Participation in education and completion of Year 12, by identified and potential carer status, HILDA 2005

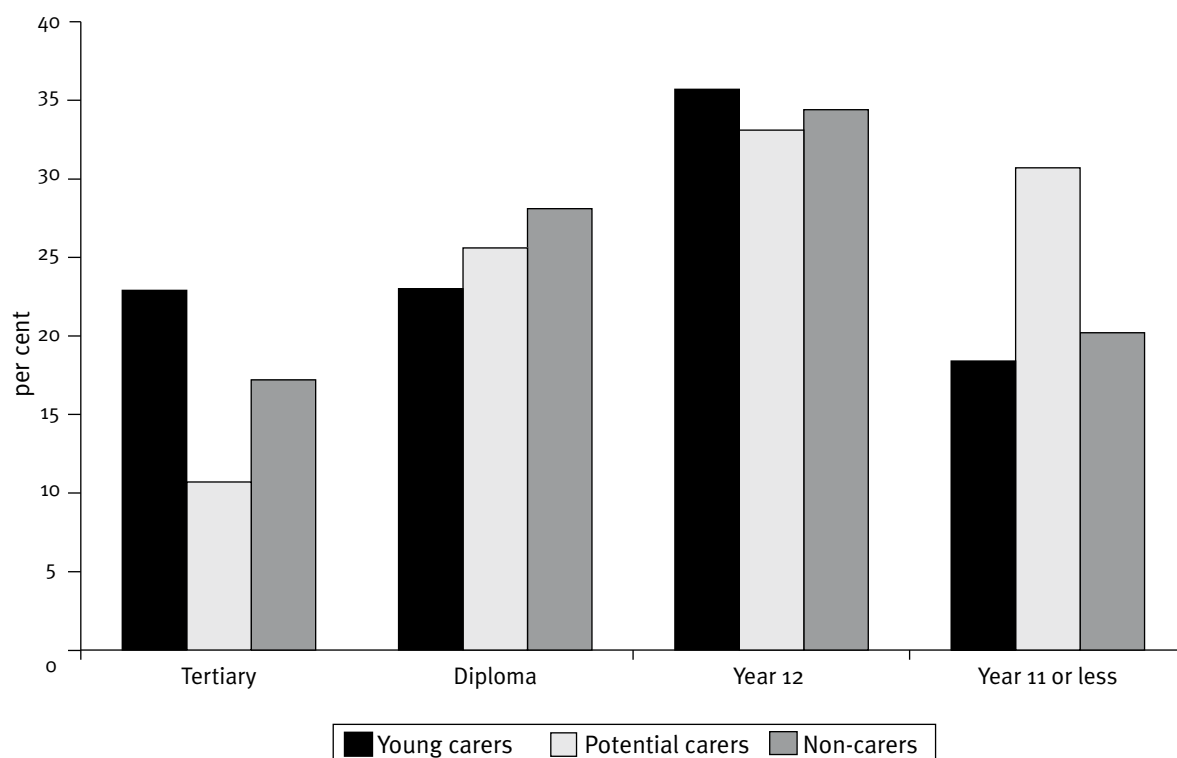


Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Figure 8 examines the highest educational qualifications of young people aged 19 to 24 years by identified and potential carer status. As noted above, potential young carers were less likely to have tertiary qualifications and more likely to have left school at Year 11 or earlier than identified carers or non-carers. With respect to education then, potential young carers had a profile that appeared less highly educated than non-carers and young carers.

Figure 8: Highest education qualification completed, all young people aged 19 to 24 years, by identified and potential carer status, HILDA 2005



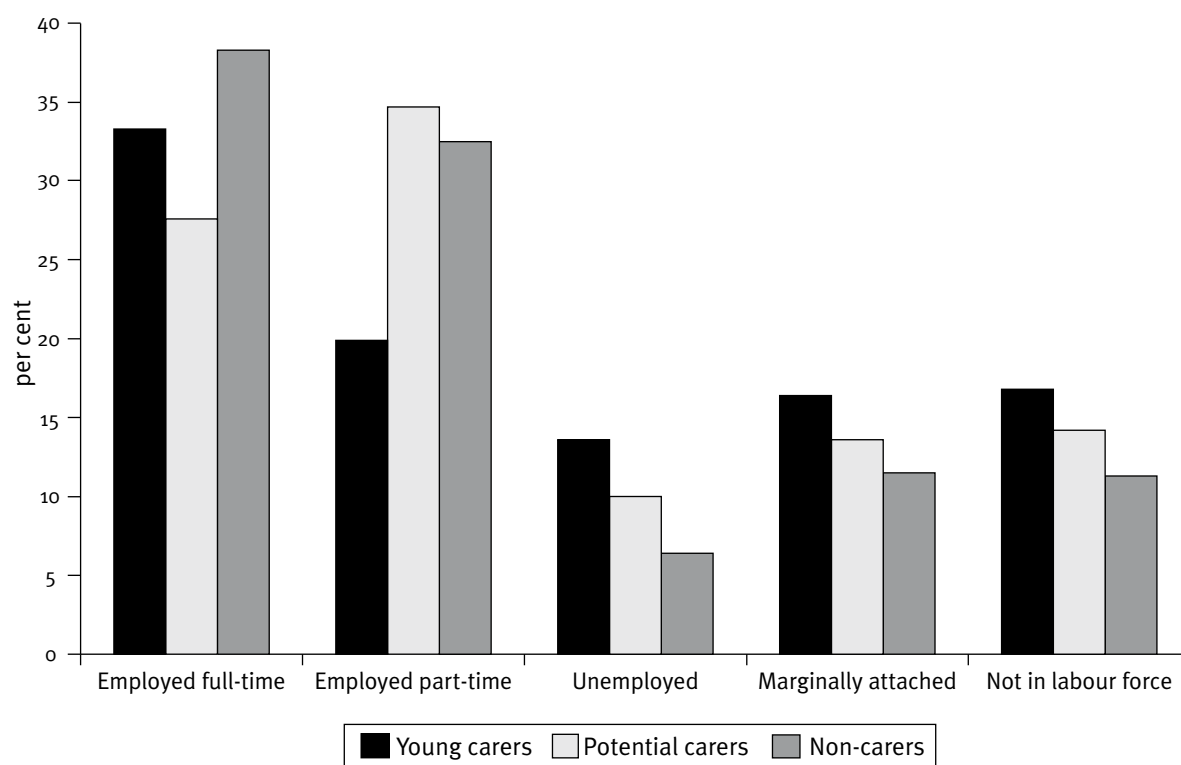
Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Participation in employment

Figure 9 compares the employment profiles for young identified carers, potential carers and other young people. Potential young carers were less likely than both identified carers and non-carers to be working full-time, although more likely to be working part-time. A higher proportion of young potential carers were unemployed, marginally attached and not in the labour force than young people who were not carers, although in each of these categories, it was a lower proportion than the identified carers. Overall, the labour force status profiles bear a greater resemblance to identified carers than non-carers. The relatively low proportion of this group in full-time employment may be suggestive of difficulties in accessing time for employment due to caring roles that are not recognised and possibly not supported by appropriate services. Alternatively, the low levels of full-time employment may be a result of another factor unrelated to care, such as the age composition of the potential carer group, which, as noted above, contains more young people aged 15 to 19 years.

Figure 9: Labour force status, all young people aged 15 to 24 years, by identified and potential carer status, HILDA 2005



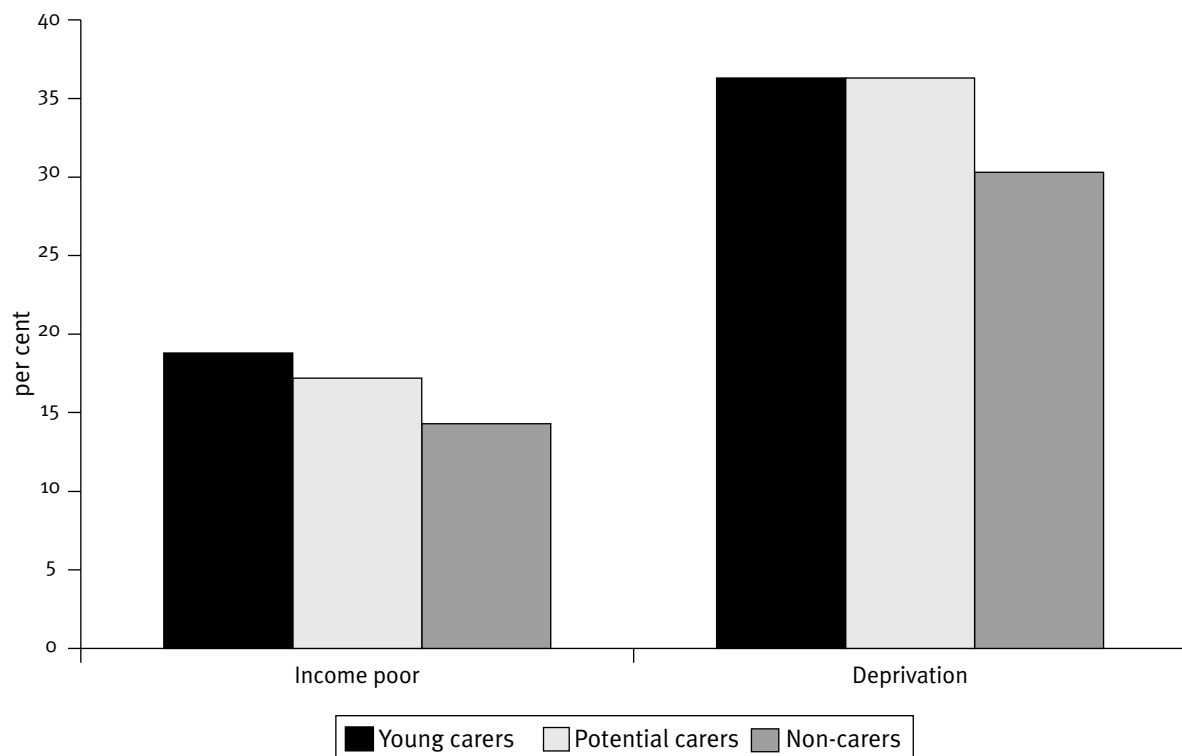
Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

Income poverty and deprivation

Young potential carers were, like young carers, more likely than non-carers to be living in households characterised by low economic resources. Their household income poverty rate was 17 per cent compared with 19 per cent for young identified carers and 15 per cent for non-carers (Figure 10). Young potential carers also had a rate of deprivation that was the same as identified young carers (36 per cent), and which was higher than the rate for non-carers (32 per cent) in this age group. These findings highlight the association of households with a person with disability or long-term illness with economic disadvantage as noted by Saunders (2005).

Figure 10: Poverty and deprivation rates, all young people aged 15 to 24 years, by carer status, HILDA 2005



Note: Weighted percentages.

Source: HILDA version 5.0, Wave 5, 2005.

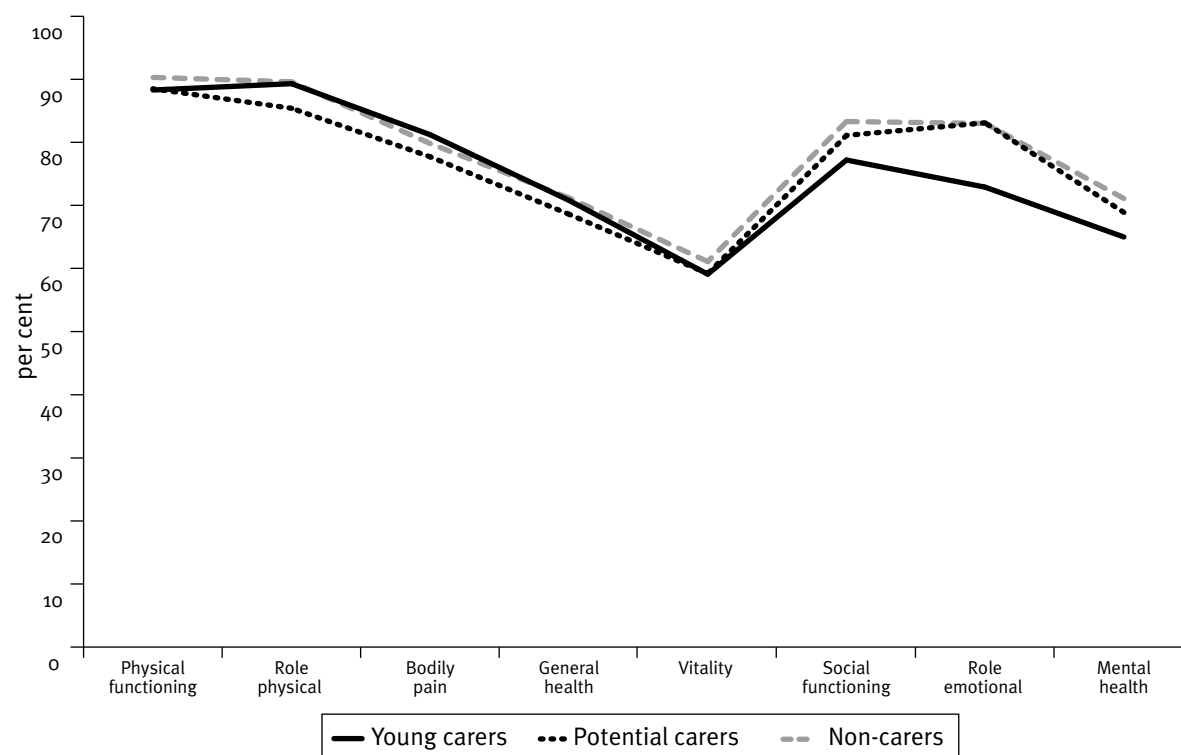
Health

The HILDA survey includes the SF-36 in the self-completion questionnaire. The SF-36 is a health-related quality of life instrument encompassing 36 questions on aspects of self-reported physical and mental health (Ware et al. 1993; Ware, Kosinski & Keller 1994). Responses from 35 questions in the SF-36 are used to construct eight subscales with an additional item addressing health transition. If the scores for all eight subscales are obtained for an individual then two further summary measures can be constructed: the Physical Health Component Score (PCS) and Mental Health Component Score (MCS). The scores for all measures range from 0 to 100 with higher scores indicating better health-related quality of life. The HILDA data provide the transformed scores for the eight subscales, which were then used to construct the PCS and MCS based on means, standard deviations, and factor score coefficients for the Australian adult population (ABS 1997 p. 31).¹²

Figure 11 identifies the person weighted mean scores on the SF-36 subscales for young people aged 15 to 24 years in the HILDA survey by identified and potential carer status. The lines in Figure 11 depict the profiles for each group across the subscales, so the lines should be compared to each other. Identified young carers have similar average scores compared to the non-carers on the subscales which relate more to physical

health on the left side of the graph, but generally lower scores than the non-carers on the subscales relating more to mental health on the right side of the graph including: social functioning, role emotions and mental health. The potential young carers had slightly lower average scores on the subscales relating to physical health than non-carers and young carers, but like non-carers, they have higher scores than young carers on the subscales relating to mental health.

Figure 11: SF-36 profiles for young people aged 15 to 24 years, weighted mean scores on SF-36 subscales, by carer status



Note: Weighted means.

Source: HILDA version 5.0, Wave 5, 2005.

These patterns are confirmed by analysing the two summary scales: the MCS and the PCS. Table 26 reports the average MCS and PCS for young people distinguished by identified and potential carer status. Young carers have significantly lower average scores on the MCS (around 3 to 4 percentage points difference) compared to potential carers and non-carers, indicating poorer self-reported mental health. The lack of significant differences between the average scores for the PCS for young people in the HILDA survey suggests that young carers do not have significantly poorer physical health than other young people. The most salient finding from this analysis is the self-reporting of poorer mental health by young carers in the HILDA study.

Table 26: Average MCS and PCS for young people aged 15 to 24 years, mean (weighted) scores, by broad carer status

	n	Mental component summary (MCS)			Physical component summary (PCS)		
		Mean	95% confidence intervals		Mean	95% confidence intervals	
			Lower bound	Upper bound		Lower bound	Upper bound
Young carers	84	*43.9	41.5	46.3	55.7	54.1	57.2
Potential carers	479	47.7	46.2	48.1	53.5	52.7	54.1
Non-carers	1409	47.9	47.4	48.4	54.4	54.1	54.8

Note: *Denotes significant difference between carers when compared to potential carers and non-carers in one way analysis of variance (ANOVA) test, $p < 0.05$.

Source: HILDA version 5.0, Wave 5, 2005.

3.5 Summary

This section explored three nationally representative data sources on young carers to describe their demographic and care situation characteristics, participation in education and employment, and health. The gender and age dimensions of care giving identified in the literature review are apparent in the prevalence statistics from all data sources. In the Census, while a similar proportion of males and females aged 15 to 19 years report care giving responsibilities, it is evident that young females aged 20 to 24 years are more likely to be carers than their male counterparts. Data from the SDAC show an overrepresentation of young women among primary carers, or those having main responsibility for care, while HILDA showed that young women made up a higher proportion of those caring for someone outside their own household. The gendered impact of care giving is particularly evident in the statistics on participation in employment discussed below.

According to the Census data, caring is also more prevalent among Indigenous young people, with young Indigenous women aged 20 to 24 years reporting the highest rates of care provision of all young people. Other analyses of the Census report that caring is also more prevalent among those from culturally and linguistically diverse backgrounds (Hill et al. 2009). The new data on care giving available in the 2006 Census will offer a unique opportunity to examine the characteristics of young Indigenous and culturally and linguistically diverse carers and indicates that further research is needed in this area.

Data in the SDAC 2003, which provide the most comprehensive count of young carers, support other analyses of the Census showing that carers are more likely than non-carers to live in lone-parent families. Data in SDAC 2003 also show that young carers, like older carers, are more likely than non-carers to have a disability themselves. The tangible and intangible obligations and responsibilities of young carers are evident in the data on provision of assistance by young primary carers in SDAC. One-quarter of young primary carers are providing care for more than one care recipient and over half of all young carers are providing care to a person with a profound or severe disability. These care recipients require assistance either all or some of the time for self-care, communication or mobility. The fact that slightly more than one-fifth of young primary carers had the main responsibility for care of their spouse or partner adds a new dimension to the understanding of the circumstances of young carers rarely discussed in the literature. These are most likely to be young people in the 18 to 24 year age range. Young carers in the SDAC data were most likely to be caring for a person with a physical restriction or chronic pain. The low proportion of young carers who were identified as providing care for a person with mental illness in the SDAC are at odds with the literature on young carers who are being supported by specialist projects in the United Kingdom (Dearden & Becker 2004). More research is needed to gain a more complete picture of the circumstances of young people who provide care for a person with a mental illness in Australia.

Previous research analysing the SDAC 1998 discussed in the literature review (Section 2) has suggested that young primary carers were significantly less likely to participate in education and employment. In all data sources examined here, it appears that young primary carers and young carers are still disadvantaged with respect to participation in employment; however, their rates of participation in education as recorded in SDAC and HILDA are possibly now closer to that of their non-carer peers. These findings in the sample surveys (SDAC and HILDA) are, however, not reiterated in the lower rates of completion of Year 12 for young people identified in the whole population survey of the Census (Hill et al. 2009), and do not reflect the qualitative studies outlined in Section 2, and the primary qualitative data collected for this study analysed in Sections 4 and 5 that indicate that young carers face many challenges in maintaining their participation at school.

The findings regarding lower participation of young carers in employment are much more consistent and reiterated in the multivariate analysis. Controlling for a number of factors, young primary carers were significantly less likely to participate in employment than other young people. As a corollary, all young carers, and young primary carers in particular, were more likely to be in receipt of a government pension or benefit compared with non-carers. These circumstances of employment disadvantage and receipt of income support are reflected in the data on household equivalised income distribution which show that of all young carers (primary carers and carers) nearly 40 per cent live in households in the bottom two income quintiles compared with only 25 per cent of young people who are not carers. Further evidence of the economic disadvantage of young people who are carers is found in the higher poverty and deprivation rates of young carers compared with non-carers in the HILDA data. These findings corroborate the conclusions of the review of the national and international literature that low income is very likely to frame the socioeconomic circumstances of young carers.

The HILDA data provide a new and rich data source for analysis of the circumstances of young carers. Responding to concerns about the existence of ‘hidden’ carers, particularly among young people, the analysis explored the circumstances of identified and ‘potential’ young carers. The results suggest there may well be a significant group of young people whose caring responsibilities go undocumented in public discourse and unrecognised by themselves or named by them as care giving. In this case, it may be that their care responsibilities are so embedded in familial relationships and obligations that any additional domestic work undertaken on behalf of, or assistance given to, a care recipient is seen by them as unremarkable. Defining potential carers as those young people living in a household with a child or adult with a long-term health condition, disability or impairment, the data show that this group is significantly larger than the group of self-identified young carers. Young men are overrepresented in this group, as are young people aged 15 to 19 years. The analysis here does not intend to imply that all these young people have care responsibilities at a level that requires policy responses or intervention. Rather it aims to highlight the extent to which the experience of disability and illness in another family member may be a part of the everyday lives of young people and may have impacts on their lives.

The analysis thus also aimed to explore any similarities in education and employment participation, economic circumstances, and health between these potential young carers and other self-identified young carers. Overall, it found that potential young carers aged under 19 years were more likely to still be at school than other young people; however, among the 19 to 24 year age group they appeared to have achieved lower levels of education. The employment profiles of potential young carers had similarities to those of young carers, with a lower proportion of potential carers in full-time employment and more unemployed, marginally attached or not in the labour force than non-carers. Potential carers also showed similarities to young carers with respect to their economic circumstances, with higher rates of income poverty and deprivation than young people who were not carers. However, against these findings of similarities between potential carers and young carers is the finding that the health profiles of potential carers were more like that of non-carers than young carers. While all groups of young people reported similar scores on self-reported physical health, young carers (co-resident, ex-resident and other carers) had significantly lower scores on self-reported mental health scales than other young people, indicating that care is associated with emotional and mental health costs for these young people.

Overall then, the evidence in this section is suggestive of costs of care in terms of education and employment participation, economic resources, and the mental health of young people. The longer-term implications of such costs experienced around the crucial transition from childhood to adulthood will be able to be explored in further detail in future waves of the HILDA data. While the evidence presented here on whether potential carers have similar profiles to young self-identified carers is somewhat mixed, future research should still consider this group when exploring other aspects of the lives of young people.

4 Qualitative analysis: focus groups with young carers

4.1 Introduction

More often than not, research into the experiences of young carers is replete with language such as ‘challenges’ ‘difficulties’, and ‘missing out’. However, this language does not adequately capture the reality of all young caring. Young caring covers a broad spectrum of experiences that can be compounded or alleviated by factors such as the number of people being cared for, the carer’s age, the presence of other family members to help with care, the carer’s relationship to the care recipient, the care recipient’s illness, the socioeconomic circumstances of the family, and whether the carer and care recipient are able to access formal services and supports.

Other significant factors that can influence a young person’s caring experiences and trajectory include lone parenthood, low income or poverty, culturally and linguistically diverse background, Indigenous background, and lack of appropriate services. It is the complex interaction of all these factors that place young carers along the spectrum of caring experiences. This research shows that at one end of this spectrum, caring can have a slight impact on a young carer’s life, while at the other end of the spectrum, where care responsibilities are intensive, care giving can have a profoundly negative impact on a young carer’s life, particularly with respect to education, employment and mental health. For some young carers, caring can be a stressful and all-consuming responsibility that leaves reduced time for the usual range of adolescent and young adult activities, in particular education, employment and social life with friends. For many young carers, however, caring can be an enriching experience through which they gain skills, become more responsible and mature, and develop strong family bonds.

4.2 Methodology

Qualitative data were collected through focus groups with young carers aged from 11 to 25 years in New South Wales, South Australia and the Australian Capital Territory. This age range was chosen in order to work within the guidelines of the Human Research Ethics Committee at the University of New South Wales, which gave approval for this project and the focus groups to proceed.

In all, 11 focus groups were run at three Young Carer camps in Sydney, Adelaide and Canberra with a total of 68 young carers aged between 11 and 25 years (Table 27).¹³ The number of participants in each focus group ranged from three to 12. Efforts were made to organise the focus groups along age lines, as this was noted to be an influential stratifying factor in terms of communication style and knowledge level (Wood-Charlesworth & Rodwell 1997). Participants were recruited through consultation with Carers NSW, and Carers South Australia, both of which hold camps for young carers to provide respite and recreation, as well as information about services.

Table 27: Composition of focus groups with young carers

Camp	Date	Age group	Organisation	Focus groups	No. of participants
Sydney	April 2007	13–17 years	Carers NSW	4	14
Adelaide	April 2007	11–16 years	Carers SA	4	19
Canberra	July 2007	18–25 years	Carers NSW	3	35

The focus groups were held at Young Carers and Young Adult Carers camps, organised by Carers NSW and Carers South Australia. These camps provided an ideal opportunity to conduct focus groups with an already assembled group of young carers, subject to their consent, and their parent's consent if they were less than 16 years of age. It removed the need to organise a focus group location and travel to and from the location for the young carers. In addition, both organisations made a camp counsellor available at each focus group discussion if any of the issues discussed upset the participants or if they wished to talk about any matter after the discussion. By conducting the focus groups at the Young Carer camps we were not impinging on young carers' caring responsibilities, but rather accessing them during their designated 'time off' caring duties. At the same time, however, an invitation to take part in research initiated by 'university researchers' may have been viewed by these young carers as an unwelcome intrusion into their only opportunity for a break (Hill 2006).

Study participants

Young carers wishing to attend the camps completed an application form. In the application form for the New South Wales camp, for example, young carers provided information on who they provided care for, their relationship to that person, and their illness/disability. In addition, they indicated whether they were the main carer for that person/s, whether they lived with only one parent/guardian, whether the family's main source of income was from Centrelink payments, what support services the family accessed, and whether they wanted information on other support available. The application form also included a list of yes/no statements pertaining to the young carer's circumstances at school, at home and with friends and family. The young carer was also invited to provide any additional information to support their application. We did not seek or have access to this confidential information collected by the Carers Association for each young person.

Given the demand for places at the camps, the carer organisations had to rank applicants according to selection criteria and allocate places based on what they assessed as young people in greatest need. Applicants who are the main carer, or take on significant caring responsibilities, including washing, bathing and cleaning, or who have experienced recent trauma or difficult circumstances, or are caring for more than one person with an illness or disability were given the highest priority rating. Other information provided in the application form was also used to give the young carer a priority rating. Thus the camps also gave us the opportunity to include young carers assessed by the respective carers associations to be in greatest need of a break.

By running the focus groups at the Young Carer camps, young carers from rural and regional Australia who under normal circumstances would have remained 'hidden' and undetectable by the research radar were given the opportunity to participate.

It is important to emphasise that the findings presented in this section are not submitted as 'representative' of all young carers. Indeed, a qualitative approach does not aim at being representative of a particular population. Instead, the value of a qualitative approach lies in the fact that it explores the 'how' and 'why' questions and enables development of a more in-depth understanding of the issue under study. The approach seeks to shed light on the ways in which individuals understand themselves and their circumstances.

All the young carers who participated in the focus groups identified themselves as 'young carers'. We have therefore not been in contact with young people who are not identified, either by themselves or others, as being within this category (this is explored further in Section 5). Moreover, given the carer associations' camp wait-list selection process, it is likely that the research captured the experiences of carers with particularly high

levels of responsibility. Nevertheless, even within this group of self-identified young carers, the qualitative research findings reveal great variation in their level of responsibility and experiences.

Research topics

Separate focus group schedules were designed for those aged under 18 years and those over 18 years. The focus group schedule for the younger cohort explored topics such as the good things associated with caring; becoming a carer; support from family and level of responsibility; school, free time and health; usage/non-usage of formal services; and hopes and plans for the future. Additional topics explored with the older cohort included type/hours of employment or reasons for not being in employment, and desire to undertake further education or training. While the focus group schedules were structured, we explored other issues that were raised, unprompted, during the course of the discussion. All focus groups were recorded with the participants' consent.

Given the difficulty of gleaning the specifics of each participant's caring history in a group discussion, we designed a survey that asked the carer to provide some demographic information (age, sex), place of birth, parents' place of birth, whether their parents were employed and who they lived with. The survey asked the carer to indicate the number of people cared for, their relationship to that person and their disability. In addition, the participants were asked to indicate how many hours per week they spent providing care and the range of tasks they carried out in their caring role. All focus group participants completed the survey before the discussion began.

The rationale for including the two age cohorts in the study (11 to 17 years and 18 to 24 years) was to gain insight into how caring responsibilities affect young carers at different life stages, namely, school-age carers and those who are/might be expected to be making the transition from school to further education or training, or from education into employment and moving out of the family home. Ideally, a longitudinal study of young carers through the life course would provide greater insight into the long-term impact of caring from a young age. However, this was not within the scope of the current project, hence the importance of conducting research with different age cohorts of carers.

Ethical considerations

The choice of focus groups over individual interviews was dictated largely by the opportunity presented by the carer associations to conduct the research at the camps they hold for young carers. Nevertheless, the literature highlights many advantages of using focus groups rather than individual interviews when conducting research with children and young people. These include:

- peers dilute the power imbalance between the researcher (adults) and the research participants (children and young people) (Hill 2006; Morgan & Krueger 1993)
- being in the company of supportive peers (Hill 2006; Punch 2002)
- more fun and more humorous (Punch 2002)
- hearing what others have to say and finding 'stuff in common' (Hill 2006; Punch 2002)
- not being singled out (Punch 2002).

Some drawbacks of the focus group method noted in the literature include resentment if an individual dominates the discussion and reluctance to disclose information, particularly of a sensitive nature, in a group setting (Hill 2006). This latter point is particular pertinent to the study of young carers and it is quite likely that all of these benefits and drawbacks influenced the data collection in this research.

Hill notes that the stances children take to research are a product of 'their general orientation to communication and the specific context' (2006, p. 75). Thus he proposes that children's stances can include engagement, openness, self-protection (reluctance to contribute personal material), detachment (reluctance to

provide more than minimal responses) and subversion (rule-breaking by providing false or joking responses). In this research, the participants' stance was largely one of engagement and openness. It is likely that the 'context' of the focus groups played a significant role in the quality of the narratives provided to the researchers. The setting of the camps proved most conducive to exploring young carers' experiences and the issues that mattered to them, because the camps assembled a group of young carers in need of respite and provided opportunities for them to connect with others in similar circumstances.

4.3 Qualitative data—focus group findings

The focus groups were approximately one hour in duration and were recorded and transcribed in full. During analysis, the researchers thematically sorted and coded the focus group transcripts. Given time and budget constraints, it was not possible to involve the young carers in analysing the transcripts.

Participant characteristics

A total of 68 young carers participated in focus group discussions at Young Carer and Young Adult Carer camps in Sydney, Adelaide and Canberra. Participants ranged in age from 11 to 25 years, with half clustering around the ages of 14–15 years and 18–19 years. In reporting on the focus group findings, distinctions will be made, where relevant, between young carers (those aged under 18 years) and young adult carers (those aged between 18 and 25 years).

Just over half the participants were female ($n=37$) and all but two of the young carers were born in Australia. Six of the young carers reported that both parents were born overseas, while a further 12 reported that one of their parents was born overseas. One-third lived in urban locations, one-quarter lived in regional locations and two-fifths lived in rural locations. Almost half the young carers ($n=31$) reported that their mother was employed and over half ($n=37$) reported that their father was employed.

Pathways into caring

Focus group findings reveal that for the young carers in this study, four main pathways led to the onset of caring responsibilities. Some young carers believed themselves to have been born into caring, some assumed greater caring responsibilities as they grew older, others experienced a sudden onset of caring responsibilities due to a diagnosis or illness or a change in circumstances, and others made an active choice to provide care.

Born into caring

Some young carers perceived caring as a way of life. It was simply something they had always done. Some of these carers had older siblings with disabilities, or were born to parents with a disability or illness, or had younger siblings close in age for whom they assumed a caring role at a young age. For example, S's older brother was born with a disability and once S learned to do things for himself he started doing them for his brother. T had a brother four years his junior, with Asperger's syndrome: 'So I've been caring for him sort of all his life'. Similarly, P had three younger siblings with Asperger's syndrome, for whom she has been caring for as long as she can remember.

Gradual increase in caring responsibilities

Other carers described how their caring responsibilities gradually increased as they grew older. Some had older siblings undertaking a great deal of caring responsibilities and as they themselves grew older they started to contribute. Others had parents with a disability, whom they started helping when they were able to do so.

So I gradually started taking on the responsibilities that she no longer could 'cause my sister left home several years before that.

Sudden onset of caring

The onset of caring responsibilities happened relatively rapidly for some young carers due to an accident, the diagnosis of an illness or due to a change in family circumstances, such as moving in with grandparents, one parent leaving the family home, or a sibling leaving home.

I'm caring for my sister who was injured from a hit-and-run accident for just like the last five months ... I can't relate to any of you guys having been born into the role.

W described how he became a carer for both of his grandparents in 1999 'cause that's when I moved in with them'. C became a carer the previous year when it was discovered that her sister had an eating disorder. R became a carer when he was 7 years old when his dad was diagnosed with lung disease. B's caring responsibilities for her mum increased when her father moved out and she also cares for an autistic brother. One young adult carer caring for her sister, considered her sister's move from the parental home to her university campus as the starting point of her caring role. Although she looked out for and supported her sister when they both lived at home with their parents, she never felt the term 'carer' was appropriate. However, now that they were both living away from home, she felt the term 'carer' was an accurate description of her role and responsibilities.

Choosing to care?

For most young people in this study, caring was not a choice they made. It was seen simply as something they do, because they are born into it or there is no one else to do it. This observation illustrates and corroborates the findings from the SDAC analysis discussed in Section 2, which shows that most young carers (76 per cent) stated that they took up their role as carer because they felt that they could provide better care than someone else, or that it was the responsibility of a family member to provide care, or they felt an emotional obligation. One young carer in the focus groups caring for her mother with depression described how over the years her mother's behaviour had led to her estrangement from friends and other family members. Consequently, there were few people willing to care for her, so the responsibility had fallen to her daughter.

So I sort of got stuck with ... There's me and my Nan is sort of like the financial support and I'm sort of the psychology ... I'm sort of the one she thinks that will understand ... So I'm there for her when she needs me. So I sort of got stuck with her—not in a bad way, but ...

For other young people, caring was a responsibility they accepted grudgingly and which they regarded as a chore:

Sometimes I feel like it's a chore and I want a break from it and I don't want to be doing it anymore ... but you know you've got no choice.

A theme in the literature is that informal caring is predominantly an interpersonal and reciprocal relationship between family members, embedded in a sense of normative obligation (Daly & Lewis 2000). This sense of responsibility and obligation was articulated clearly by one young carer:

I think it's sort of like a sense of responsibility and sort of duty because she's my mum and there's no-one else and I'm her daughter and I **should** [own emphasis] because I'm her daughter. I feel that I should be there for her because she was there for me, and she raised me and that I have a sort of duty to go and pay that debt back to her.

The focus groups did reveal, however, that young carers occasionally make caring an active choice. One young adult carer described how she gave up work two years earlier in order to take on caring responsibilities for a friend, because his mother was no longer capable of caring for him. This young adult carer was very happy with her decision and knew that her friend appreciated her. Another young carer who, once she turns 18 years old, intends to become her sister's guardian also described making the choice to care.

Merging pathways

A number of young carers in the study provided care for more than one family member (as is also evident in the analysis of the SDAC in Section 2). Even though the onset of caring generally began in one of the ways

described above, some young carers described how they subsequently assumed caring responsibilities for other family members through a different pathway. W, for example, was ‘born into caring’ for his younger brother, but later had to assume caring responsibilities for both parents due to the onset of illnesses:

I’ve been caring since the age of 4, about then. That’s not when the onset of my mum or my father’s problems ... No, my brother was born with his syndrome.

Similarly, T has cared for her mum and brother since she was young, but in recent times she has also assumed caring responsibilities for her father:

But my dad, it only happened like two years ago when he got chronic heart failure and it’s just like ‘Thanks Dad’ [laughs]. So now I have to care for him.

H’s caring responsibilities gradually increased with age. Her mother was left with partial paraplegia as a result of a car accident when H was 1 year old and was cared for primarily by H’s father and older sister until H was old enough to help out from the age of 5 years. Her parents divorced and her mother remarried when she was 7 years old. Seven months after the marriage, her stepfather contracted viral meningitis, which led to mental illness. Her sister has since left the parental home, leaving H as the primary carer for both her mother and stepfather.

I think the biggest shock for me was when it came for me to have to care for [stepfather] as well especially because I’d just gotten that taste of not having to be the primary carer and so ... I got this little taste of what it felt to maybe have more freedom and then it [the caring responsibility] just kind of doubled in size.

The caring trajectories described by the carers in this study highlight how a young person might begin caring by one pathway and later assume an additional caring role via another route.

Some of the carers’ stories demonstrate an intensity of caring responsibilities where the young person cares for a parent who is incapacitated due to physical and/or mental illness and also cares for a non-disabled sibling/s because the parent is unable to do so. P, for example, has cared for her mother, who has limited mobility, since she was very young and has also taken on caring responsibilities for her brother who is nine years her junior. Similarly, another young female carer described how her mother was diagnosed with multiple sclerosis when she herself was 10 years old. In the absence of her father, she now cares for her younger brother, cooks and cleans the house.

4.4 Identifying as a carer

The issue of identifying as a young carer emerged in some of the focus group discussions. Before being referred to carer associations, few of the participants had considered themselves ‘young carers’. They did not consider their responsibilities to be exceptional in any way. They saw the tasks they performed as ‘normal’, ‘routine’, ‘everyday’ tasks. This was particularly the case for those who had been caring for a long time.

I’ve grown up with it and it’s normal.

I was brought up that way, having to look after my brother and it was just sort of my way of life. So I didn’t realise that I was a young carer.

Many young people found it hard to relate to the term ‘carer’, because they considered what they did as simply ‘helping out’ rather than ‘caring’. One saw himself as ‘a sibling with a few more responsibilities’ while another described how it was difficult to determine ‘where the caring starts and just being a helpful child stops’. For another young carer: ‘I don’t feel like I’m caring. I just feel like I’m helping. It’s not a big deal’. However, one of the young adult carers described how she rejected the term ‘carer’ in the past, but lately has started to feel comfortable with the term and its applicability to her situation:

Because even though she’s my sister, I do a lot of other things that sisters wouldn’t do and wouldn’t have to do, and you know, that title now is ok.

Warren contends that helping others with personal and intimate care ‘most clearly distinguishes young carers from other children and young people who do not assume caring roles in the family’ (2007, p. 140). S spoke of helping her mother with such tasks in the past, but maintains that at the time she was not a carer. It was only later when she began helping around the house that she felt the label ‘carer’ was appropriate:

Well, I used to help my mum when I was a younger age, like getting in and out of the shower and stuff, but I wasn’t a carer at the time. I was just like helping around and stuff. And I guess I just became a carer ‘cause mum needed help and we decided, just you know, put my name down and help out a bit around the house.

Some participants talked about how they felt when found out about the label ‘young carer’. For most, it was a welcome revelation that their experiences marked them out as being exceptional in some way and conferred value on their contribution to their care recipient’s wellbeing. On being asked how they felt about being called ‘young carers’, two focus group participants responded ‘Special!’ in unison. The term, they said, made them feel ‘unique’ and was an acknowledgment that they helped others.

For other young carers, identifying as a young carer was not about embracing a label, but rather an acknowledgement of something intrinsic to their very being:

It’s part of life and honestly if I wasn’t caring for my mum I wouldn’t know what to do, ‘cause it’s a part of me.

Being a carer is such an integral part of your life.

For others, being identified as a young carer was important because it was an acknowledgement of the responsibility they had. One young carer described finding out about the label of ‘carer’ as an affirmation of the challenges he had to deal with:

It made me step back and look at the past few years and go ‘Oh my gosh! My schoolmates weren’t dealing with this.’ And yeah it just affirmed that yeah no wonder things have been so hard.

Finding out about ‘young carers’ was a revelation for another young person. While he had never regarded his caring role and responsibilities as anything other than normal household chores, the label helped him recognise that he did shoulder a lot more responsibility than his peers.

It sort of dawned on me how much responsibility I’ve got. Before that it was just you know, normal work, sort of chores almost. It’s the way I’ve been raised.

The focus group findings underscore how important it is for these young people to identify themselves as young carers, because it enables them to join networks of other young people in similar circumstances. As noted, many young carers do not recognise that they are undertaking caring duties or shouldering responsibilities beyond the norm for their peers. Nevertheless, they are often acutely conscious that they are different to their friends. Others, however, recognise that they have far more responsibilities than other young people of their age, but they had never met another young carer and felt alone and isolated. The young carers in this study described discovering other young people with similar roles, responsibilities and feelings as a ‘relief’, ‘inspirational’ and made them feel ‘a lot better’.

One young adult, who had previously attended a carer support group, emphasised the importance of being able to tap into networks of other young carers. The support group, however, comprised adults caring for their own children or partners and the young carer had felt ill at ease with the generation gap. When he did learn there were support networks for young carers, he was relieved to discover ‘other people in this world that actually are my age that go through the same thing’.

Another benefit of embracing the term ‘carer’ was that it made it easier for young people to explain their situation and circumstances to others.

Adopting, accepting or embracing the term ‘carer’ can bring many benefits for all carers, particularly in accessing support. One participant made the point that sometimes it can be hard for young carers to find out what assistance is available. However, in the same breath, she articulated the difficulty inherent in making young carers aware of the support they can access when they do not identify themselves as carers:

It's more that there are those services there, but you don't really get told about it. Like I didn't know anything about ... even that I was a carer until we got contacted by respite care and they told us about this camp.

Difficulties can arise, however, if self-identification as a carer is not officially reciprocated. Study participants acknowledged that eligibility criteria for accessing income support payments and carer allowance needs to be stringent (discussed further in Section 5). However, one young adult carer described how Centrelink's rejection of her application for Carer Allowance had a very negative impact on her self-concept as a carer. She had struggled with coming to terms with the label 'carer' and felt undermined by Centrelink's rejection of her claim, because for her it meant the agency did not recognise her as a carer. It is difficult for young people to understand how criteria for receipt of support are determined and applied, and as encapsulated in the case of this young adult, rejection of a claim may be perceived as rejection of their carer identity.

4.5 Level of responsibility

The young carers' stories revealed a wide variation in the level of responsibility they shouldered. This variation was influenced by a number of factors including the number of people being cared for, the presence of other family members to assist with care, the carer's relationship to the care recipient, the care recipient's illness and the carer's age. The interaction of these factors influenced the type and intensity of chores the young carers performed.

Number of care recipients

Most of the young carers (n=48) were caring for one person, while one-quarter (n=15) were caring for two people and four were caring for three people. The multiplicity of care responsibilities for the young people in these focus groups reflects the findings from the SDAC analysis (see Section 2), where 11 per cent of young carers were caring for more than one person. However, because of the selection criteria the carers associations used to choose young people to participate in the camps, it is likely that young people with high levels of responsibility were selected to become focus group participants. This caveat is important when interpreting the focus group findings as it is likely that the researchers heard the voices of young carers with a significant degree of responsibility, which does not reflect the experiences of all young people providing care.

Presence of other family members to help with care

Among the older age cohort, half were primary carers (n=17) and among these primary carers, four were the sole providers of care. All the other carers indicated that other family members also provided care either in a greater, equal or lesser capacity (n=14). The majority of these older carers lived with the person for whom they cared (n=30) although five did not. Four of these older carers were living with their partner and while none indicated they were providing care for their partner, one was caring for her partner's brother.

Among the younger cohort, many were providing care in households where a parent was the primary carer for another family member. The amount of caring support they provided varied from situation to situation. In some cases, the presence of an additional sibling lightened the load of caring when responsibility was shared.

I think that I'm quite fortunate in that I'm in a family of six, I'm not the primary carer so caring gets sixth, if that makes any sense? It gets divvied up. Not equally. Predominantly it falls on my mum, but it means that we can all pitch in.

In other cases, the responsibility for caring falls predominantly onto one sibling. Reasons given by young carers who took on a larger share of responsibility than their siblings included being the eldest, or being more considerate and actively choosing to be the main carer. S, for example, described how when she was younger she wouldn't let her brothers take care of her sister, because she wanted to do it all. Now, however, she would like some assistance, but her brothers are unwilling to help.

The caring relationship

The experience of caring depends to a large extent on the young carer's relationship to the care recipient. A child caring for a sibling has a very different experience from a child caring for a parent. When a child provides care for a sibling, they may be doing so in the company of parents and other siblings. When a child provides care for a parent, they may, in effect, be the primary carer if the other parent works full-time or if they live in a lone-parent family. Sometimes young carers caring for a parent may be an only child or they may be an eldest child and have to provide care for younger siblings on the parent's behalf in addition to caring for the parent. Much of the disability rights literature dismisses the notion of the 'parentification' of young carers, because it undermines the role of the parent with a disability (see Section 1). Nevertheless, in some cases, a young carer has to provide care for younger siblings on the parent's behalf, although this does not negate the other forms of emotional care, which the parent is able to provide for all family members. In this study, mothers were the largest group of care recipients (n=28), followed by brothers (n=25), sisters (n=21) and fathers (n=12). Other care recipients (n=8) included stepfathers, grandfathers, grandmothers, friend and partner's brother.

Care recipient's illness

The young carers were providing care for individuals with a broad range of congenital and acquired physical and mental disabilities. These included cerebral palsy, multiple sclerosis, blindness, autism, spina bifida, brain damage, spinal cord injury, depression and psychosis. The intensity of the experience of managing these diverse illnesses varied a great deal and could involve providing physical, practical and/or psychological assistance.

Carer's age

The young carers who participated in this study ranged in age from 11 to 25 years, with the majority clustering around the ages of 14 to 15 years (n=16) and 18 to 19 years (n=19). Nevertheless, the onset of caring responsibilities was reported as beginning very early for some young people (some from as young as 2 years), while others began caring in their twenties. Many, however, had difficulty determining at what age their caring responsibilities started and simply provided survey responses such as 'all my life', 'always', 'since birth', 'I have always been a carer'. The survey data also reveal that age influences the types of tasks young carers undertake. Carers aged 18 years and over are significantly more likely to help their care recipient with dressing, eating, paying bills and banking, attending medical appointments, giving advice and organising social activities (Table 28). Tasks such as showering, cleaning the house, cooking, comforting, and listening were undertaken to a similar extent by young carers under 18 years and carers over 18 years.

Table 28: Caring tasks young carers undertake

Type of support	Activity	Under 18 years	18 years or over
		per cent	
Physical	Showering	22	26
	Dressing	32	60
	Helping with eating	22	43
Household	Cleaning the house	91	86
	Cooking	81	83
	Helping with bills and banking	22	63
Medical	Going to medical appointments	44	63
	Helping with medication	56	66
Emotional	Comforting	84	89
	Listening	88	94
	Giving advice	63	83
Social	Organising social activities, such as going to movies, sporting events, visiting family and friends	44	83

Note: Percentages sum to more than 100 because participants were able to cite more than one activity.

Source: Adapted from Noble-Carr and DFACS 2002b.

4.6 Young carers' home duties

When discussing the issue of young carers, the questions that often arise are: What distinguishes the tasks undertaken by a child or young person who is called a carer from those undertaken by a child or young person without caring responsibilities? Is it the **quantity** of care provided? Or is it the **type** of care provided? These questions are fraught with difficulty because there is no baseline from which to determine normal versus heightened levels of responsibility (Warren 2007). As one study participant expressed it: 'A lot of the time it's just explained by being a teenager with a few extra chores.' However, in large part, it is the interaction of the factors described in the previous section that influences the type and intensity of chores young carers perform. In the survey responses, young carers indicated the range of activities they undertook when providing care (Table 29).

Table 29: Home duties young carers undertake

Type of support	Activity	Yes (%)	n
Physical	Showering	24	16
	Dressing	46	31
	Helping with eating	32	22
Household	Cleaning the house	87	59
	Cooking	81	55
	Helping with bills and banking	43	29
Medical	Going to medical appointments	54	37
	Helping with medication	60	41
Emotional	Comforting	85	58
	Listening	90	61
	Giving advice	72	49
Social	Organising social activities, such as movies, sporting events, visiting family and friends	57	39

Note: Percentages sum to more than 100 because participants were able to cite more than one activity.

Source: Adapted from Noble-Carr and DFACS 2002b.

Household tasks

Most participating young carers indicated that they undertook household tasks. Four-fifths of focus group participants reported that they helped with cleaning the house and cooking, and half indicated that they helped with bills and banking. In the focus groups, participants elaborated on the household chores they performed as part of their caring responsibilities. Within the range of responsibilities, some young carers were responsible for discrete tasks within the home while others were responsible for managing the whole household.

I wasn't doing that much until my mum got diagnosed and then I was doing mainly all the stuff around the house.

So after a period of about three years, I was managing the entire household, which is what I do now.

Other responsibilities within the home included providing child care for siblings if the parent was incapacitated and helping siblings with homework. Managing other siblings' involvement in household tasks can also be the responsibility of a young carer:

He [brother] helps out, but not like ... he kind of makes things worse at the same time. Like he does the dishes, he does them pretty slow and he doesn't do them right. We're trying to teach him. When he cooks tea I've got to help him out a bit, 'cause he just gets confused and stuff.

Emotional support

Most young carers also indicated in the survey that they provided emotional support in the form of listening to and comforting their care recipient. Examples of emotional support that emerged during the focus groups ranged from calming down siblings with developmental disorders, including Asperger's syndrome and autism, to providing counselling support for a depressive parent:

I just always remember having to help out with him, because he was like really, really stressful when he was young.

I'm sort of the psychology ... I'm sort of the one she thinks that will understand. I can listen to her even if she doesn't make sense or it's not like real, it's going on in her head.

A young woman caring for her anorexic sister described the uneasiness she feels as a consequence of being her sister's confidante and support. With the support program her sister is undergoing, she has been designated her sister's support person. She feels very conflicted about having to keep her sister's confidence, because she feels she should tell her parents some of the things her sister tells her.

Social support

Over half the participants provided social support to their care recipient by organising or facilitating outings and social events with family and friends. A number of the young carers also indicated they provide educational support for their siblings with disabilities.

Medical

Over half the participants indicated in the survey that they accompanied their care recipient on medical appointments and three-fifths said they helped their care recipient with medication. Helping with medication usually entailed making sure the care recipient took medication, although one young carer said she sometimes had to administer injections.

Physical

In the survey, carers were asked to indicate what type of physical support they provided to their care recipient. Almost half helped with dressing, one-third helped with eating and one-quarter helped with showering. In the focus group discussions, a few young carers described providing this type of help. One young carer described how from the age of 6 she started taking her sister to the toilet, dressing her 'basically just started by helping mum with little things, basically helping the family, cleaning up'. Another young carer described how she provides this type of assistance to her mother:

So in my mum's case, you know I have to wash her and I have to dress her and things like that.

While provision of personal and intimate care is generally a clear distinguishing feature of the responsibilities of a young carer, the level of responsibility assumed by young people providing other types of care (that is, managing the entire household) can also distinguish them as shouldering responsibility well beyond the norm.

Perceived level of responsibility

Uprichard (2008) notes that children's 'reflections on self-competency are derived from relational observations between themselves and others, where the "other" can be both other adults and other children' (2008, p. 305). During the focus groups, it became apparent that many young carers could only judge their level of responsibility in comparison to their peers. For many, their responsibilities were ordinary, everyday, routine tasks that they had to perform and were not considered to be outside the 'normal' range of a child's responsibilities within the home. However, as some became aware of their peers' responsibilities within the home, they began to regard their own as well beyond the normal range of household chores. One young carer described how she never knew that she was any different from her friends and peers who did not have caring responsibilities. After spending time at her friends' homes she came to the realisation that she had 'a lot of responsibility that a lot of people don't have'. Other comments included:

I think that when I started going through high school and noticing that a lot of my peers did have both of their parents ... and both their parents were able bodied ... double income sort of families. At that point I started thinking or realising that there were obvious differences between different family situations ... when I started noticing how different I was from ... a lot of my friends, that's when I noticed.

Other kids will go 'Oh what do you cook? What do you clean for?' and I just say to them 'You don't know what my life's like.' And they just go 'Oh, okay'. So it's just become part of the routine, part of the schedule. If mum's not able to do it, I do it. It's just so routine.

In the exchange that follows the other young carers focus on what they describe as their peers' lack of independence and their immaturity. It provides a good example of how many young carers validate their level of responsibility by focusing on how it helps them develop independence and resilience:

A: Lots of people at my school are really lazy. Their parents do everything for them. They pay them so much money for doing nothing. They break phones, they get new ones.

T: [interrupts] They don't understand, because if they're just getting paid for no reason then they're not learning from anything.

L: [interrupts] Because they're not learning to budget, like we are. We know how to budget.

A: They're being given stuff, what we're spending on for wheelchairs and things like that.

L: You know, like you said, they broke a phone and they go 'Mum, I broke my phone, can I have a new one?', they have a new one the next day. But with us, you know we break a phone, we've got to save for it.

One young carer, however, articulated the ambivalence that she feels about her imposed maturity as a consequence of caring—both valuing and resenting it:

I know my friends from before I started caring, their parents are fit and healthy. Their parents do everything for them ... One way, it's annoying that I have to do it, but in another way I feel pity for them, because when they move out of home they won't have a single clue as to what they're supposed to be doing. One of my friends is in that situation. She just ... she can't look after herself, she can't look after the house, she can't cook or anything ... I think I'm just upset that I have to take on more and more responsibility as mum gets worse.

4.7 Support—formal and informal

The focus groups explored what types of formal and informal support the young carers and the person they cared for received. The level of support the young carers received from other family members varied in large part according to the care relationship involved, that is, whether the young carer was caring for a sibling or caring for a parent. Where young carers are caring for a sibling, they are often secondary carers, with the parents as primary carers. In many of these situations, the young carers reported that 'everyone' in the family helps out with caring. Yet even when there are several siblings in the home, sometimes one takes on a greater caring role for their sick or disabled sibling:

In my family, I do most of it, but they do help.

But they [brothers] don't really do anything, it's more so me.

Not surprisingly, more of the young adult carers took on primary caring responsibilities compared to the younger cohort. In some cases, participants also received some support from other family members:

I'm the primary carer. As well I have help from my mum two days a week and those two days a week I go to work.

Yeah I'm just doing it by myself. I do have family that lives close and you know if we need a lift somewhere on the odd occasion that we do. Otherwise everything else is done by myself.

In other cases, the primary caring role was split between the young carer and the parents according to the carer and care recipient's living arrangements:

Basically it's me and my mum. Sort of mum is the primary carer cause they live together and at the moment I'm living away from home and I take [sister] out a couple of days a week or I'll go over there and baby-sit if mum's away or stuff like that. But back in the day when I lived in the family home I had a large caring role. Mum would go away for weekends or be studying and I'd take on the primary role.

It's sort of split between mum and dad and myself. Like when she's at uni, I've got her and I do all the caring and when she's at home, they'll do it.

In another case, two young adult carers who were siblings shared primary caring responsibility for another sibling. All three had grown up in foster care and had no other family to provide support. The family resilience and strength provided by these siblings to each other was evident.

The caring situation of young carers caring for a parent also depends on whether there is another parent present in the home and/or other siblings. However, even in two-parent families, young carers sometimes have to take on primary caring responsibilities, because the non-disabled parent has to go to work, sometimes to compensate for the lost income of the disabled parent. For example, R provided most of the care for his dad, because his mum worked full-time in three jobs. He did not get much help from other family members, but his older ‘immature’ (his description) brother had started to help out more than he used to. And, S was in home-schooling and was finishing Year 12 two or three years later than she might have because of interruptions due to her caring role. Although she lived in a two-parent family, her father worked full-time, so S was primary carer for her mother. When caring for a parent, the presence of other siblings can either lighten the load or add to the burden if the young person also has to take on responsibility for younger siblings.

The focus groups also explored whether the young carers received any help from extended family. Some reported getting none at all, sometimes due to family tensions or distance, particularly for those who had parents who were born overseas:

We don’t get along with our family very well. There’s just arguments ... so we don’t really have help except for my brother ‘cause he’s like a carer as well.

Some young carers did get help from extended family, usually from grandmothers. Often this help was highly valued and much appreciated, but sometimes, the young carers saw their relatives’ input as more of a hindrance than a help. For example, R reported that his grandmother tried to help out sometimes ‘but she doesn’t really know what to do’. Similarly, C said her grandparents tried to help out ‘but they kind of make it worse sometimes’.

A number of young carers mentioned that they occasionally received help from friends or neighbours. One young carer who had moved from an urban to a regional location spoke of the community spirit and receiving informal community support:

The good thing about where we live now, it’s like a whole community spirit and I haven’t really asked for anything you know since we left. And the good thing is the neighbours have come over and check on him ... One of the girls that owns a cafe ... she rang up and ... she brought him over some food.

Formal support

Most of the young carers reported receiving some formal support and services and this is a clear reflection of the recruitment process employed in this stage of the study.¹⁴ Many of the young carers got home care services, which included domestic assistance, personal care, respite care and counselling.

Another service my sister gets is ... she goes to [respite centre] and it’s like respite and it’s a house and she gets to stay there and she gets excited because that gives my mum a break.

We use counselling services, because it gets really hard, because it’s so much in one household. All you do is bounce back and forth. It just puts too much pressure on.

Other types of formal support received included having a driver to take the care recipient to school, tutoring, and support groups for the care recipient. One young carer appeared somewhat bemused by the fact that she received more support as a carer than her care recipient did. This was echoed by another young carer who was grateful to be able to access counselling and respite, but felt it would be very beneficial if there was more support available for her care recipient—‘somewhere for her to go and talk’.

Why some carers get no support

Even when support services were available, the findings show that some young carers and their families did not have information about them, did not know who to contact, or how to access support. In some cases, they simply did not know what support was available or had difficulty accessing it:

Trying to find or get in contact with people with the services was the hardest bit, like you knew that they were there, but just trying to get in contact with the right people to get the things you wanted.

Well, I honestly have no idea what's available and I have no idea who to go to and ask. To tell you the truth, I wouldn't know where to start.

Because of the accessibility of services. Not every young carer is eligible to access that ... But things like respite and that, they can be very rigid about exactly who's allowed ... It's 'Who's caring for who? And how many hours?'

For one young adult carer, geographical remoteness contributed to her sense of isolation. She felt that growing up in regional New South Wales made it very hard to find out about the types of services and supports available to carers and those they care for.

Like not being metropolitan-based and not being in an area where ... Well I mean there probably are a lot of other carers, but I don't know where to find them.

Several young carers mentioned the unreliability of services. S, for example, described how on occasions, the meal service people did not show up at all, so his brother did not get a meal until S got home from school: 'No-one's sort of reliable enough'. Similarly, H described how the respite she had organised for the period she attended the young carers' camp had failed to turn up. As a consequence of these bad experiences, many young carers were reluctant to use services.

Other young carers were reluctant to avail themselves of support services, because they did not feel they were appropriate for their family:

I can't really have people come into my house, know exactly how to deal with my family 'cause everybody's different. They may be trained in ways to do things, but they won't, I bet you they won't have come across too many [brother's name], so ...

I've never used a formal service. It just seems kind of strange like having someone else come and do it ... Yeah I don't think I will use them.

M said that her family could get respite to look after her brother, but that it was hard to get the same person each time and her brother was only comfortable with certain people: 'So then you'll be worrying about whether it's going to go well'. Another young carer living in a regional location said her family could not access respite care because there was no one suitably qualified in the area to care for her brother.

For some young carers, certain types of services were appropriate, while others were not. H described how she accessed domestic services, but has not accessed personal care for her mother, because that would make her mother feel very uncomfortable. H emphasised the fact that just because her mother had a disability she still had rights, feelings and opinions that she needed to respect:

And so I think that's a really important thing. As well as having all these services available and being able to access them, I think you have to find the right thing that suits you. So you know personal care didn't suit me, but domestic did. There's a lot of balancing acts in being a young carer.

The level of responsibility a young carer takes on often increases, as they get older. In some cases, a family may cease accessing a particular service as children get older and can start to pitch in around the home:

We cancelled the domestic services a couple of years ago now, because we can vacuum ourselves and everything.

Another young carer explained that his family had no need to access formal support because 'there's always someone there to sort it out'.

It is evident that a significant proportion of young people participating in the focus groups saw provision of care as a family matter, one which they were most skilled and experienced to provide, and to do so in a way that respected their care recipient's needs and sensitivities, and often their dignity. There is a sense in which these young people see themselves as protecting the privacy and integrity of the whole family. This is illustrative of the findings from the SDAC analysis (Section 2) in which most young carers (76 per cent) said they took up their roles as carers because they felt they could provide better care than someone else, that it was the responsibility of a family member to provide care or they felt an emotional obligation.

Desired support

Unmet support needs young carers in this study identified included domestic help, respite, financial assistance, transport assistance and counselling for the care recipient. Analyses of the national Australian data sets (from the ABS and HILDA) outlined in Section 3 demonstrate that many young carers, when compared with their peers, live in households experiencing low income, poverty and financial hardship. It is therefore unsurprising that financial assistance was by far the most commonly-cited support need.

Some of the young carers felt that the financial assistance available to carers was inadequate. One young carer mentioned that his mum received Carer Allowance and he thought it probably paid for the groceries, but that was about it and opportunities for family outings were more limited than they had been in the past:

My dad used to take us out to [restaurant] and go to the movies every few months. But because things have gotten so tight and prices have gone up, it just makes it a lot harder to do things and go places.

There was a perception among some of the young carers that Carer Allowance was ‘very hard to get and it’s not much money’. Another young carer was very critical of the inadequacy of the allowance: ‘It is not enough to care for my mum with all the things she has’. Another felt that young carers were financially disadvantaged relative to older carers because they are not recognised as being carers.

Medical costs were a huge drain for many of the young carers’ families:

‘Cause the medical bills. Medicine costs us about \$300 a month ... and also then the doctor’s fees ... it’s very expensive.

A number of carers mentioned that they would like to be able to access more, reliable respite. In one case, a young carer said her family could only access a certain amount of respite each year, but beyond that they had to pay for the care. Her mother had high needs, consequently there were fewer respite places and it was an expensive form of care. Another young carer thought it would be appreciated if his family could access funding for a holiday in order to give the whole family respite. Another spoke of the importance of respite, not just to give the family a break from caring duties, but to give the care recipient an opportunity to go somewhere away from the family and meet other people:

The family can love the person, right? But they can’t be their friend. They need friends and that’s where respite comes in ‘cause like respite is people that they interact with, people that they can befriend and my sister has developed lifelong friends because of respite.

Many young carers mentioned that they needed assistance with transport. B, for example, was not sure how her mother would be able to get home from hospital after her next operation. Other transport issues raised included difficulties with old cars, the cost of petrol, and cars that were unsuitable for wheelchair users. Domestic help was an identified need for a smaller number of carers: ‘We would like someone to come and clean in the house, but we can’t afford it.’

Importance of young carers camps

In many of the focus groups, participants spoke about the value of attending carers camps in order to get some time out from their caring responsibilities and having the opportunity to meet other young carers. Nevertheless, all were conscious that the camps only provided short-term respite.

Researcher: So how would you describe coming to these camps, in meeting other young carers?

S: It’s great

T: It’s like a holiday. It’s like having a break.

L: You get to be yourself. You get to be a kid again.

E: You get to be who you want to be, instead of having to help, you can just be free, be yourself.

T: Free for, like, three days. And then go home and you have to start again. [Agreement from other participants.] Well, what’s really difficult for me is the starting again part ‘cause I’m really bad at changing.

The older carers spoke of the value of attending the carer camps, in particular being able to meet other people in a similar situation. The camps made them feel better about their lives; more accepted, more relaxed, reassured, and created a sense of solidarity among them.

4.8 School and caring

The challenge of combining caring and school varied greatly according to young carers' responsibilities. This can be affected by the care recipient's illness or disability or how they are faring at a particular time. For some, caring generally had little impact on their schooling; for others, the demands of caring took a heavy toll on their education. Among the difficulties faced by young carers were poor concentration, tiredness, having to take days off school, and difficulty completing assignments. All but two of the younger cohort of participants were pursuing their high school education—one was undertaking TAFE studies and one had dropped out of school.

Poor concentration/fatigue

A number of young carers mentioned that they often had difficulty concentrating in school or on their homework, because their thoughts were so occupied with the needs of their care recipient.

It stresses you out a lot. So like doing homework and stuff, you have to find the time to do it first of all. And then when you do have the time you don't really feel like doing it, because you're so stressed out and emotionally drained. And at school it's the same, 'cause like some days you've just really had a rough morning and you have to go to school and do work and you just sit there half the time not taking anything in.

Others reported falling asleep at school, because they had to stay up late doing homework after they had finished their household chores and caring responsibilities.

Time off school

Taking time off school was a strategy young carers used to manage caring demands. At these times, the needs of the care recipient were given priority. Some young carers took time off to spend with their care recipient, or to manage household chores that were falling behind due to their care recipients' ailing health.

There's just times when you've got to take a break ... So I take three days off school while he's in hospital just doing things around the house that he would normally and stuff like that. So it can affect your school work, taking time off and not having time to do your homework and your assignments if you're really, really busy.

Difficulty completing assignments

Finding the time to complete assignments was a challenge for many young carers. Feeling pushed for time, failing to complete assignments or forgetting to do them at all were common complaints.

Sometimes you might have an assignment due, but you're so busy caring that you can't finish it.

Others reported having to stay up late to complete assignments because they were busy doing household chores and a few young carers caring for siblings with cognitive and/or behavioural disabilities said that their siblings sometimes destroyed their homework. Many young carers also reported sometimes having to arrive at school late due to their caring demands.

Teachers' awareness

Many study participants reported that their teachers were aware of their caring circumstances and in most cases understood, were supportive and gave them extensions on their assignments. Others felt disappointed by their teachers' lack of support, to the point that one young carer dropped out of school as a result of what she perceived as her teachers' lack of understanding. Other participants reported that even though some of their teachers knew they were caring for someone at home, they felt their teachers' priorities and their own priorities were at odds:

I think that it's only natural that I think that schooling takes a totally second position to caring. You know, I'm depended on, people are depending on me. I think if anyone was put in a position where they had two people depending on them and they had schoolwork, I think the people would definitely take the priority.

In another exchange, where a number of young carers expressed their disappointment with their teachers' lack of understanding of their caring situation, the hurt expressed by a 13 year-old female carer is evident:

It's just like, 'Live in our shoes for a day and see what it feels like.' That's really what I want to do is I want to tell them to live in my shoes for a day.

In some cases where teachers showed some leniency towards young carers by giving them extensions, the carers reported that their classmates would often feel disgruntled by what they perceived as 'special treatment':

People sort of go 'Why are you getting an extension?' ... But, you know, you just haven't had the time and that and a lot of them, you know they don't know about your caring situation. Most of them know about my dad, my friends, but they don't sort of know about my sister.

In a few of the focus groups, participants talked about school counsellors. While some found them supportive, others found their attempts to help them annoying. In one exchange, the young people expressed their impatience with their school counsellors. It became clear that what these young carers were looking for from a school counsellor was a sympathetic ear, not someone to tell them what 'strategies' they needed to put in place to achieve a particular 'outcome'.

Suggestions from the young carers to help them better manage school and their caring responsibilities included assistance with transport, more assistance with household chores from other family members and from formal services, and more awareness raising at school about the circumstances of young carers. This last suggestion was raised by several participants who said they were 'given a hard time' by some of their schoolmates and teachers who did not understand what they had to do as carers. One participant was very pleased that she could access tutoring and plans to do so when she is in Year 12.

Despite the evident strain of combining care and education, for many young carers school brings respite, a space in which they are able to pursue their own scholarly and other interests, to be with friends and play sport. Many were highly motivated students with clear plans for tertiary study. Many participants were able to indicate their future study and employment plans, but expressed some concerns as to whether they would encounter constraints on realising their aspirations.

Home schooling

A small number of participants had begun home schooling in recent years in order to manage the demands of caring and school. Pursuing their studies from home gave them greater flexibility to fit their caring responsibilities around their education. The perceived advantages of home schooling included being able to manage one's own time and being able to get extensions on schoolwork more easily.

That way I can stay home and ... when I get the five minutes here or there jump onto the computer and type up some extra work and assignments and that sort of stuff. And I find it gives me a little bit more, a lot more flexibility in my work and time at home.

You can have extensions. They understand if you don't get your work in. They're a lot more lenient.

T described a typical home schooling day where she fitted periods of study around her household chores:

We get up at 6.30 in the morning, have breakfast, get the parents, get [brother] breakfast and then we do the dishes and do the cat's tray and hang washing out. Basically that's called the morning chores. Then I sit down and I do some study, I get my lessons [for] about 2 hours or so. And then back on to like lunch chores and all that like getting lunch ready and all that, doing dishes and then back on to study. In between doing the study and stuff I have to help mum and dad like getting cuppas and stuff.

The participants did not, however, consider home schooling to be the solution for all young carers who were having trouble managing caring and school. S made the point that home schooling requires 'a tremendous

amount of discipline' and a supportive parent/adult to help keep the student's education on track. Moreover, the focus group findings showed that widespread use of home schooling would remove from young carers the 'respite' that school provides: their own space for education, friendship, sport and peer group interaction.

Young adult carers' reflections on caring and high school

Many of the young adult carers in the study were able to reflect on the impact their caring responsibilities had on their high school years. Some were able to identify the longer-term repercussions of an interrupted high school education and others spoke of how their caring responsibilities set them apart from their peers.

A number of young adult carers described how the pressures of caring led them to drop out of high school. One described how she 'went through a spiral' and made some bad decisions because 'I was rebelling against the fact that I had so much responsibility and I hated it'. However, she was pleased to report that she was back on the right track two years later. Another young female carer reported going through a similar experience. However, she was very conscious of the repercussions of dropping out of school, particularly the fact that she could not get into university, because she had done so badly in high school. Consequently, she feels that she is several years behind her peers on her educational pathway:

Like I finally figured out my path now, but I'm 22. I mean kids my age are half way through uni now and I'm still finishing off a TAFE course, so I mean that makes it difficult as well.

Other young carers reflected on their difficulty fitting in with their peers at school. Many felt that their caring experiences set them apart and made them different from their peers. This feeling of 'being different' coupled with the 'highs and lows' of being an adolescent meant a number of young adult participants reflected on their high school years as a period of emotional turmoil:

Then you've got the social hierarchy in high school and you know, are you in the popular group? Are you in the other group? And you're outcast if they know you've got a brother with problems or a family member or a sibling with a disability as well.

4.9 Post-school education, training and labour market participation

Among the over 18 year-old group of young adult carers, most were studying or in employment (n=20) or combining the two (n=10) and five were unemployed. Some were completing their High School Certificate and others were at university or TAFE. Courses of study included commerce, illustration, business administration, engineering, desktop publishing and education. The young adult carers' stories show that for many young carers who struggled to fit their caring responsibilities around their high schooling, this juggling act can continue into their post-school education and training.

Some described how they had less time to devote to study than they would like because of their caring responsibilities and others reported that sometimes they simply had to drop everything because their care recipient was unwell. Some students found their university teachers very accommodating of their caring responsibilities, whereas others were less so.

My sister went into surgery and yeah big, big stress in the family and my mother was talking to my lecturer and she basically said, 'Well she'll have to get over it and concentrate on her studies'.

[My university teachers] are so understanding with that kind of stuff. Like [head of school], I told her everything. I told her my life and what's been going on and she just said, 'If anything happens just get up and walk out. You don't even have to let me know.'

Many felt that more support should be provided on campus to students with caring responsibilities, while another commented favourably on the allowances the university admissions system made for people who had faced difficulties during their High School Certificate year, including caring responsibilities or illness.

Caring responsibilities can also encroach on some young people's employment. Some described how they would struggle to explain to their employer if they had to take time off work in an emergency. This contrasted

with the situation of another participant who had an understanding and flexible work environment; she worked in a group home for people with a disability. Another described how she had to give up work because her workplace would not accommodate her caring responsibilities by allowing her to reduce her hours of employment. For other young employed carers, caring responsibilities took precedence over work and other commitments, with some saying they had already told their families that, if need be, they would give up work if their care recipient's condition worsened.

I'm willing to pack it all in, my degree and everything, sell my business, stay home ... Like, I'd rather do that than watch my dad die.

Many young employed carers contrasted their situations with employed parents whom they regarded as being better accommodated by employers than carers. Again, this touches on norms and expectations surrounding care giving that do not envisage young people as care providers: 'If the employers understood our role as like a parenting role it would be so much easier.' The young carers felt that a little more compassion and flexibility from employers would go a long way toward helping them balance their work and caring responsibilities.

A young adult carer who was neither studying nor in the labour force explained that she was caring for a friend and enjoyed the role, because she knew she was needed and appreciated. For these reasons, she had no plans to look for a job in the foreseeable future.

I'm going to do what is right now, I enjoy caring, and that's what I'm going to do. So you know I'm not going to try and stress myself out and try and get a job because that's the norm.

4.10 Income support

A number of young adult carers were receiving either one or both of the payments Carer Payment or Carer Allowance. Some received Carer Allowance when they were at school and became eligible for Carer Payment when they finished high school. Applying for income support payments through Centrelink was generally perceived as a complicated process, with many having trouble completing the forms.

My mother is having great troubles getting the Carers Allowance or Payment; I'm not sure what it is, because of the difficulty of the forms.

Some of the young carers recognised that Centrelink needed to be careful when assessing eligibility for income support payments; however, they felt that this 'makes it hard for the genuine carers'. Some felt Centrelink needed to be more flexible in catering for the differing needs of carers and their care recipients. One young adult carer described feeling disheartened and devalued as a carer when Centrelink rejected her application for Carer Allowance, because her care recipient's disability was not considered severe enough.

4.11 Free time

As with most of the issues explored in the focus groups, discussions about free time highlight the significance of a young carer's position along the caring spectrum. The amount of free time the young carers enjoyed varied, depending on the intensity of the care they provided.

Some participants reported no constraints at all on their free time due to caring and reported being involved in a range of social and sporting activities typical of young people without care responsibilities. These activities included socialising with friends, going to the movies, playing PlayStation and X-box games, archery, cycling, sailing and playing football. For other young carers, however, free time had to be 'managed' or structured around periods when they were not 'on call':

The only time I can get away is when my mum's sleeping, but that's kind of convenient because the night time is probably my time of choice to go out and socialise.

Many carers fit their social activities round their caring responsibilities. Others combine social activities with caring responsibilities by participating in leisure activities with their care recipient:

We've had a horse for 12 months and me and [sister] share the experience of having a horse 'cause she is trained in it too. She's been doing riding for the disabled for years and I volunteered there so she got to a level where she's RDA [Riding for the Disabled Association] and now I'm continuing that with her.

My sister does a fair bit of sailing so I get to sail with her and do paralympics training.

Many of the young adult carers brought up the difficulty of fitting a social life around caring responsibilities. One participant described how she has to spend her weekends catching up with her studies, because her caring responsibilities take up so much time during the week. When she does manage to make plans with friends she often has to cancel at the last minute if her sister needs her assistance. Other carers described the difficulty of making and keeping plans, while others felt planning was futile: 'I hardly ever bother making plans 'cause ... most of the time I don't get around to doing whatever I want to do'.

Missing occasional social activities was a common complaint among young carers. Many expressed resentment that they had to miss social activities with their friends due to their caring responsibilities. For a smaller number of participants, the demands of caring curtailed their social activities to the point that they had to give up certain activities entirely.

Reluctance to participate socially with friends

Focus group discussions also revealed that some young carers were reluctant to take breaks or socialise, because they felt they should stay home and help around the house. In many cases, this reluctance is tied up with a sense of guilt about doing something for themselves, because the person they care for is at home or other family members do not cope as well when caring alone. Given the findings from the Australian data analysis in Section 3 that young carers are significantly more likely than their peers to live in low income households, it is not surprising that financial constraint was raised as a factor restricting involvement in social activities. It must also be noted that a number of focus group participants spoke of the stigma attached to disability and illness in a family, a stigma they felt extended to the young person providing care. As a result, they often restricted their own social activities to minimise the lack of acceptance they perceived in many of their peers.

4.12 Friendships and relationships

Friendships and relationships with peers were both a source of support and disappointment for young carers. Many caring for siblings reported that their friends were comfortable around their siblings, so their caring responsibilities had no detrimental impact on their friendships. On the other hand, others reported that their friends felt awkward around the person they cared for and made up excuses to avoid having to spend time in their home. One young carer caring for her father who had a mental illness said that when she invited friends around to her house, they made up excuses not to come. As a result, she has stopped inviting them to her home: 'If they show up, they show up, if they don't, they don't'.

Other participants reported losing friends due to their caring responsibilities. Their friends simply could not understand why they could not 'just drop everything to go watch a movie'. A young adult carer described how she fell out with a good friend who felt she always put the needs of her care recipient first.

I was really upset about it, but now I just decided that if my sister is the most important thing to me and if she can't understand that then I just don't need her in my life.

Others described being 'dropped' by their friends after the friends met their disabled sibling.

I've had people come to my house, like friends I know come to my house meet my brother and then don't want to talk to me again.

For some participants, their friends' ability to accept their caring responsibilities and the person they cared for was an indicator of good character.

It's the friends who do come in and say hi to my brother ... They're the ones who you can keep. They're good friends.

A number of the young adult carers spoke of the maturity that comes with age and how their peers were now more accepting of their caring role.

My friends understand that now that we're older and they come to my house they understand now. It's good.

I've had so many friends come and go in my life, and recently especially since once everyone's over eighteen, nineteenish they're usually very understanding.

Many reported that being a young carer set them apart from their friends and peers making it difficult for them to relate to them. These young carers reported feeling more mature than their peers and this was summed up succinctly by one young carer: '[Caring] makes us grow up a lot faster than we normally would'. Many felt they had outgrown their peers and were more inclined to befriend people who were older.

My mum says I'm a lot more mature than a lot of the people in my year and I find that I am because I see more things than what they do.

I can't relate to my friends as well as I used to. I've kind of outgrown them 'cause I'm more mature than they are now.

Because caring responsibilities curtailed social activities and gave many young carers different priorities to their peers, many felt awkward in social situations.

They're just like talking about parties ... You don't even think about things like that. You're thinking 'What happens if dad blacks out tonight? Do I do this, this, this and this?' And they're thinking about who's going to get drunk fastest on the weekend.

In one of the focus groups with young adult carers, participants spoke at length about 'the barrier' that develops between carers and their non-carer friends. This barrier was described as an 'uncomfortable atmosphere' that develops when friends met a disabled care recipient. In many cases, the young carers noted that their friends felt awkward or nervous and were not even conscious that they were putting up a barrier.

My friends are well intentioned, but you can see on their face they are so far out of their comfort zone. They just don't know how to deal with the situation.

On the other hand, participants did not encounter this barrier with other carers.

I could take anyone from here and introduce them to my brother and not flinch, not think twice about it, 'cause I know they'd be completely ok with it.

While many young carers reported losing friends as a consequence of their caring responsibilities, many also reported making friends through carer networks. The value of having carer friends was that they understood what it meant to be a carer and the problems and pleasures that go with the responsibilities. Moreover, friends who were carers understood that it was not always possible to make social commitments. In one exchange, the young carers discussed the difference between friends who are carers and those who are not:

Researcher: How do the friends here [at carer camp] differ to the friends you have at home?

Two young carers in unison: They understand. [Agreement from all]

J: They just know what you're going through, so you're not ... if you're feeling upset and that, they know it's to do with the caring role.

T: It's just that carers understand what carers are going through. It's like really, really understanding.

S: And you don't have to explain yourself.

The impact of caring on intimate personal relationships arose in the focus groups with young adult carers. Several described being in a relationship with people who could not accept their caring responsibilities or the person they cared for. In all of these cases, the relationship ended and many other focus group participants provided reassuring words of support to these young adult carers. The general feeling was that the young carer

was better off without their former boyfriend/girlfriend. One young carer who described her partner as ‘very supportive’ was aware that her caring responsibilities bothered him even though he never said anything to her. She recognised that the problem was that she often put her sister’s needs before his. Some young carers revealed they had formed relationships with other young carers and some were engaged to be married.

4.13 The emotional impact of caring

In each focus group, we asked the participants a direct question about how they felt about the activities they undertake in their caring roles. This section reports on their responses to that question. However, this provides only a partial insight into the young carers’ feelings. Feelings about caring cannot be examined in isolation from different facets of life and comments about school, friends and free time often provided additional insight into the emotional impact of being a carer. Nevertheless, when asked directly how their responsibilities made them feel, the young carers described a range of predominantly negative emotions, such as frustration, feeling overwhelmed, stress, guilt and annoyance. Occasionally some participants reported positive emotions and were able to identify good things about being a young carer (see Section 4.15).

Frustration

For some participants, feeling frustrated was part of being a carer. A number of the young people caring for siblings with cognitive disabilities felt frustrated with their siblings’ lack of understanding and cooperation when they were trying to help them.

Sometimes it gets a bit frustrating when you try to help him and he just doesn’t listen. Thinks it’s a joke and just keeps going and it just gets frustrating sometimes.

One participant felt frustrated with her younger brother who she felt was not pulling his weight around the house. Another caring for both her mother and stepfather explained that she sometimes felt frustrated with their lack of understanding about how much responsibility she shoulders.

The lack of community awareness of young carers was a source of frustration for another.

It’s just so frustrating that so few people kind of understand about being a carer. It’s not something that’s really talked about very often.

Many felt frustrated and resentful when their caring responsibilities interfered with their social activities.

When you have to forgo your friends and all those things are very important when you’re fifteen, sixteen; yeah that’s when I felt the pressure the most.

Feeling overwhelmed

Many participants described how their caring responsibilities sometimes left them feeling overwhelmed.

I wasn’t doing that much until my mum got diagnosed and then I was doing mainly all the stuff around the house. It felt like sometimes ‘Oh my god, why do I have to do it all’ and ‘I’m only a kid and I’ve got homework to do, I’ve got friends to be with’ and stuff like that.

Despite feeling overwhelmed at times, some young carers described how they have to just get on with it because there is no one else to take their place.

At times it gets a bit much and you get annoyed thinking ‘Why can’t somebody else be doing this?’ You know, ‘I’ve had enough of doing it’, but you can’t sort of stop because somebody’s got to do it.

Feeling stressed

The pressures of caring also left some young carers feeling stressed and emotionally drained.

It stresses you out a lot. So like doing homework and stuff, you have to find the time to do it first of all. And then when you do have the time you don’t really feel like doing it because you’re so stressed out and emotionally drained.

Feeling guilty

A small number of the young carers mentioned that they sometimes feel guilty that they are not doing enough to care for their care recipient. A 17 year-old female carer who cares for her autistic brother said she sometimes feels guilty when her mum gets stressed because she feels like she's not doing enough to help out. S, a 15 year-old male who cares for his mum, also talked about feeling guilty:

S: Sometimes I feel like I'm not doing enough to be [unclear] carer. And sometimes I might have a really busy day or something and then I'll realise or ... stuff like that.

Facilitator: So you have this sense of 'I should be doing more' or...?

S: Yeah.

Feeling annoyed

Some young carers described feeling annoyance when caring responsibilities cut into their free time. This was expressed by C, a 15 year-old female who cares for her sister:

It's kind of annoying sometimes, because you just want to go and have fun with your friends but you can't ... but it's nice to help out.

Feeling positive about care giving

A few participants reported that helping others made them feel happy and that it was good to be appreciated:

I wouldn't consider leaving my caring role. Like you know, I enjoy caring a lot. Like I know I'm appreciated and I get told that a lot, so I don't mind doing it.

You feel a bit better about yourself because you know that you're helping them 'cause they can't do it by themselves.

4.14 Health and caring

As with most other facets of young carers' lives explored in the focus groups, the impact of caring on health varied greatly according to level of responsibility. Some reported no detrimental effects while others described a range of physical and emotional impacts.

For some, the unrelenting demands of caring left them little time to care for themselves. As a result, many young carers reported always feeling run down and tired and that finding the time to eat properly was a challenge.

But I think with caring, it's not getting enough sleep, not looking after your own health, you know, a lot of stress and a lot of worry if you're worried about whoever you're caring for and that really runs you down.

The unrelenting nature of caring also aggravated the effect of minor illnesses and many indicated that they did not have time to relax and recuperate when they were sick, because there was always too much to be done.

When you do get sick, like a cold or anything like that, it's tripled, because your life just does not stop.

The demands of caring left a number of the young people in physical pain; for example, B reported having carpal tunnel syndrome in both hands and has problems with the muscles in her neck due to the physical strain of caring for her mother. The emotional cost of caring also took its toll on some young carers. One participant described how she moved out of home because she could no longer handle the strain of her mother's illness.

'Cause last year like basically every night she had a fit and one of them went for heaps longer, then she stopped and had another one about five minutes later ... And then I just couldn't handle it, so I went and lived with my Nan for a while.

Participants spoke of a range of ways in which care giving affected them emotionally: they might feel angry when demands on them became excessive; and feel emotionally drained by their ill family member's needs and

the manifestations of their illness. These focus group narratives corroborate the finding in the HILDA study, which found that young carers have a higher rate of self-reported poorer mental health than their age peers (Section 3).

4.15 The benefits of caring

The focus groups explored the young carers' perceptions of the benefits of the care they provided. All participants were able to identify benefits either to themselves and/or to those for whom they cared.

Responsibility

Many participants spoke of how they were more responsible or independent as a consequence of their caring responsibilities. In many cases, they made this assessment in relation to how they perceived their peers. For many, this responsibility was evident in the life skills they had acquired through caring, in particular daily living skills such as cooking, cleaning and ironing.

Responsibility. You learn how to take care of yourself, take care of the household. If you had to move out, I think we're a lot better equipped to look after ourselves than a lot of other people our age.

Maturity

Many felt that their caring responsibilities had made them more mature and wise than their peers. They saw themselves as having a more realistic view of the world, more awareness of other people's problems and awareness that life has both highs and lows. In many ways, this translated into being more patient, more perceptive, understanding, non-judgmental and stronger as a person.

I also think another thing is that I'm learning things and I'm experiencing things that a lot of people might not ever experience and a lot of people might not experience until they are older.

However, the costs of such responsibilities were sometimes also stated:

You grow up faster and you learn things faster and you learn things sooner than everyone else will. And I also think that in a way you kind of maybe don't get, like, all the teenage years ... and teenage experiences.

Strong family bonds

Participants also regarded the strengthening of family bonds and relationships as a very positive outcome of caring.

Having a sibling who is disabled I think created a really strong bond in our family.

Helping others

Other participants identified helping someone else as a key benefit of caring both for themselves and the person being cared for. One young person saw his caring role as important for easing the pressure on his parents.

Takes a bit of pressure off my parents if me and my other brother help out so they're not forced to do all the work 'cause they both work full-time and they're pretty tired at the end of the day, so it can be hard for them sometimes.

Additional benefits of caring acknowledged by the young adult carers included the rewarding aspects of observing improvements in the health and wellbeing of their care recipient, improving their quality of life, and developing a more caring perspective. One young adult in particular felt that being a young carer instilled a sense of pride.

So I feel like the caring role is a blessing in disguise almost. Not at all times, but when you get that sense of reward, when you see the benefits of your work, yeah you have a sense of pride. And to know that, to give it a name, to say that you are a young carer, yeah it affirms that.

Acceptance of people with disabilities

A few participants felt they were more at ease with people with disabilities because they lived with someone with an illness or disability. For some young carers, this acceptance of people with disabilities extended to greater acceptance of all people.

You just see each person for who they are more, because you had to see through a disability in one person and you start to see through all people in the same way.

Many participants stressed the importance of respecting the rights of people with a disability. For one participant, the lack of interest and acknowledgement accorded to young carers was secondary to the lack of respect shown to people with disabilities.

Friendships

Some participants felt that caring had opened up new friendships to them. Many described how they lost friends as a consequence of their caring responsibilities and were relieved to have the opportunity to meet and befriend other young carers through networking opportunities such as Young Carer camps. Again, this provides an interesting example of how young carers negotiate the consequences of caring that produced the loss of friendship in the first place.

4.16 Future aspirations and constraints on realising them

On the whole, the young carers in the study had high aspirations and were optimistic about their future. They anticipated achieving their goals, even if it took a bit longer than they would ideally like. Many had occupational aspirations that were clearly shaped by their experience of being a carer. The jobs to which they aspired included medical doctors, veterinarians, an occupational therapist, a rescue paramedic and psychologist. Others were keen to draw attention to the issue of young carers through political lobbying and public relations work. Many were conscious that caring had shaped their plans and could identify the benefits of their caring role. S, for example, felt that caring would help her get into medicine, because entry requirements include passing an interview.

I think people who care have a lot more empathy and sympathy than a lot of mainstream students who are going through so I think that would be a big plus for it.

Other occupational aspirations included joining the army, teaching, policing, farming, being a butcher, modelling, architecture and acting.

Future plans the young adult carers expressed included traveling, buying a house, getting married and having children. For some young adult carers, however, moving out of the family home was constrained by the demands of caring. Some expressed a reluctance to move far away (or at all) from the family home, because they did not want to move away from their care recipient and wanted to be available to support their family.

I think location will be a big thing in that I don't want to be too far away from my sister.

Like no matter where I am I always want to be close to my family even when I've moved out.

For others, guilt was a factor influencing their reluctance to move out. Others did wish to move far away, but felt it was not an option given their caring responsibilities.

If you speak to my friends they're all like 'I want to move as far away as I possibly can'. That's not really an option for us.

A number of the carers envisaged their caring role would continue and could see that it could place some constraints on their future plans. One young carer said that she would probably have to study part-time; another was accepting of the constraints of care when he spoke of achieving his goal 'whether it takes 15 years or four years'. Other concerns the young carers expressed included what would happen if anything happened to their healthy parent and what would happen if the disabled parent's condition worsened.

The only thing that sometimes I worry about is like, it's awful to say, but when, if my mum dies, who's going to look after my dad? I'm the oldest. Will his mum do it? She might be gone. Who's going to do it? Or if my dad goes, who's going to look after my mum?

4.17 Discussion

The rich sources of evidence and understanding emerging from the focus group research is illustrative and illuminative of the findings of the analyses of the national data sets: *Census of Population and Housing 2006*, *ABS Survey of Disability Ageing and Carers 2003* and the *HILDA survey 2005*.

It is evident from listening to the young carers who participated in this project that young care giving is constituted by a diverse set of experiences and circumstances, affected by:

- the age of the carer and their relationship to the person/s for whom they provide care
- the intensity of their care giving responsibilities
- the period of time over which they have been carers
- the extent to which they receive support from family members and are able to access formal support services
- the extent to which they are able to draw upon close friendships, in particular with other young carers.

What is overwhelmingly apparent from the focus groups is that despite the diversity of experiences, young carers show levels of commitment, courage, generosity and understanding well beyond what might be expected at their ages, and well beyond what general community perceptions hold of young people and their expected contributions to family life.

For young carers, as noted in the theoretical framework of 'social care' (Daly & Lewis 2000):

- **Care is labour** that is very likely to occupy time, which might otherwise be available for participation in education, training, employment and social/friendship activities. The labour aspect of young care giving is evident with respect to the multiple care giving and household activities, including physical and emotional supports which young carers provide, sometimes with few informal and formal support services. The areas of young people's lives most affected by care giving include their schooling; for older carers, their employment; and for all young carers, their opportunities for friendship and social life. However, the diversity of young carers' responsibilities and the continuum of intensity of the care they provide must be recognised, in that age and intensity of care interact to determine the impacts of care on other life domains.
- **Care is located in a normative framework** within which young people may not identify themselves as carers but as family members carrying out their expected responsibilities and obligations. This is the context in which many young people express the view that despite the evident strains of care giving they are able to identify, they nevertheless express the wish to continue with their responsibilities so as to protect the strength and integrity of their families and contribute to the health and wellbeing of the person for whom they care. However, when they do identify themselves as carers, and do become aware of the range of supports and services that may benefit their care recipient and themselves, they are able to identify a range of supports and services that would enable a genuine private–public sharing of the responsibilities of care in the case of their own families.
- **Caring incurs costs**, which may include the strains imposed on combining education and care, entering further training, and combining employment and caring. Caring may frequently carry costs to friendships and social life, and costs to emotional and mental health. Most significantly, the evidence of these focus groups, combined with findings from the analyses of the national data sets outlined in Section 3, is strongly suggestive of the financial strains imposed by both care giving and disability or long-term ill health within the family. Financial strain is evident with respect to many domains of young carers' lives, illustrating what the quantitative analyses show—that the household incomes of young carers are likely to be significantly

less than the household incomes of their peers. This is especially important with respect to perceived lack of access to services, and to missing out on those aspects of life that might relieve the care giving burden and the burdens of ill health and disability.

- **Young carers identify benefits as well as costs:** they perceive profound contributions to the wellbeing of the care receiver and the whole family; they see their caring responsibilities contributing to the wellbeing and integrity of the whole family. Young carers also perceive that they acquire valuable skills, including a sense of maturity, independence and a deep sense of achievement, which they believe should be much better recognised and more widely valued and respected.

The young carers identified formal services that they and their families receive and appreciate and that they would like to see more widely available. They noted, in particular, the importance of **adequate financial support**, given the costs of ill health and disability and the constraints imposed on their parents' employment; and of **respite care for longer hours** for their care recipient to benefit both the care recipient and the young carers themselves.

Longer respite care is especially needed so the young people can be relieved of the time strains on their education, and can participate more with their friends and in social activities—and so all involved in the care relationship can 'have a break' from the intensity of care giving. Assistance with domestic activities, and especially with transport, was often emphasised. Further, to relieve the strain of balancing education and care and employment and care, focus group participants spoke of the need for schools, universities and workplaces to institute more flexible arrangements to fully and appropriately recognise their care giving responsibilities.

5 Qualitative analysis—focus groups with policy makers and service providers

5.1 Introduction

This section presents findings from discussions with policy makers, service providers and carer advocacy organisations. Two focus groups and one interview were conducted with 16 service providers and policy makers between April and July 2007. Participants included staff from government departments whose programs and services cater to the needs of young carers and their families; a range of representatives from carers associations across the country; as well as other non-government community services organisations providing care services and programs for people with disabilities and their carers.

The purpose of these focus groups and interview was to identify beneficial policies and services that are currently in place and might be extended and developed to support young carers with respect to:

- school retention and balancing care and education
- entry into and retention in further education and training
- labour force entry and ongoing labour force participation
- participation in social and friendship networks.

The focus groups also explored:

- the extent to which young people who provide informal care identify themselves as young carers
- strategies for identifying hidden young carers so age appropriate supports may be provided to them
- what the participants in the focus groups saw as the support needs of young carers and the service gaps.

The following analysis is based on interviews, focus groups and meeting minutes with policy makers, service providers and carer advocacy organisations. The participants in the research worked in policy development and administration, advocacy, information and referral services and front-line delivery of support services to young carers.

5.2 Participating organisations' programs and services for young carers

The organisations that participated in this research provided services and programs for young carers that most commonly included: information and referral; respite, camps and social activities; and educational support, most often through tutoring programs. Each area of support is detailed below.

Many of these services were funded by FaCSIA as part of the former Young Carer at Risk Program, designed to support young people up to the age of 25 years who are at risk of not finishing secondary education because of their care responsibilities. Young people may engage in this program for up to 12 months. The FaCSIA Young Carers at Risk program provides young carers with access to up to five hours in-home respite per week during

school term to support their attendance in education or training. Young carers may also apply for a fortnight of respite care each year to undertake activities, such as studying for exams, training or recreation.¹⁵ This program provides a flexible approach to respite. Young carers may consolidate the five hours per week of respite available, or help shape the two-week block of respite.

State and territory departments also fund programs, and some services negotiate corporate sponsorship or grants to contribute to the services they provide for young carers. Carers Australia and the state and territory carers associations operate programs specifically for young carers. A number of the service providers who participated in this research were part of the young carer programs in these associations. The manner in which these services are delivered is diverse and the participants described many creative and individually tailored approaches to supporting young carers. In addition to direct support for young people, the service providers spend considerable time developing and maintaining networks through which to promote their work and to help develop an understanding among other service providers, teachers and school counsellors, and health professionals (among others) about young carers and their needs.

Information and referral services

Information and referral services are often at the centre of the programs provided for young carers by the organisations whose staff participated in this research. Service providers want to inform young people, who may not identify themselves as carers, about the services and supports they might access and to provide them with referrals to mainstream services that might support them in their care roles.

Young carer service providers use a range of mechanisms to inform young people about the support services for which they might be eligible. They provide information about local services through personal contact by telephone, home visits, recreation days and camps, and through these contacts make referrals to other services. The service providers also visit schools and address the students to inform them of the kinds of services young carers might access. Officers in each state and territory carers' association provide information and referrals to counselling services. Written information is also provided to young carers in information kits developed by Carers Australia, in newsletters and youth media, such as magazines. Carers associations operate a free-call and email information service.

Respite, camps and social activities

Recreational and social activities are designed to serve three purposes, to:

- alert young carers and their families to the services available to them. For example, a few services hold information days that combine fun activities with guest speakers or other forms of information provision.
- provide young carers with opportunities to meet other young carers and to participate in recreational activities, typically with other young people, but not necessarily young carers. Service providers spoke of providing assistance so young carers may participate in sports training and competitions, or music lessons.
- bring young carers—and sometimes their families—together. Camps are a common means of implementing this element of the services. As well as providing young people with opportunities for social participation and recreational activities, these events are intended to help them connect with other young carers and create supportive networks, give young people some respite from their care responsibilities, provide information, offer counselling services, and develop a range of skills associated with managing care responsibilities, completing school requirements and maintaining good health and wellbeing. One example of such a camp was a rugby league coaching camp for Aboriginal young carers that introduced young Aboriginal men as mentors.

One service provider described how their service used social interaction to encourage all carers, including young carers, to create their own support networks:

I coordinate a number of social support programs and that is to facilitate carers to establish their own networks, their own social networks and or peer support. And the young carer program becomes part of that ... We have a slightly different approach in [state]. We're the only state that runs a comprehensive social program and we use that as a

gateway for carers. It's bottom-up service really, which means carers can enter when they feel comfortable and actually access the service when they're comfortable with it. And they use that as a gateway to engage other services such as systemic advocacy, counselling or training and education.

Educational support

Given the focus of the Young Carers at Risk Program on helping young people complete high school, educational support was one of the more common forms of support service providers offered. Service providers indicated that they arranged tutoring, homework clubs, and a homework centre with computer equipment and tutors. During the focus groups two examples of state-based programs were described. First, the South Australian Government under its School Retention Action Plan has a program for helping young people who leave school early or are at risk of disengaging from school well before school leaving age, and for recognising young people with care giving responsibilities as one of the groups needing support and flexible schooling programs (South Australian Government Social Inclusion Unit 2006). Second, the New South Wales Government in its *Carers Action Plan 2007–2012* states that attention will be given to further developing resources for school principals, counsellors and year advisors to enable better recognition of young carers and their educational needs (NSW Health 2007).

Innovative, individually tailored support

The young carer service providers are creative and careful in ensuring that the support they provide is tailored to the needs of each young person. In this they are in accord with policy makers who emphasise the flexibility built into the guidelines of the Young Carer at Risk Program. One service provider, who said that 'sometimes it is the small things that make a difference', spoke of the diversity of support she could provide.

So it could be shopping, cleaning the house, personal care for the day, tutoring, transport, financing piano lessons, tennis lessons, school camps, movie vouchers. Really a broad range and I think that's what it needs. This service is so flexible, and it really needs to be.

5.3 Identifying young carers

Young carer service providers and policy makers are concerned with the issue of identifying young carers. They observed that young people rarely identify themselves as carers with support needs, and are therefore outside the reach of service provision, or recognition in the school system. This corroborates the observations made in the focus groups with young carers themselves, that many had been caring for a long time before they recognised or 'named' their status as a 'young carer'. Participants in the service providers/policy makers' focus groups stated that organisations, including health and community services that might provide young carers with support, often failed to recognise their existence, and overlooked them as potential service users. Participants regarded this a critical issue for young carers, because without recognition that young people may have considerable caring responsibilities, their circumstances are likely to go unnoticed and their needs unmet.

Identifying as young carers

Policy makers and service providers agreed that young people rarely regard themselves as young carers. They observed that young people rarely approach services of their own accord, unless they are referred to services by school staff or by other formal contacts, since they accept and carry out their responsibilities as an integral part of family life.

They just do it, because it's what they do, and they've always grown up with it, or they're taking it on for someone else in the family.

They don't like the word 'young carer' and they don't identify, so for them it's not a name that fits for what they're doing for their family.

This confirms the findings of the focus groups with young carers, many of whom spoke of not recognising for a long time that they shouldered greater responsibilities than their peers. Before coming into contact with young

carer support services, most simply saw themselves as young people ‘helping out’ other family members. This speaks to the normative framework of familial obligations in which care is embedded (Daly & Lewis 2000).

Both service providers and policy makers agreed that the number of ‘hidden’ young carers is substantially greater than the number of young carers who are in contact with service organisations. One participant made the following estimate:

If you look at the whole school system ... basically you’re averaging one in every two or three people within each class has caring duties. There’s a huge number in the school who have a common bond and yet there’s reluctance to identify.

Another explained that the very long-term nature of many young people’s care responsibilities made it crucial to identify them at a young age. This is because, in her professional experience, being a carer while young may be the precursor to an adult life undertaking informal care, if opportunities to complete school, enter tertiary education and training and employment are not provided and if the young person is not able to participate fully in these domains.

Service providers identified a number of reasons for young people remaining hidden as carers. ‘The word “carer” has all sorts of connotations’, observed one participant. These include a sense that caring is the responsibility of the parents, with the result that it might seem inappropriate for a young person to describe themselves as a carer.

The carer seems to have been stripped of their job, and their responsibility for the family to provide for their children [but instead] the children are providing for the family or parents.

This could affect a family’s view about whether a young person might be eligible for income support, particularly if another family member is receiving carer-related payments. For example, in a family where a parent receives Carer Payment or Carer Allowance, the young person might not feel they could or should describe themselves as a carer. As one service provider explained:

Their initial reaction is, ‘Na, na, na. I’m not the carer, mum gets the pension’.

The term ‘carer’ is also associated with older people providing care, ‘the old lady whose husband has had a stroke’; so young people might respond ‘That’s not me, that has nothing to do with me’. Sometimes ‘carer’ seems inappropriate because the care work is intermittent, as it is likely to be for children of parents with mental illness.

The service providers understood that the reasons culturally and linguistically diverse young carers might remain unidentified differ between cultures. However, they observed that there is a strong expectation in culturally and linguistically diverse families that young people will provide care.

With the young person of culturally and linguistically diverse background, there’s often a cultural background that says, ‘This is the way we care when they’re this age ... this is the family way we do it’. And the young carer is just a part of that. But they don’t, they’re not set apart and the families don’t go out of their way to set them apart either, and say, ‘Oh, but you do a caring role’ and ‘You’re a young carer’ and ‘Let’s get you this’.

Another service provider noted that explaining about care responsibilities and available resources to culturally and linguistically diverse young carers involved an additional barrier due to a lack of cultural knowledge on the part of the service provider. It was also felt that some young people are reluctant to refer to themselves as young carers because they fear the reaction of their peers and teachers; negative reactions which are often grounded in the stigma surrounding both physical and mental disability.

Young men are thought to be considerably less likely than young women to identify as carers. Participants saw two reasons for this, both relating to gendered expectations about care. First, if a young woman is available to do care work in the family, then a young man in the same family might not undertake care. Second, in cases where young men are providing care, it was felt they would be less likely to admit to it, or even recognise it because taking on a caring role contravenes social expectations of masculinity.

One service provider, who knew a sister and brother who both provide care for another sibling said:

Young female carers are much more likely to be open about their caring role, whereas young male carers, they do it and do it frequently ... but are not as open about what they do.

Further, with respect to the gendered nature of recognising themselves as carers, there was general agreement in the focus groups that young women use young carer support services more often than young men.

However, despite the many reasons young people might not readily identify as young carers, service providers felt that for some young people accepting the label of 'young carer' was empowering.

I asked one of our young carers what she thought of the term 'young carer' and did she like it. And she said at first she thought that it was really foreign to her and she thought, 'No, I'm just looking after my sister. I don't know what this means.' And then she said, after she understood what it actually meant, she realised that actually was what she did. And she accepted that label and she's okay with it ... Some people find they go, 'Yes, thank god, that is what I've been doing. There's something here for me.'

Again, this corroborates the findings of the young carers' focus groups that described how finding out about the label of 'young carer' was a welcome revelation because it was an acknowledgement of the responsibility they had and an acknowledgment that they helped others. Further benefits of accepting or learning about the label 'young carer' included being able to tap into networks of other young carers and being able to seek formal support.

Very young carers

Participants observed that very young carers, those in primary school, might face greater difficulties than older young carers in accessing support services. This might occur for two interconnected reasons: lack of recognition that young children could provide care, and concern that it is inappropriate for young children to have care responsibilities. These factors could affect parents' support for their children's participation in support programs, as well as affecting service providers' acceptance of young carers into the programs. These concerns echo what has been found elsewhere in the literature: the notion that a young person may have significant caring responsibilities contravenes social norms and expectations surrounding provision and receipt of care.

One service provider commented that some parents were reluctant for their children to be designated as young carers and participate in young carer programs because they were afraid that child protection authorities might remove the children. Again, the Australian and international literature has identified this concern about unwelcome intervention from child protection authorities. Another service provider said it might be inappropriate for children under the age of 11 or 12 years to be significant providers of care in their families.

I'm very cautious of child protection and I think that if you have like an 8 year-old person to care for mum or dad, I think that's too young to be a carer. The wellbeing of the child is a very big thing; it's not just a carer issue.

It should be noted that participation in the Young Carers at Risk Program has an upper age limit (25 years) but not a lower age limit. In a meeting with program workers, a policy maker stressed the importance of flexibility regarding ages. The policy maker pointed out that, while the program targets young people who might not complete high school, children who struggle in primary school are likely to face difficulties completing high school: therefore, their participation in programs should be encourage and supported.

Lack of recognition of young carers by services and organisations

The service providers felt that young carers were overlooked by many organisations and services in many circumstances. This meant they were likely to remain hidden, and as a result their care work was not recognised, their eligibility for support was restricted and they were unlikely to be treated as care participants in the family.

For example, some service providers noted that young carers often remained invisible and their roles unrecognised when their family member engaged with health and medical professionals. Despite their often-detailed knowledge of their care recipient's medical needs, young carers tended to be ignored by health and medical professionals with regard to treatment and the implications of the care recipient's condition on their care responsibilities. While service providers recognised it was not always appropriate, for privacy and confidentiality reasons, to include a young person in discussions with medical practitioners, they were concerned that young carers remained almost entirely invisible and outside the formal health care process. Two service providers discussed this issue:

A: It's the recognition factor. Even if they do know about carers, the person comes in and they don't go, 'Hang on a minute, who brought you here and are they okay?' They just don't do that.

B: And they would never talk to kids.

A: No they ignore kids.

One service provider described such a situation as one in which young carers were seen as children and, as children, not regarded as active participants in provision of family care. This lack of recognition contributes to young carers remaining hidden.

Failure to recognise that young people provide care may also result in their use of support services or receipt of financial support being restricted, either through formal eligibility criteria, or through a denial of service due to staff interpretation of who qualifies as a carer. Policy makers noted that some respite services had age restrictions that effectively excluded young carers. One service provider described the reaction of mainstream services to the needs of young carers:

I find that when I refer a young carer to the mainstream service the answers are horrendous, from a 15 year-old looking after her mum. 'Where's dad?' 'A—none of your business', 'B—this is a bad situation', 'C—we don't refer children', so it's a lot of ... red tape and boxes.

This service provider felt the mainstream services were ill-equipped to address the needs of young carers: they did not understand the circumstances of young carers; they did not have appropriate services to offer; or had eligibility criteria that denied services to young people.

5.4 How young carers access support

As noted, rarely did young people seek out and approach services independently; they were usually referred to the program. One exception was direct contact through Carers Australia's email service. The association had run a 1800 telephone call-in service, but found that young people rarely called the number because its operating hours coincided with their attendance at school or work. However, the email address was very popular. Staff believed that one of the advantages of email contact was that it allowed young people to communicate with the service while remaining anonymous; they could approach support with caution, getting to know the staff and service before initiating face-to-face contact.

Staff described two key routes through which young carers found out about young carer programs and support services. One was by referral through other organisations and the other was through word of mouth. Service providers spoke of young people being referred to their services most often through community organisations or schools, either by school counsellors, teachers or school nurses. In addition, service providers mentioned referrals coming from other counsellors, hospitals, social workers in hospitals, youth services, respite centres, other young carer organisations, community nurses, detention centres, drug and alcohol programs, neighbours, Big Brother and Sister programs, government departments, aged care assessment teams and mental health workers. Carers associations used existing networks to find young carers. Policy makers noted their reliance on existing networks. Participants felt that carers associations could find young people who had 'fallen through both the education and welfare nets', particularly young people in regional and rural areas, and among culturally and linguistically diverse and Indigenous young carers.

The service providers reported that many young people made contact with services because they had heard about them from other young people. In some cases, young carers' parents contacted the service seeking support for their son or daughter. Parents often found out about young carer services through other parents, for example, at specific disability or illness support groups. Not surprisingly, given the importance of word of mouth to promote the services, one service provider noted that a one-on-one approach seemed to be the most successful way of encouraging young people to attend or their parents to permit attendance.

5.5 Finding hidden young carers

Encouraging young carers to use support services

The service providers noted that they undertake a range of strategies to encourage young people who do not identify as carers to use their services. These address the two key elements that workers perceive as inhibiting young carers' use of services. The first involves encouraging young people and their parents to use the services, without expecting them to identify as young carers. The second involves encouraging greater recognition and referral of young carers by other organisations. Service providers persuaded young people to use the resources their service offered, telling them they were there to be shared, or that 'young carer' was just a project name, that young people could use the service without identifying with the label.

Another service provider used a similar strategy, describing the actual range of services, rather than referring to the services as being for 'young carers'.

I say I work with young people, and some look after their mother, some look after their dad, some look after their siblings. I don't say I work with young carers, I tell them what I am doing and I break it down, because I think, personally I don't like the labelling. I don't like to put the labels out there, 'You're a carer' and 'You're a care recipient', 'You're a migrant', and 'You're an aged person'.

Okay, you are doing the shopping, the cooking, the cleaning and you look after your brothers and sisters. I work with young people like yourself. I think it makes more sense.

Such an approach, she felt, made both parents and young people more comfortable about seeking assistance from her service.

However, one service provider explained that time placed limitations on such an approach, as there was not always sufficient time to have lengthy discussions with young people. Sometimes service providers could only describe the service and hope that the young person would make contact later.

One service provider explained that although parents might not regard their child as a young carer, when the program sent a survey to the parents, they would then be surprised to discover that the child was actually classified as a young carer. This can enable parents to be more comfortable about their children's participation in the program. Another service provider spoke of the need for considerable sensitivity when approaching young carers. For example, if a parent did not recognise that they had mental health problems, they might become angry with both the young person and the service provider if it was suggested that the young person was a carer in need of support. This type of situation needed direct contact with the young person, often through school counsellors.

Other approaches taken by the service providers include:

- a social program for all carers that acted as a gateway to other services
- advertising in the general carers newsletter, which some parents read
- media campaigns, especially in magazines that target young people.

Developing networks to encourage referrals

Service providers described spending considerable time developing and maintaining networks through which they shared information about their service and encouraged referrals from other organisations. They saw this as a role that included educating organisations about the existence of young carers and how they might be identified, as well as informing them about the existence of support services. They described promoting their work in a variety of contexts with a wide range of people and organisations including Aboriginal and Torres Strait Islander Liaison Officers, medical services, Home and Community Care Officers, disability services, Indigenous elders, school counsellors, youth services, youth clubs, interagency meetings, presentations to schools, social workers in hospitals and family support services.

One service provider described this aspect of her role as follows:

Because the work for young carers is fairly new in [this state], the focus of my role is in developing networks of service providers. So raising awareness of young carers, particularly across the state, developing networks of service providers, networks of young carers.

Another service provider spoke of the importance of support from within Indigenous communities:

I am fortunate enough to help with two Koori ladies, so there's that link with the community. I got together with them. They take posters and flyers and pass them around the community.

These contacts ensured that information about young carers was made available to the communities.

Finding young carers in schools

Policy makers and service providers recognised the importance of schools as a major venue in which young carers might be found. For this reason, Carers Australia has developed information kits for teachers in high schools and KidsMedia has developed kits for primary schools. Service providers described mixed success in promoting their services through schools or encouraging schools to refer young carers to their service. While all agreed that schools are a central contact point, not all workers had found schools to be responsive or understanding of young carers' circumstances. Nonetheless, when schools are receptive, they can be a highly effective venue through which to bring information to young people about young carer services.

5.6 Addressing the main problems young carers face

Low income and poverty

Service providers identified low income and poverty as central issues that shaped many young carers' experiences and affected their capacity to engage in education and social activities.

Absolutely across the board, because caring has a cost, a financial cost.

It would be rare they felt, for the costs of care and the drain on available income not to be part of a young carer's family problems.

One service provider said that even among families with higher levels of income, care could be a significant drain on resources.

There's a section that are reasonably okay, but the cost of caring means that it's not just something that comes with a low income.

One service provider linked young carers' low incomes with their parents' receipt of income support because they were often not in employment. She reported that most families with whom she worked were lone-parent families relying on government income support; other young carers were in two-parent families, some of whom also relied on income support, usually as a consequence of disability or chronic illness.

A great need existed, among those on very low incomes, for basic items and for school materials. Two service providers had the following exchange:

A: Some carers can't afford schoolbooks, they can't afford school clothes, they can't afford ...

B: Telephone, hot water ...

A: Yep, it's quite huge. And expecting a kid to go to school and not be in the same clothes, or even to buy a uniform. Getting into trouble from their maths teacher because they know they can't pay for their maths book, and then losing part of their grade. It has a real impact.

One service provider felt that financial disadvantage framed the experience of all the young carers with whom she worked.

Services could sometimes provide funds to assist a young carer in some way, for example, in education, or in social activities, in this way alleviating some of the restrictions young carers face due to their limited financial resources.

Both service providers and policy makers in the focus groups discussed the issue of access to income support for young carers. Service providers reported that young carers face a great deal of complexity when applying for either Carer Payment or Carer Allowance. The service providers reported attempting to support young carers to negotiate their way through the application process, but one said the process was confusing and that more information and guidance was needed.

I will say the information we get from Centrelink is difficult but definitely more clarification about the younger carers and some clarity would be particularly helpful.

Young carers may be eligible for income support in the form of Youth Allowance or Carer Payment, or be eligible to receive Carer Allowance, provided they meet the criteria. According to the perceptions of many service providers in the focus groups, one of the issues young carers applying for Carer Payment or Carer Allowance face is lack of recognition that young people can even be carers. One service provider relayed the experience of receiving a call from a Centrelink staff member who asked:

'Can young people be carers?' ... And I've already done this presentation to the social workers at Centrelink, but he wanted me to help support him in his conviction that it's not appropriate and he should reject the application. But that happens. They don't know.

Another service provider said that while a few young people did claim Carer Allowance or Carer Payment, this was not the case for many because, she believed, 'they are not recognised as a carer'. However, one service provider noted a mechanism that might help identify young carers: any young person aged under 16 years applying for income support be automatically referred to a Centrelink social worker, who might be in a better position to recognise the young person's caring responsibilities and identify appropriate forms of income support for which the young person might be eligible.

Beyond recognition as young carers, applications for Carer Payment were further complicated by the requirement that carers not spend more than 25 hours per week in education or employment. The service providers noted that it was difficult for young people to meet this requirement while enrolled at school. Policy makers noted that an alternative form of support for young carers might be Youth Allowance, and young carers might be exempt from activity testing due to their care responsibilities. Some policy makers were less certain of the appropriateness of providing income support like Carer Payment to young carers, and worried that 'giving a young carer the Carer Payment could set them on the road to welfare dependency in the long term'. However, some staff also noted that 'a young carer is often doing the same work as an adult carer and therefore should be eligible'.

Education

While service providers and policy makers alike identified education as a key area of difficulty for young carers, they also viewed it as an institutional setting in which young carers could gain a great deal of benefit. Central to young carers' problems with education was a lack of recognition of their responsibilities. The

difficulties young carers face include interrupted attendance, late arrival at school at certain times, difficulties completing homework and assignments on time, and stigma associated with the illness or disability of their family member. For young carers, the benefits of continuing at school are primarily ensuring the successful completion of their secondary education with the subsequent opportunities this confers, compared with early school leaving. In addition, the school may provide a valuable point of contact for referral to support services, a cherished space to meet with friends, a form of respite from care work and a 'normalising' influence. Participants described school as very often a 'respite' for young carers and essential to their wellbeing.

Not only did service providers believe education to be a highly important matter for young people, but they also felt young carers themselves gave education high priority.

A lot of the kids are very, very keen on tutoring. And I think that is firstly because their school work is behind because of their caring role because mum and dad may not be able, or don't have the time to help them with their homework, so they're behind. But I think also the help keeps them in the stream so they can catch up in school and be like everyone. And they just want to fit in. I'm surprised because I thought they would want more time with their friends, but the majority of them want tutoring even during school holidays.

The service providers spoke of a lack of recognition by schools of young carers' responsibilities. For example, they told of young people trying to explain why their caring responsibilities had interfered with their education, but their explanations were not viewed as legitimate. Such experiences can result in a lack of confidence by young people that their care responsibilities will be recognised on future occasions.

This young girl told everyone who would listen about her dad, and the dementia, and whatever else, and it didn't help. So that makes young carers resistant to even bringing it up.

One service provider said young carers need understanding and appreciation of the challenges they face; however, they do not want this to be 'shouted from the rooftops'.

First and foremost, the young carers want to be listened to, but they want to be believed. Like, 'I'm really not lying when I say my homework is not done to an acceptable quality because my sister has autism and she didn't sleep last night. That's really not a lie.' So it's not being listened to, being believed. I was talking to someone and she goes, 'Oh, you don't have to spend a lot of money in developing services for young carers in schools, just have your school systems understand them, believe them, and provide flexible options for them.'

Another service provider added that ideally schools would have:

That awareness and that lens from which to understand, you know, if there's a child in the classroom that they're worried about, just to consider—would they be a young carer? Rather than being quick to think that that person is just lazy or they're disengaged or they're not reaching their potential.

One service provider felt it was widely believed that young people would like to have a single contact point in the school, someone such as a teacher, psychologist, pastor or school counsellor who understands their circumstances and helps them negotiate their way through education problems. Another mentioned the need for flexible school programs that could accommodate the needs of young carers. Such programs would provide young carers with access to study materials in advance, so they can draw on them to study when they have the opportunity. Policy makers suggested that flexible programs similar to those provided for young mothers who remain in school education should be available to young carers. One example of a flexible education policy is 'Step Up Community Learning' for South Australian high school students through which young people can seek recognition in their school assessment of the skills they have developed through care provision.

Respite care for the care recipient could be of great assistance to young carers who are studying. One service provider mentioned that some young carers go home from school at lunchtime to check on family members; if respite care were provided, a care worker could do this check instead. Similarly, if the young person had access to a telephone at school, they might be able to phone home instead of visiting in person. Services, such as cooking the family meal so young people can complete their homework, were also mentioned as measures that might make a positive difference. While some services of this nature do exist, the service providers stressed they were only available in the short term. The participants noted further complexity that could arise for young

carers from culturally and linguistically diverse backgrounds in their schooling, especially if the young people were trying not to divulge the details of the illness or disability affecting their parent.

The service providers noted that young carers' problems negotiating education do not cease at the end of high school. Young people considering or undertaking tertiary studies also face challenges due to their caring responsibilities. Young people's access to universities and TAFE are inhibited by, among other things, an inability to spend the length of time necessary to travel to campus and an inability to find other formal or informal care givers who could provide care in their absence.

Social and recreational opportunities

Service providers echoed the findings of the young carer focus groups, when they recognised that young carers often found it difficult to participate in social and recreational activities, due to lack of time and financial resources, difficulties with transport, stigma about illness and disability, and lack of opportunities to take part in social events.

In recognition of the importance of schools for the social engagement of young carers, service providers noted that young carers who were not at school were at particular risk of social isolation. One service provider explained that she was very worried about young carers who had been home schooled for several years:

A lot of the young carers I've talked to have moved schools three times and then they give up and go to home school. And then they've got no friends at all, they just stay at home all day. I'm so alarmed for these kids. It's really common after it's gone on and on. But the over eighteens, many of them will just email us and say, 'I don't have one friend', which is just terrible. They've got no one to confide in, they don't even know how to make friends and maintain that chit chat.

Service providers agreed that young carers often reported having very limited, if any, social networks. One said:

Where they've got no friends, they're not going out, they're stuck at home. Quite commonly, the conversation is around their mental health and they're profusely depressed and some have been depressed for a very long time.

As such, service providers saw creating social opportunities for young carers as essential to helping them maintain good mental health and wellbeing.

As reported by young carers themselves (Section 4), the focus groups with service providers found that while some were able to take part in friendship activities at school, they often found it difficult to take their friends home. A service provider pointed out the difficulties young people had negotiating such events:

It's explaining it to the person you want to bring home. And then it's the reality of how the person that they're coming home to ... behaves and that whole thing. And then there's the expectations of what they [the young carer] have to do while the person's there with them ... so it's very stressful.

Lack of financial resources also affects a family's ability to take part in recreation together, as a family.

A lot of them haven't been out as a family for a long, long time because again, there's no money. They are too poor to take her to the cinema; it's a lot of money just to go there, if you don't drive, public transport, it's a big hurdle, or they just don't have the time.

Financial disadvantage also affects young people's social lives with their peers. One service provider noted large disparities between young carers in this regard, in part due to access to financial resources. Some young carers are very isolated; others and their families are closely linked into social networks and recreational activities. Service providers saw schools as a key link in provision of support to young people to enable them to engage in sporting and recreational activities, providing opportunities for friendship and supportive networks to develop.

Potential homelessness

Some service providers also raised the issue of homelessness among young carers and their families. One participant believed there was a lack of knowledge about some young carers' pathways into homelessness. This service provider thought that some young carers might consider leaving home, even with the attendant risk of homelessness, as the only escape from a level of care responsibility they no longer felt able to provide. Another responded, 'I wonder where they've gone, the ones that disappear'. Other service providers discussed homelessness among the families of young carers:

A: I know whole families that are referred to me when they're in crisis accommodation awaiting housing ...

B: The whole family could be homeless together or they could be homeless because the carer just wants to leave the home.

C: We give a lot of letters of support to gain housing or priority housing placement for the whole family.

5.7 Service gaps and suggestions for policies and additional support services for young carers

Service providers and policy makers made a series of suggestions for policies and services for young carers, which tended to fall into two areas. The first was for greater recognition of young carers as a group requiring assistance. The second was for those services already available to young carers to be expanded so as to address unmet need. In addition, service providers and policy makers spoke of specific services that currently operated or could be developed that would address particular needs in ways that are both age appropriate and culturally sensitive.

As might be expected, given the prominence accorded to the widespread lack of recognition of young carers, this was a central matter that policy makers and service providers believed should be addressed in future policy and service delivery. Service providers are already attempting to address this issue through building and maintaining networks and connections with other organisations in their region; however, they felt that considerably more policy recognition was needed. Some key policy domains in which additional efforts should be made to foster better understanding of young carers are the education system, health services and youth services.

Policy makers emphasised that informing teachers about the needs and circumstances of young carers is essential: Carers Australia is keen to explore ways to work in partnership with the various education systems. The issue for schools is not just about individual teachers being flexible in their interactions with young carers and accommodating their responsibilities (important as this is), but the provision of support by 'the school as a whole'. If the understanding and response is not a systemic one across the whole school, young carers could interact with teachers who recognise their care responsibilities, and with others who do not. Working with schools requires 'a whole school commitment'. While both service providers and policy makers felt that much good work had already been done in informing school staff and students about young carers, they agreed that more needed to be done.

Both service providers and policy makers stated that health professionals providing medical care to care recipients might be mobilised to refer young carers to support services. Policy makers particularly noted the potentially significant role that allied health services might play.

Service providers also suggested that mainstream youth services might be used to help identify hidden young carers and to provide support to them. Compared to carer organisations, youth services might be better attuned to the concerns of young people, better understand the education system and young people's educational needs, and better navigate other support services that would be suitable for young people.

An important element to ensure more widespread recognition of young carers in the services system is for existing mainstream services to extend their eligibility criteria so they are able to include young people. Policy

makers noted that while project officers who work at state and territory carers' associations could refer young carers to respite services, not all young people would be eligible due to age restrictions. Service providers and policy makers raised the issue of families where drug or alcohol misuse is a problem as an example of where young carers' needs are often overlooked and little understood.

A need for expanded support services

Service providers expressed awareness of the limits of their programs. This was evident, for example, when one service provider explained the support she had provided to help a young person attend soccer training.

We've got a young carer who is the state representative for soccer under eighteens at the moment. So her mother's only social outing is to go with her daughter to her practices. Mum can't drive because [of her illness]. The 15 year old is not able to. They get limited taxi vouchers. So how are they, how is she meant to maintain her recreational activities and social network and it is the social network for her, take mum along? ... There's no one out there going, 'Hey this family, in one small simple way, could be supported in a massive way'. There's no one out there looking at the big picture, and we find ourselves in that role, but not able to help with everything.

The service providers were aware of the limited resources and programs available for young carers. Accordingly, while they attempted to encourage more young people to use their services, they also wished to draw attention to the strain that an increased client load could place on the service and the difficulties that might result if young people had to be turned away. Two service providers had the following exchange:

A: The more information that we provide and the more resources that are out there puts a lot more strain on the system, so it's a catch twenty-two ...

B: And I think that not wanting to be another disappointment and saying 'Sorry, we don't want to take this, sorry we're full'. And we're conscious and we're sensitive to that because they are such a vulnerable group of young people.

Service providers were concerned about the ongoing needs of young carers for respite care, domestic assistance and tutoring. For some young carers these needs continued beyond the 12-month limit for engagement with the Young Carers at Risk program, but there were often no other organisations able to provide regular respite services, tutoring or help with domestic tasks. In addition, one service provider was concerned about inconsistency and the multiplicity of people who provide services to each family. She described the range of employees and agencies that might visit the home of a young carer:

One service will provide one thing, the other another thing, and so before you know it you've got four different people on your list and I think most people wouldn't like that ... first there's one agency and then there's another and then they change and the social worker's involved. It's like a train station or the airport.

She said, 'We need the same company to be doing the housework on Monday and the cleaning on Friday'. Similarly, this service provider felt it would be better for young people and their families if the same person provided respite each time.

Distance is a further limit to the capacity of service providers in regional and remote areas. The vast areas their agency is expected to cover sometimes means they cannot support young people living in more remote areas. A service provider in a sparsely populated region said:

Geographically it's more manageable when you're in a small area. Like in [my area], I go out, probably drive up to an hour, any further than that and I just don't do it. It's impossible. I don't handle those [more distant cases].

Both service providers and policy makers noted the age differences among young carers, pointing out that the needs of the very young and of 25 year olds were likely to be vastly different. Added to this are the different forms of care that young people provide. One might be caring for a parent, another for a sibling and another for their own child with a disability. As one policy maker noted, the support services and policies available must accommodate the diversity of circumstances and needs.

Specific groups of young carers need particular forms of service, and this is not always felt to be possible within available resources. Culturally and linguistically diverse young carers are one such group. One service provider felt that knowledge of a young person's cultural background, culturally appropriate resources, and

bilingual workers would help service providers to better meet the needs of culturally and linguistically diverse young carers.

Many service providers spoke of developing particular programs for Indigenous young carers or tailoring their approach to encourage Indigenous young carers to use their services. However, they also acknowledged that Indigenous young people did not always readily come to their organisation. For example, one Northern Territory service provider reported that Indigenous young carers were coming to the program, but slowly.

Specific service recommendations and examples of best practice

Consistent with their creativity in providing support for young carers, service providers and policy makers suggested a number of initiatives that could be developed or expanded to support young carers. A number of focus group participants raised the possibility of providing support for young carers entering employment. Finding a job is difficult for those young people who left school early, or who missed the sessions at school in which their peers learned how to prepare a resume, and how to seek a job. Some young carers might lack role models for employment if no one in their immediate family is in employment due to their disability or illness. Unlike other young people, young carers might not have opportunities for part-time employment during their teenage years, and so miss important employment experience in the casual and part-time jobs students commonly undertake. The most commonly suggested responses to young carers' employment difficulties were entry into training and further education, and mentoring.

Also identified was a significant gap in transport services, restricting young people's participation in social, further education and recreational activities, as well as making their care responsibilities more difficult. Participants suggested that transport vouchers might be an appropriate way to address this issue for young people, as vouchers would give them flexibility to undertake trips to social and recreational activities, as well as shopping and other care responsibilities for their families.

5.8 Discussion

Analysis of the interviews and focus groups with policy makers, service providers and advocacy organisations, and minutes of meetings of agencies that work with young carers revealed three key themes:

- a recognition of young carers and the need to identify hidden young carers
- the centrality of education as a site for identifying and supporting young carers
- the need to expand provision of age-appropriate and culturally sensitive support services and appropriate forms of financial support.

Service providers and policy makers observed that the greatest difficulty for young carers in accessing support was a lack of recognition, either on the part of young people themselves, their families, or the organisations and institutions with which young carers come into contact. Many young people have provided care throughout their lives and do not regard what they do as 'caring'; it is just what they do. Organisations are often not aware that young people provide any kind of care, since the cultural expectation is that young people **receive** care, that they do not **give** care. Agencies that support carers in general might have age eligibility criteria that exclude young people and/or staff that may not see young people's need for support as legitimate or readily able to be accommodated. Participants in the focus groups overwhelmingly agreed there is a great need to continue educating organisations about the existence of young people who provide care, and to promote support in a way that does not require them to identify explicitly as 'young carers'.

Central in the project to increase recognition of young carers is schools. Educational institutions play an important role in the lives of most young carers. Service providers said that young carers were keen to receive academic assistance, that schools were important for maintaining both academic achievement and social connectedness, and that young carers, through schools, might learn about the existence of other young carers

and the support for which they might be eligible. However, schools that do not recognise the responsibilities of young carers or are not sensitive to young carers' educational needs may deny them support and understanding. A lack of support from school staff and bullying from other students might lead young carers to turn to home schooling, where they face extreme isolation. Turning all schools into a supportive environment for young carers through a whole-of-school commitment is a key priority for both policy makers and service providers. The research also highlighted the need for flexible practices recognising the responsibilities of care givers in institutions of further education, including TAFE colleges and universities, and in workplaces.

In addition, participants in these focus groups, like the young carers themselves, raised the issue of enabling young carers to receive appropriate forms of income support for which they might be eligible, given the strains imposed on their employment, both while at school and on leaving education. Further, this is an important issue because a significant proportion of young carers are in low-income households subject to the financial strains of disability or illness, in addition to the costs of caring.

Finally, young carer service providers felt their services play an important role in supporting young carers. Their flexible and creative approaches to giving young carers educational and social opportunities were facing greater demand than they could provide. Participants identified groups of young carers with specific support needs that were not always adequately or appropriately met. These include young people of Indigenous or culturally and linguistically diverse backgrounds, those in remote areas and young carers who are home schooled. Participants recommended that these subgroups of young carers be carefully considered in future policy development. In this context, it should be noted that the analysis in Section 3 shows that young carers of culturally and linguistically diverse and Indigenous backgrounds are overrepresented among identified young carers and are also likely to be overrepresented among hidden young carers.

6 Conclusions

This study aimed to provide new insights into the circumstances and needs of young Australians who provide informal care for family members or friends who are chronically ill or who have a disability. The study included a review of national and international literature on young carers; quantitative analysis of three nationally representative data sources; qualitative research with young carers; and qualitative research with service providers and policy makers. The study was informed by and adds substantially to previous Australian and international research on young carers. The quantitative analyses of national data sets (*Census of Population and Housing 2006*; *Survey of Disability Ageing and Carers 2003*; HILDA survey 2005) provide valuable, up-to-date and unique insights into the breadth, diversity and complexity of young caring, the socioeconomic-demographic characteristics of young carers and the associations between their care giving and their education, employment, income and health. In addition to analysing the circumstances of young people identified in these data sources as carers, we undertook an analysis of young people in the HILDA data who are defined as ‘potential’ carers because they live in a household with a child or adult with a long-term health condition, disability or impairment. The characteristics of these young people are explored and compared with young people who are identified as young carers.

The findings of the quantitative analysis are complemented and illuminated by the qualitative analysis derived from focus groups held with young carers, policy makers and service providers.

The review of the Australian and international literature indicates that children and young people become carers in two interconnected circumstances: through individual and family decisions opting for informal care within the family, and because other adult carers are not available within the kin network (for example, in lone-parent families); and through a lack of appropriate, accessible and affordable formal services. Furthermore, the literature shows that low income is a common dimension in the lives of young carers and their families. In many instances, the experiences of low income and the additional costs associated with disability or chronic illness, as well as care giving in a household, are associated with strained financial resources.

In contrast to much of the caring literature that emphasises the ‘stress’ and ‘burden’ associated with care giving, this research has sought to present a more comprehensive picture of caring by focusing not only on the challenges associated with caring, but also the ‘worth’ of care, as perceived by young carers themselves. This research extends and develops the social care theoretical framework (Daly & Lewis 2000) as a means of understanding the circumstances of young care giving. For young carers, care is labour; it is based within a normative framework of obligation and responsibility; and it incurs both direct and indirect (opportunity) costs, in the form of strains on education and restrictions on labour force participation, which may have long-term implications for future employment and income; and lower rates of perceived mental health and wellbeing. Nevertheless, caring also produces benefits: profound contributions to the wellbeing of the care receiver and the family, and acquisition by the carer of valuable skills and a deep sense of achievement.

The literature strongly suggests that young carers tend to be located in identifiable socioeconomic-cultural circumstances, very often in low-income families, and in families of migrant and/or culturally and linguistically diverse backgrounds, where provision of care is often considered vital to family functioning and where formal health and social services are seen as insufficient, culturally inappropriate or intrusive. In addition, analysis of ABS data (Census 2006) shows that young people of Indigenous background and young people of culturally and linguistically diverse backgrounds are more likely than other young people to be young carers.

Analyses of the three data sources provide insights into the extent and nature of care giving undertaken by children and young people. The gendered nature of care giving is borne out by this analysis. The data show that all young carers are relatively evenly split between male and female; however, females constitute a substantially higher proportion of primary carers aged over 18 years. The gendered impact of care giving is particularly evident in the statistics on participation in employment, which show that young women carers

have lower rates of employment than their female age peers who do not have care responsibilities, and also have lower rates of employment compared with male carers. In large part, this is shaped by gendered societal expectations surrounding care giving. Discussions with service providers and policy makers revealed that care work disproportionately falls to young women within the family. This is largely influenced by norms surrounding care giving, which may preclude many young men from admitting to being carers even when they are in effect providing care, because care is considered to be 'women's work'. Analysis of the HILDA data similarly suggests that young men are more likely than young women to be 'potential carers'.

In addition, the Census data indicate that there is a greater prevalence of young carers among Indigenous young people than among their non-Indigenous age peers. This finding is consistent with Australian studies that have shown that the giving and receiving of care are an integral part of everyday life within Indigenous communities, and also consistent with the higher rates of chronic illness and disability among Indigenous people at younger ages. This is of some concern given that the costs of care are likely to be compounded in families and communities that experience higher rates of disadvantage (in terms of education, employment, income and health) relative to the non-Indigenous population. The importance of providing culturally appropriate formal services and assistance with education to support young Indigenous carers and their care recipients is evident.

The data analysis indicates that young carers are significantly more likely than their age peers to be in lone-parent families. This is corroborated by the data from the focus group discussions with policy makers and service providers, which revealed that many young carers they work with came from lone-parent families. This may occur if there is no one else to care for a lone parent with an illness or disability. In other situations a child may have to take on caring responsibilities for a sibling if the lone parent is the only income earner in the household.

Although most young carers are, like other young people, Australian born, Census data suggest a higher proportion of young people from culturally and linguistically diverse backgrounds are carers (Hill et al. 2009). This reflects other Australian and international research that highlights the embedded, normatively expected nature of care within culturally and linguistically diverse families. Additionally, it may be indicative of the perceived cultural inappropriateness of formal services or that young people from culturally and linguistically diverse backgrounds face greater challenges when trying to access support and services from formal care providers.

In the United Kingdom context, Warren (2007) notes the difficulty associated with determining what constitutes caring responsibilities compared with normal household chores. Nevertheless, she found that young carers perform a wider range of domestic, emotional, nursing and intimate care tasks and they spend longer on these responsibilities than other children. The survey completed by the young carer focus group participants in this study showed that young carers' responsibilities varied according to their age. Carers aged 18 years and over are more likely to help their care recipient with dressing, eating, paying bills and banking, attending medical appointments, giving advice and organising social activities. Tasks such as showering, cleaning the house, cooking, comforting, and listening were undertaken to a similar extent by young carers regardless of age. The obligations and responsibilities of young carers are evident in the data on provision of assistance by young primary carers in the SDAC analysis. One-quarter of young primary carers are providing care for more than one care recipient and over half of all young carers are providing care to a person with a profound or severe disability. These care recipients need help either all or some of the time for self-care, communication or mobility.

In all data sources examined here, young primary carers and young carers are disadvantaged with respect to participation in employment, and this is especially so for young women. However, their rates of participation in education as recorded in SDAC and HILDA are possibly now closer to that of their non-carer peers than they were in earlier ABS surveys in the late 1990s. These findings in the sample surveys (SDAC and HILDA) are, however, not recapitulated in the lower rates of completion of Year 12 for young carers identified in the whole population survey of the Census (Hill et al. 2009), and do not reflect the qualitative studies outlined in the

literature review and the primary qualitative data collected for this study that indicate that young carers face many challenges in maintaining their participation at school.

The circumstances of employment disadvantage and higher-than-average reliance on income support (compared with their age peers) are reflected in the data on household equivalised income distribution, which show that of all young carers (primary carers and carers) nearly 40 per cent live in households in the bottom two income quintiles compared with only 25 per cent of young people who are not carers. Further evidence of the economic disadvantage of young people who are carers is found in their higher poverty and deprivation rates compared with non-carers in the HILDA data. These findings corroborate the conclusions of the review of the national and international literature that low income is very likely to frame the socioeconomic circumstances of young carers. In addition, there are mental health dimensions to these findings. While all groups of young people reported similar scores on self-reported physical health, young carers had significantly lower scores on self-reported mental health scales than other young people, indicating that care is associated with emotional and mental health costs for these young people. In this context, it should also be noted that the SDAC 2003 analysis shows that young carers, like older carers, are more likely than their age peers to have a disability themselves.

The focus group discussions with service providers and policy makers also identified low income as a central issue that shapes most young carers' experiences and affects their capacity to continue in education and participate in social activities.

Much of the caring literature acknowledges the existence of 'hidden carers', that is, people who undertake caring roles and responsibilities yet do not identify themselves as carers. The analysis of two key sources of Australian data on young carers illustrates the complexities of identifying and supporting young carers. The fact that the SDAC 2003 identifies twice as many young people aged 15 to 24 years providing care as the *Census of Population and Housing 2006* suggests that even official estimates of the number of young carers must be understood within the limitations of population census methodologies. This corroborates research by Becker (2004, 2007) and Warren (2007) among others who note that census data significantly underestimate the prevalence of young carers. This also confirms the service providers' and policy makers' focus group finding that the number of hidden young carers is substantially greater than the number of young people who are in contact with service organisations and who identify themselves as young carers.

Responding to concerns in the literature and those expressed by service providers and policy makers about the existence of hidden young carers, the analysis in this report identifies and explores the circumstances of what is defined as potential young carers. Where potential carers are defined as young people living in a household with a child or adult with a long-term health condition, disability or impairment, the findings suggest there may well be a significant group of young people whose caring responsibilities not only go undocumented in public discourse but also remain unnamed by them as care giving. This group of potential carers had lower participation in employment, and a higher proportion were unemployed or marginally attached to the labour force than young people without care responsibilities. Potential carers had higher rates of income poverty and deprivation compared with non-carers.

The very rich sources of evidence and understanding emerging from the focus group research illustrate and illuminate the quantitative analysis. Through listening to the voices of young carers, the research demonstrates that young caring covers a broad spectrum of experiences. This is shaped by a number of factors including:

- the age of the carer
- the number of people being cared for
- the presence of other family members to help with care
- the care recipient's illness
- the carer's relationship to the care recipient (that is, whether the care recipient is a sibling or a parent)

- the period of time over which they have been carers
- the socioeconomic circumstances of the family
- whether or not the carer and care recipient are able to access formal services and supports.

It is the complex intermingling of these factors that influences the care trajectory of a young carer and places them along the caring spectrum. What is overwhelmingly apparent from these focus groups is that despite the diversity of experiences, young carers show levels of commitment, courage, generosity and understanding well beyond what might be expected at their ages, and well beyond the general community perceptions of young people and their expected contributions to family life.

Returning to the theoretical framework of ‘social care’ (Daly & Lewis 2000), for young carers:

- **Care is labour**, which occupies time that might otherwise be available for participation in education, training, employment and social/friendship activities. The levels of responsibility young carers assume is evident; young carers provide a wide range of domestic, emotional, nursing and intimate care tasks. At the same time, however, the diversity of young carers’ responsibilities varies according to their position along the caring continuum and often age, intensity of care and sex interact to determine the impacts of care on other life domains.
- **Care is located in a normative framework** within which young people may not identify themselves as carers but as family members carrying out their responsibilities and obligations. The normative framework of care may shed some light on why many young people do not identify themselves as carers. The focus groups with young carers revealed that few had ever considered themselves to be ‘young carers’. They simply regarded their roles and responsibilities as ‘normal’, ‘routine’, ‘everyday’ tasks. This was confirmed in the focus group discussions with service providers and policy makers. This is the context in which many young carers express a desire to continue in their caring role in spite of the challenges they face, thus contributing to family resilience and integrity. Nevertheless, identifying as a carer, or being identified as a carer by a service provider or teacher enables young people to seek services and supports to help them and their family member requiring care.
- **Caring incurs costs** that may include interrupted education and labour force participation that may have long-term implications for future secure employment and adequate income; reduced opportunities to pursue friendships and social life; and costs to mental health. Both the quantitative and qualitative data point to the financial strain imposed by both care giving and disability or long-term ill health within a family. The data provide compelling evidence that young carers are more likely than their peers to live in low-income households. It is possible that this may affect their capacity to access services and supports to help them in their caring role. The qualitative data reveal that the areas of young people’s lives most affected by care giving include their concerted attempts to combine caring responsibilities with their schooling; for older carers, their employment; and for all young carers, opportunities for maintaining friendship and social and recreational activities.
- **Caring provides benefits as well as costs:** Young carers identified a number of benefits associated with the care they provide. These include acquisition of valuable skills, such as responsibility, maturity, independence and a deep sense of achievement and worth, which many young carers believe should be much better recognised and more widely valued and respected. Providing care contributes to family integrity and resilience through strengthening family bonds, contributing to the wellbeing of the care receiver and sharing the responsibilities of care.

In order to estimate the ‘worth of care’ young carers provide, it is essential to understand both sides of the caring coin; that is, the costs and benefits of care, as young carers themselves understand their experiences and contributions.

Formal support needs the young carers identified include adequate financial support; respite care; assistance with domestic activities and especially with transport; flexible and sensitive schooling arrangements

recognising their care responsibilities; and TAFE, university and workplace arrangements to allow them to better manage their combinations of education, employment and care.

This research raises a number of important policy implications. As noted in Section 5, a range of programs and support services are available to support young carers. These include information and referral; respite, camps and social activities; and educational support programs. Nevertheless, the study also highlights a number of support needs and service gaps.

A key policy implication of the study is the importance of raising awareness of young carers and their responsibilities. This was brought into sharp focus by the quantitative analysis that drew attention to the existence of a substantial number of young people who do not identify themselves as young carers but appear to have caring responsibilities. Community and professional education to raise awareness of young carers is needed to inform educational institutions, health and community service providers, and mainstream youth services of the existence of young carers. Moreover, awareness-raising campaigns would help young people in particular caring circumstances to recognise themselves as young carers and seek support. Discussions with policy makers identified a range of strategies for identifying young carers, including identifying young people with caring responsibilities in schools; encouraging young people who have caring responsibilities to use support services; and developing cross-agency networks to encourage referrals to services.

The centrality of schools in efforts to help young carers emerged very clearly in this research. Greater awareness on the part of teachers of young carers' circumstances is essential, as is access to flexible learning programs to accommodate young carers' circumstances. Turning schools into a supportive environment for young carers through a whole-of-school commitment is a key priority for both policy makers and service providers.

Another key policy implication of this study is the importance of providing young carers and their families with appropriate financial assistance. A consistent finding in all stages of this study is that financial disadvantage frames the circumstances of young carers. The quantitative analysis showed that young carers' employment participation rates were lower than their non-carer peers and that a higher proportion of young carers live in households in the bottom two equivalised income quintiles. The qualitative fieldwork with the service providers, policy makers and young carers also emphasised the importance of adequate financial assistance.

Three key challenges exist for young carers wishing to access income support: first, the application process is difficult to navigate; second, Centrelink staff may be unaware of the existence of young carers; and third, eligibility for Carer Payment requires that carers not spend more than 25 hours per week in education or employment. These challenges call for clearer information and guidance to help young carers navigate the application process, the importance of educating Centrelink staff about the existence of young carers and a review of Carer Payment eligibility requirements to ensure young carers combining education and care are not disadvantaged.

The importance of culturally appropriate support is also vital in addressing the needs of young carers. The quantitative data showed that young carers of culturally and linguistically diverse and Indigenous backgrounds are overrepresented among identified young carers and it is suggested that they are also likely to be overrepresented among hidden young carers. Further research is needed to explore in greater depth the circumstances and needs of young carers of culturally and linguistically diverse and Indigenous backgrounds and young carers in rural and remote areas, so that their needs can be better addressed in policy and service development.

Formal services received and appreciated by young carers and their families and which they and service providers would like to see more widely available are:

- adequate financial support, given the costs of ill health and disability and the constraints imposed on their own and their parents' employment

- respite care for longer hours for the care recipient, to benefit both the care recipient and the young carers, so they can complete their education with less strain and participate in friendship and social activities.

Assistance with domestic activities and especially with transport was often emphasised. With respect to relieving the strain on balancing education and care and employment and care, the focus group participants spoke of the need for more flexible arrangements that schools, universities, TAFE colleges and workplaces might put in place to accommodate care giving responsibilities more fully and appropriately.

The importance of supporting young carers and their families through a whole-of-family approach and the most appropriate and effective ways in which this might be done are issues that received considerable attention in this study. It is recognised that supporting young carers will contribute to the wellbeing of the family member requiring care and the whole family, and conversely, that supporting the person requiring care will benefit the young carer by minimising their care burden and alleviating their sense of anxiety about their own responsibilities.

The research identified the following issues for policy development:

- raising awareness of young carers in a range of institutional settings, including schools, the health care system, and mainstream family and young people's services
- recognising the centrality of education as a site for identifying and supporting young carers through whole-of-school commitments
- taking a whole-of-family approach to service development and provision that recognises the close connections between support for young carers and support for the family members for whom they provide care
- providing appropriate and timely information about available services and supports to young carers and their families
- recognising the importance of age-appropriate and culturally-appropriate services and supports
- addressing unmet support needs for domestic help, respite, transport assistance and counselling
- providing appropriate and adequate financial assistance to young carers and their families
- providing assistance with entry into post-school training and further education
- providing assistance with seeking and entering employment
- recognising the specific support needs of young carers whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous background, culturally and linguistically diverse backgrounds and those in rural and remote areas.

Development of policies and services for young carers and their families is relevant to a number of Australian Government and state and territory portfolios and programs within a number of departments. This is also of great significance for non-government community service organisations and carers' associations across Australia. Thus comprehensive and cohesive policy and program development across government portfolios and coordination between levels of government and the community sector is very important. It is hoped that this report will contribute to the development of policies and programs and to the knowledge of practitioners so as to benefit young carers and the people for whom they care.

List of shortened forms

ABS	Australian Bureau of Statistics
CURF	Confidentialised Unit Record File
FaCSIA	Department of Families, Community Services and Indigenous Affairs
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HILDA	Household, Income and Labour Dynamics in Australia
SDAC	Survey of Disability, Ageing and Carers
TAFE	Technical and Further Education

Endnotes

- 1 According to Denzin (1970), the rationale behind a triangulated approach is to iron out any biases and deficiencies that can stem from studies that use a single investigator, methodology, theory or data. This, he felt, makes research findings more robust, provides a sound basis for theory construction, and enhances confidence in the findings if they are mutually reinforcing.
- 2 Kroehn and Wheldrake (2006) found that while young carers identified with the label 'young carer' and felt it described their role, they did not like being called a young carer because it implied a choice to care they felt they did not have.
- 3 The survey was based on a random sample of 2000 households carried out in 2003 for the National Alliance for Care Giving, in collaboration with the United Hospital Fund.
- 4 At the time of writing this report the only data available from the Census was that published on the ABS website. This research team has undertaken subsequent analysis of the characteristics of the young carers in the Census published in Hill et al. (2009).
- 5 Data reported here on the SDAC may not exactly match the data reported in Hill et al. (2009) due to slight differences in the sample. In Hill et al. (2009) the focus was on examining trends between 1998 and 2003, and hence, a different carer identification variable was used to provide concordance between the two time periods.
- 6 This paper uses unit record data from the Household, Income and Labour Dynamics in Australia (HILDA) survey. The HILDA project was initiated and is funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (MIAESR). The findings and views reported in this paper, however, are those of the author and should not be attributed to either FaHCSIA or MIAESR.
- 7 The differences in estimates may also be due, in some degree, to sampling error that affects the estimates from SDAC and HILDA but not those from the Census. Sampling error is the difference between estimates derived from a sample of persons to the figure that would have been identified if the entire population had been surveyed (ABS 2005).
- 8 Analysis of potential carers as undertaken in HILDA is in this report. For an analysis of some of the characteristics of potential carers in the Census see Hill et al. (2009).
- 9 Chi square=10.1933, $p=0.0170$, Cramer's $V=0.0656$.
- 10 Chi square=12.8086, $p=0.0051$, Cramer's $V=0.0742$.
- 11 Marginal attachment means the young person 'wants to work and is actively looking for work but not available to start work in the reference week'; or they 'want to work and are not actively looking for work but are available to start work within four weeks' (ABS 2001).
- 12 The method used to transform the subscales is outlined in Russell, Ball and Spallek (2007). The MCS and PCS were only calculated for those individuals for whom all subscales were available. Twelve of the 96 young carers (co-resident, ex-resident and other carers) in the HILDA sample were excluded from the analysis on this basis.
- 13 A telephone interview was conducted with one young adult carer who wished to participate in the research, but was unable to attend a camp focus group.
- 14 As noted in Section 4.2, the focus group participants were recruited through Carers NSW and Carers SA. Thus all self-identified as young carers and all had contact with a carers advocacy organisation.

Consequently, this stage of the study does not include the perspectives of young people who are not identified, either by themselves or others, as being young carers. Nevertheless, unlike quantitative methodologies, a qualitative approach does not aim at being representative of a particular population. Instead, the value of a qualitative approach is that it allows the researcher to investigate the subjective experiences and circumstances of individuals and to generate a wide-ranging understanding of the topic under study.

- 15 The respite services for young carers are delivered through the Australian Government Respite and Care Link Centres and the information, referral and advice services are delivered through Carers Australia, which subcontracts to state and territory carer associations.

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