

# **Young carers: Social policy impacts of the caring responsibilities of children and young adults**

Final Report

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## **Final Report of Australian Research Council Linkage Grant LP07755940**

### ***Young Carers: Social policy impacts of the caring responsibilities of children and young adults***

This report is based on findings from an Australian Research Council Linkage Grant (LP07755940) titled *Young Carers: Social policy impacts of the caring responsibilities of children and young adults* (HREC 07243).

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The **Research Partners**: are Carers New South Wales and Carers South Australia, and government agencies in South Australia (SA) and New South Wales (NSW): in SA, the Social Inclusion Unit in the Department of Premier and Cabinet, the Department of Families and Communities, the Department of Education and Children's Services, the Department of Further Education, Employment, Science and Technology, and the Children, Youth and Women's Health Service; and in NSW: NSW Health, the Department of Family and Community Services, Ageing, Disability and Home Care, and the NSW Commission for Children and Young People.

The views expressed in this report are those of the authors and do not necessarily reflect the views of the above Departments or the responsible Ministers.

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## Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ARC	Australian Research Council
CALD	Culturally and Linguistically Diverse
Census	Census of Population and Housing
CR	Care Recipient
CRCC	Commonwealth Respite and Carelink Centre
DFaCS	Department of Families and Community Services
DoHA	Department of Health and Ageing
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HREC	Human Research Ethics Committee
LGA	Local Government Area
NRCP	National Respite for Carers Program
NGO	Non-Government Organisation
NSW	New South Wales
ONS	Office for National Statistics
QLD	Queensland
SA	South Australia
SPRC	Social Policy Research Centre
SDAC	Survey of Disability, Ageing and Carers
NSW	New South Wales
NT	Northern Territory
Tas	Tasmania
UNSW	University of New South Wales
UK	United Kingdom
US	United States
Vic	Victoria
WA	Western Australia
YAC	Young Adult Carer
YC	Young Carer

## **Executive Summary**

### **Introduction and research objectives**

This report is based on findings from an Australian Research Council Linkage Grant (LP07755940) titled *Young Carers: Social policy impacts of the caring responsibilities of children and young adults* (HREC 07243). The Australian Bureau of Statistics (ABS) (2008) defines a carer as a person who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people. The assistance has to be ongoing, or likely to be ongoing, for at least six months.

In 2003, there were 348, 600 young people aged up to 24 years providing care in Australia:

- 170,600 children and teenagers up to age 17 (3.6 per cent of this age range).
- and a further 178,000 young adults aged 18-24 years (9.1 per cent of this age range). (Australian Bureau of Statistics (SDAC), 2004).

These numbers are considered an underestimate, since some young people are reluctant to reveal caregiving within their families or do not see themselves as carers. In the last two decades in Australia, the United Kingdom and to a lesser extent the United States, Canada, New Zealand, Ireland, and some parts of continental Europe, there has been growing recognition of young carers as a social category with experiences and needs distinct from those of their peers. In recent years, young carers have become a growing focus of research, public policy, and the design and delivery of community services, especially in the UK and Australia.

The research in this report fills a critical gap in Australia, by contributing a theoretically-informed and policy-focused quantitative and qualitative study on young carers. The findings provide innovative contributions to theories of care provided by young people; evidence about the diverse socio-economic and demographic characteristics of young carers and care recipients, young people's pathways into care provision, and the impacts of caring on their education, employment, social participation and health; and the development of supportive policies and services.

The research objectives were to:

- conceptualise and analyse young carers within a comprehensive framework which focuses on the circumstances, experiences and meanings of the care-giving/receiving relationship for both caregivers and receivers, and the policy frameworks which affect those relationships;
- develop a model analysing international policy frameworks (in particular in the UK) for supporting young carers and their families, so as to place Australian policies within a comparative context;
- identify the range of education, training and employment arrangements and support/information services in Australia at government and NGO levels which might flexibly recognise, support and open up opportunities for young people with informal care-giving responsibilities;

- identify the extent to which the promotion and provision of appropriate, accessible and affordable support services would assist in removing/reducing the barriers to education, training, employment and social participation
- formulate a cost/benefit analysis of the costs of care for young carers (at the time of care-giving and potentially through later adult years) with respect to impacts on participation in education, employment and receipt of market income;
- engage in knowledge transfer with all relevant organisations, policy-makers and service providers, especially the NSW and South Australian governments, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Carers Associations, schools, as well as young carers and their families. The purpose is to provide evidence to inform development of policies and services across Government departments and across government/NGO provider sectors to facilitate whole of government and cross-sectoral policies and services.

This Project includes a number of research strands:

- a review of the literature;
- quantitative analysis of ABS *Census of Population and Housing 2006*;
- interviews and group activities with young carers and young adult carers; interviews with people receiving care from a young person;
- focus groups with policy makers and service providers;
- and an audit of policies and services relevant to young people who provide care.

Ethics approval was received from the University of New South Wales Human Research Ethics Committee (HREC 07243) to conduct all parts of the research.

### **Literature review**

The literature review examined emerging themes, theory and evidence relating to young carers and young adult carers in Australia and internationally. This component provided a vital starting point for considering gaps in research, developing theoretical frameworks, and helped identify issues to be explored both in the quantitative and qualitative survey research and in the audit of policies and services.

The available research explores the demographic characteristics, family circumstances and needs of young carers. Key themes to emerge in the review are:

- Young carers are more likely live in lone parent, low resource households and a higher rate of caring is found in young people from Indigenous and culturally and linguistically diverse backgrounds.
- In the SDAC data, young women and men have similar rates of caring overall, but young women are more likely to be primary carers, defined by the ABS as those carers providing the most informal assistance to a person with one or more disabilities. This suggests that there are socio-cultural expectations drawing more young women than young men into informal care, expectations associated with gender differentiated practices of care itself as well as differences in participation in tertiary education and labour force participation.

- The majority of young carers care for a parent.
- Young carers take on a wide range of tasks, such as housework, shopping, cooking, and dealing with health professionals and financial matters and are also likely to perform care of an emotional, physical and intimate nature.
- While young people who are not defined (and would not define themselves) as a carer may perform some of these tasks, young carers often devote significantly more time to them and take on higher levels of responsibility.
- Literature from the UK and Australia indicate that young carers are usually proud of what they do, hope to receive recognition and respect for their caring, usually come from close-knit families and often manage well (despite considerable constraints on other parts of their lives) with their additional responsibilities.
- However, negative impacts from their caring roles are also identified, such as difficulties in school retention and attainment which may compromise opportunities for further education, training and employment.
- Time constraints due to caring responsibilities, combined with their often low income household circumstances, can also affect young carers' social lives, including their friendships and social and recreational activities. This can impact on social integration, physical health and personal wellbeing.
- Young carers were twice as likely as their peers to have a disability themselves.
- There may be a lack of awareness and understanding of young carers' life circumstances by those around them, including teachers in schools and further education settings, community service providers, health care professionals and the wider community.
- Australian, UK and US research shows that young people are participating in informal care as a result of a number of inter-related factors: personal and family preferences for informal care within the family; the absence of other available informal carers within the family/kin network and lack of appropriate, accessible and affordable formal care services.
- In recent years, Commonwealth and state/territory government agencies and non-government organisations have established a range of support services for young carers, especially in Australia and the UK such as:
  - income support through Carer Payment and Carer Allowance
  - respite services, counseling, educational support and recreational activities for young carers,
  - as well as support services for the person receiving care.
- In Australia the Young Carers Respite and Information Services program provides information to young carers to support them in managing the challenges which they face in their caring role (Commonwealth of Australia, 2011) and the network of Carers Associations across Australia plays a significant role in information provision about relevant services.
- There are few evaluations about the effectiveness of services for young carers. International research has produced some evaluations of support programs for carers in general, although results are not conclusive (Eagar et al., 2007).

- In Australia some government programs for carers have been reviewed (see an overview in Carers Australia, 2008), but few systematic evaluations of specific young carer programs are in the public domain (for a rare exception, see Hodge et al., 2008).
- There is, however, growing awareness of the importance of addressing issues faced by young carers in accessing formal support services, receiving flexible respite care, having their needs in the education system recognised and accessing services in regional and remote areas.

### **Young carers: geographical analysis of rates, pathways into and impacts of caring**

The data analysis examined the ABS *Census of Population and Housing 2006* in order to identify rates of caring and the circumstances of young carers and young potential carers aged 15-24 years. Customised data were purchased in Supertable format and from the ABS and analysed at State/Territory and Local Government Area (LGA) level. Geographical mapping of the Census data was undertaken to identify the distribution of the prevalence of caregiving by young people across Australia, focussing in particular on Indigenous carers and carers of CALD background. Pathways into caring for young people were explored, such as cultural background and Indigeneity, lone parent households and low resource households, and location in metropolitan, regional and remote areas. Particular emphasis was placed on the impact of caring on young carers' participation in education and employment, their rates of unemployment and whether they were in the labour force. Comparisons were made between these circumstances for young people who were identified in the Census as carers, young people who may be categorised as potential carers, and young people who did not appear to have caring responsibilities, as identified in the Census.

- Young carers were defined in this analysis as young people aged between 15 and 24 years who responded positively to the question about the provision of unpaid care, help or assistance on the Census form.

Given policy concerns about young people who do not identify as carers the analysis also developed the category of 'potential carers'

- Potential carers were young people who lived in a household with another person who had a disability themselves but did not indicate that they were a carer on the carer question: a disability in this case was restricted to those who indicated on the Census form that they always or sometimes needed help with the core activities of self-care, communication and mobility due to a long-term condition.

We do not assume that all young people in this group are necessarily carers. However, the analysis aimed to map the characteristics of the young carers and potential carers to identify any similarities between these two groups.

Key findings are:

- Young women are generally more likely to be carers than young men in all States and Territories in Australia and in both age groups, but that young men are more likely than young women to be potential carers.
- Caring was more prevalent in the older age group (20-24 years), while potential caring was more prevalent in the 15-19 years age group.
- Rates of caring and potential caring were higher in the NT, lower in the ACT and generally higher in LGAs in regional and remote areas.

The literature has identified key factors that are associated with pathways into caring for young people, such as cultural background and Indigeneity, lone parent households and low resource households. The analysis of the Census confirms that young carers and potential carers are overrepresented with regard to all these factors.

- Indigeneity and low resource households were more prevalent among young carers and potential carers living in regional and remote areas.
- Higher rates of young carers from culturally and linguistically diverse backgrounds were found in the major cities.
- LGAs with relatively high rates of lone parent households in the young carer and potential carer population were found in both cities and regional areas.
- Young carers and potential carers in the 15-19 years age group were more likely to live in lone parent and low resource households than those in the 20-24 years age group.
- Young carers, but not potential carers, were more likely to be contributing to the domestic work and child care undertaken in their households than their non-carer peers.
- Young carers and potential carers were generally disadvantaged with respect to participation in education and employment and had higher rates of unemployment than their non-carer peers.
- Regional and remote areas tended to be associated with the highest levels of disadvantage for young carers and potential carers regarding education and employment.
- Young carers and potential carers in the older age group (20-24 years) had greater disadvantage than the younger age group (15-19 years) with respect to non-participation in either employment or education, perhaps indicating that there are fewer supports for these young people or that the caring role may become more entrenched as young people grow older. This finding may have important implications for young people's transitions into adult roles in the public sphere, particularly with respect to entering and retaining employment and ensuring adequate market income.

### **Young people providing care and people receiving care: Findings from the interviews, surveys and group activities**

The qualitative component of the study with young people providing care and people receiving care incorporated interviews, activity sessions and an online questionnaire, and used a "whole of family approach" to understand key aspects of the experiences, circumstances and needs of young carers, young adult carers and their care recipients.

Semi-structured interviews with young carers, young adult carers and care recipients were primarily carried out in New South Wales and South Australia; however a few participants were also recruited from Queensland and Victoria. The participants were from metropolitan, regional and rural locations, and participants were recruited with the assistance of the Partner Organisations. Participants were recruited to one of three groups: young carers (aged 7 to 17), young adult carers (aged 18 to 25) and adults (aged 18 and over) who were receiving care from a young person.

The purpose of the interviews was to explore the experiences of caregiving-its nature and intensity, pathways into caregiving, socio-economic and demographic circumstances of young carers, young adult carers and their families, young carers' and young adult carers' participation in education, employment and social activities with friends, and their future aspirations. Twenty-three young carers, 13 young adult carers (one provided a written response), and seven people aged 18 and over who received care from a child or young person participated in the interviews. In each group, both male and female participants were interviewed across a range of ages. The interviews were recorded, transcribed and analysed thematically using NVivo.

The data collected from the interviews were complemented by an online questionnaire that all participants were asked to complete. The questionnaire took about 15 minutes to complete and the participant was offered the help of the researcher when filling it out. In most face-to-face interviews, the young people (and in some cases, the care recipients) asked for the researcher's help to fill out the questionnaire. In these cases, the researchers asked the participants' permission if they could leave the tape recorder on. This elicited some additional data. Thirty-three questionnaires were received from young carers and young adult carers which comprised almost all of the participants interviewed.

Also, there were three activity sessions carried out with young carers in South Australia and New South Wales, which utilised a more participatory method for learning about young carers' experiences. They incorporate a number of distinct research activities carried out over a half day (3-4 hours), interspersed with fun activities. The young carers were recruited through carer support groups, who would organise an extended outing with the young carers during which we could come in and conduct a few research activities. The total number of participants across three separate days of activity sessions (two in New South Wales and one in South Australia) was 44 young carers and one young adult carer. The participants were male and female across a range of ages.

The combination of interviews with young participants (both young carers and young adult carers) and care recipients, plus valuable data from young participants' questionnaires provided a comprehensive story about the experiences of young carers from diverse perspectives. The main areas of analysis included young people's pathways into caring, their identification with being a young carer, the relationship with their care recipient, and the impacts of caregiving on various areas of their life.

Through this analysis we were able to gain a better understanding of the positive and negative impacts of caring on these young people's lives, how these impacts have changed during their caring role, and how they perceived the potential consequences in the future. There were similarities and differences between young carers and young adult carers' experiences and perspectives. The level of divergence in the responses of

the two age groups varied across the different areas of their lives. For example, young adult carers were better able to reflect on their pathway into caring, the changing nature and intensity of caring tasks, and the relationships they had with the person they cared for. Young carers were more likely to link their pathway into caring and identify with being a young carer when they attended a young carer camp or because a family member told them. In other words, their identity as a carer became apparent to them in circumstances where others “named” their responsibilities as caregiving.

Also, variation in caring tasks and responsibilities often related to whether the young person was a primary carer or the oldest sibling, and the complexity of family dynamics and the care recipient’s illness or disability. With regard to the impacts of caring on the young people’s education, employment, social life and health, findings from the interviews and questionnaires showed that the consequences of caring appeared to be more intense at an older age, demonstrated by young adult carers’ experiences and perspectives about the negative aspects of caring and the consequences for their future aspirations. However, both age groups of participants identified various positive aspects about their caring role, most often linked to the strong relationship formed with the care recipient and their family, and also the maturity and wider sense of perspective and experience they gained from their role. There were also some identifiable differences in experiences and perspectives depending on whether the young participant was caring for a parent compared to a sibling, and whether the nature of the care recipient’s illness or disability was primarily physical or related to mental health.

It is also interesting to note the care recipients’ perspectives of their relationship with the young person caring for them, with respect to the impact of caring on the young person’s life experiences. For example, while some care recipients acknowledged the impacts of the young person’s caring role on their life, they were less likely compared with the young people themselves, to say that the young person’s caring responsibility was the priority in their life. Almost all of the care recipients interviewed noted the strong relationships which they had with the young people caring for them, and most expressed strong feelings of love, admiration and respect, and a desire to maintain a normal life for the young people caring for them.

The information gained from the questionnaire and the interviews with young carers and people receiving care provides significant knowledge of formal services used and considered important by participants, their own service usage and factors militating against service access and usage. This complemented the focus groups with service providers and policymakers and the policy audit in helping to identify a range of supportive and valued services. These included flexible education and training options, flexible employment arrangements and support/information and accessible respite services in Australia at government, NGO and workplace levels.

### **Findings from the focus groups with policy makers and service providers**

Seven focus groups were carried out with 47 policy makers and service providers in New South Wales and South Australia. The strongest themes to emerge and those most prevalent in the focus group discussions about the key issues experienced by young carers reinforce and extend the findings of previous research on young carers. These included:

*Recognition and awareness:* Many participants noted that organisations, services and staff generally fail to identify a young person with caring responsibilities as a carer, or may not be aware that young carers exist. In addition, young people who provide informal care often do not themselves identify as carers due to their perception that caring responsibilities are a normal part of their obligations and responsibilities as family members; fear of stigma associated with the disability, mental health or problematic drug use of the person for whom they care; or fear of possible child protection interventions.

*Engagement in education:* Many young carers were perceived by the focus group participants to be at risk of disconnecting from their education. This resulted from missing school or being unable to complete schoolwork and homework assignments due to a lack of support and inflexible approaches to education practices in some schools. It was noted that young carers have lower school retention rates and difficulties transitioning to post-school tertiary education and training which may have long-term implications and affect the employment opportunities of young carers. Flexible educational practices were identified in some schools that supported young people to complete their homework and to continue their education. It was clear from the focus groups that schools are a central site for assistance and support for young carers, and that many young carers see their school time as “respite” from their family caring responsibilities.

*Mental health:* Focus group participants felt that young carers’ mental health may be adversely affected by a number of factors, including the stress of the caring role, fatigue and social isolation from peers and friendship groups. These findings align with concerns raised in interviews with young adult carers, where deteriorating mental health was raised as a concern by those who experienced physical and mental strain due to long durations of and intense caring responsibilities.

*Groups at greater risk or with increased need for services:* Participants in the focus groups indicated that young Indigenous carers are particularly wary of seeking support from government services due to past experiences of Indigenous children’s removal from families and communities. They also noted that young caring is a particularly significant issue as care needs arise frequently due to higher rates of severe chronic illness and disability among Indigenous Australians, compared with the non-Indigenous population. Caregiving is perceived and supported by family and kin as part of normal family life and obligations, which may lead to reduced identification of Indigenous young people as carers.

Young carers in rural and regional areas were seen to experience geographic and social isolation, including a relative lack of support services. Participants reported a lack of transport services due to costs of fuel and long distances, young carers being unable to drive themselves into town, and poor and unreliable public transport services.

A number of gaps in support service for young carer were identified including:

- Participants noted that there were insufficient services for care recipients and that their family members had insufficient services available in particular:
  - 18-25 year olds;
  - CALD young carers;

- Indigenous young carers;
  - Children of parents with problematic drug use; and
  - Young carers in rural and remote areas.
- Due to fragmented service provision, many participants supported a case management model, with a case manager skilled at working with young carers to act as an advocate, ensure coordinated services, consider their family context and engage with young people individually over the long-term.
  - The short-term nature of service funding which lead to discontinuity of staff or a reduced number of staff hours.
  - Insufficient flexibility in service delivery.
  - Lack of effective strategies to identify young carers in a wide range of agencies and sites like schools and health services central to young people's lives.

These gaps identified by the service providers and policy makers were also identified by young carers in the interviews, and through the policy audit component of this research project (Section 6). Young people identified a lack of availability and flexibility of respite services as a primary difficulty in being able to better manage and balance their caring role with other responsibilities, notably education, employment and social activities. In the policy audit, case management carer support is categorised as a preventative approach to supporting young carers; however these types of services are not as prevalent as other types of services.

#### *Best practices and policy solutions*

Key issues identified by participants with respect to best practice included:

- Young people's involvement in a service or organisation and good policies and practices in place to support young carers gain the skills needed to contribute to the service or agency.
- Flexibility in service delivery, regardless of the type of service so that the individual needs of the young carer and their personal context could be addressed, especially with respect to education. Innovation and creativity were described as the main ingredients in successful programs.
- Case management approach although participants did not always use the term 'case management', they spoke of having one contact person who would locate services and act in the young carer's interests. Regular communication, a solid relationship based on trust and long-term and consistent engagement were identified as essential elements for success.
- Interagency work operating through cooperation and collaboration between organisations was seen as crucial to providing responsive services for young carers.
- Working with the families and involving other members of the family were perceived by participants as a successful method of addressing the needs of young carers, although they argued that the young carer should remain the central focus.
- Whole of family approach - Both service providers and policy makers responded positively, but with caution, to the idea of a whole of family approach. Several were already undertaking this kind of work. Some noted

that working with the whole of family approach was complex and time consuming, often beyond the boundaries of existing resources.

Future priorities for policy consideration identified by participants included focusing on:

- young adult carers aged 18-25;
- children whose parents have problematic alcohol and other drug use;
- Indigenous young carers;
- young carers in rural areas; and
- young carers of people with mental illness.

### **Policy audit**

The final component of the research encompassed an audit of policies, including legislative frameworks, services and programs of direct relevance to young carers. An audit of the number and types of services targeting young carers in all Australian jurisdictions was made.

An innovative framework for categorising young carer policies and services according to their goals and types of intervention was developed. Three categories of service goals and types of intervention were identified:

- **Assistance** services aim to support young carers in their caring responsibilities. They aim to help young carers cope with their role, and encourage them to seek additional help, either for themselves or the person they care for. The services in this category are usually provided over the short-term and include support such as information, advocacy and referral, short-term counselling and peer support.
- **Mitigation** services aim to reduce the care burden by lowering the intensity of caring, either by reducing the time spent on caring or by easing the young carer's responsibilities. The support provided also aims to reduce the long-term negative impacts of caring on the young carer, for example in their education or social life. Mitigation-type services are usually provided over the longer term and are more intensive than assistance services. Examples of these types of services include respite services for the young carer, flexible education arrangements, financial assistance and regular provision of home care.
- **Prevention** services aim to avoid the entrenchment of a young person's caring role to such an extent that it adversely affects outcomes across a range of domains, including school, employment, social relationships, health and wellbeing. Preventative services may preclude negative impacts of caring responsibilities by providing adequate support to the family when a disability or chronic illness first manifests itself. Preventative policies and services aim for optimum combinations of formal and informal support through early intervention tailored individually to each family and personalised case-management. They encompass a whole-of-family approach, the integration of social, health and disability services (Cass et al, 2009) and a 'no wrong door' approach where all service entry points provide referrals to relevant services (Carers Australia, 2009).

The policy audit focused on two areas:

- carer policies – legislation, actions plans, frameworks and charters; and
- programs and services targeting young carers– education, information, support and resources including income support.

In Australia, various government-funded support programs and services exist specifically for young carers and there is also a range of carer programs that are available to carers of all ages. It should be noted that these generic services for carers of all ages, for example, Home Care in New South Wales, also provide substantial and essential services to support young carers, as noted by feedback provided by the New South Wales Interagency Steering Committee. However the scope of this audit was limited to programs identifying young carers as a specific target group as the experiences and needs of young people providing support differ considerably from older carers. The audit did, nevertheless, include some generic programs and services that provide direct respite for care recipients and support to young people at risk where young carers were identified as a target group. In the audit, each program or service was assigned to the categories in the framework according to its stated aim/s and type/s of intervention/s. Often a program or service aimed to achieve multiple goals and was therefore assigned to one or more categories within the framework.

A comprehensive list of policies, programs and services designed to support young carers in each state, territory and the Commonwealth was compiled from various sources including: focus groups, service brochures, policy documents, reports and websites. The information in the Commonwealth, New South Wales and South Australian audits was sent to Research Partners and Carers Australia to verify the information collected and identify gaps. In addition the New South Wales Interagency Steering Committee and Carers Australia provided comments on the New South Wales and Commonwealth audits respectively. Due to a lack of resources, the policy audits of programs and services in other states and territories were not subject to the same validation process and were therefore not included in the analysis using the analytical framework.

The application of the analytical framework to the audit of existing programs and services designed for young carers in the Commonwealth, New South Wales and South Australia shows that most fall into the assistance and mitigation categories, while few contain preventative elements. The vast majority of services specifically designed for young carers focus on providing support and/or addressing negative outcomes for young carers rather than preventing them from occurring. Services and programs for young carers with a preventative approach emerged as a gap in services and this observation was reiterated in the information provided by service providers and young carers. This was particularly the case with respect to preventative services in education and employment, and individual case management to balance caring and other responsibilities. As noted, generic services for carers and the people for whom they provide care, such as Home Care in New South Wales, although outside the scope of this audit, also provide considerable support to young carers. Further research is required to examine their role in supporting young carers and their relationship to the analytical framework.

The implications of these findings draw attention to the need to place greater emphasis on an early intervention and prevention approach for young carers with the provision of adequate, appropriate and affordable services to the person in need of

support. This approach would facilitate the early identification of young carers, thereby reducing the likelihood of intensive young carer responsibilities becoming entrenched, which are likely to lead to negative outcomes in the short and longer-term. However, this should not be interpreted as negating or not valuing the vital support provided to young carers through assistance and mitigation type services. In some cases it is possible to effectively ameliorate negative outcomes for young carers by providing assistance and mitigation-type services. In circumstances where the young carer's role has become entrenched, assistance and mitigation may provide appropriate and effective support in the short term. Some young people may choose to provide care, and therefore need services that support them or mitigate the intensity and frequency of their responsibilities. These findings highlight the need for appropriate services, tailored to individual families' needs and preferences based on optimal combinations of formal and informal support to ease the frequency, intensity and the constraints imposed by young people's caregiving.

# 1 Introduction

## 1.1 Background and objectives

This report outlines the key findings of Young Carers: Social policy impacts of the caring responsibilities of children and young adults (LP0775594). The study was funded by the Australian Research Council (ARC) and supported by ten Partner Organisations: Carers NSW; NSW Health; Ageing, Disability and Home Care in the NSW Department of Human Services; NSW Commission for Children and Young People; and the partners in South Australia were: Carers SA; Social Inclusion Unit in the Department of Premier and Cabinet; Department for Families and Communities; Department of Education and Children's Services; Department of Further Education, Employment, Science and Technology; Children, Youth and Women's Health Service. The University of NSW HREC approval is HREC 07243.

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What do we mean by 'young carers'? The Australian Bureau of Statistics (ABS) (2008) defines a carer as a person who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older people. The assistance has to be ongoing, or likely to be ongoing, for at least six months. Data about the number of young carers in Australia from the ABS *Survey of Disability, Ageing and Carers, (SDAC) 2003* suggest that in 2003 there were 348,600 young people aged up to 24 years providing care in Australia (Australian Bureau of Statistics, 2004). Of these 348,600 young people providing care, there were 170,600 children and teenagers up to age 17 providing support and assistance usually to family members (estimated at 3.6 per cent of their age range), and a further 178,000 young adults aged 18-24 who were providing care (comprising 9.1 per cent of young adults in this age range) (Australian Bureau of Statistics (SDAC), 2004).

In the last two decades in Australia, the United Kingdom (UK) and to a lesser extent the United States (US), Canada, New Zealand, Ireland, and some parts of continental Europe, there has been growing recognition of young carers as a social category with experiences and needs distinct from those of their peers. In recent years, young carers

have become a growing focus of research, public policy, and human services, especially in the UK and Australia.

This Report of the project includes a number of research strands: a review of the literature; quantitative analysis of ABS *Census of Population and Housing 2006*; focus groups with policy makers and service providers; interviews and group activities with young carers and young adult carers; interviews with people receiving care from a young person; and an audit of policies and services relevant to young people who provide care.

The research fills a critical gap in Australia, by contributing a theoretically-informed and policy-focused quantitative and qualitative study on young carers. The findings provide innovative contributions to theories of care provided by young people; evidence about the diverse socio-economic and demographic characteristics of young carers and care recipients, young people's pathways into care provision, and the impacts of caring on their education, employment, social participation and health; and the development of supportive policies and services.

The research aimed to:

- conceptualise and analyse young carers within a comprehensive framework which focuses on the circumstances, experiences and meanings of the care-giving/receiving relationship for both caregivers and receivers, and the policy frameworks which affect those relationships;
- develop a model analysing international policy frameworks (in particular in the UK) for supporting young carers and their families, so as to place Australian policies within a comparative context;
- identify the range of education, training and employment arrangements and support/information services in Australia at government and Non-Government Organisation (NGO) levels which might flexibly recognise, support and open up opportunities for young people with informal care-giving responsibilities;
- identify the extent to which the promotion and provision of appropriate, accessible and affordable support services would assist in removing/reducing the barriers to education, training, employment and social participation
- formulate a cost/benefit analysis of the costs of care for young carers (at the time of care-giving and potentially through later adult years) with respect to impacts on participation in education, employment and receipt of market income;
- engage in knowledge transfer with all relevant organisations, policy-makers and service providers, especially the New South Wales and South Australian governments, Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), Carers Associations, schools, as well as young carers and their families. The purpose is to provide evidence to inform development of policies and services across Government departments and across government/NGO provider sectors to facilitate whole of government and cross-sectoral policies and services.

## 1.2 Overview of research study

In the first strand of research, team members held focus groups with policy makers and service providers in order to develop a better understanding of the issues, challenges and best practices relating to the diverse needs of young carers (aged up to 17 years) and young adult carers (aged 18-25 years) from different cultural backgrounds, and living in different locations across Australia. Seven focus groups were conducted involving a total of 47 policy makers and service providers in New South Wales and South Australia. Three focus groups were held in Adelaide, two in central Sydney, one in south western Sydney and one in Dubbo.

The second strand of research was a literature review on emerging themes, theory and evidence relating to young carers and young adult carers in Australia and internationally. This component provided a vital starting point for considering gaps in research, developing theoretical frameworks, and helped identify issues to be explored both in the quantitative and qualitative survey research and in the audit of policies and services.

The third strand involved an analysis of the ABS *Census of Population and Housing 2006* in order to identify rates of caring and the circumstances of young carers and young potential carers (aged 15-24, an age range necessarily determined by the data available from the Census); family composition; the nature of the care provided; young carers' participation in education and employment; their household income and resources. Also identified were young carers' contributions to the domestic work and child care undertaken in their households. Geographical mapping of the Census data was undertaken to identify the distribution of the prevalence of caregiving by young people across Australia, focussing in particular on Indigenous carers and carers of culturally and linguistically diverse (CALD) background. Pathways into caring for young people were explored, such as cultural background and Indigeneity, lone parent households and low resource households, and location in metropolitan, regional and remote areas. Particular emphasis was placed on the impact of caring on young carers' participation in education and employment, their rates of unemployment and whether they were in the labour force. Comparisons were made between these circumstances for young people who were identified in the Census as carers, young people who may be categorised as potential carers, and young people who did not appear to have caring responsibilities, as identified in the Census. The extent to which caregiving was associated with aspects of disadvantage among young carers was also explored.

The qualitative component of the study incorporated interviews, activity sessions and an online questionnaire, and used a "whole of family approach" to understand key aspects of the experiences, circumstances and needs of young carers, young adult carers and their care recipients. Interviews with young carers, young adult carers and care recipients were primarily carried out in New South Wales and South Australia; however a few participants were also recruited from Queensland and Victoria. The participants were from metropolitan, regional and rural locations, and participants were recruited with the assistance of the Partner Organisations. Participants were recruited to one of three groups: young carers (aged 7 to 17), young adult carers (aged 18 to 25) and adults (aged 18 and over) who were receiving care from a young person. The purpose of the interviews was to explore the experiences of caregiving-its nature and intensity, pathways into caregiving, socio-economic and demographic circumstances of young carers, young adult carers and their families, young carers'

and young adult carers' participation in education, employment and social activities with friends, and their future aspirations. The data collected from the interviews were complemented by an online questionnaire that all participants were asked to complete. Also, there were three activity sessions carried out with young carers in South Australia and New South Wales, which utilised a more participatory method for learning about young carers' experiences.

The team also conducted an audit of policies, including legislative frameworks, services and programs of direct relevance to young carers. A comprehensive audit of the number and types of services in all Australian jurisdictions was made and analysed using an innovative framework developed to identify the objectives of different types of services. Programs and services for young carers at the Commonwealth level and for each state were identified and categorised as *Assistance*, *Mitigation* or *Preventative* services, or a combination of the three. Findings from the audit enabled the analysis to identify gaps in services, with respect to the types of services available for young carers.

### **1.3 Outline of the report**

This report presents the key findings from each strand of the research. Section 2, the literature review, outlines key research findings and theoretical frameworks identified in the Australian and international literature on young carers. Section 3 presents an analysis of the *ABS Census of Population and Housing 2006* which provides a geographical analysis of rates, pathways into and impacts of caring by young people across different regions in Australia, for two groups – young carers and potential young carers. Section 4 discusses findings from the qualitative component of the research, which included the interviews, questionnaires and activity sessions. This section is divided into findings from the interviews with young people (young carers and young adult carers) and people receiving care from a young person. Section 5 describes findings from the focus groups with policy makers and service providers, identifying the main themes and issues discussed and how these perspectives relate to findings from the interviews with young people. Section 6 reports on the policy audit, focusing on Commonwealth policies and programs and those in South Australia and New South Wales. These findings identify gaps in services, and relate these gaps to the different service objectives that are identified by the framework established to categorise service objectives.

## 2 Literature review

### 2.1 Empirical research

Young people have always provided support to family members as a customary part of family life. However, awareness and recognition of young carers as a defined group, or as a construct in public discussions and policy discourse, is a relatively new phenomenon. In the 1990s and early 2000s carer advocacy groups, government agencies and academic researchers (e.g. Carers Association of Australia, 1996; Becker, Aldridge and Dearden, 1998: 11; DFaCS, 2002), drew attention to the fact that some children and young people fulfill responsibilities well beyond those normally expected of their age group.

Over the last 15 years, researchers have created a fairly comprehensive picture of the circumstances and characteristics of young carers in English-speaking countries, particularly in the UK and Australia, and to a lesser extent the USA, Canada, New Zealand and Ireland (e.g. Cass et al., 2009; Hill et al., 2009; Hunt, Levine and Naiditch, 2005; Baago, 2005; Gaffney, 2007; O'Connell, Finnerty and Egan, 2008). In other developed countries such as in continental Europe, research on young carers has been slower to develop (Becker ed., 1995; Becker, 2007). In sub-Saharan Africa, care by young people is significant and widespread due to the HIV/AIDS epidemic and limited formal support services, as highlighted by a body of empirical research is beginning to appear (Evans, 2010; Becker, 2007; Robson et al., 2006).

While young carers are defined slightly differently in each country, the term generally refers to children and young people up to age 17 and young adults aged 18-24 who provide substantial unpaid support to a family member with a chronic illness, disability, mental health issue, problems with alcohol or other drugs, or frailty associated with older age (for Australia: Carers Australia, 2008; the UK: Office for National Statistics (ONS), 2003; the USA: Hunt, Levine and Naiditch, 2005 – in the US the phrase young caregiver is more commonly used).

Despite differences in the definition of a young carer, including variations in age range, the proportion of young carers in those countries where research is available is fairly consistent. For example, data from Australia, the UK, the US and Ireland indicate that between two and four per cent of children and young people up to 18 years of age perform significant caring tasks (Cass et al., 2009; Hill et al., 2009; Becker, 2007; Hunt, Levine and Naiditch, 2005; Central Statistics Office, 2007). Amongst young adults, the rates of caregiving range from an estimated five per cent in the UK for young people aged 16-24 (Becker and Becker, 2008a) to nine per cent in Australia for young people aged 18-24 (Australian Bureau of Statistics, 2004). It is generally assumed that these numbers are an underestimate, since some young people are reluctant to reveal caregiving within their families or do not see themselves as carers, and some adults who provide responses to surveys do not report that there are young people in the household providing care (Cass et al., 2009; Hill et al., 2009; Smyth, Blaxland and Cass, 2011).

The ABS (2008) defines a carer as a person who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or persons who are elderly. The assistance has to be ongoing, or likely to be ongoing, for at least six months. The ABS *Survey of Disability, Ageing and Carers (SDAC)* (2004)

estimated that in 2003 there were 348,600 young people aged up to 24 years providing care in Australia. Of these, there were 170,600 children and teenagers up to age 17 providing support and assistance usually to family members (estimated at 3.6 per cent of their age range), and a further 178,000 young adults aged 18-24 who were providing care (comprising 9.1 per cent of young adults in this age range) (Australian Bureau of Statistics, 2004).

The available research explores the demographic characteristics, family circumstances and needs of young carers (Baago, 2005; Cass et al., 2009; Hill et al., 2009; Hunt, Levine and Naiditch, 2005; Young, Grundy and Jitlal, 2006). Young carers are more likely than their peers to live in single-parent families and in low-income or low resource households (Hunt, Levine and Naiditch, 2005; Hill et al., 2009, Becker, 2007). In Australia, caregiving by young people is considerably more prevalent in Indigenous families than in non-Indigenous families. It is also evident that the prevalence of young people providing care is greater in families of minority ethnic backgrounds in Britain (Becker, 2007), or families from CALD backgrounds in Australia (Hill et al., 2009).

Gender composition is important because it highlights the characteristics of young people who have the main responsibility for caregiving. In Australia, females comprise 49 per cent of all young carers aged up to 17 years and 49 per cent of young adult carers aged 18-24 years. But gender parity is not the case when the composition of primary carers is considered: primary carers are defined in the ABS SDAC 2003 as those carers providing the most informal assistance to a person with one or more disabilities (Cass et al, 2009). Young women comprise 81 per cent of primary carers aged 18-24, indicating that while both young men and women engage in some forms of caregiving, the majority of young adults who provide the most care are female. This suggests that there are socio-cultural expectations drawing more young women than young men into informal care, expectations associated with gender differentiated practices of care itself as well as differences in participation in tertiary education and labour force participation (Fisher and Tronto, 1990; Daly and Lewis, 2000; Cass, et al, 2009). Sixty-two per cent of all young carers aged 10–24 years care for a parent; 34 per cent for another relative or a friend; and four per cent for a partner (Hill et al., 2009).

The wide range of caring tasks performed by young carers can encompass housework, shopping, cooking, and dealing with health professionals and financial matters. Young carers are also likely to perform care of an emotional, physical and intimate nature (e.g. Warren, 2007; Cass et al., 2009). While young people who are not defined (and would not define themselves) as a carer may perform some of these tasks, young carers often devote significantly more time to them and take on higher levels of responsibility. For example, in a study by Moore, young carers who participated in the study were engaged in caregiving for an average of 6.4 hours per day and many were unable to identify the number of years they had been caring, instead stating ‘always’ (Moore, 2005b).

The Australian, UK and US research shows that young carers often indicate that they are proud of what they do, hope to receive recognition and respect for their caring, usually come from close-knit families and often manage well with the additional responsibilities of care (Aldridge and Becker, 1998, 1999, 2003; DFACS, 2002; Hunt, Levine and Naiditch, 2005). However, due to the extent and intensity of their caring

responsibilities, other areas of young carers' lives can be negatively affected. For example, research has shown that many young carers experience difficulties at school as a result of their caring responsibilities (Moore, 2005a; Warren, 2007; Cass et al, 2009; Becker and Becker, 2008b; Moore, McArthur and Morrow, 2009). In 2003 in Australia, young carers aged 18–24 years were less likely than non-carers of the same age group (66 per cent compared to 73 per cent) to have completed year 12 or equivalent (Australian Bureau of Statistics, 2008).

This, in turn, may compromise their opportunities for further education and training, along with their long-term employment prospects. Quantitative studies in both Australia (Hill et al, 2009; Australian Bureau of Statistics, 2008) and Britain (Yeandle and Buckner, 2007) have found that young carers, in comparison with their peers who are not engaged in caring responsibilities, are less likely to be studying or in full-time employment; if employed, they are more likely to be working part-time and more likely to be in receipt of government income support.

Time constraints due to caring responsibilities, combined with their often low income household circumstances, can also affect young carers' social lives, including their friendships and social and recreational activities. This can impact on social integration, physical health and personal wellbeing (Price, 1996; Morrow, 2005; Butler and Astbury, 2005; Thomas et al., 2003; Cass et al, 2009; Aldridge and Becker, 1993). Analysing data from the ABS *SDAC 2003*, Cass et al. (2009) found that young carers were twice as likely as their peers to have a disability themselves. All of these difficulties may be compounded by a lack of awareness and understanding of young carers' life circumstances by those around them, including teachers in schools and further education settings, community service providers, health care professionals and the wider community (Cass et al, 2009; Moore, 2005a; Dearden and Becker, 2002).

Australian, UK and US research shows that young people are participating in informal care as a result of a number of inter-related factors: personal and family preferences for informal care within the family; the absence of other available informal carers within the family/kin network and lack of appropriate, accessible and affordable formal care services (Price, 1996; Hunt, Levine and Naiditch, 2005; Moore and McArthur, 2007; Cass et al., 2009). Aldridge and Becker (1999) in the UK found that the factors that draw children and young people into unpaid care work include the nature of the illness or condition of the family member and how it relates to the need for care, support or supervision; the intensity and duration of the condition; and the fact that children and young people are co-resident and are therefore perceived, and perceive themselves as immediately available to provide support. This is especially so in cultural circumstances where kin reciprocity is expected, often normative in family functioning (eg in families of ethnic minority background); and when the formal health and social services are insufficient, or seen as inappropriate. Lack of income to purchase formal services is significant in single parent and low income two parent families.

Young carers aged 18–24, often termed 'young adult carers', comprise a larger proportion of their age group than do children or teenage carers, at approximately 9 per cent of young people in Australia aged 18-24 years (Cass et al, 2009). Surveys across countries have identified between 5 and 9 per cent of young adults as carers (Cass et al., 2009; Becker and Becker, 2008a; Levine et al., 2005). Young adult carers are at a critical life-course stage. On the cusp of adulthood, member of this age group

are typically participating in further education and training, entering the labour force, forming independent households and entering into intimate relationships, or at least have aspirations to make these significant life transitions. Therefore young adult carers have support needs similar to but also different from those of children or adolescent carers on the one hand, and older adult carers on the other.

Until a few years ago, policy and research had largely subsumed young adult carers within the group of adult carers. Recent studies focusing on young adult carers in the UK and Australia (Dearden and Becker, 2000; Yeandle and Buckner, 2007; Becker and Becker, 2008a; Hill et al., 2009) have found that they experience difficulties in achieving educational qualifications or regular employment.. This may compound the financial constraints that many of their families face and in particular may limit their future employment opportunities. Caring may also constrain the young adults' social lives and their ability to leave home and form autonomous households. Unpublished local studies conducted by UK carers projects, summarised by Becker and Becker (2008b), highlight the lack of age-specific support services. Many young adult carers feel they have outgrown services for adolescent, school-aged carers, but are too young for adult carer services, which they perceive as directed at middle-aged people caring for aged parents.

While young carers of all ages (including young adult carers) identify constraints that their caring responsibilities place on them, studies have also shown that many are committed to their caring and derive pride and satisfaction from it. However, young carers consistently identify the need for more support services for themselves and the people they care for (e.g. Cass et al., 2009; Moore and McArthur, 2007; Becker and Becker, 2008b). Australian research has found that the majority of carers under the age of 25 whose care recipients needed assistance did not use formal services (Bittman et al., 2004; Thomson et al., 2005). The reasons given by carers include: many young people providing informal care do not identify as a 'carer' and consider that they do not need formal services. Other young carers however indicate that the reasons for not using formal services reside in the characteristics of the services themselves and the rules determining their allocation: the nature of services may not match their particular needs; services may not be available, or have convenient hours of operation, or may not be affordable. The reasons given in the literature for young carers having greater difficulty accessing services than older carers include: some service providers lack awareness about their specific needs; young people and their families do not have information about services; transport difficulties constrain access to services; and young people mistrust services and are reluctant to use them. Similar findings have been reported for young carers in the UK (Morgan, 2006).

In recent years, Commonwealth and state/territory government agencies and non-government organisations have established a range of support services for young carers, especially in Australia and the UK. Services include major resources such as government-provided income support through Carer Payment and Carer Allowance in Australia, and information provision by government and non-government sources. There are also respite services, counseling, educational support and recreational activities for young carers, as well as support services for the person receiving care, relevant to the condition, eg disability, medical condition, mental illness or frailty due to age, which establishes the need for care. In addition, in Australia the Young Carers Respite and Information Services program provides information to young carers to

support them in managing the challenges which they face in their caring role (Commonwealth of Australia, 2011) and the network of Carers Associations across Australia plays a significant role in information provision about relevant services.

There are few evaluations about the effectiveness of services for young carers. International research has produced some evaluations of support programs for carers in general, although results are not conclusive (Eagar et al., 2007). In Australia some government programs for carers have been reviewed (see an overview in Carers Australia, 2008), but few systematic evaluations of specific young carer programs are in the public domain (for a rare exception, see Hodge et al., 2008). There is, however, growing awareness of the importance of addressing issues faced by young carers in accessing formal support services, receiving flexible respite care, having their needs in the education system recognised and accessing services in regional and remote areas (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009; Hill et al, 2009; Cass et al, 2009; Commonwealth of Australia, 2011).

Little research has been conducted about the perspective of the care recipients in the caring relationship. Aldridge and Becker (1994) interviewed 10 parents for whom young people provided care. The study demonstrated the complexity of the caring relationship, where both participants in the relationship occupy different roles at the same time and therefore may have contradicting needs, rights and responsibilities: the child is both a carer and a young person, while the parent is both a care receiver and a parent, and does not cease to be apparent when being the recipient of care. Being dependent on their child for support and assistance may make the parent feel guilty or fearful. The authors found that parents were expending considerable effort to reconcile their conflicting roles, to give the children what they needed and to provide a family life that was as normal as possible.

This was confirmed in a study of mothers using wheelchairs or walking frames (McKeever et al., 2003). In an effort to provide 'good mothering' through accommodating their children's preferences for their established friendships and current schools, several mothers remained in a home that was unsuitable for their own mobility needs. Evans' (2009) interviews with 12 mothers who were care recipients in the UK, most of whom were black African migrants living with HIV, highlighted different cultural norms and their impact on care arrangements in the family. Most of the young carers were girls rather than boys, since in their African cultures they were expected to perform household and caring duties as a "natural" part of their gender roles. Other findings were similar to the studies mentioned above: the mothers' guilt about having to rely on their children, and generally strong emotional bonds within the family.

The fact that some children take on caring responsibilities for their parents has led to the concern that the children may be 'parentified' (Early and Cushway, 2002), that is, taking on parenting roles at a premature time, with adverse effects on their own social development and future adult relationships. This notion has been criticised by the disability rights movement, particularly in the UK (e.g. Keith and Morris, 1995; Morris, 1997a and 1997b; Prilleltensky, 2004), which argues that children may take on practical household and caring tasks, but that the parents' emotional and psychological place as parents within the family usually remains intact. (We note that while this may be true of many parents with physical disabilities who are the focus of

the studies cited above, those suffering mental illness, or who may be affected by substance misuse, may not always be able to provide adequate emotional and psychological care for their children.) These authors contend further that acknowledging children as ‘young carers’ characterises their parents with disability as inadequate and thus undermines their role as parents. To reconcile these apparently conflicting perspectives, researchers in the UK and Australia (see Becker, 2007) have been advocating a whole-of-family approach to research and policy that identifies and recognises the needs of both the young people and those for whom they care, and does not construct a zero-sum policy scenario.

## 2.2 Theoretical frameworks

Previous Australian research on young carers has been largely empirical and descriptive, and it has not engaged centrally with the theoretical and conceptual debates in the area, and the development of frameworks which might best inform policy development. Conceptual frameworks that are relevant to research on young carers include:

- young carers’ engagement in different *modes of care*;
- the exercise of *agency* within a number of constraints; and
- the balance between *formal and informal care* provision and how this influences agency and modes of care.

### Modes of care

Care is an essential facet of human activity that may occur within and between generations. Fisher and Tronto (1990) describe caring as a process that involves complex, interrelated aspects or modes of care:

- *caring about* – involves recognising the need for care and that these needs should be met. ‘Caring about’ implies a connection to and concern for others, but this concern does not necessarily lead to overt action.
- *taking care of* – involves taking responsibility for responding to identified needs for care and determining how these needs will be met. This mode of caring requires knowledge of the care situation.
- *caregiving* – involves concrete caring activities or the hands-on work of care. ‘Caregiving’ often requires an intimate knowledge of the care situation and considerable time and energy of the carer.
- *care-receiving* – involves the responses to the caring process by those in need of support. This is an important aspect, as the response to care is a way of determining if needs have been met.

Fisher and Tronto see these modes of care as interrelated because they build on one another. For example, for someone to take responsibility for organising support to meet identified needs or ‘taking care of’, they must first notice that there is need for care or ‘care about’. Once care needs are identified, they can be met through the provision of concrete caring activities or ‘caregiving’, which can be provided by informal or formal support or a combination of these. The reciprocal nature of caring is evident within the modes of ‘caregiving’ and ‘care-receiving’, particularly with

respect to young carers, who are often engaged in providing assistance to parents who in turn provide support and care to them.

### **Agency within constraint**

Caring requires resources such as time, knowledge and skills. Conversely, a lack of resources can constrain carers' ability to provide care (Fisher and Tronto, 1990) and look after their own needs. Constraints exist at various levels and are interconnected, and young carers live and perform their caring tasks – in other words, exercise agency – within these constraints (Smyth, Cass and Hill, 2011).

*At the intra-familial level*, constraints include the intensity and duration of the illness or condition, as well as individual and family decisions to opt for informal care. Factors shaping these decisions include family obligations and expectations – particularly in culturally and linguistically diverse and Indigenous families – or love for the person requiring care, but also gender, co-residence and family composition and structure, such as single parent households and the disruption of extended family networks, eg as a result of migration (Cass et al., 2009: 13; Becker and Becker, 2008b: 15). A major constraint, therefore, is the absence of other appropriate or available carers within the family and extended kin network.

Young carers can also be pushed into care by *socio-economic disadvantage* that limits knowledge of, access to and affordability of formal care options, to the extent that such options are not even conceivable, particularly when disadvantage is exacerbated by geographic distance from services (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009; Hill et al., 2009; Cass et al., 2009). Limited material resources and lack of linguistically comprehensible information may also shape intra-familial expectations of intensive informal care. In other words, the decision to 'keep it in the family' may not be born of genuine choice but of economic and social disadvantage (Olsen, 2000).

At a macro level, the provision of informal care can be a result of the *policy and service framework*, including the lack of appropriate, accessible, affordable and good quality formal support services (Dearden and Becker, 1998; Olsen, 2000). This includes the absence of such services, but also the reluctance among young carers and their families to access existing services for fear of attracting stigma or formal intervention from statutory child protection authorities (Cass et al., 2009; Hill et al., 2009; Becker and Becker, 2008b). Access to appropriate services and programs is a key issue in alleviating constraints on the agency of young carers, as it can, for example, reduce the intensity and frequency of their caregiving, or enable them to cease caregiving altogether.

### **Balancing formal and informal care**

Another concept relevant to young carer research concerns the optimum mix between informal and formal care. Informal care is provided by family and friends, including young carers, while formal care is supplied by community support services, through either government organisations, non-government not-for-profit agencies or market providers. In practice, care provision often consists of a mix, where informal support is supplemented by formal support, very often the terminology used is that of carers being "partners in care" with health and community services providers (Commonwealth of Australia, 2011:19). Combinations vary over time in each family,

as support needs and formal service provision change. However, considerations of younger age which may involve age-inappropriate levels and types of care responsibilities for young people, may make the concept of “partners in care” problematic as a policy goal.

As explained above, decisions to use informal care are often due to constraints at the intra-familial, socio-economic and macro policy levels. Because of the latter, governments have the potential to influence the level of informal care provision by funding, providing and regulating formal care services (Moullin, 2007: 8). Governments also have the potential to affect the level of informal care need through an investment in preventative services (ibid). While such interventions may be costly, informal, ‘unpaid care’ is not cost free: the costs of providing support are borne by the informal carers (Moullin, 2007; Daley and Lewis, 2000), and this is especially salient where the caregiver is a child or young person, since the costs may be incurred over the long-term (Table 2.1).

**Table 2.1: Forms of care provision** (following Fisher and Tronto, 1990)

	<b>Informal care</b>	<b>Formal care</b>
Source of care	Care provided informally by young people	Care provided formally by government, NGOs, market
Constraints	Families use informal care due to socio-economic constraints, geographic access constraints and lack of appropriate, accessible and affordable services	Services are available, affordable, accessible and appropriate
Costs incurred	Young carers incur all costs of caring, both in the short and longer-term	Society at large shares the costs of caring in optimal combinations
Main mode of caring	‘Caregiving’	‘Caring about’

As the level of formal support increases, the provision of informal care may decrease, although not necessarily to the same extent. In some cases, access to formal care requires informal support, for example in the form of transport or supervision (Land, 2002: 22). It is also possible that the *nature* of the informal care changes as more formal support becomes available. Research indicates that the provision of formal care services, while not relieving the need for informal care, may reduce the intensity of care and the character of the caring tasks (Hoffmann and Rodrigues, 2010). The relationship between formal and informal care, and the extent to which they operate as

‘substitutes’, seems closely related to the intensity of the needs of the care recipients, the nature of the caring tasks, and the character of the formal service, such as whether it is nursing care or domestic assistance (Bolin et al., 2008; Bonsang, 2009). Increased access to and use of formal support has the potential to shift the main mode of care from ‘caregiving’ towards ‘caring about’, thereby reducing the costs of care for young carers and their families.

Balancing formal and informal care requires an optimal mix of both forms of provision, where each family receives adequate formal support supplemented by informal care, if required. The optimal mix for each care situation will vary depending on the intensity and duration of the illness or disability, the age of the child or young person providing care, cultural expectations of intra-familial care, and family composition and structure.

### 3 Young carers: geographical analysis of rates, pathways into and impacts of caring<sup>1</sup>

#### 3.1 Introduction

The following section reports on data analysis using the ABS *Census of Population and Housing (Census) 2006*. Customised data were purchased from the ABS in Supertable format and analysed at State/Territory and Local Government Area (LGA) level.

The analysis below uses the following definitions:

**Young carers** were young people aged between 15 and 24 years who responded positively to the question about the provision of unpaid care, help or assistance on the Census form:

*“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 relating to old age?”*

The Census also asks questions about whether a person has a need for assistance and the reasons for need for assistance or supervision:

*Does the person ever need someone to help with, or be with them for:*

- *self-care activities*
- *body movement activities*
- *communication activities?*

Due to concerns about hidden carers and young people who do not self-identify as a carer we also developed another category of young persons who were ‘potential carers’ for analysis.

**Potential carers** were young people who lived in a household with another person who had a disability themselves but did not indicate that they were a carer on the carer question: a disability in this case was restricted to those who indicated on the Census form that they always or sometimes needed help with the core activities of self-care, communication and mobility due to a long-term condition. In this analysis we have classified these young people as ‘potential’ rather than ‘hidden’ carers because we do not wish to assume that all these young people are necessarily carers. The analysis maps the characteristics of these young people alongside the young carers to examine whether there are any similarities.

There are a number of limitations of the Census data that should be borne in mind when interpreting the analysis:

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<sup>1</sup> Some of this section is based on a forthcoming article: Hill, T., Thomson, C. and Cass, B (2011), ‘Young carers: Location, education and employment disadvantage’, *Australian Journal of Labour Economics*, (in press).

- The undercount of young carers in the Census compared with the ABS SDAC: the population of young carers identified in the Census is about half the size of that estimated by SDAC. This result is most likely due to the different method of data collection and the different questions used to identify carers. So it is likely that the prevalence rates of caring identified in the Census are a minimum.
- Second – as a predominantly self-enumerated survey the Census has higher levels of non-response to questions, including the carer question, than other surveys. At this stage in the analysis non-respondents to the carer questions and other questions have been excluded from calculations.
- Third, while the analysis reports on Census data from the whole Census, cells which have small numbers are likely to be unreliable due to the randomizing that the ABS undertakes to ensure confidentiality.
- Finally, there is the issue of interpreting Census data from remote communities. Although the ABS has an Indigenous Enumeration Strategy, which involves awareness campaigns to encourage participation and identification, culturally and linguistically sensitive collection methods, and consultation with Indigenous communities, there are still issues about undercounting the Indigenous population, the mobility of the Indigenous population and questions about the relevance of household composition definitions. Researchers have also raised questions about the relevance of the Census process and categories to the circumstances of Indigenous populations in remote communities (see, Morphy, 2007a, 2007b; and Morphy, Sanders and Taylor, 2007). Thus, data from remote areas should be interpreted with caution.

### **3.2 Rates of caring**

Figure 3.1, Figure 3.2 and Table 3.1 outline the rates of care provision and potential caring among young men and women across all the States/Territories. The graphs indicate that:

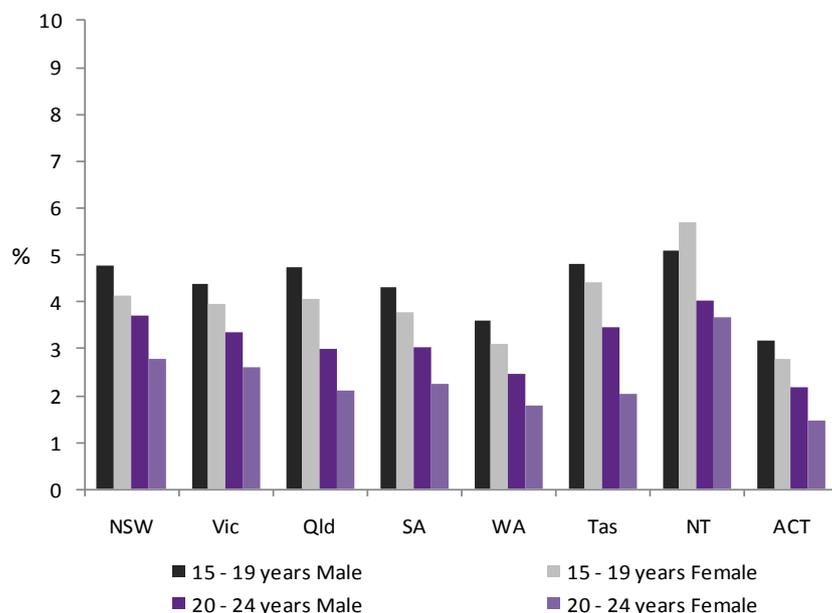
- Young women are more likely than young men to provide care in both age groups.
- The highest rate of care provision is by young women aged 20-24 years.
- The highest rates of care provision are in the Northern Territory.
- Young men are more likely than young women to be potential carers.
- Young people in the 15-19 years age group are more likely to be potential carers than those in the 20-24 years age group.
- Young men more likely to be potential carers than young women in each age group, except for the 15-19 years age group in the Northern Territory.
- Rates of potential caring are relatively similar across States/Territories but lower in the ACT.

**Figure 3.1 Proportion of young people who are carers by age, sex and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.2 Proportion of young people who are potential carers by age, sex and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Table 3.1 Proportion of young people who are carers and potential carers by age, sex and State/Territory, 2006 (per cent)**

	Carers				Potential carers			
	15 - 19 years		20 - 24 years		15 - 19 years		20 - 24 years	
	Male	Female	Male	Female	Male	Female	Male	Female
<b>NSW</b>	4.3	5.4	5.0	7.0	4.8	4.1	3.7	2.8
<b>Vic</b>	3.9	4.8	4.4	6.6	4.4	4.0	3.4	2.6
<b>Qld</b>	3.7	4.6	4.1	6.0	4.7	4.1	3.0	2.1
<b>SA</b>	3.9	4.9	4.5	6.6	4.3	3.8	3.0	2.3
<b>WA</b>	3.4	4.4	3.8	5.8	3.6	3.1	2.5	1.8
<b>Tas</b>	4.1	5.0	4.6	6.7	4.8	4.4	3.4	2.0
<b>NT</b>	5.6	6.7	6.3	8.9	5.1	5.7	4.0	3.7
<b>ACT</b>	4.0	4.8	4.1	5.6	3.2	2.8	2.2	1.5

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### 3.3 Where are young carers and potential carers located?

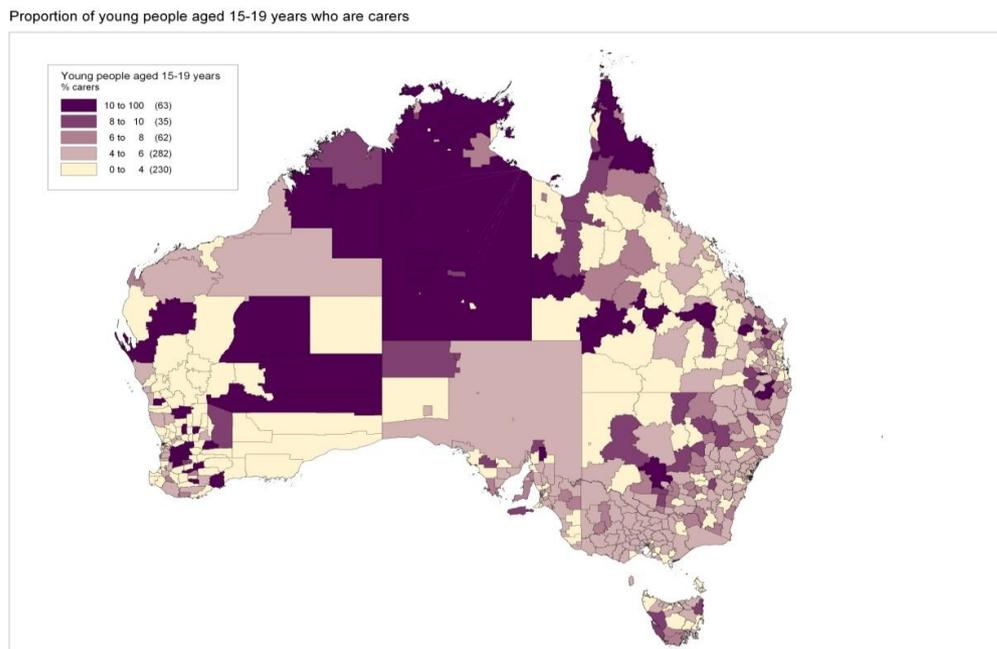
Figure 3.3 and Figure 3.4 outline the proportion of young people who are carers by Local Government Areas (LGAs) across Australia. Comparing the rates for major cities versus other areas shows that:

- None the major cities have LGA's where more than 8 per cent of young people in the 15-19 years age group are carers. Only the LGA of Hunter's Hill in Sydney has 8.1 per cent of the population of young people aged 20-24 years who are carers. All other LGAs with higher rates of informal caring (over 8 per cent) are outside of major cities.

Figure 3.5 and Figure 3.6 show rates of potential caring for LGAs across Australia for young people aged 15-19 years and 20 -24 years respectively. Comparing major cities and other areas it is evident that:

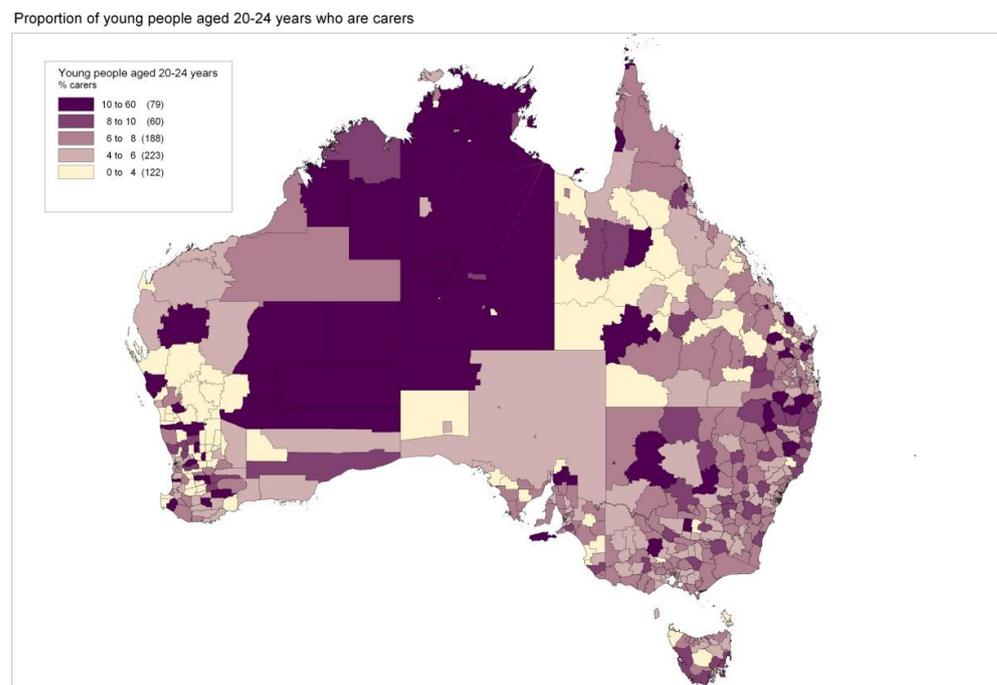
- Apart from Fairfield in Sydney in which 8.1 per cent of young people aged 20-24 years are potential carers, regions with over 8 per cent of young people in either the 15-19 years age group or the 20-24 years age group are outside of major cities.

**Figure 3.3 Proportion of young people aged 15-19 years who are carers by Local Government Areas, 2006**



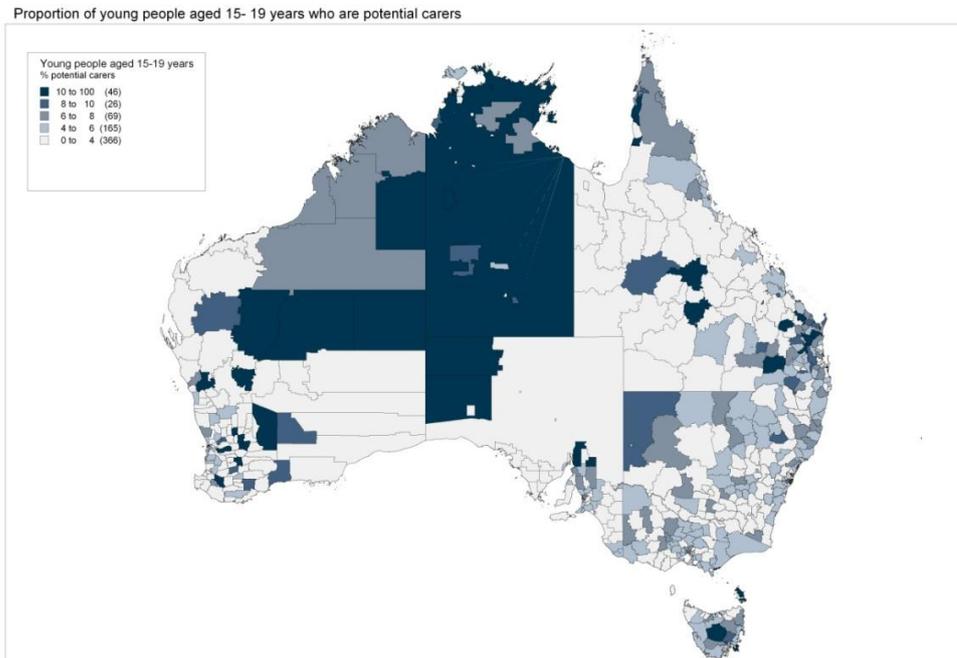
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.4 Proportion of young people aged 20-24 years who are carers by Local Government Areas, 2006**



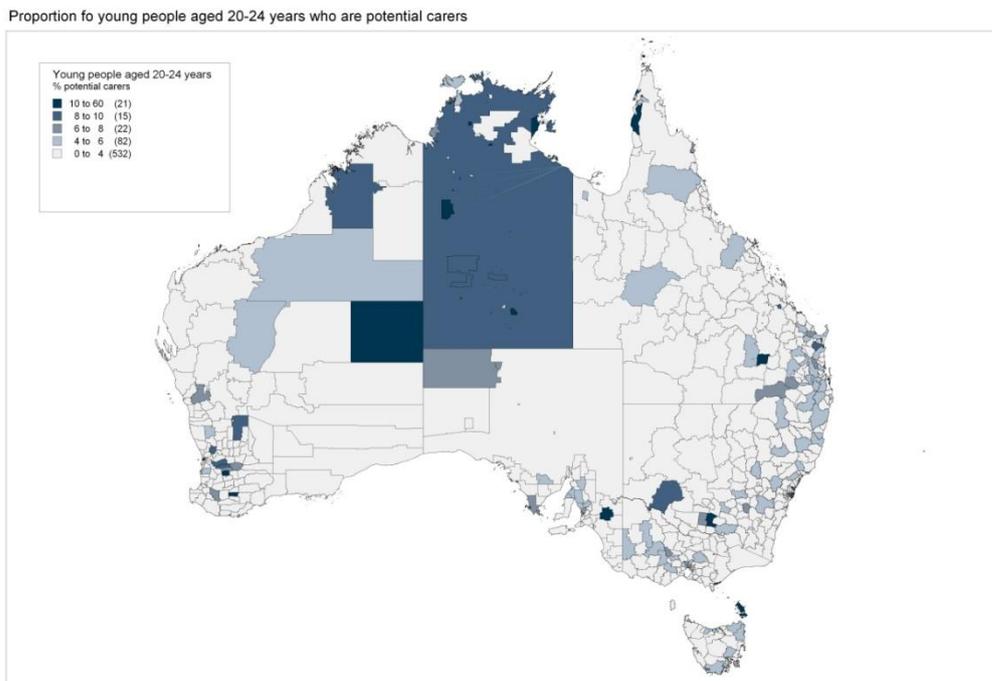
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.5 Proportion of young people aged 15-19 years who are potential carers by Local Government Areas, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.6 Proportion of young people aged 20-24 years who are potential carers by Local Government Areas, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

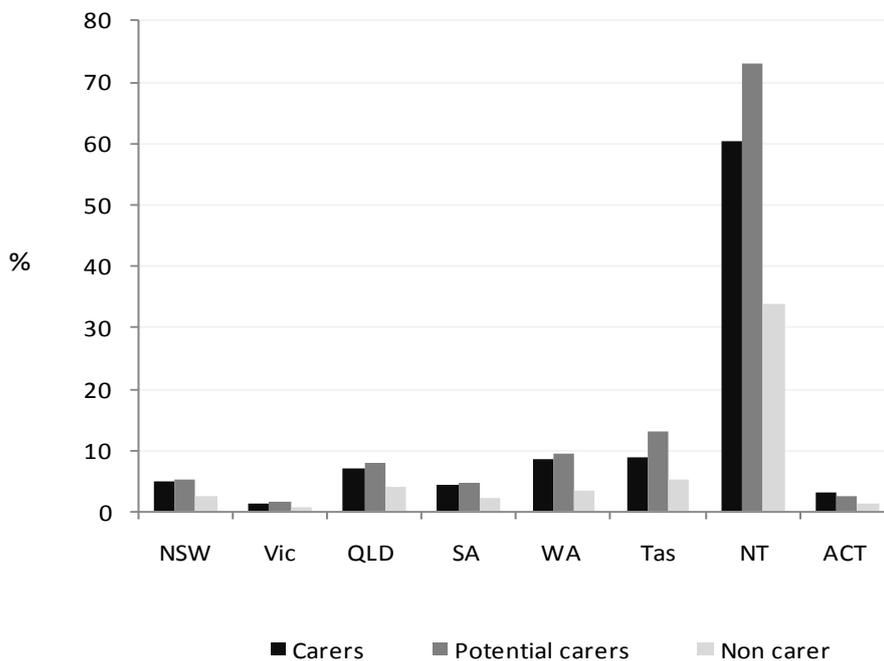
### 3.4 Pathways into caring: socio demographic characteristics

The literature indicates that there are numerous reasons that young people may become carers within their family. Key factors include the extent of access to formal services and supports for the person with disability, chronic illness or frailty due to older age. The literature suggests one reason for not accessing formal services is the lack of culturally appropriate services. This factor would therefore suggest that young people who are from Indigenous and culturally and linguistically diverse backgrounds may live in families who have greater difficulty in accessing appropriate supports. This in turn is likely to result in a higher rate of informal caring among young people in these communities.

#### Indigeneity

Figure 3.7 below reports on the proportion of young people who are Indigenous by carer and potential carer status in each State and Territory and Table 3.2 provides the same data for young people disaggregated by age and sex. It is evident that in all age and sex categories young Indigenous people are overrepresented in the young carer and potential carer populations. Among young men and women in both age groups, Indigenous young people either provide care or are in the potential carer categories at rates that are twice that of their representation in the non-carer population.

**Figure 3.7 Proportion of young people (aged 15-24 years) who are Indigenous by carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

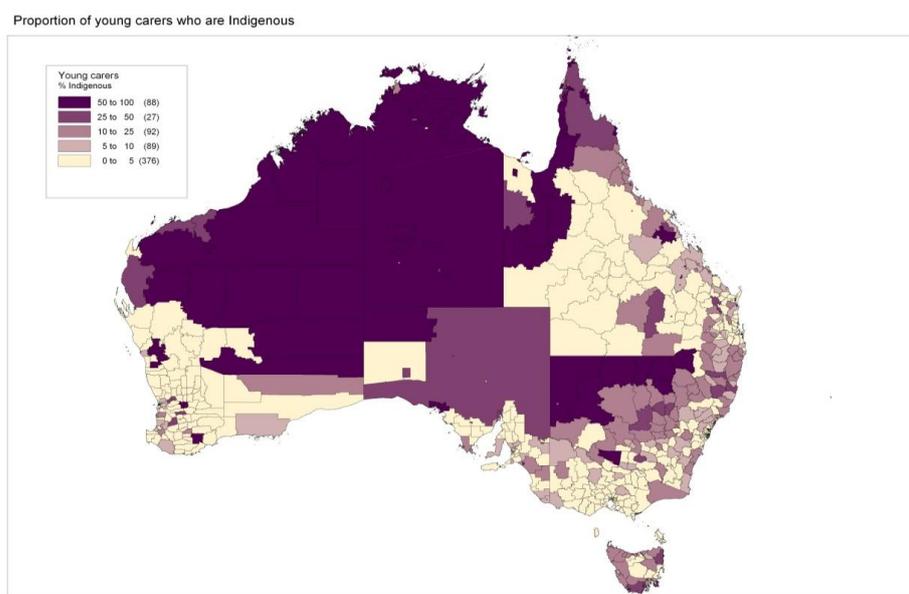
**Table 3.2 Proportion of young people who are Indigenous by carer status, age, sex and State/Territory, 2006 (per cent)**

	Male 15-19			Female 15-19			Male 20-24			Female 20-24		
	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers
New South Wales	5.5	6.6	3.0	6.0	5.9	3.1	4.1	4.2	2.3	4.5	4.1	2.4
Victoria	1.7	1.5	0.8	1.8	2.0	0.9	1.2	1.3	0.7	1.2	1.3	0.7
Queensland	8.3	7.8	4.4	7.5	8.7	4.5	6.1	7.8	3.4	7.1	7.7	3.6
South Australia	4.6	5.1	2.4	4.7	4.8	2.5	4.2	3.3	1.9	3.9	5.0	2.0
Western Australia	8.5	9.7	3.6	10.0	10.1	3.7	7.7	8.3	3.0	8.3	9.7	3.3
Tasmania	10.1	16.0	6.0	9.8	13.6	5.5	7.5	9.8	4.5	8.6	10.2	5.0
Northern Territory	56.3	67.5	37.7	62.4	75.7	37.0	65.3	73.9	30.2	58.3	75.3	30.9
Australian Capital Territory	3.8	3.5	1.6	4.6	1.1	1.5	1.5	3.6	1.4	3.1	1.9	1.3

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

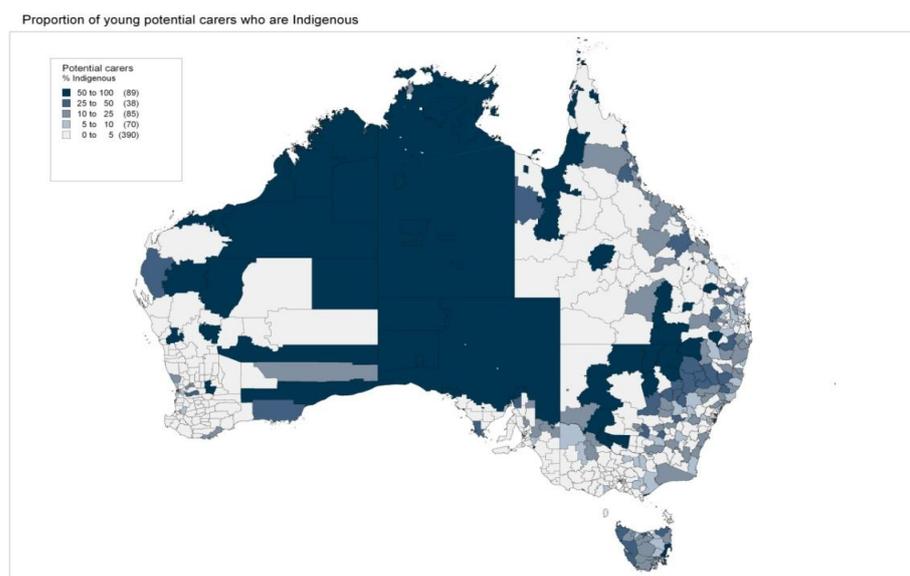
Figure 3.8 and Figure 3.9 show the proportion of young carers and young potential carers respectively who were Indigenous by LGAs in Australia. Similar to the distribution of young Indigenous people generally, a higher proportion of young carers and young potential carers were Indigenous in the more regional and remote LGAs.

**Figure 3.8 Proportion of young carers aged 15-24 years who are Indigenous, by Local Government Areas, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.9 Proportion of young potential carers aged 15-24 years who are Indigenous, by Local Government Areas, 2006**

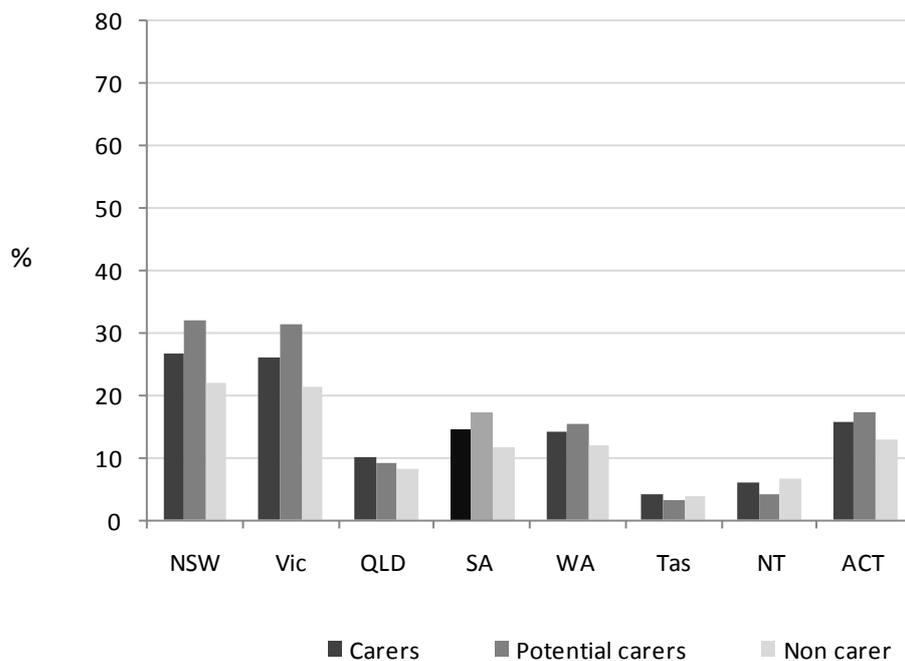


Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Cultural background

Figure 3.10 and Table 3.3 below report on the proportion of young people who are from CALD backgrounds by carer status in each State and Territory. The data indicate that in most States and Territories, young people from CALD communities are overrepresented in the young carer and young potential carer population, although not to the same extent as Indigenous young people.

**Figure 3.10 Proportion of young people aged 15-24 years who are from CALD backgrounds by carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations  
 Notes: CALD backgrounds are young people who speak a language other than English at home and do not identify as Indigenous

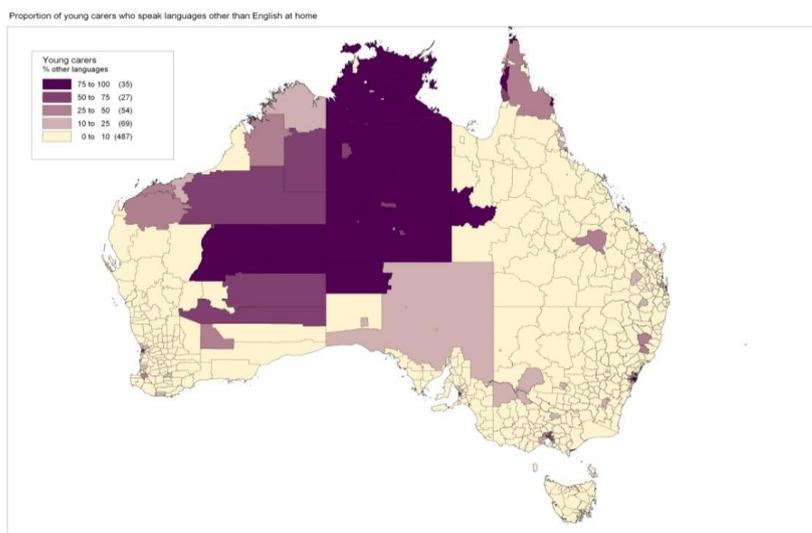
**Table 3.3 Proportion of young people who are of CALD back ground by age, sex, carer status and State/Territory, 2006 (per cent)**

	Male 15-19			Female 15-19			Male 20-24			Female 20-24		
	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers	Carers	Potential carers	Noncarers
New South Wales	24.3	27.0	18.5	24.4	28.9	18.8	29.6	35.8	25.0	28.2	39.8	25.4
Victoria	23.6	26.2	17.7	23.9	28.1	17.6	30.0	35.0	25.1	26.4	39.1	24.2
Queensland	8.9	7.5	6.7	9.6	7.9	6.9	12.0	11.2	9.4	9.9	12.9	9.3
South Australia	13.9	16.0	9.6	12.6	13.9	10.0	16.4	21.3	13.8	14.4	20.5	13.4
Western Australia	13.3	12.0	9.8	12.0	13.7	10.4	16.3	18.7	13.9	14.8	20.8	13.6
Tasmania	3.4	2.7	2.6	3.8	2.6	2.8	7.5	4.2	5.3	2.8	4.1	4.9
Northern Territory	8.7	3.8	6.2	5.5	4.6	7.1	5.0	5.7	6.9	5.7	3.1	6.6
Australian Capital Territory	14.9	15.5	11.3	13.5	17.0	12.0	18.1	15.9	14.0	16.1	22.8	13.8

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

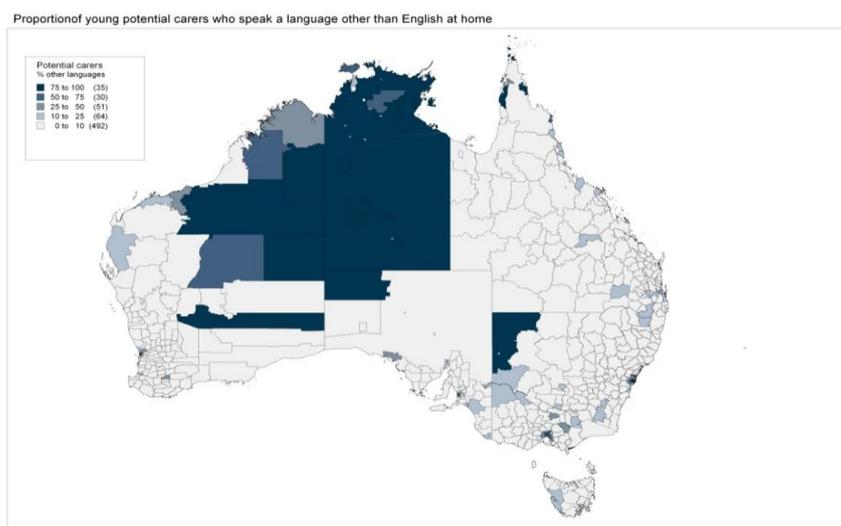
Figure 3.11 and Figure 3.12 show the proportion of young carers and potential carers in LGAs who speak a language other than English at home while Figure 3.13 describes the same data for some major cities. LGAs with a relatively high proportion (over 50 per cent) of young carers who spoke a language other than English at home were in Melbourne, Sydney and remote areas in the Northern Territory, Western Australia, South Australia and Queensland where it is likely that young carers may speak Indigenous languages. A similar finding held for young potential carers.

**Figure 3.11 Proportion of young carers aged 15-24 years who speak languages other than English at home by Local Government Areas, 2006**



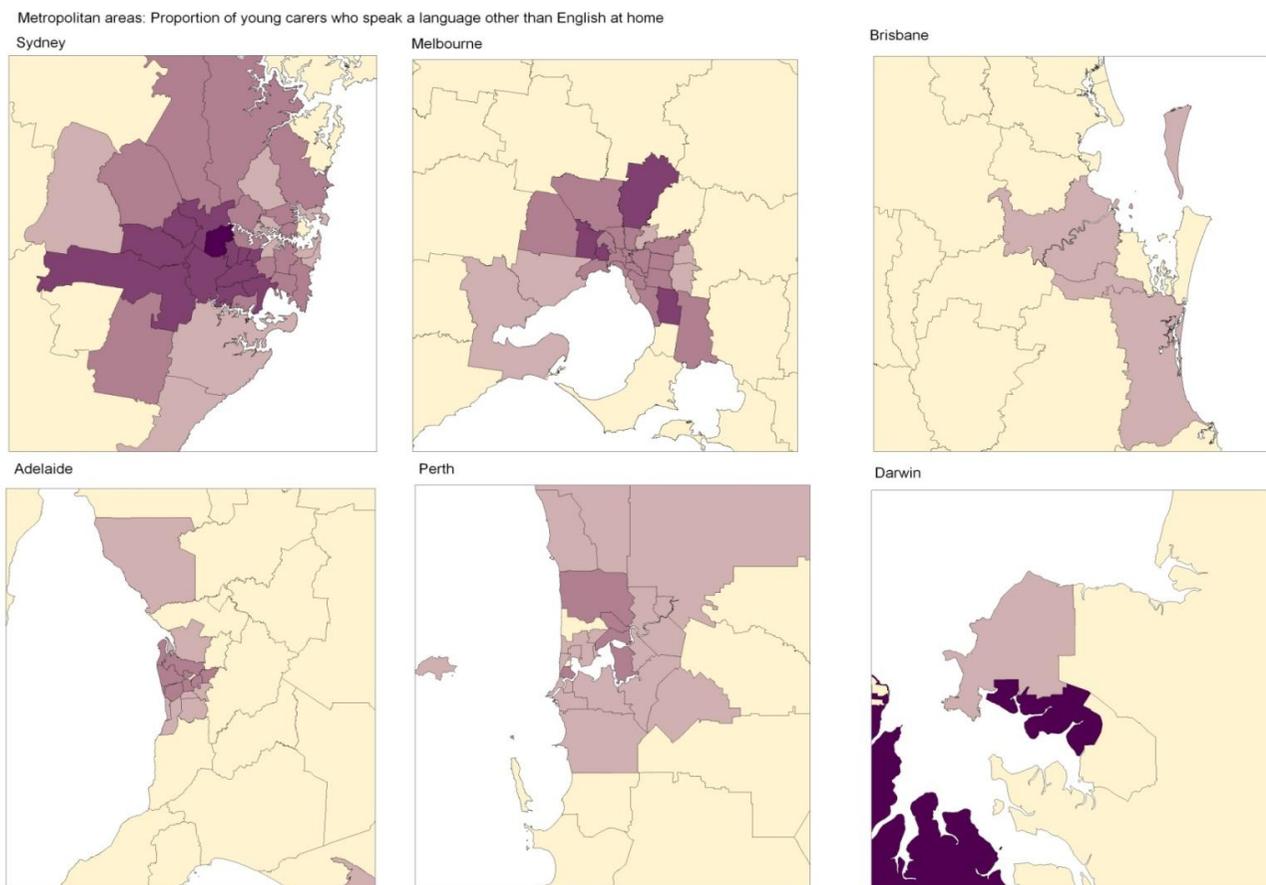
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.12 Proportion of young potential carers aged 15-24 years who speak languages other than English at home by Local Government Areas, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.13 Young carers from culturally and linguistically diverse backgrounds by metropolitan Local Government Areas, 2006**

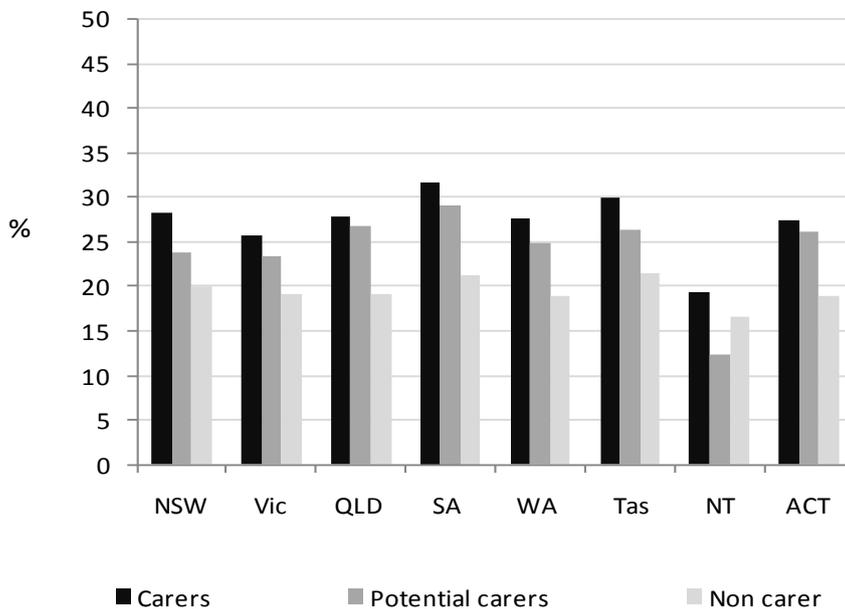


Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Lone parent families**

Another reason that young people may become carers is the lack of alternative informal supports, particularly the lack of another adult in the household. It would therefore be anticipated that young people living in lone parent households may have a greater likelihood of providing care. Figure 3.14 and Table 3.4 report on the proportion of young people living in lone parent households by carer status for all States and Territories. In all States and Territories, apart from the Northern Territory, where the gap was only 3 per cent, young carers were 8-10 percentage points more likely to live in lone parent households than non-carers. The gap for potential carers was slightly less, but young people living in lone parent households were also over-represented in this group.

**Figure 3.14 Proportion of young people living in lone parent households by carer status and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author’s calculations

**Table 3.4 Proportion of young people living in lone parent households by carer status and State/Territory, 2006**

	Carers	Potential carers	Non carer
NSW	28.2	23.8	20.0
Vic	25.7	23.3	19.1
QLD	27.8	26.8	19.0
SA	31.7	29.0	21.3
WA	27.7	24.8	18.9
Tas	29.9	26.4	21.4
NT	19.4	12.4	16.6
ACT	27.5	26.2	18.9

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author’s calculations

Table 3.5 disaggregates the data by age and sex and shows that young carers (male and female) aged 15-19 years are more likely to be living in lone parent households than young carers in the older age group (20-24 years). The same finding holds for young people generally.

**Table 3.5 Proportion of young people living in lone parent households by age, sex, carer status and State/Territory, 2006**

	15 - 19 years						20-24 years					
	Male			Female			Male			Female		
	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers
New South Wales	25.5	21.1	20.2	25.0	19.8	20.0	19.0	18.3	13.4	19.8	16.6	13.4
Victoria	24.7	20.5	19.6	23.5	20.4	19.7	17.9	17.9	12.7	17.7	15.6	12.6
Queensland	26.5	22.1	20.6	25.2	23.3	20.1	16.9	18.8	11.7	19.6	18.4	12.0
South Australia	28.5	23.5	21.9	28.8	22.6	21.3	20.3	22.1	13.6	20.8	20.8	13.8
Western Australia	27.7	20.5	19.8	24.5	20.9	19.5	16.6	20.2	12.2	19.2	16.4	12.0
Tasmania	26.9	21.8	22.0	26.1	22.3	21.2	16.3	21.0	12.5	22.6	15.1	14.3
Northern Territory	22.5	13.2	19.1	17.3	11.6	17.7	12.0	11.7	10.3	14.7	7.0	10.5
Australian Capital Territory	25.3	22.4	21.1	27.2	23.9	21.0	19.0	16.9	12.2	17.1	18.5	11.0

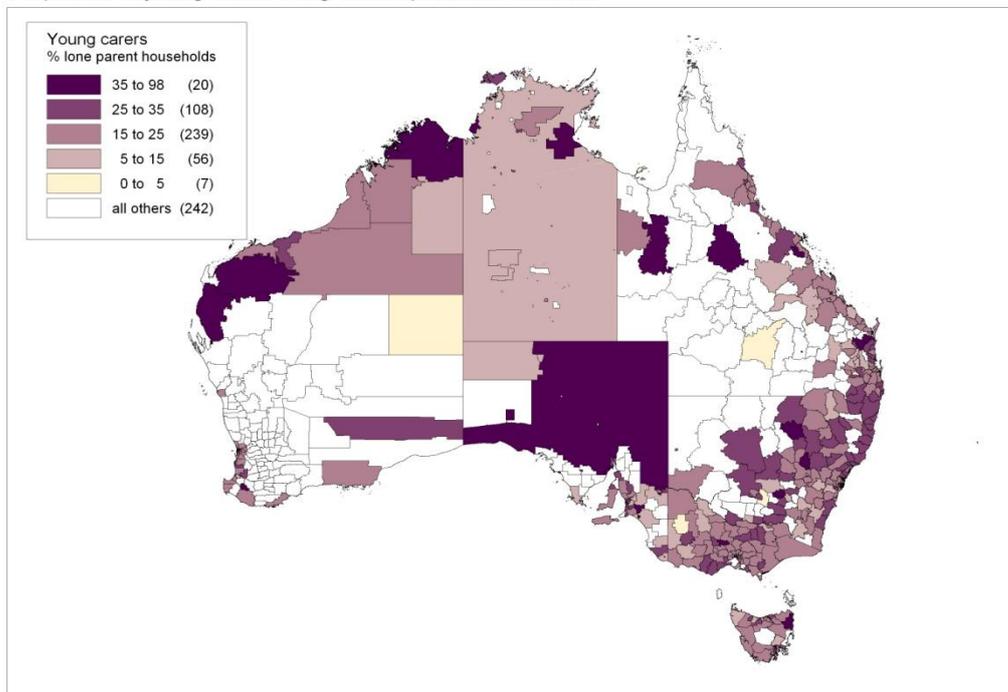
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

Figure 3.15 shows the proportion of young carers and potential carers living in lone parent households in LGAs across Australia. Comparing the major cities and regional areas indicates that:

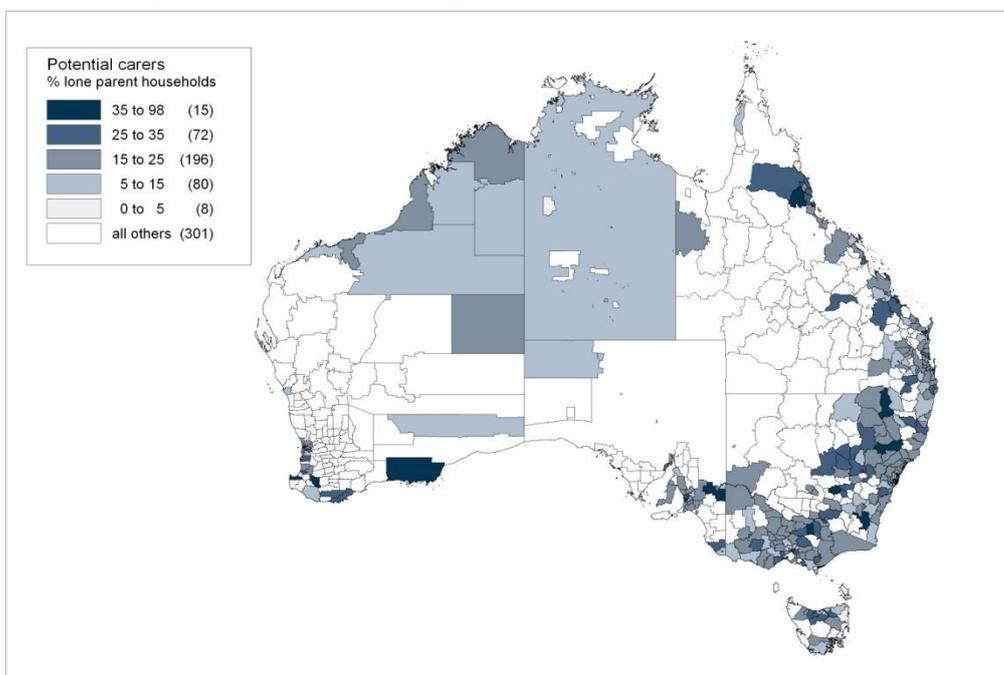
- A number of major cities (Sydney, Melbourne and Darwin) had no LGAs with a relatively high proportion (over 25 per cent) of young carers living in lone parent households. However, other cities (Hobart, Adelaide, Perth and Brisbane) had areas where over 25 per cent of young carers lived in lone parent households. The rates of living in lone parent households varied across the regional and remote areas with some areas in all States and Territories having high rates above (25 per cent).
- The findings for young potential carers were more mixed with nearly all cities containing LGAs with over 25 per cent of young potential carers living in lone parent households. In most States and territories except for the Northern Territory, some LGAs in regional and remote areas also had relatively high rates of lone parent households among the young potential carer population.

**Figure 3.15 Proportion of young carers and young potential carers aged 15-24 years living in lone parent families by Local Government Areas, (areas with small numbers excluded), 2006**

Proportion of young carers living in lone parent households



Proportion of young potential carers living in lone parent households

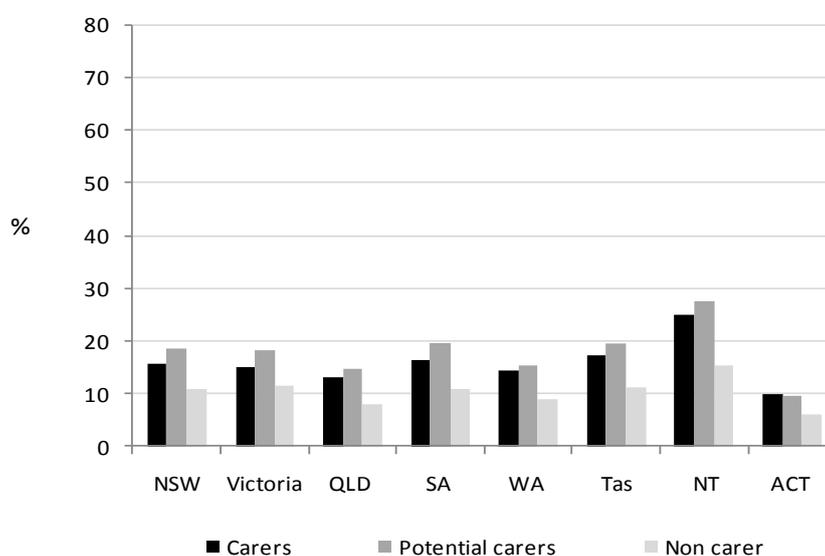


Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Low income and low resource households

One of the factors identified in the literature on young carers is that their circumstances are often framed by lower economic resources and financial disadvantage. Lack of income and economic resources may reduce the possibilities for families to purchase formal services and supports, which may lead to higher rates of informal caring among young people in the household. Young carers and young potential carers were more likely than non-carers to be living in low income households in all States and Territories (Figure 3.16 and Table 3.6). In most areas, young potential carers were more disadvantaged than young carers on this measure.

**Figure 3.16 Proportion of young people aged 15-24 years living in low income households by carer status and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

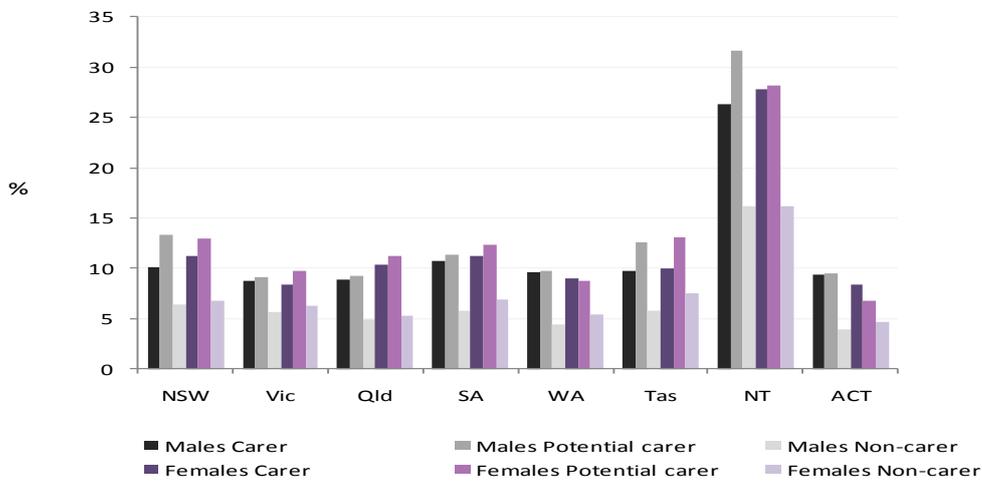
**Table 3.6 Proportion of young people aged 15-24 years living in low income households by carer status and State/Territory, 2006**

	Carers	Potential carers	Non carer
NSW	15.8	18.6	10.8
Victoria	15.2	18.1	11.5
QLD	13.0	14.8	7.9
SA	16.4	19.5	10.8
WA	14.3	15.5	8.8
Tas	17.2	19.6	11.3
NT	25.0	27.6	15.2
ACT	10.0	9.5	6.0

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

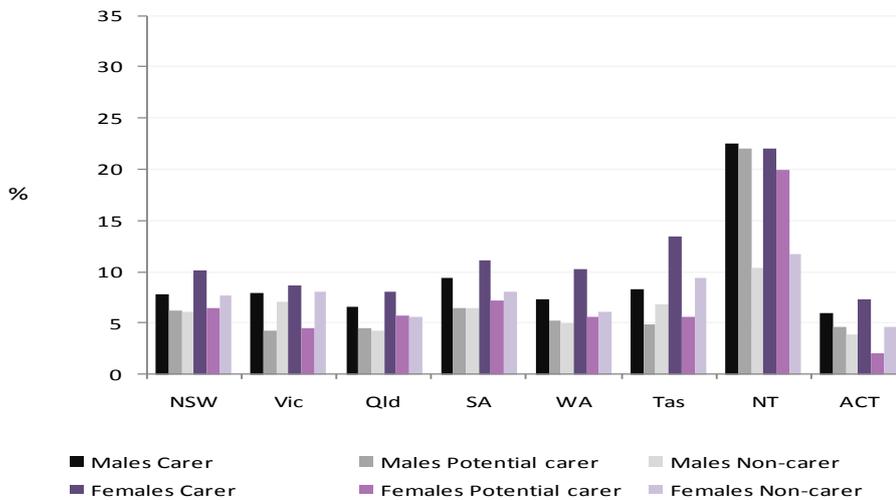
Income provides one measure of available resources to purchase support for the caring role, however, financial disadvantage may be compounded if the family also has low levels of resources and does not own or is not in a position to purchase a home. Figure 3.17, Figure 3.18 and Table 3.7 explore households with two measures of low levels of resources, which include households with both low levels of income (less than \$250 per week equalised income) and who are not home owners or purchasers. It is evident that in most States and Territories, young potential carers in the age group 15-19 years have higher rates of disadvantage than young carers, whereas in the older age group, 20-24 years, young carers generally (except in Northern Territory) have higher rates of disadvantage than young potential carers.

**Figure 3.17 Proportion of young people aged 15-19 years living in low resource households by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.18 Proportion of young people aged 20-24 years living in low resource households by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Table 3.7 Proportion of young people living in low resource households by age, sex, carer status and State/Territory, 2006 (per cent)**

	15-19 years						20-24 years					
	Males			Females			Males			Females		
	Carer	Potential carer	Non-carer	Carer	Potential carer	Non-carer	Carer	Potential carer	Non-carer	Carer	Potential carer	Non-carer
<b>New South Wales</b>	10.1	13.3	6.4	11.2	12.9	6.8	7.8	6.2	6.1	10.2	6.5	7.7
<b>Victoria</b>	8.8	9.1	5.6	8.3	9.7	6.2	8.0	4.2	7.0	8.7	4.5	8.1
<b>Queensland</b>	8.9	9.2	4.9	10.3	11.2	5.3	6.6	4.5	4.3	8.1	5.8	5.5
<b>South Australia</b>	10.7	11.3	5.8	11.2	12.3	6.9	9.4	6.5	6.4	11.1	7.1	8.1
<b>Western Australia</b>	9.6	9.7	4.4	8.9	8.7	5.4	7.3	5.3	5.0	10.3	5.6	6.0
<b>Tasmania</b>	9.8	12.6	5.7	10.0	13.1	7.5	8.3	4.9	6.8	13.5	5.6	9.4
<b>Northern Territory</b>	26.4	31.6	16.1	27.8	28.2	16.2	22.6	22.1	10.3	22.0	19.9	11.7
<b>Australian Capital Territory</b>	9.4	9.4	3.9	8.4	6.8	4.6	6.0	4.6	3.9	7.3	2.0	4.6

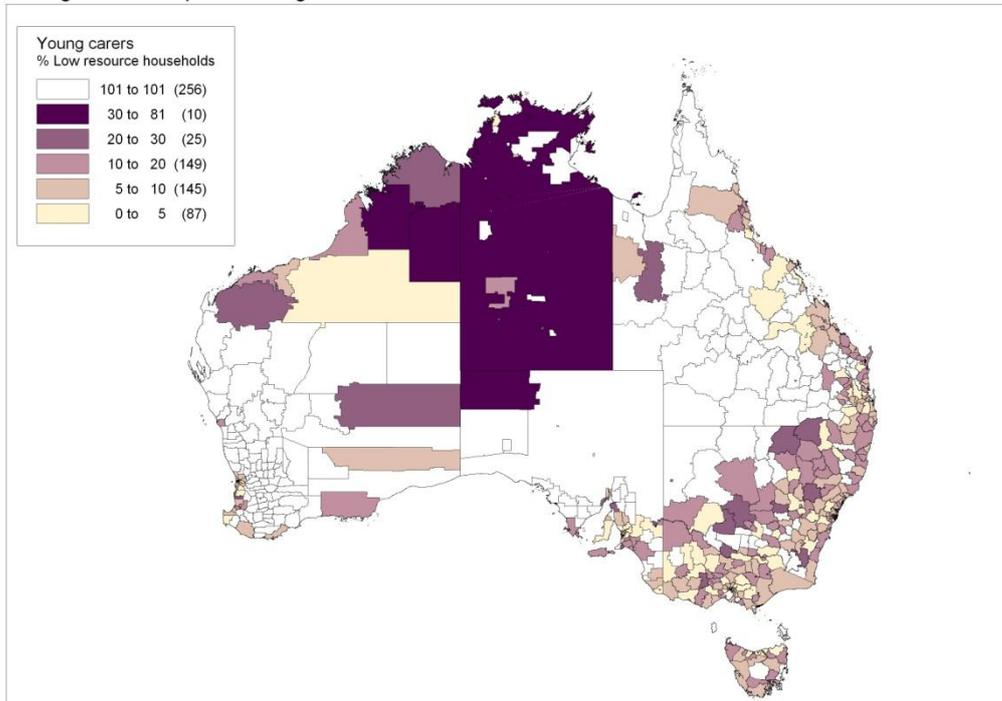
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

Figure 3.19 shows the rates of relative disadvantage for young carers with respect to living in low resource households. Comparison between major cities and other areas shows that:

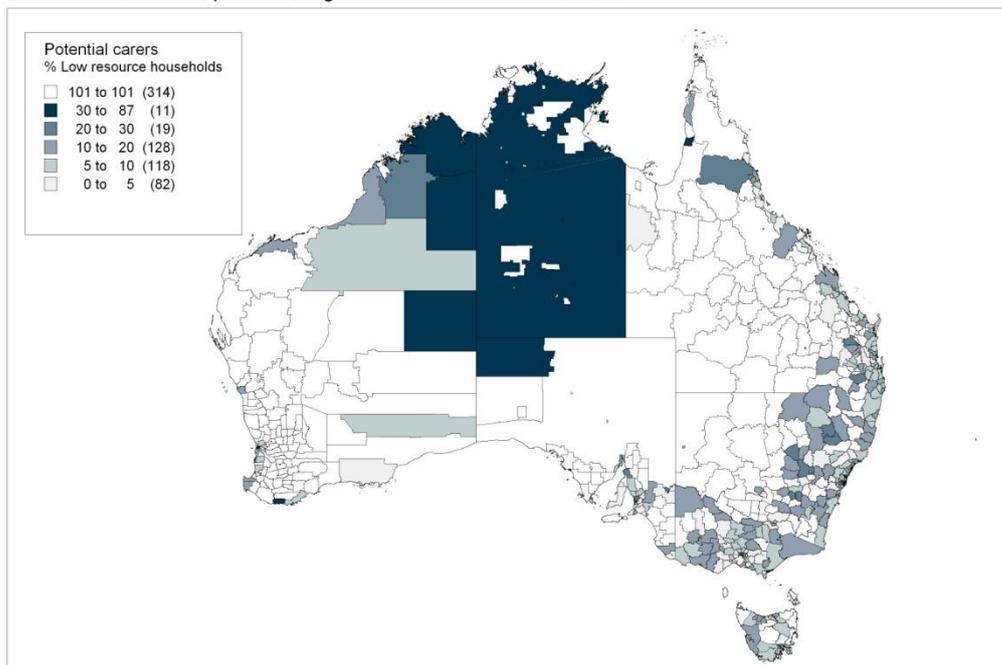
- High rates (over 30 per cent) of young carers living in low resource households, that is, in a household where the equalivalised income was less than \$250 per week and the home was not owned or being purchased, were found in the remote areas of Northern Territory, Western Australia and South Australia and regional Victoria (Thamarrurr, Mornington, Tiwi Islands, Walangeri Ngumpinku, Halls Creek, Yarrabah, Kunbarllanjja, Unincorporated Northern Territory, Anangu Pitjantjatjara and Derby-West Kimberley).
- In the major cities most LGAs have fewer than 20 per cent of young carers living in low resource areas. However, in some inner-city LGAs in Sydney, Melbourne, and Adelaide between 20 and 30 per cent of young carers lived in low resource households and such areas were also found in regional New South Wales and Victoria.
- A similar finding held for the young potential carer population (high rates of disadvantage on this measure in regional and remote areas including Tennant Creek, Halls Creek, Kowanyama, Denmark, Arltarlpilta, Ngaanyatjarraku, Yarrabah, Wyndham-East Kimberley, Anangu Pitjantjatjara, and Unincorporated Northern Territory). The main exception to this finding was that the LGA of Melbourne had relatively high rates (around 36 per cent) of low resource households among the young potential carer population.

**Figure 3.19 Proportion of young carers and potential carers living in low resource households by Local Government Areas, 2006**

Young carers: Proportion living in low resource households



Potential carers: Proportion living in low resources households



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

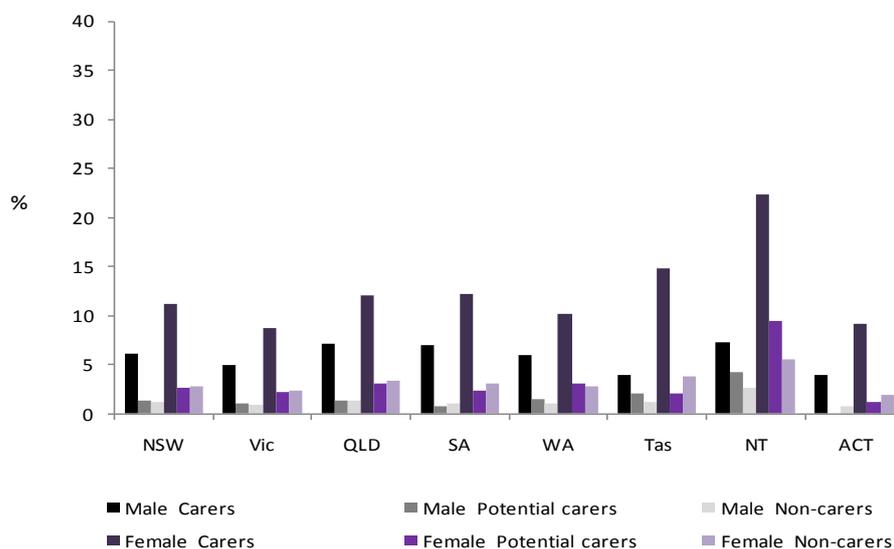
### 3.5 What do young carers do?

The literature shows that young carers take on a wide range of tasks and responsibilities—ranging from personal care and additional domestic tasks to home maintenance and transport. The extent of their contributions to the household and their responsibilities will depend on their specific care situation. The *Census 2006*, for the first time, asked about individual contributions to unpaid domestic work and to unpaid child care for other people. Figure 3.20 and Figure 3.21 below show the proportion of young people who provide 15 hours or more per week of domestic work by carer status, age and sex. The patterns are similar for all States and Territories. In both age groups, young carers are around two to three times as likely as potential carers and non-carers to undertake 15 hours or more per week of domestic work. In both age groups, higher rates of domestic work are found for female young carers than male young carers. Young carers, males and females, in the older age group (20-24 years) are more likely to provide a significant contribution to domestic work than young carers in the younger age group (15-19 years). In particular, in the 20-24 years age group, between 20-35 per cent of young female carers provided 15 hours or more per week of domestic work compared with around 10-15 per cent of young women who were non-carers in this age group.

Figure 3.22 and Figure 3.23 also suggest that young carers are much more likely to take on child care roles than either potential carers or their non-carer peers. Contrary to the finding for domestic work, young carers in the age group 15-19 years were more likely than carers in the 20-24 years age group to be providing child care. However, once again, young female carers in both age groups were more likely than male young carers to be taking on this (perhaps) additional caring role. It should be noted that the Census data do not permit a distinction between child care for a child with a disability or illness as compared to child care for another child without such conditions.

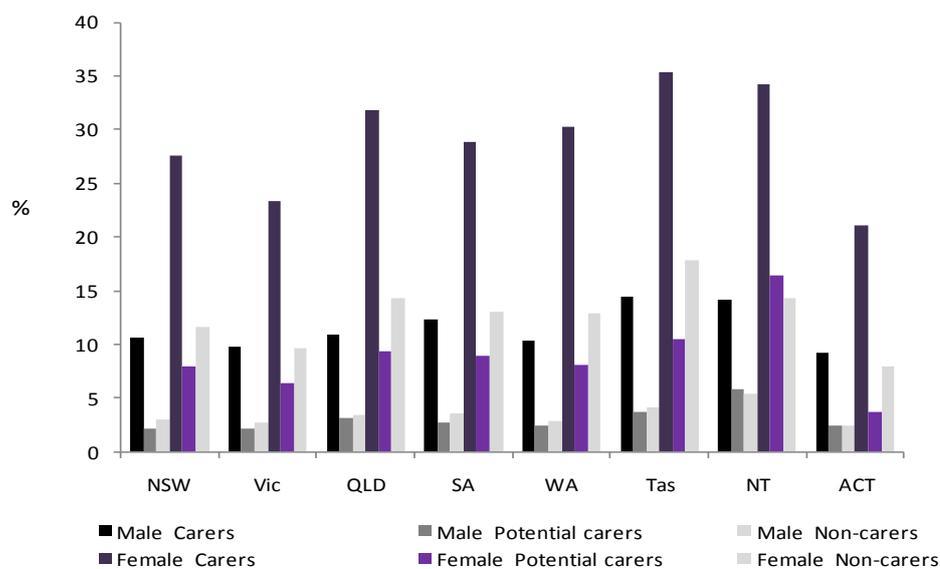
### Domestic work

**Figure 3.20 Proportion of young people aged 15-19 years undertaking 15 or more hours per week of domestic work by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

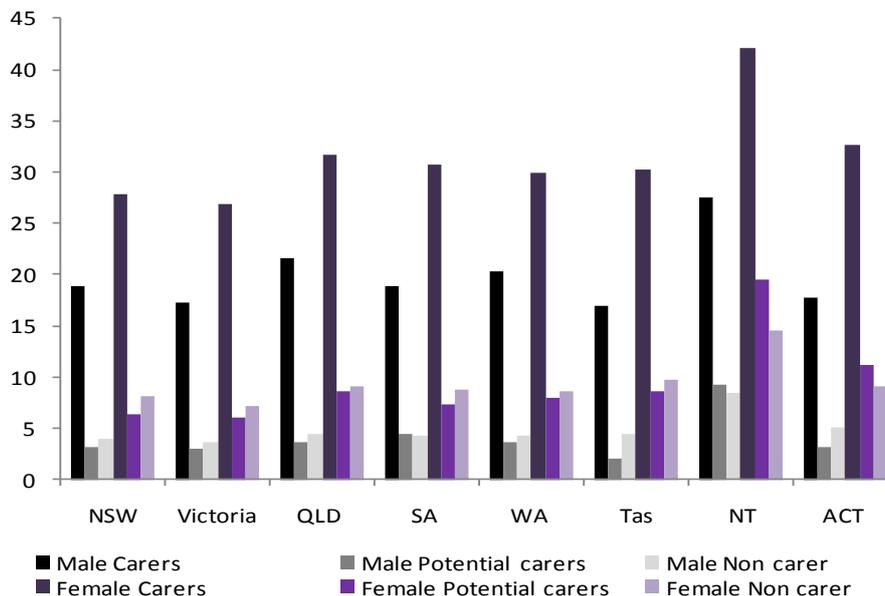
**Figure 3.21 Proportion of young people aged 20-24 years undertaking 15 or more hours per week of domestic work by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

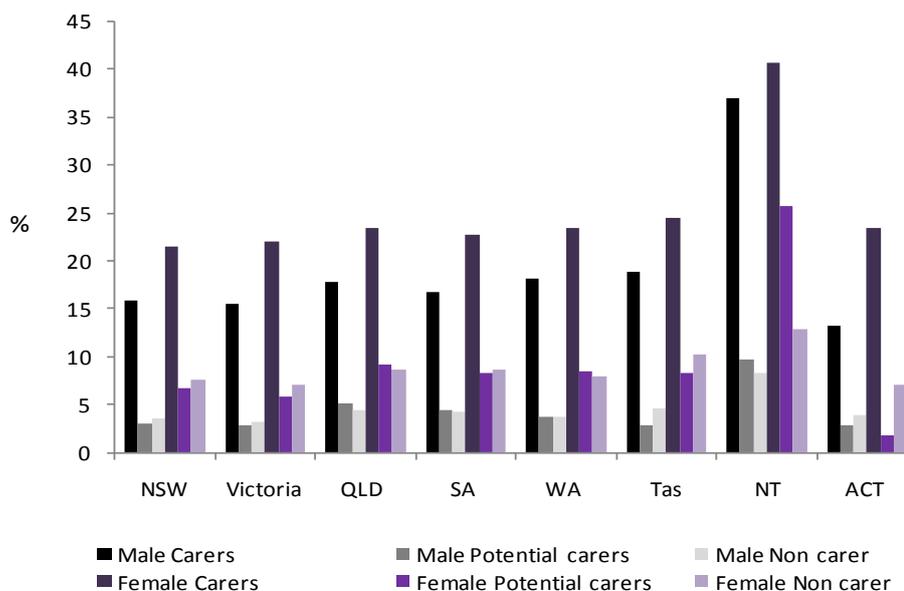
### Child care

**Figure 3.22 Proportion of young people aged 20-24 years providing unpaid care of another person's children week by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.23 Proportion of young people aged 20-24 years providing unpaid care of another person's children week by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### **3.6 Impacts of caring on young people**

Informal caring encompasses both the tangible responsibilities of concrete caring tasks and labour and the intangible responsibilities of emotionally caring about a person and paying attention to needs that might arise. The effect of these responsibilities may be reduced time and energy for participation in education and employment, social and community participation and leisure activities.

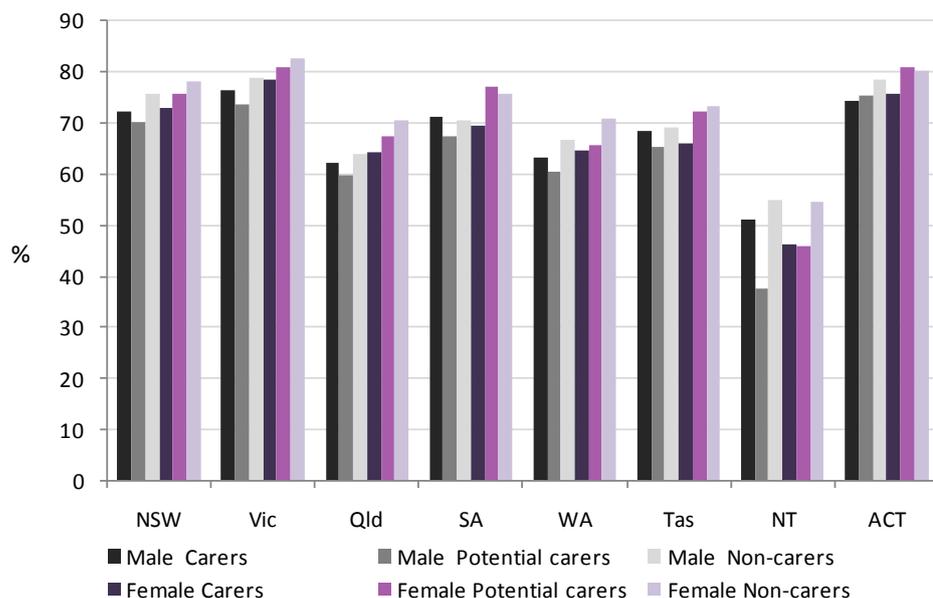
#### **Education: participation rates and gaps**

Figure 3.24, Figure 3.25 and Table 3.8 show rates of participation in education for young people by carer status, age and sex in States/and Territories. Figure 3.26 and Figure 3.27 show the gaps between carers, potential carers and non-carers in participation rates, for all States and Territories for the two age groups.

In all States/Territories, apart from the Northern Territory, over 60 per cent of young people aged 15-19 years participated in education, irrespective of carer status. For the older age group (20-24 years) rates of participation in education were lower with around 20-40 per cent of young people in this age group engaged in education.

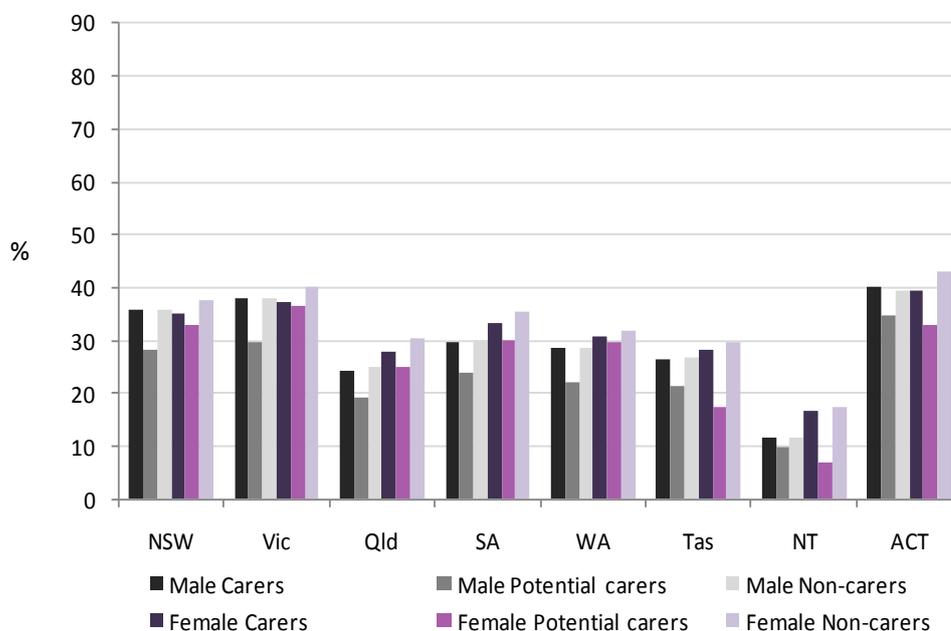
Patterns of participation by carer status were similar across most States/Territories. In the 15-19 years age group, young male potential carers had lower rates of participation in education than young male carers and young male non-carers. For young women in this age group, young carers generally had the lowest rates of participation followed by young potential carers and then non-carers. In the 20-24 years age group young potential carers had the lowest rates of participation in education and the gaps between carers and non-carers were generally slightly lower in this age group compared with the 15-19 years group. However, gaps between potential carers and non-carers were generally slightly higher in the 20-24 years age group than in 15-19 years group.

**Figure 3.24 Proportion of young people aged 15-19 years in study by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.25 Proportion of young people aged 20-24 years in study by sex, carer status and State/Territory, 2006 (per cent)**



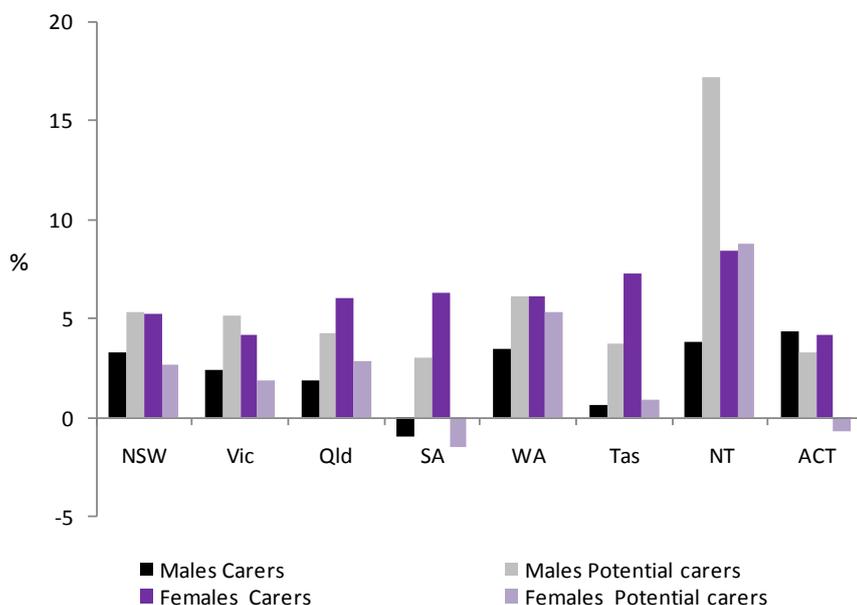
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Table 3.8 Proportion of young people in study by age, sex, carer status and State/Territory (per cent)**

	15-19 years			Female			20-24 years			Female		
	Male	Potential	Non-	Carers	Potential	Non-	Male	Potential	Non-	Carers	Potential	Non-
	Carers	carers	carers	Carers	carers	carers	Carers	carers	carers	Carers	carers	carers
New South Wales	72.4	70.3	75.6	73.0	75.6	78.2	35.7	28.2	35.8	35.1	33.1	37.6
Victoria	76.3	73.6	78.8	78.6	80.9	82.7	38.1	29.6	37.9	37.4	36.5	40.3
Queensland	62.3	59.9	64.1	64.4	67.5	70.4	24.2	19.4	24.9	27.8	25.1	30.6
South Australia	71.3	67.4	70.3	69.3	77.2	75.7	29.7	23.9	29.9	33.3	30.3	35.4
Western Australia	63.1	60.4	66.5	64.8	65.5	70.9	28.8	22.3	28.6	30.7	29.6	32.0
Tasmania	68.4	65.3	69.0	66.0	72.3	73.2	26.4	21.6	26.9	28.1	17.4	29.7
Northern Territory	51.0	37.6	54.8	46.2	45.9	54.7	11.7	10.0	11.6	16.7	6.8	17.4
Australian Capital Territory	74.2	75.2	78.6	75.9	80.8	80.1	40.3	34.8	39.4	39.5	32.9	43.0

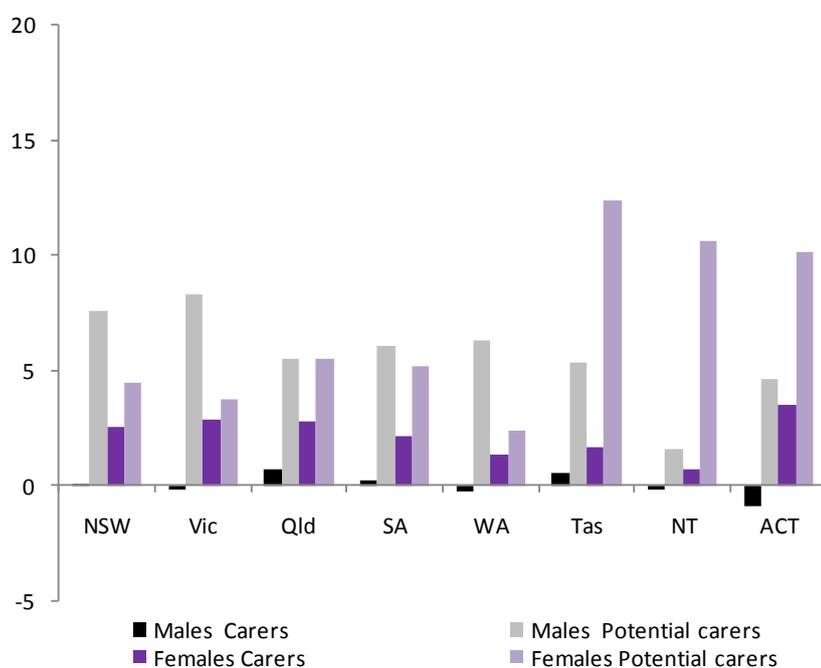
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.26 Gaps between carers, potential carers and non-carers aged 15-19 years in rates of participation in study by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.27 Gaps between carers, potential carers and non-carers aged 20-24 years in rates of participation in study by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

Figure 3.28 shows the gaps in participation in study for young carers and potential carers compared with non-carers by LGAs. The gap is calculated by subtracting the education participation rate for young carers or potential carers from the education participation rate for non-carers, so that larger negative numbers are indicative of greater carer or potential carer disadvantage.

For the young carer map, darker shades of purple indicate a greater disadvantage in terms of lower rates of education vis a vis non-carers, and the blue areas indicate areas where young carers actually have higher rates of participation in education than their non carer peers. Young carers had lower rates of participation in study in around 74 per cent of LGAs under consideration. For the potential carers, darker grey/black areas indicate areas of highest disadvantage whereas the red areas indicate areas where young potential carers were more likely than their non-carers counterparts to be in study. Young potential carers were more disadvantaged than non-carers with respect to education in around 37 per cent of the LGAs considered.

There were no clear patterns of disadvantage or advantage for young carers and potential carers when comparing the city LGAs with those in the regions. In Sydney for example, no LGAs had a young carer disadvantage over 10 per cent, although a number had a 5-10 percentage point disadvantage (Auburn, Canterbury, Botany Bay, Hunter's Hill, Randwick, Manly and Sutherland Shire). In a number of LGAs in Sydney in the more affluent areas, young carers were more likely to participate in education than their non-carer peers (10-20 percentage points North Sydney, Lane Cove, 1-5 percentage points Warringah, Mosman and Waverley)

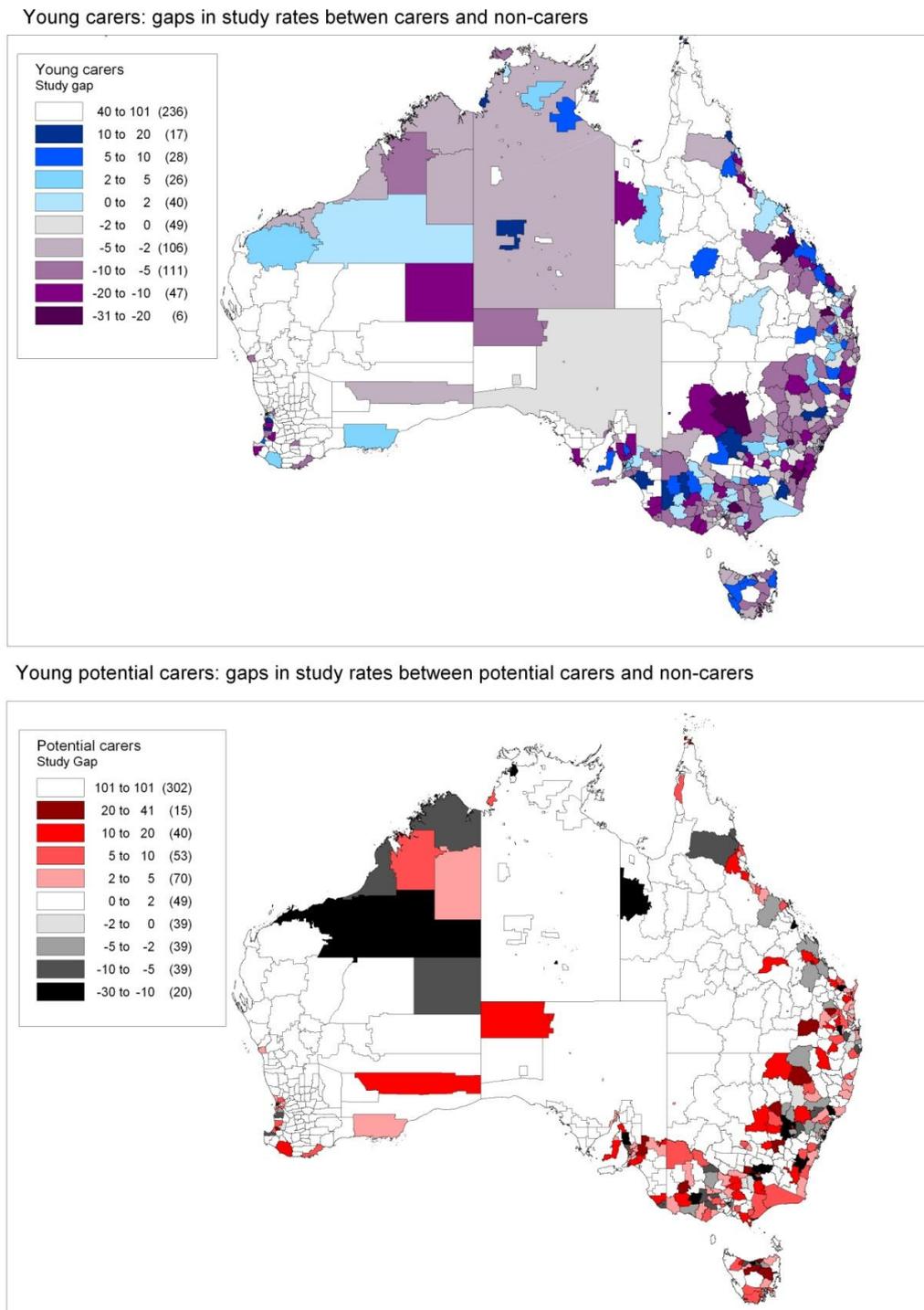
In regional New South Wales, there were a number of areas of significantly higher carer disadvantage (a 20-30 percentage point gap) and these included Cobar, Palerang, Blayney. Other areas had a young carer advantage (10-20 percentage points): Upper Hunter Shire, Carathool, and Snowy River.

In South Australia, the regions of most education disadvantage (10-20 percentage points) were Copper Coast, Wakefield, Goyder, Light, Mallala, Naracoorte and Lucindale, Port Lincoln, Wakefield and Lower Eyre Peninsula. However, there were also areas of young carer advantage with respect to participation in study (over 10 percentage points), including The Coorong and Walkerville.

Australia wide, the regions of most disadvantage (20-30 percentage point gap) were outside of major cities and included: Broadsound, Wondel, Cobar, Blayney, Palerang, and Murrindindi.

A similar mixed pattern held for young potential carers with disadvantage and advantage in both cities and regional areas. In Sydney, areas with most disadvantage for potential carers (5-10 percentage points) were Willoughby, Leichhardt, Burwood, Marrickville, Botany Bay, and Pittwater. In the New South Wales regions some areas had high levels of disadvantage (10-30 percentage points): Dungog, Palerang, Cabonne, Greater Hume Shire and Cowra. However, a 10-20 percentage point advantage for young potential carers was found in North Sydney and Waverley in Sydney and a number of regional areas. In South Australia, the region of highest disadvantage for young potential carers (10-20 percentage points) was Wakefield, although a number of regional LGAs also had a young carer advantage.

**Figure 3.28 Gaps in study rates – carers and potential carers by Local Government Areas, 2006**



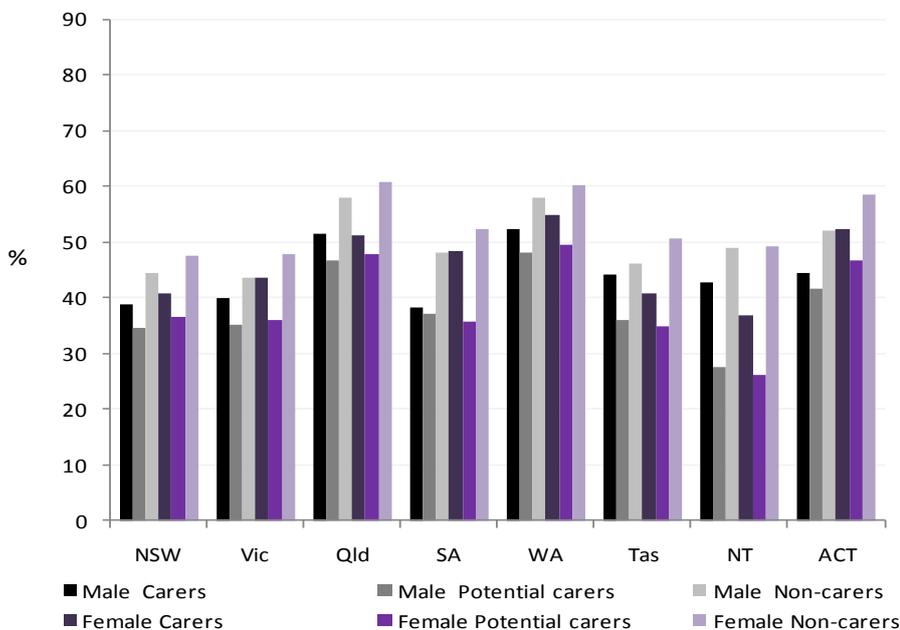
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Employment rates

Participation in employment may pose additional challenges for young carers compared with their non-carers peers. Young carers' time commitments may make it difficult to work specific hours or in specific locations with longer travel times between home and work.

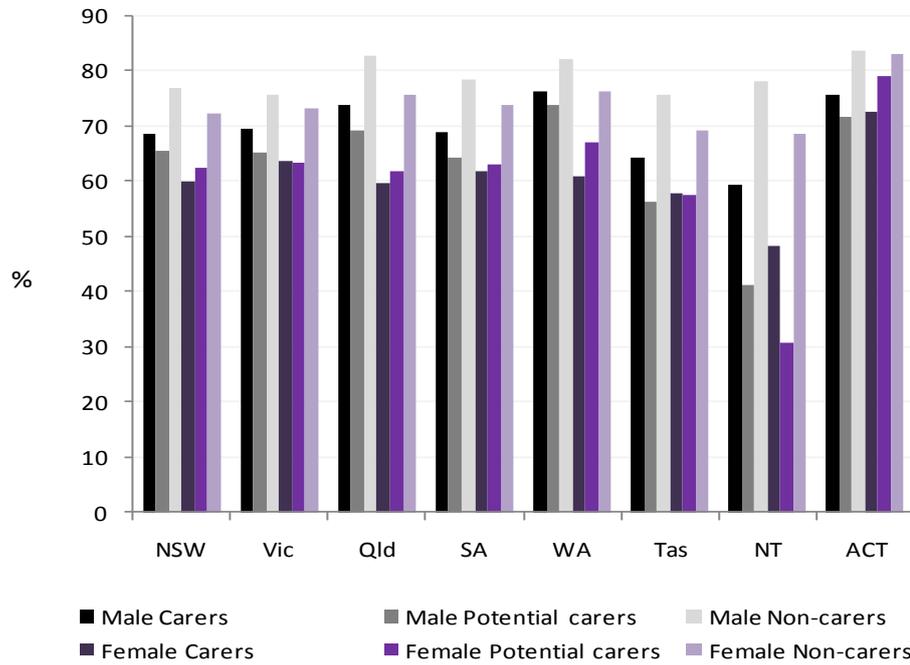
Figure 3.29, Figure 3.30 and Table 3.9 below indicate the proportion of young people who are employed by carer status, age and sex in each State/Territory. Between 25 to 60 per cent of young people in the 15-19 years age group were employed compared with 30 to 85 percent of young people in the 20-24 years age group. Potential carers had the lowest rates of participation in employment in the 15-19 years age group and among young men aged 20-24 years. For young women aged 20-24 years, young carers had lower rates of participation in employment than potential carers and non-carers in a number of States/Territories. In the 15-19 years age group in a number of States, male young carers had lower rates of employment than female young carers. However, in the 20-24 years age group, female young carers had lower rates of employment than male young carers in all States and Territories. This gendered element among the older age group (20-24 years) is further emphasised in the finding that the gap between carers and non-carers was higher for young women than young men in nearly all States and Territories (Figure 3.31 and Figure 3.32). In the younger age group (15-19 years) young female potential carers were more disadvantaged (bigger gap) than male potential carers.

**Figure 3.29 Proportion of young people aged 15-19 years in employment by sex, carer status and State/Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.30 Proportion of young people aged 20-24 years in employment by sex, carer status and State/Territory, 2006 (per cent)**



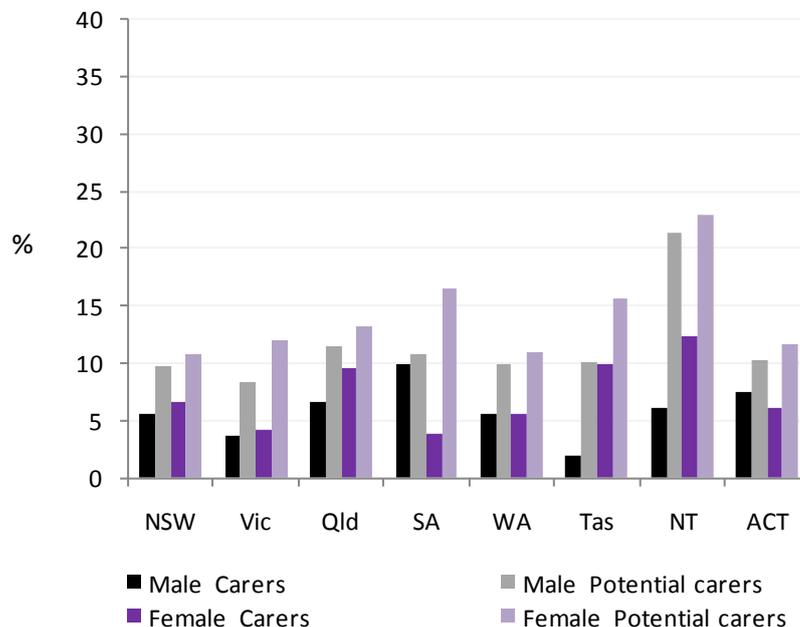
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Table 3.9 Proportion of young people aged 15-24 years in employment by age, sex, carer status and State/Territory, 2006 (per cent)**

	15-19						20-24					
	Male			Female			Male			Female		
	Carers	Potential carers	Non-carers									
New South Wales	38.8	34.6	44.4	40.9	36.6	47.4	68.5	65.4	76.9	59.8	62.4	72.3
Victoria	40.0	35.3	43.7	43.7	35.9	47.8	69.4	65.1	75.7	63.7	63.3	73.1
Queensland	51.4	46.7	58.1	51.3	47.7	60.9	73.9	69.3	82.8	59.8	62.0	75.6
South Australia	38.3	37.3	48.1	48.4	35.7	52.3	68.8	64.4	78.5	61.7	62.9	73.8
Western Australia	52.4	48.0	58.0	54.7	49.4	60.3	76.4	73.7	82.3	60.8	67.0	76.2
Tasmania	44.2	36.1	46.1	40.7	35.0	50.7	64.3	56.2	75.7	57.9	57.5	69.3
Northern Territory	42.9	27.5	48.9	36.8	26.2	49.2	59.3	41.2	78.1	48.1	30.7	68.5
Australian Capital Territory	44.5	41.7	52.0	52.4	46.8	58.5	75.7	71.5	83.6	72.8	79.0	83.1

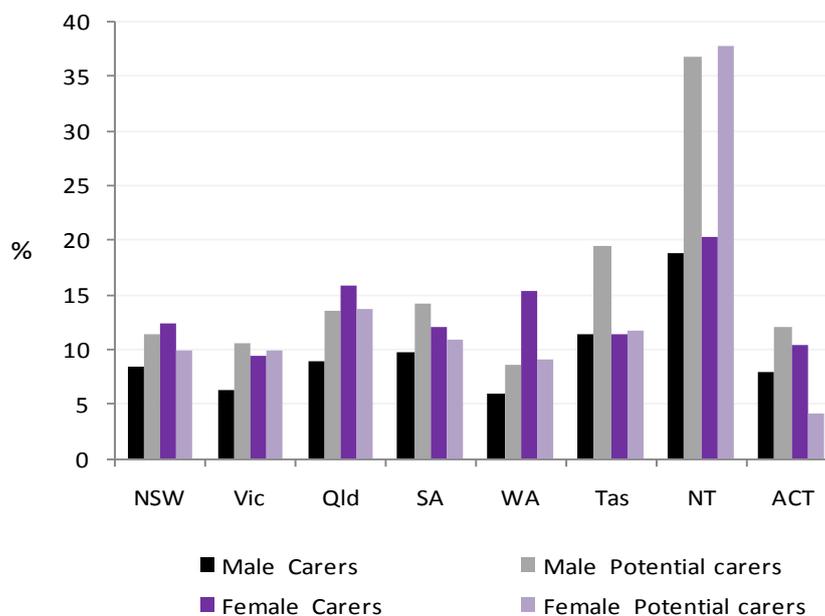
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.31 Gaps between carers, potential carers and non-carers aged 15-19 years in rates of participation in employment by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.32 Gaps between carers, potential carers and non-carers aged 20-24 years in rates of participation in employment by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### **Gaps in employment rates – carers and potential carers by LGAs**

Figure 3.33 shows the gaps in employment rates for carers and potential carers for LGAs. Once again the gaps are calculated by subtracting the employment participation rate of non-carers from the employment rate for young carers or potential carers. Thus a higher negative number is indicative of greater young carer or potential carer disadvantage. The colour coding for the maps is the same as for study gaps maps: for young carers, purple areas indicate areas where young carers had lower rates of employment and blue areas indicate areas where young carers had higher rates of employment compared with their non-carer peers. Darker areas indicate areas of greater disadvantage or greater advantage. For young potential carers, grey/black areas indicate areas where young potential carers had lower rates of employment and red areas indicate areas with higher rates of employment than their non-carer peers. Darker areas indicate higher levels of advantage or disadvantage.

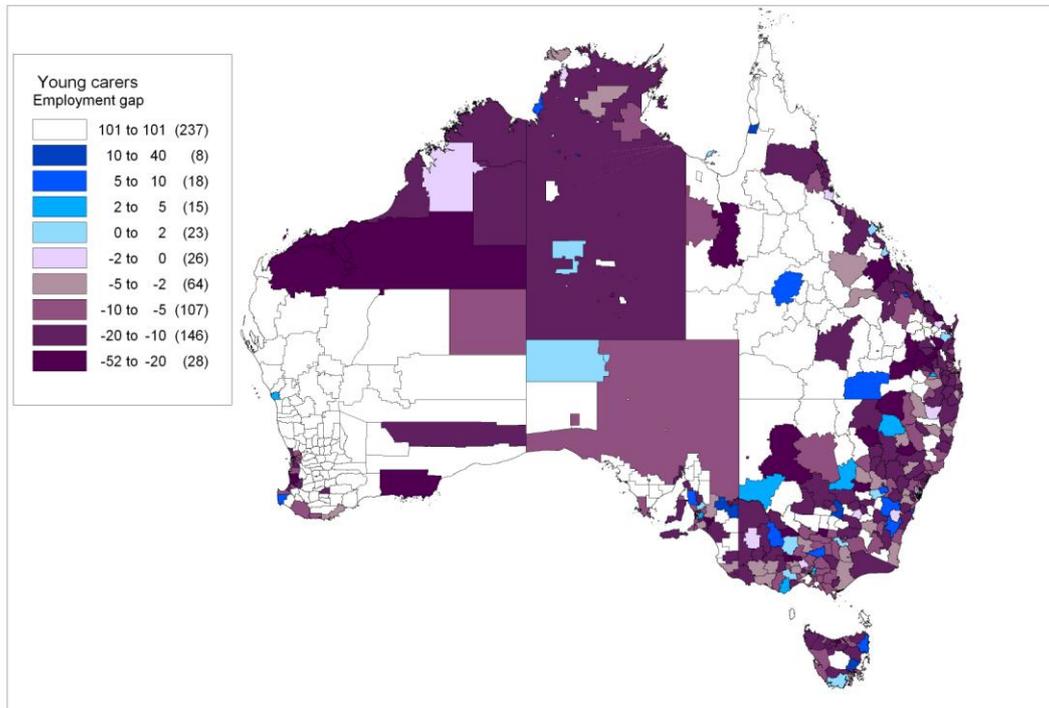
Overall, in most regions (around 85 per cent) young carers had lower employment rates than non-carers and a similar finding held for young potential carers in around 94 per cent of LGAs. LGAs in both metropolitan and regional areas had areas of advantage and disadvantage for carers. However, none of the LGAs in major cities had employment gaps over 20 per cent, so that the 28 LGAs with the highest young carer disadvantage were all in regional areas. In regional New South Wales, LGAs with employment gaps for young carers over 20 percentage points were Forbes, Moree Plains, Liverpool Plains, Coonamble, Berrigan and Central Darling. In Sydney, areas of greater disadvantage for young carers were in Penrith, Blacktown, Camden and Campbelltown and North Sydney where young carers were 10- 20 percentage points less likely to be employed than their non-carer counterparts. However, in some areas in Sydney, young carers had higher employment rates than their non-carer peers and, with the exception of Strathfield, these areas were more likely to be in affluent areas of Sydney such as Pittwater, Ku-ring-gai, Mosman, Manly, Willoughby, Woollahra and Randwick.

In South Australia, the regions with the highest level of young carer disadvantage (over 18 per cent) were The Coorong, Whyalla, Port Augusta and Murray Bridge. In Adelaide, the areas where young carers were most disadvantaged with respect to employment were Playford, Charles Sturt, Walkerville and Marion, while in the LGAs of Adelaide and Adelaide Hills young carers had higher employment rates than their non-carer peers.

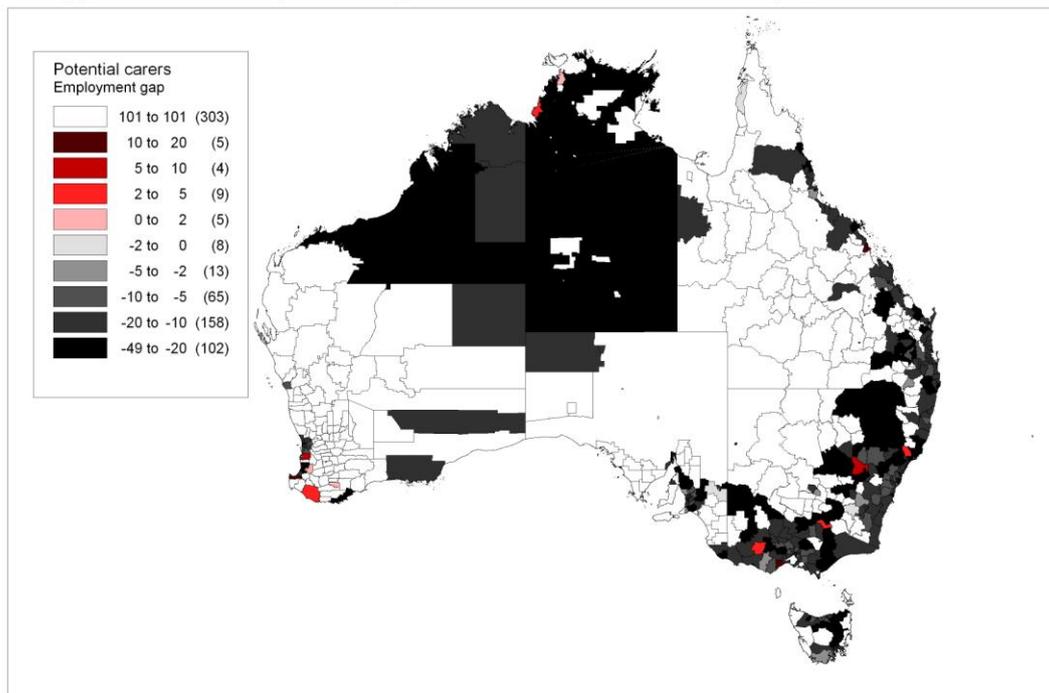
A similarly mixed finding of advantage and disadvantage for regions and metropolitan areas was evident for potential carers, although in the vast majority of areas young potential carers had lower employment rates. Young potential carers had higher employment rates in three LGAs in Sydney (Pittwater, Willoughby and Burwood). The most disadvantaged LGA for young potential carers was North Sydney. LGAs where young potential carers had the highest disadvantage and employment rates that were over 30 percentage points lower than non-carers in regional areas of NSW included: Cootamundra, Greater Hume Shire, Gunnedah, Gwyndir, Lachlan, Parkes, and Moree Plains. In SA and Adelaide, young potential carers had lower employment rates in all LGAs considered and the regions with the most disadvantage (over 30 percentage points) were Alexandrina, Grant, Port Pirie and Renmark Paringa.

**Figure 3.33 Gaps in employment rates – carers and potential carers by Local Government Areas, 2006**

Young carers: Gaps between carers and non-carers in employment rates



Young potential carers: Gaps between potential carers and non-carers in employment rates



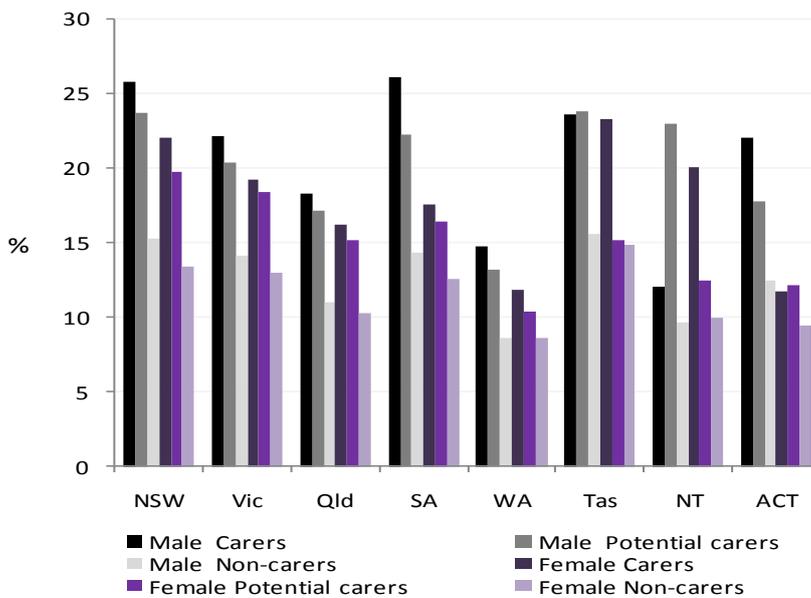
Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Unemployment rates

Unemployment rates reflect the extent to which young people wish to engage in paid work and are looking for work but are unable to find suitable employment. There may be a number of reasons for this situation, including lower levels of human capital due to interrupted schooling or work histories due to care responsibilities or it may reflect difficulties in finding appropriately flexible employment in order to manage care responsibilities. Care responsibilities may also restrict young people’s job choice due to the need to find paid work in relatively close proximity to their home. Figure 3.34, Figure 3.35 and Table 3.10 report on unemployment rates for young people by carer status, age, sex and State/Territories.

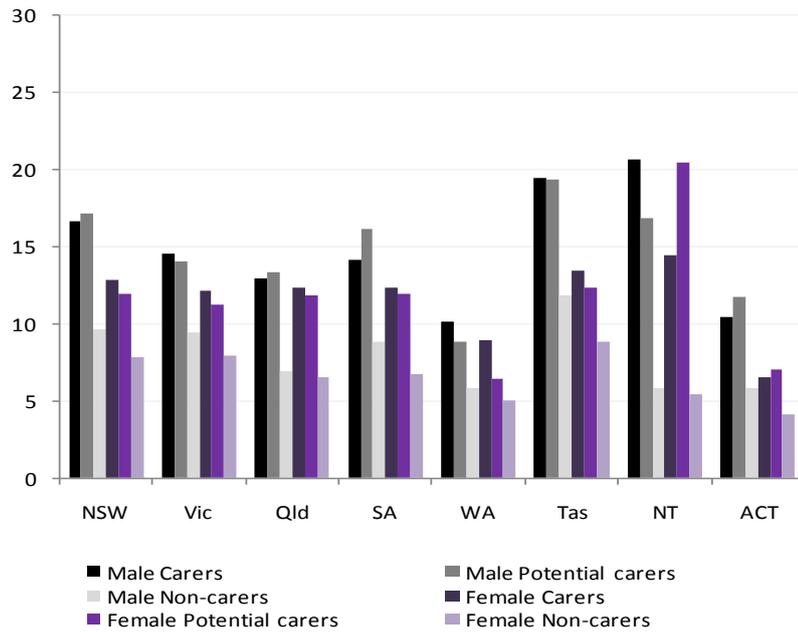
Unemployment rates ranged from between around 10 per cent to 25 per cent for young people in the 15-19 years age group and 5 to 20 per cent in the 20-24 years age group. In both age groups, young carers and potential carers generally had higher rates of unemployment than non-carers. In most regions, young male carers had higher rates of unemployment than young female carers.

**Figure 3.34 Unemployment rates of young people aged 15-19 years by sex, carer status and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author’s calculations

**Figure 3.35 Unemployment rates of young people aged 20-24 years by sex, carer status and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Table 3.10 Unemployment rates of young people aged 15-24 years by age, sex, carer status and State/Territory, 2006 (per cent)**

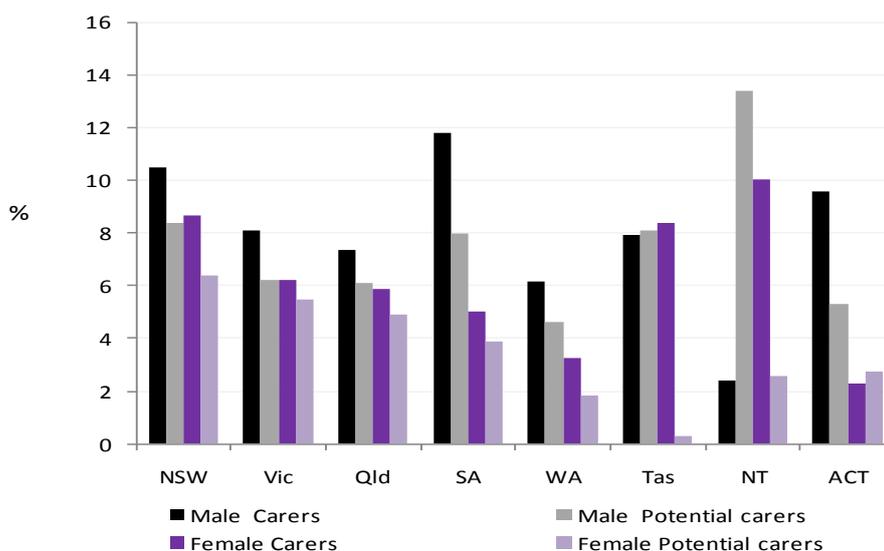
	15-19						20-24					
	Male			Female			Male			Female		
	Carers	Potential carers	Non-carers									
New South Wales	25.7	23.6	15.2	22.0	19.7	13.4	16.7	17.1	9.7	12.8	11.9	7.8
Victoria	22.2	20.3	14.1	19.2	18.4	12.9	14.5	14.1	9.4	12.1	11.3	7.9
Queensland	18.3	17.1	11.0	16.2	15.2	10.3	12.9	13.4	6.9	12.4	11.8	6.6
South Australia	26.1	22.3	14.3	17.5	16.4	12.5	14.1	16.2	8.9	12.3	11.9	6.8
Western Australia	14.8	13.2	8.6	11.8	10.4	8.6	10.1	8.8	5.8	9.0	6.4	5.0
Tasmania	23.5	23.7	15.6	23.2	15.2	14.8	19.4	19.3	11.9	13.5	12.4	8.8
Northern Territory	12.0	23.0	9.6	20.0	12.5	9.9	20.6	16.8	5.9	14.5	20.5	5.4
Australian Capital Territory	22.0	17.8	12.5	11.7	12.1	9.4	10.5	11.7	5.8	6.6	7.0	4.1

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Gaps in unemployment rates

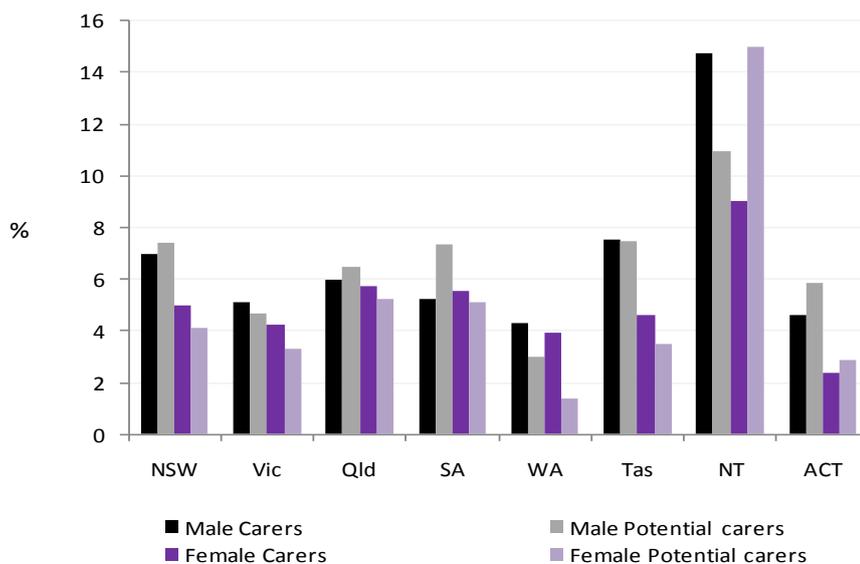
The gaps in unemployment rates between young carers, potential carers and non-carers are described in Figure 3.36 and Figure 3.37. The gaps were generally highest for young male carers in the 15-19 years age group in most States and Territories, except for Tasmania and the Northern Territory.

**Figure 3.36 Gaps in unemployment rates between carers, potential carers and non-carers aged 15-19 years by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.37 Gaps in unemployment rates between carers, potential carers and non-carers aged 20-24 years by sex and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### **Gaps in unemployment rates by Local Government Areas**

Figure 3.38 shows the variations in gaps in unemployment between young carers and potential carers and non-carers for LGAs in Australia. Gaps are calculated by subtracting the unemployment rates of non-carers from the unemployment rates of young carers and potential carers. The first map reports the gaps for young carers. In this map purple areas indicate areas where young carers have higher unemployment rates than non-carers and blue areas are LGAs where young carers have lower unemployment rates. In the second map, grey/black areas are those where young potential carers have higher unemployment rates and red areas are those where young carers have lower unemployment rates.

The unemployment gaps showed advantage and disadvantage for young carers in both the regional and metropolitan areas, although in 87 per cent of the LGAs considered in the analysis young carers had higher unemployment rates than their non-carer peers. Few metropolitan areas had unemployment gaps for young carers that were over 20 percentage points, indicating that nearly all the areas where young carers were most disadvantaged with respect to unemployment were in the regions. A similar finding held for young potential carers where they had higher unemployment rates in 82 per cent of LGAs considered and the most disadvantaged areas were in the regional areas.

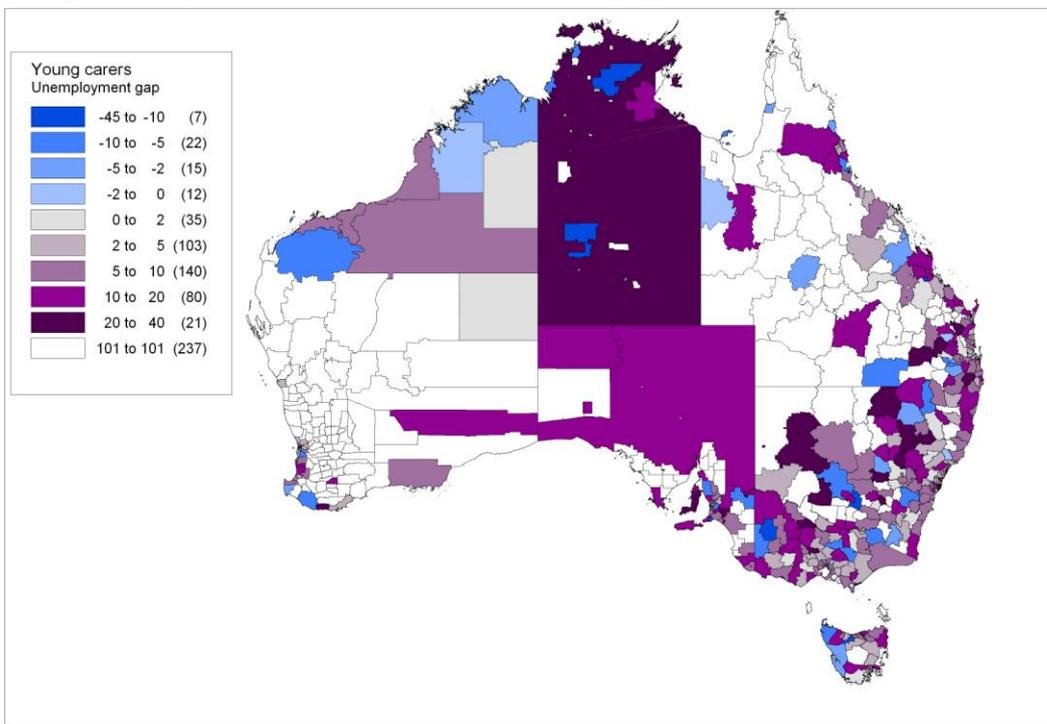
In Sydney, young carers had unemployment rates that were higher than their non-carer peers in all LGAs apart from Mosman. The two areas where young carers were most disadvantaged were Blacktown and Campbelltown, where young carers had unemployment rates that were 10 – 20 percentage points higher than their non-carers peers. Young carers had unemployment rates that were 20-40 percentage points higher than their non-carer peers in a number of New South Wales regional LGAs including: Central Darling, Cootamundra, Forbes Hay, Kyogle, Liverpool Plains, Warrumbungle, Wellington and Walgett.

In South Australia, two regional LGAs had gaps in unemployment rates between young carers and non-carers that were over 20 percentage points and these were Murray Bridge, and Yorke Peninsula. In Adelaide, the LGA with the highest gap (over 20 percentage points) was Walkerville.

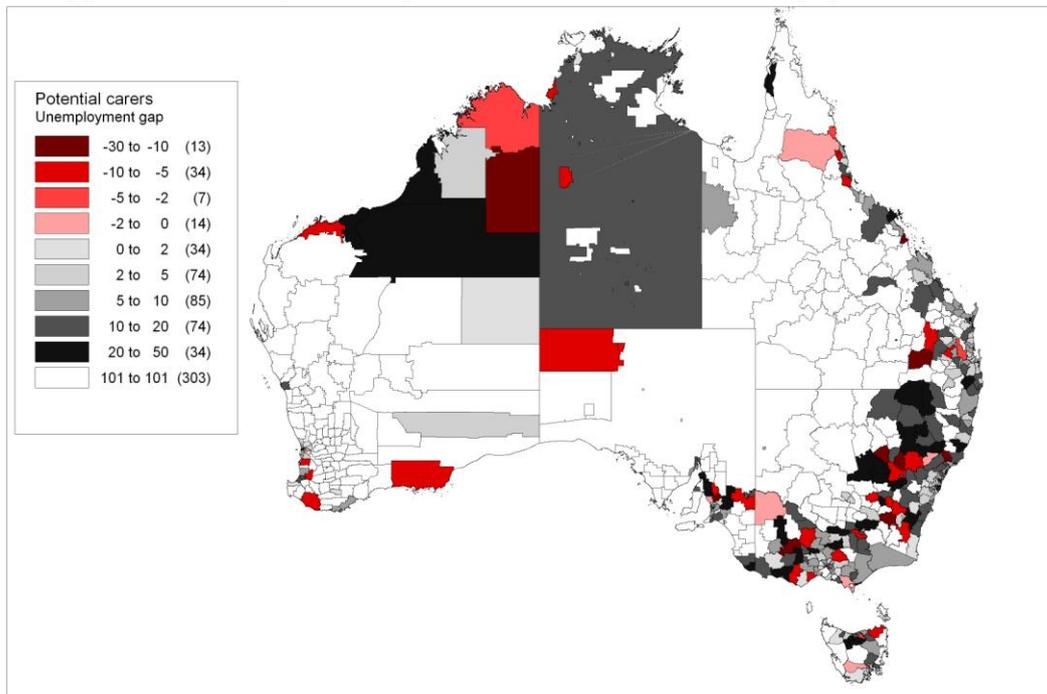
In New South Wales, young potential carers had unemployment rates that were over 30 percentage points higher than their non-carer peers in the LGAs of Cowra, Gunnedah, Gwyndir, Parkes and Warrumbungle Shire and a number of other LGAs had gaps of between 20-30 percentage points. In South Australia, five LGAs had gaps in unemployment rates between young potential carers and non-carers of over 20 percentage points and these were Grant, Mid-Murray, Mount Gambier, Port Pirie City and Wakefield.

**Figure 3.38 Gaps in unemployment rates by Local Government Areas, 2006**

Young carers: Gaps between carers and non-carers in unemployment rates



Young potential carers: Gaps between potential carers and non-carers in unemployment rates

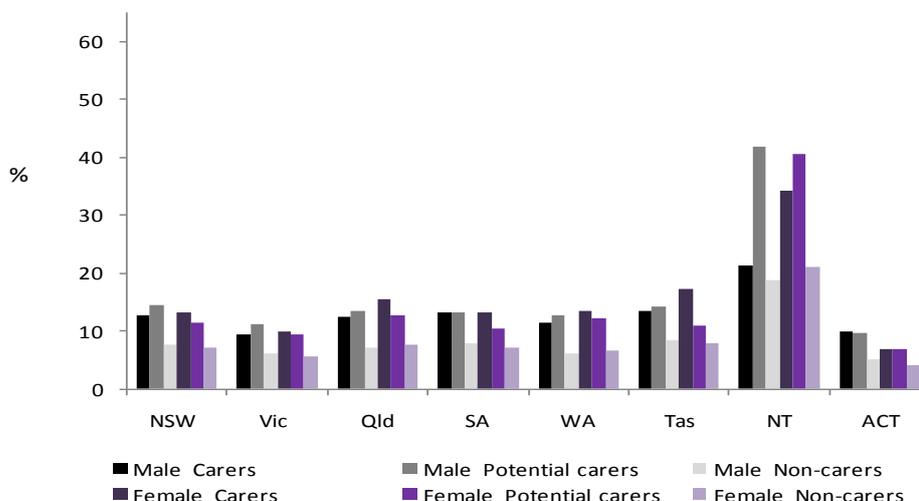


Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

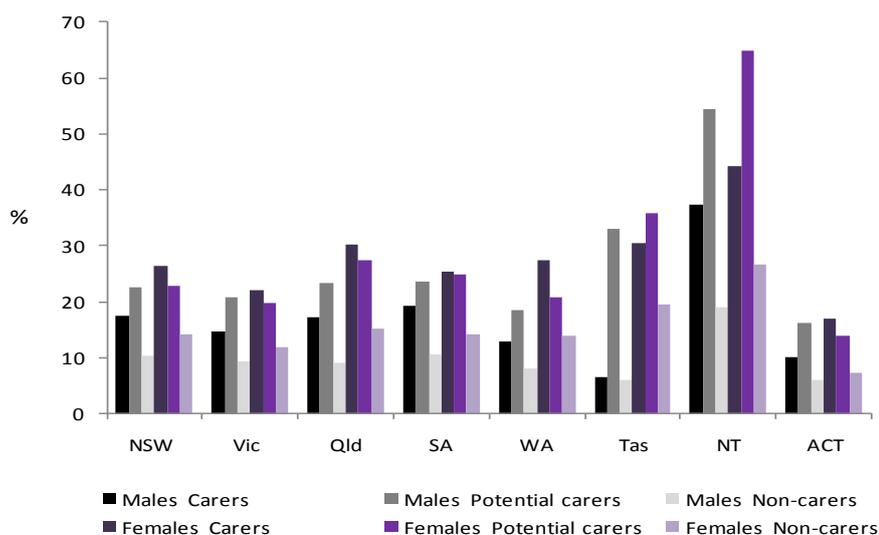
### Non-participation in employment or education

The impact of informal care on young people’s futures may be most profound if young people are unable to participate in either education or employment at the crucial stage of transition from high school to adulthood. Rates of non-participation for young people ranged from 5 per cent to just over 40 per cent in the 15-19 years age group and were generally higher in the 20-24 years age group (Figure 3.39, Figure 3.40 and Table 3.11). In all States and Territories, and in both age groups, young carers and potential carers had higher rates of non-participation than non-carers.

**Figure 3.39 Rates of non-participation in education or employment of young people aged 15-19 years by sex, carer status and State/Territory, 2006 (per cent)**



**Figure 3.40 Rates of non-participation in education or employment of young people aged 20-24 years by sex, carer status and State /Territory, 2006 (per cent)**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author’s calculations

**Table 3.11 Rates of non-participation in education or employment of young people aged 15-24 years by age, sex, carer status and State/Territory, 2006 (per cent)**

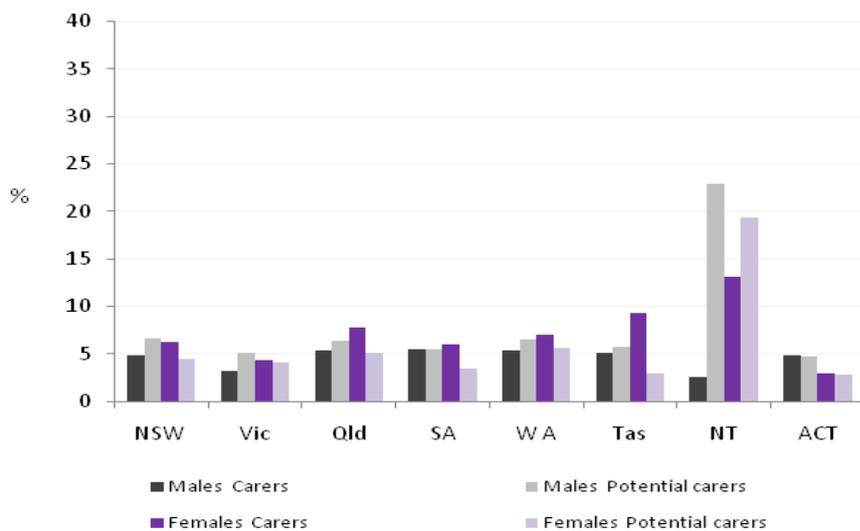
	15-19 years						20-24 years					
	Male			Female			Males			Females		
	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers	Carers	Potential carers	Non-carers
New South Wales	12.6	14.4	7.8	13.3	11.5	7.0	17.5	22.6	10.3	26.3	22.8	14.2
Victoria	9.4	11.2	6.1	9.8	9.5	5.5	14.8	20.7	9.3	22.0	19.9	12.0
Queensland	12.5	13.6	7.2	15.4	12.6	7.6	17.3	23.3	9.1	30.3	27.4	15.1
South Australia	13.3	13.3	7.8	13.1	10.5	7.1	19.2	23.5	10.6	25.4	24.9	14.2
Western Australia	11.5	12.7	6.1	13.6	12.2	6.5	12.9	18.4	8.0	27.5	20.8	13.9
Tasmania	13.5	14.2	8.4	17.2	10.9	7.9	6.5	33.0	6.0	30.4	35.9	19.6
Northern Territory	21.4	41.8	18.8	34.3	40.5	21.2	37.2	54.4	19.1	44.2	64.8	26.6
Australian Capital Territory	9.9	9.7	5.1	7.0	6.8	4.0	10.1	16.2	5.9	17.0	14.0	7.4

Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### Gaps in rates of non-participation

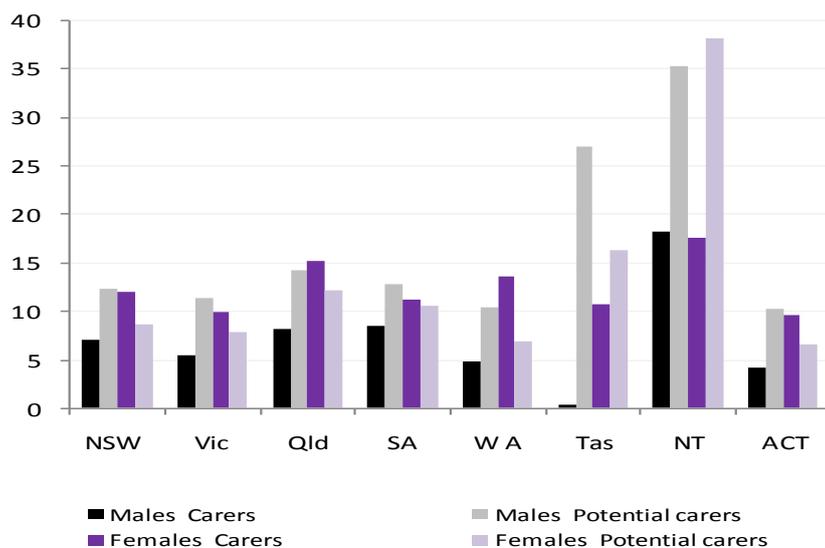
Figure 3.41 and Figure 3.42 show that in the 15-19 years age group there was a similar level of disadvantage for males and female carers, however, in the older age group (20-24 years), young females carers had higher levels of disadvantage with respect to non-participation in either education or employment.

**Figure 3.41 Gaps between carers, potential carers and non-carers aged 15-19 years in rates of non-participation in employment or education and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

**Figure 3.42 Gaps between carers, potential carers and non-carers aged 20-24 years in rates of non-participation in employment or education and State/Territory, 2006**



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### **Gap in rates of non-participation in either education or employment**

Figure 3.43 shows the gaps in rates of non-participation in either employment or education between young carers and young potential carers when compared with their non-carer counterparts. The map colour coding is similar to all previous maps of LGAs. The gaps are calculated by subtracting the non-carer rate of non-participation from the carer rate and potential carer rate of non-participation. Thus higher positive values indicate greater disadvantage.

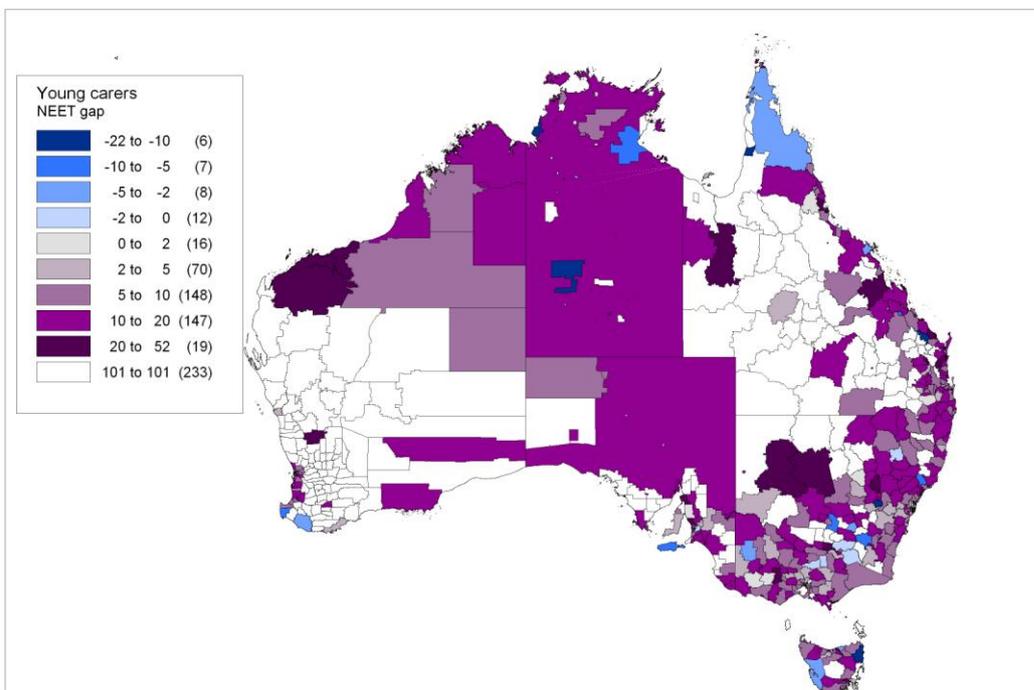
In the majority of LGAs in Australia, young carers and young potential carers had higher rates of non-participation than their non-carers peers (92 per cent of LGAs for young carers and 87 per cent of LGAs for young potential carers). While advantage and disadvantage for young carers and potential carers were distributed in both metropolitan and regional areas, most of the LGAs with higher rates of disadvantage for young carers and potential carers were in the regional areas rather than the cities.

In Sydney, young carers were most disadvantaged in the LGAs of Penrith and Campbelltown where they had rates of non-participation which were 10-20 percentage points higher than their non-carer counterparts. In regional New South Wales, young carers were most disadvantaged in the LGAs of Central Darling, Cobar, Corowa Shire and Wellington, where the gap between young carers and non-carers in rates of non-participation in education or employment was over 20 percentage points. In South Australia, young carers were most disadvantaged in the LGAs of Mallala and Port Pirie City and Districts.

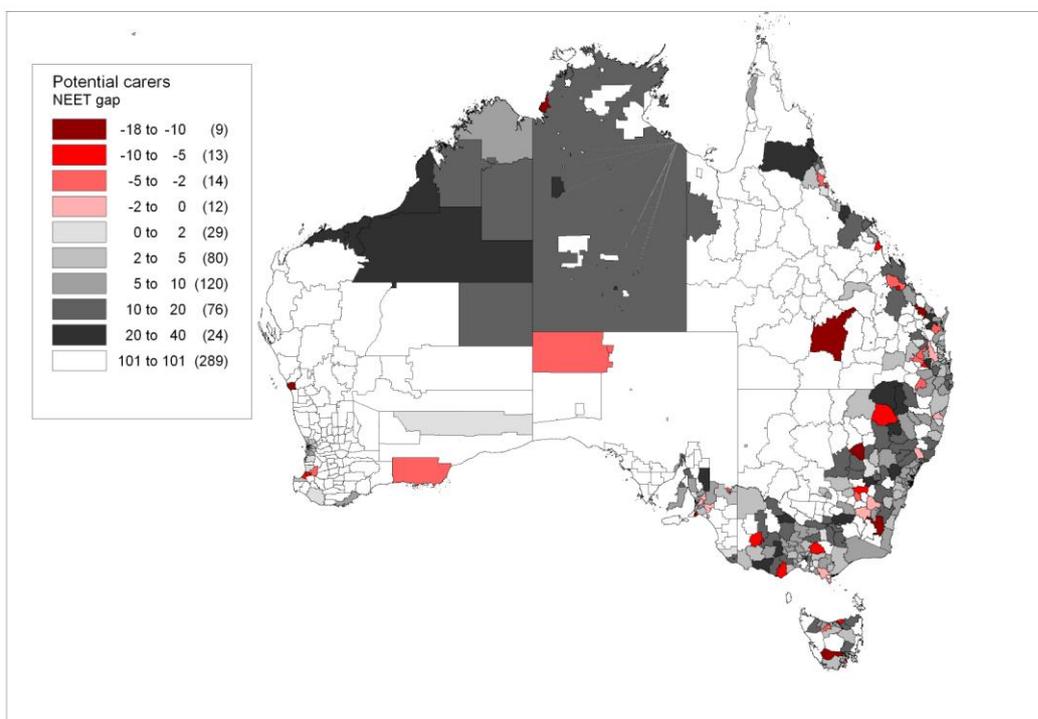
In Sydney, the LGAs where young potential carers were most disadvantaged compared with their non-carer peers were North Sydney, Mosman and Botany Bay and in Adelaide the LGA with the largest gaps were Campbelltown and Port Pirie City and Districts. Young potential carers were most disadvantaged in the LGAs of Cowra, Greater Hume Shire, Gunnedah, Gwyndir, Lithgow and Moree Plains in regional New South Wales and in Goyder in regional South Australia (with a gap of over 20 percentage points).

**Figure 3.43 Gaps in rates of non-participation in either education or employment by Local Government Areas, 2006**

Young carers: Gap in rates of non-participation in employment and education



Potential carers: Gap in rates of non-participation in employment and education



Source: ABS Census of Population and Housing 2006 Customised Supertables, Author's calculations

### 3.7 Summary

This analysis explored the ABS 2006 Census data on young carers and potential carers to identify rates of caring and the circumstances of these groups. The analysis found that young women are generally more likely to be carers than young men in all States and Territories in Australia and in both age groups, but that young men are more likely than young women to be potential carers. Caring was more prevalent in the older age group (20-24 years), while potential caring was more prevalent in the 15-19 years age group. Rates of caring and potential caring were higher in the Northern Territory, lower in the Australian Capital Territory and generally higher in LGAs in regional and remote areas.

The literature has identified key factors that are associated with pathways into caring for young people, such as cultural background and Indigeneity, lone parent households and low resource households. The analysis of the Census confirms that young carers and potential carers are overrepresented with regard to all these factors. Indigeneity and low resource households were more prevalent among young carers and potential carers living in regional and remote areas, while there were higher rates of young carers from culturally and linguistically diverse backgrounds in the major cities. LGAs with relatively high rates of lone parent households in the young carer and potential carer population were found in both cities and regional areas. Young carers and potential carers in the 15-19 years age group were more likely to live in lone parent and low resource households than those in the 20-24 years age group.

The Census data also show that young carers, but not potential carers, were more likely to be contributing to the domestic work and child care undertaken in their households than their non-carer peers. The literature highlights the impact of caring on young carers' participation in education and employment. The Census data confirm that young carers and potential carers were generally disadvantaged with respect to participation in education and employment and had higher rates of unemployment than their non-carer peers. While the young carer and potential carer disadvantage varied across geographical areas of Australia, the analysis showed that regional and remote areas tended to be associated with the highest levels of disadvantage for young carers and potential carers on these measures. Young carers and potential carers in the older age group (20-24 years) had greater disadvantage than the younger age group (15-19 years) with respect to non-participation in either employment or education, perhaps indicating that there are fewer supports for these young people or that the caring role may become more entrenched as young people grow older. This latter finding may have important implications for young people's transitions into adult roles in the public sphere, particularly with respect to entering and retaining employment and ensuring adequate market income.

## **4 Survey findings of young people providing care and people receiving care**

### **4.1 Introduction and aims**

This section of the report aims to explore key themes that have arisen in the Australian and international literature and to interpret and illuminate the findings of the quantitative analysis, such as the gaps in rates of education and employment between young carers, young adult carers, potential young carers and non-carers. This section also explores differences in access to services. This section aims to do so by using a “whole-of-family approach”, talking with young carers, young adult carers and where possible people receiving care from a young person, to explore the experiences and meanings of the care-giving/receiving relationship and the policy frameworks which affect those relationships. It aims to explore the diversity of young carers’ responsibilities and relationships within their families and in their wider kin, friendship and community networks, and their participation in schooling, further education, training and employment. It also develops an understanding of the experiences of care recipients and how they envisage the needs of their caregivers and their own needs.

The data collected in the interviews are complemented by an online questionnaire that explores the socio-economic and demographic circumstances of young carers and their families including family composition and history, the circumstances and needs of the person being cared for, and the health and disability status and wellbeing of family members. With respect to both carers and care recipients in the interviews and the questionnaire, information was sought on knowledge of formal services, service usage and factors militating against service access and usage. This complements the policy audit and focus groups with service providers and policymakers in helping to identify the range of education, training, employment programs and support/information services in Australia at government, NGO and workplace levels which might flexibly recognise, accommodate and open up opportunities and reduce barriers to education, training, employment and social participation for young people with informal care-giving responsibilities.

### **4.2 Methods**

This research strand included qualitative interviews and questionnaires with young people and care recipients and activity sessions with small groups of young carers. The carer groups of participants were categorised into cohorts according to their age and school status, which acts as a useful proxy for delineating the life course stage of the carers. Using this approach, young carers (YC) were defined in this study as aged 7 to 17 years and young adult carers (YAC) were defined as aged 17 to 25 years. Therefore, for young people aged 17, their assigned category was determined by whether they were in school or not.<sup>2</sup> Participants interviewed included young carers, young adult carers, and people receiving care who were aged 18 or over, across New South Wales, South Australia, Victoria and Queensland. The interviews were semi-structured and asked about a range of subjects, including caring role, care relationship, school, work, friends and relationships, health and service use. The interviews lasted for a duration of approximately 45 minutes and were conducted face-to-face

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<sup>2</sup> If they were in school they were included as young carers and if they were in higher education or employment they were categorised as young adult carers.

or by phone, and alternate arrangements were used (written responses) to accommodate participants' needs.

Participants were recruited using an arms-length approach with the assistance of the project's Partner Organisations and a range of other government and non-government carer, consumer and other organisations. We interviewed 23 young carers, 13 young adult carers (1 provided a written response), and 7 people aged 18 and over who received care from a child or young person. In each group, we interviewed both male and female participants across a range of ages. Ethics approval was received from the University of NSW HREC (HREC 07243) to conduct all parts of the research. (An overview of the participants' details is presented in Table 4.1.)

**Table 4.1: Interview participants by type of interview, gender, age, and state**

		<b>Young Carer</b> (7-17) (no. = 23)	<b>Young Adult Carer</b> (17 – 25) (no.= 13)	<b>Care Recipient</b> (no. = 7)
<b>Gender</b>	Male	15	5	3
	Female	8	8	4
<b>State</b>	NSW	18	5	6
	SA	3	6	1
	Other	2	2	0
	(VIC and QLD)			

a. Notes: One young adult carer was aged between 20 and 25 but did not specify further

The interviews were recorded, transcribed and analysed thematically using NVivo.

Those who participated in an interview were also asked to complete a short online questionnaire. The questionnaire took about 15 minutes to complete and the participant was offered the help of the researcher when filling it out. In most face-to-face interviews, the young people (and in some cases, the care recipients) asked for the researcher's help to fill out the questionnaire. In these cases, the researchers asked the participants' permission if they could leave the tape recorder on. This elicited some additional data. The questionnaire asked about demographics, including age, household composition, care recipient demographics, and caring tasks, services used, and participants' wellbeing. The demographic data collected in the questionnaire was combined with the interview data to build up a comprehensive picture of each participant.

We received 33 questionnaires from young carers and young adult carers which comprised almost all of the participants interviewed. Only two care recipients filled out the survey and we therefore have very limited data from this group. While two of the young adult carers did not fill out the survey, this survey produced some useful data about the characteristics of the participants, presented in Table 4.2.

**Table 4.2: Demographic data and data on care situation from online young carer questionnaire**

	<b>Young Carer</b> (no. = 22)	<b>Young Adult Carer</b> (no. = 11)	<b>Total (%)</b>
<b>Born in Australia</b>	22	10 <sup>1</sup>	100
<b>One or both parents born overseas</b>	9	4	39
<b>Speak language other than English at home</b>	2	1	9
<b>Aboriginal or Torres Strait Islander</b>	3	0	9
<b>Self reported income<sup>2</sup>:</b>			
Reasonably or very comfortable	11	3	44
‘Just getting along’, poor or very poor	10	8	56
<b>Who they provide care for<sup>3</sup></b>			
Parent	15	8	48
Sibling	14	2	48
Other family member	1	1	6
<b>Disability/illness of person they care for<sup>4</sup></b>			
Physical	15	8	70
Mental health	13	4	52
Intellectual	10	3	39
Long term illness	9	3	36
Sensory	8	3	33
Limited mobility	2	4	18
Alcohol or drug problem	6	0	18
Other	4	1	15

Notes: (1) One did not specify; (2) No participants responded they were rich, and one did not respond at all ; (3) Adds up to more than the number of participants because many young carers reported caring for more than one person, and that the person they care for has more than one disability or illness; (4) May add up to more than 100 per cent because some were caring for more than one person

We also conducted a number of activity sessions with young carers. Activity sessions are group research activities that are more participatory and interactive than focus groups. They incorporate a number of distinct research activities carried out over a half day (3-4 hours), interspersed with fun activities. The young carers were recruited through carer support groups, who would organise an extended outing with the young carers during which we could come in and conduct a few research activities.

The research activities involved the use of several tools selected to provide young carers with opportunities to share demographic information, information about their relationships with family and friends including the person they care for, the relationship between their education and their caring responsibilities, their health and wellbeing and the services they need.

The total number of participants across three separate days of activity sessions (two in New South Wales and one in South Australia) was 44 young carers and 1 young adult carer. The participants were male and female across a range of ages.

The remainder of this section discusses the results from the two groups of participants (young carer and young adult carers), using data from the (i) interviews, (ii) questionnaires and (iii) activity sessions. Following this, there is a brief discussion of themes that emerged from (iv) care recipient interviews. As mentioned, our recruitment strategy yielded fewer care recipients than planned (7 rather than 20), of whom 2 completed the questionnaire. As a result, the findings from these interviews are useful to complement the findings from the analysis of carers, but caution must be taken due to the small number of participants in this category.

### **4.3 Research Findings**

#### **Young people**

##### ***Pathways into Caring***

Participants' responses about their pathways into caring provide a diverse mix of information about how the young people's caring tasks began and how they related to the changing nature and intensity of caring as they grew older and as the care recipient's condition changed. A few commented on their pathways out of care, however the majority of young people looking after their parents or siblings did not consider their caring role a phase in their life, but rather thought of it as a continuing responsibility with many uncertainties which they would need to consider and manage in the future.

Young people's pathways into caring were often different depending on the nature of the onset of caring, reflecting whether they felt that they were 'born into caring' because a parent or sibling was already living with an illness or disability, or due to a specific onset of illness or disability that the young person remembers. However, within each of these circumstances participants still expressed diverse perspectives on the pathways into their caring role, which can largely be divided into a transition period into caring, or to a specific moment or event. For example, a participant who always remembers his mum being disabled transitioned into caring later, noting

"I never really saw it as caring until very recently...it's always just been part of just me living with mum" (YC, male).

Similarly, other participants connected their pathway into caring to increased responsibility because of the deteriorating condition of the person for whom they were providing support and assistance, or as a result of getting older and being able to take on a greater caring role. Commenting on the deteriorating condition of her father's illness, one young adult carer said,

"so I went from being just a little kid roaming around the house...[to] suddenly doing the washing and cooking and that kind of thing" (YAC, female).

Two other commonly cited pathways into caring were linked to a change in family structure and family dynamics which required the young person to take on greater responsibility (eg parental separation, older siblings moving away from home); and a realisation, or awareness of their caring role because they accessed services or attended young carer camps. Not surprisingly, participants' pathways into caring affected how they identified with their caring role and in many cases their caring role shaped their identity within their family, groups of friends and even the wider community.

### *Sense of Identity*

The experiences of participants had diverse impacts on their perception of themselves as a person and as a carer. Some were quick to assert that they did not consider themselves carers, while others said they grew into the role or accepted the label because of a young carer camp or use of a particular service. Young adults expressed a clearer understanding of their role and how it affected their identity and growth, especially their participation in education and employment and future life opportunities. However many younger participants were also very aware of their role and felt strongly attached to their caring identity, especially those who did not remember a life which was different. In some cases, participants who did not associate with being a young carer, since they saw their responsibilities as intrinsic to their family responsibilities, nevertheless still accepted the label as a necessary means to receive services. This was a strategic identification, since receipt of services was very important to their own and their family's wellbeing. There were also some participants who 'grew' into the role once they had a better understanding of what it meant. A young adult participant indicated she started calling themselves a young carer when she "hit high school and started understanding the concept a bit better" (YAC, female); while another (caring for a sibling) realised that the caring she did was not what a "normal sister or brother" does (YC, female).

Another important finding from the interviews was that many participants separated their carer identity from another (usually school) identity, suggesting that:

"at school you concentrate on work, you come home and you help look after your family" (YC, female).

Furthermore, being a carer at home also shaped a number of participants' identities at school and within their group of friends, where participants identified themselves as the 'mother' in their group, a good listener, and someone that peers could talk to when they needed comfort or support. Their caring role also shaped their identities and character in more holistic ways, with a few participants indicating their experiences helped develop them into the person they are. This was often the case where young people provided strong emotional support for their care recipient, which shaped their perspectives and they felt increased their maturity.

In particular the young adult participants talked about growing up as a carer and how they took on more of an emotional caring role as they got older and often had to deal with the changing intensity of their care recipients' condition and disability.

### *Caring tasks*

There were marked differences between young carers and young adult carers with respect to the caring tasks they did and the way they perceived their role within the family. The types of tasks and the intensity of caring were therefore dependent on age, type or nature of care recipients' conditions, and the structure and dynamics of the family. In general, young carers talked more about helping with domestic tasks such as cooking, cleaning and helping take care of younger siblings and some talked about emotional support. Young adult carers, on the other hand, were more likely to take on additional tasks, including taking the person they cared for to medical appointments, talking with health professionals and other service providers, helping out with household bills and paperwork, and providing emotional support and advice.

As might be expected, in many cases young adult carers were able to reflect on the changing nature of tasks they did over time and understand how their role had changed. For example, a young adult participant talked about her changing role over the years, commenting, "yeah,

over the years...now it's a lot more emotional" (YAC, female). It is interesting to note that a few participants also indicated a strong medical awareness, and in a couple of cases suggested that understanding their parents' condition when they are visiting the doctor is part of their 'job'.

The participants often perceived their role with respect to the changing intensity or predictability of their care recipient's illness or disability, which reflected differences in whether the condition was a physical disability or mental illness. For example, in cases when the care recipient had a physical disability the participant was more likely to talk about the daily caring tasks, and perhaps increased intensity when another family member was not able to help, or the recipient's condition deteriorated. In contrast, in cases where the care recipient had a mental illness or complex condition, participants were more likely to talk about the unpredictability of their caring responsibility.

In many cases, the intensity or nature of caring tasks was discussed with reference to the complexity of the illness, of their family dynamics, and the logistics of balancing their caring role.

### ***Complexity***

In many cases participants experienced complex family circumstances because of a concentration of illness or disability within the family (i.e. they cared for more than one family member), or when one care recipient had a complex illness and/or disability. In many cases the difficulties of balancing care were exacerbated by complex family dynamics and life trajectories, including moving house a number of times, siblings moving in and out of the house, and tensions within the immediate or extended family.

There were a few cases where the participants also had a disability or illness themselves, which affected other family members' caring responsibilities and also their education and employment prospects. Having other people in the household with health problems (in addition to the 'primary care recipient') often meant that the distribution of caring tasks changed as some members did additional tasks for others who were unwell. There were some examples of carers taking on increased caring responsibilities for the care recipient because the other parent had an accident which affected their ability to provide care.

Additionally, several participants talked about the changing nature of care as the care recipient's needs changed. For example, one young adult carer said that as her mum's physical health improved but her emotional health deteriorated she helped her with "that sort of side of things [emotional] now more than the physical side" (YAC, female).

### ***Relationships***

Both groups (young carers and young adult carers) talked about having very close relationships with the parent and/or sibling for whom they cared, and in many cases, they also said they were close to their whole family. For example, one young adult carer noted that:

"it's made mum and I a lot closer...and made me closer with my family as well you know needing their support, their needing me" (YAC, female),

This is indicative of many participants' feelings and experiences.

Participants often indicated that they thought they had 'better' relationships with their parents, compared to their peers. Young carers, more than young adult carers, talked about the reciprocal nature of the relationship with their parent in a practical way, indicating that

their parents still provided meals for them, drove them to school, etc. In contrast, young adult carers were more likely to talk about the emotional support their parents provided for them.

However there were also some important differences between young carers and young adult carers' relationships with a parent care recipient; and relationships between carers and a sibling care recipient. Young adult carers were more likely to comment on their relationship with their parent being 'different' and offered reflections on why it was different and how their relationship changed over time. One young adult carer indicated that before becoming a carer she had more of a 'normal' relationship, compared to an 'adult' relationship which began once she and her sister started caring for their mum.

The relationships participants had with their care recipient (when he/she was a parent) were also shaped by the type of illness, eg. carers expressed some mixed, or changed, feelings toward their relationship when the parent had a mental illness. A few young carers and more young adult carers talked about having to forget the past and the negative feelings they had about their parent. The young adult carers talked about having to 'ignore everything from the past' and accept their parent for who they are.

As expected, when the care recipient was a sibling the nature of the relationship was expressed differently, but still in a very positive way. Many participants talked about how important they were to their sibling, and primarily talked about being a companion and friend. For example:

"I think he always looks up...up to me...he's always wanting [me] to ...like play with him" (YAC, male); and

"whenever I'm sad or upset she always...she's always been there for me, she's always comforted me" (YC, male)

Further, young carers and young adult carers also talked about the physical help they provided, including helping put their sibling to bed, feeding, toileting, etc. When asked what their sibling does for them, many young carers indicated that they are always there for them emotionally, make them smile and laugh and keep them company.

The positive relationships young carers and young adult carers talked about were often presented as the 'best things' about being a carer. One young carer commented,

"if you don't care for someone the way you do...the way you have to when you're a carer, you don't really have that same bond or connection with them" (YC, female).

### ***The positive aspects of caring roles***

In addition to having close relationships with the person they care for, and with their whole family, most of the participants also talked about other positive aspects of their caring role. In particular they talked about a range of positive feelings they associated with being a carer, such as a sense of pride and satisfaction in what they do; and one participant indicated it was a "privilege" to be a young carer. Another positive aspect of the caring role was the practical skills and experiences gained from the additional responsibility entailed. Young carers and young adult carers commented on the domestic skills (i.e. cooking and cleaning), the caring skills (both practical and emotional) and being able to deal with a lot and manage difficult situations.

Many talked about their maturity and sense of self, which they felt was due to their caring role. For example, one participant said,

“I think that...having to take care of other people, you also ...have to take care of yourself so you learn to take care of yourself quicker” (YC, male).

Another positive aspect which both young carers and young adult carers expressed was a heightened sense of perspective, respect and acceptance of others. They suggested that caring gave them a better perspective on what was important in life; they ‘don’t judge’ others and are more likely to forgive people; and learned a lot about empathy.

Some of the participants also talked about their involvement in young carer camps and programs as positive aspects of being a carer.

Despite these positive aspects that were identified, many participants talked about the contradictory positive and negative aspects of being a carer, indicating that while they acknowledged the positive aspects they still “wouldn’t wish it on anyone” (YAC, female). The negative aspects of caring were mostly about the difficulty in balancing care with other domains of responsibility and aspirations, and always having to consider their caring role when they make decisions. This interplay of perceptions and experiences indicates some of the complex contradictions of caregiving for young people: they understand and value the contributions which they make as carers to the wellbeing of their care recipients, but are also aware of the affects on their own life which may be negative and disadvantaging. Young adults in particular perceived these contradictions.

### ***The negative aspects of caring roles***

The young carers and young adult carers identified a wide range of challenges and difficulties associated with their caring role, which were reflected in different aspects of their lives - school, further education, employment, social life and friendships, and their own health. A commonly cited negative aspect of caring was the lack of time to participate in social and recreational activities, as caring was their priority. Many commented on always feeling like they needed to be home to help with caring and the need to consider their caring responsibilities when making decisions and plans to see friends.

In addition to time constraints, some participants commented on the pressure of having a caring role, and how it takes away their childhood. For example, one young person said that

“some days you just don’t feel like caring, some days you simply want to be your age” (YC, female).

However, many participants identified coping strategies, whether explicit or implicit, in managing the difficult aspects of caring.

### ***Coping strategies***

Despite describing a number of difficulties associated with their caring role, it became clear that young carers and young adult carers adopted a number of strategies to cope with their daily lives. Some of these were explicitly adopted but others surfaced implicitly as participants described the way they managed their daily lives and responded to challenges. The main coping strategies identified were establishing a routine or schedule; separating their home and school lives; being able to find humour in difficult situations; accepting things as they are; finding the positive aspects (such as love and reciprocity) and making sure they have personal time and space. These strategies are reflected in the quotes below:

“...I just set out my day between my caring roles and my school roles...”  
(YC, male)

“You don’t know what to do. You can either get angry with it or go okay, so, I’m tired of being angry so I’m just at the ‘whatever’” (YAC, female)

“...like for me trying to understand my caring role, I’ve analysed it, deconstructed it and to a point where I’ve just come to accept it” (YAC, male)

[Commenting on being teased on the street with his mum]: “...I just explain that at least I have a relationship with my mum and they go, oh yeah” (YC, male)

There were important findings about the impacts that caring have on different aspects of the participants’ lives, most specifically education, employment, social life, health and future aspirations.

### ***Education***

Education was an important issue for the participants because the large majority (30/33) of all young carers and young adult carers who were interviewed were participating in some form of education. Generally, younger participants expressed less concern over the effects of caring on their education, while young adult participants talked about their coping strategies to manage care and education or expressed their frustration with the difficulties of balancing their education and caring tasks. A small number of young adult carers expressed strong views about the need to improve awareness about, and support for, young carers in the education system in order to ‘count them in’.

Participants occasionally talked about having to hand in assignments late, but more often indicated that they had a routine to help them manage school and caring. Most said their teachers did not know they were young carers, and in most cases they didn’t want them to know because they did not want to be treated differently. A few participants mentioned they separated the spheres of care and school and used school as an escape from home life. However, other participants found it difficult because they were always thinking about the person they cared for when they were at school.

Young adult carers were more likely to talk about the difficulty in balancing care and felt it might be to their advantage for teachers or university and TAFE tutors and instructors to know about their caring role. They were also able to reflect on the differences between their high school and university or TAFE experience, indicating that one was easier or harder to manage. While some found university or TAFE more difficult to manage because of the increased workload, others found it easier to balance because the system was more flexible and teachers were more understanding than in their high school experience.

There were a few participants who had very strong feelings about the inadequacy of the school system in catering for young carers. A few commented on changing schools and the vast differences in treatment which they experienced - from bad to good. They advocated flexible options for young carers in education practices in order to make sure that they don’t get left behind.

“One of the important things in terms of education would be to account for them in ... in their curriculum because one of the things that I found at my old school is that they were very narrow minded and that if you didn’t fit into the system, then you couldn’t participate in the system and hence couldn’t get an education. So the school I’m at now, it’s very much different, it takes that into account” (YAC, female)

Challenges with education were exacerbated when participants, generally young adult carers, were also balancing employment with their education and care responsibilities.

### ***Employment***

According to the questionnaire data, almost a quarter of all young carers and young adult carers who answered the survey were employed in some capacity (mostly part-time). Not surprisingly, young adult carers were more likely to be employed (almost half), compared with young carers, where less than 15 per cent were employed. These figures are fairly consistent with ABS's *A Profile of Carers in Australia 2008* which indicates that in 2003 just over one-quarter of young carers aged 15 to 24 were working full-time and around one-third part-time (ABS, 2008:63); however there were no young carers or young adult carers in our study who were employed full-time (two were self-employed).

Young adult carers, whether they were or were not employed, talked about the difficulty in combining work and care. Most of their concerns were linked to the need for work to be flexible and adaptable, and the need for a 'good employer'. Most young adult carers who did have jobs spoke highly of their employers and said they were very understanding of their caring role. Most said that they would not be able to work if the employer was not flexible. The participants who spoke positively about their employment experiences usually attributed this to a combination of flexible work arrangements, self-employment (working from home), or their ability to manage employment by having a routine. One young adult carer talked about the complications of combining care and work but was able to manage because of her employer's understanding and a routine that fitted with her care recipient's needs.

As expected, there were different issues identified depending on the nature of the care recipient's illness or disability. For example, a participant who cared for her mother with a physical disability was able to negotiate caring and employment by establishing a split shift routine with her employer that allowed her to be home when her mother needed her. In contrast, an unemployed participant said it would be impossible to combine care and work because of the unpredictable nature of her mothers' mental illness and you "couldn't keep up" (YAC, female). Another notable difficulty expressed about finding employment was the administrative barriers posed by Centrelink with respect to eligibility for Carer Payment, in relation to the hours of education/employment permitted under the eligibility criteria for the Payment (no more than 25 hours per week).

When young people face difficulties with balancing care and education, care and employment, and in some cases care, education and employment; it is not surprising that there are also impacts on their social life.

### ***Social life***

Young carers and young adult carers understood the impact of caring on their social life in different ways, and their experiences and perceptions varied between and within age groups. Both groups of participants talked about ways to manage their caring role, and were quick to assert that their caring role always took priority, and they needed to plan ahead to go out with friends. Both age groups indicated that they had friends who were supportive and understanding.

However, many young carers, compared to young adult carers, responded that caring did not have an impact on their social life, which was often due to having shared caring responsibilities with other family members. Also, young carers' experiences were mostly

limited to school, and whether their friends knew about their caring role, and a few expressed concerns about being teased if all their peers knew.

The responses from the questionnaire confirm that the consequences of caring on young adult carers' social lives are greater than for young carers. Young carers were much more likely to respond that they were involved in social and community activities than did the young adults; one out of the 11 young adult respondents indicated they were active in these areas.

As mentioned, the majority of young carers and young adult carers talked about having support from friends, however many still indicated that their friends could never fully understand their responsibilities. This led many participants to talk about valued friendships which they formed at young carer camps and through young carer groups, where one indicated they "just feel a bit safer with them 'cause they understand a bit more" (YC, male). Similarly, a young adult carer commented on having mutual understanding with others with caring responsibilities, since "they're not going to ask like why are you tired you know" (YAC, female). This statement reflects a common understanding among participants with respect to the negative impacts on their everyday lives, of which health consequences was often cited among young adult carers.

### ***Health***

The health consequences of caring were much more profound among the young adult carers. While a few younger participants mentioned feeling worried and tired, and several discussed feeling stressed or depressed, concerns and impacts were more concentrated among young adult carers. Their responses indicated that caring had a clear and negative impact on their perceived sense of good health. This included their physical health due to heavy lifting of furniture and equipment and in many cases lifting their care recipient. Young adult carers commented on feeling tired, exhausted, and run down; and some expressed that these impacts had intensified over time. Many young adult carers also discussed the negative effects on their mental health and identified depression, anxiety, stress and loneliness as conditions they experienced associated with their caring role. A quote by one young adult carer reflects some of the compounded health issues faced:

"...mentally drained and physically drained, I'm only 21 and I always feel tired and that sort of thing because it...if you're been doing you know lifting and supporting the person emotionally it just takes its toll on you eventually" (YAC, female).

The young adult carers' experiences and concerns reflect the consequences of intense and prolonged periods of caring. Many describe strategies they have developed to manage these concerns, such as seeing counsellors and trying to stay physically fit. However, these findings indicate that young adult carers perceived deterioration in their health related to their caring responsibilities.

### ***Future aspirations***

In addition to the current impacts young carers and young adult carers experience, their caring role also had consequences for their future aspirations in areas of education, employment and moving away from the parental home. These consequences were more acutely perceived by young adult carers, whereas young carers had a greater sense of possibility in terms of their future education and employment.

While the majority of young adult carers either intended to go on to higher education or were already attending university or TAFE, their caring responsibilities had shaped their choice of

institution (usually the one in closest proximity to home) so they could combine caring and education. When asked about the impacts of care on their educational choices, one young adult carer asserted that she

“can’t even organize her uni classes without thinking about this class is too late, I can’t take this one, let alone your future prospects” (YAC, female).

Both younger and adult participants expressed their intention to stay close to home when considering education and employment options, mentioning that they didn’t think caring would

“impede too much in further studies” but “think it may stop me from going interstate” (YAC, female).

These decisions were also largely shaped by household composition and the unpredictability of the care recipient’s condition, as the participants considered who would manage the caring and household tasks if they were away from home.

Participants also talked about their perceived lack of resources, both formal and informal, which constrained their choices and decisions for study and work.

### ***Resources***

Participants’ perceptions of resources they used and needed were fairly diverse, with many having strong views about the need for better supports and financial help; while others simply answered “no” when asked whether they would want any more help with caring.

The young adult carers were more likely than the younger participants to talk about the resources and help they received from Centrelink and other government agencies.

Both groups talked about their difficulty with transport in order to do the shopping, take their family member to medical appointments etc. In many cases this was because the parent was unable to drive because of their condition, the carer was too young to drive, or because the family did not have a car. One young adult carer talked about how expensive it was to drive (licence, registration, petrol, etc) once they had their licence and noted that transport subsidies would be very useful. Some participants and their family members received a broad range of informal support from friends and family. Some talked about their reliance on family and friends who lived nearby, however others indicated the lack of informal support which made caring very difficult.

### ***Services***

Young carers and young adult carers accessed a range of services for themselves and for the person they cared for. Approximately two-thirds of the young carers were in young carer support groups and many had attended young carer camps in the past. This is of course a reflection of the sources of recruitment of participants in this study. Participants received other support, including counselling and training skills for themselves, and in-home and out of home respite for the person they cared for. A noticeable difference between young carers and young adult carers was their knowledge of the services available to them. Young carers found it more difficult to identify or suggest services that may be of use to them; however when asked explicitly they were able to identify specific services or tasks that would be helpful.

In contrast, young adult carers were more likely to identify gaps in services and emphasise the importance of these services for young carers. Service issues that were commonly raised included the need for greater flexibility in income support eligibility (to allow carers to

work/study and receive Carer Payment), the lack of transport, and the importance of creating flexible options for care and education. The importance of flexible education and study options was often linked to the need for increased and more flexible respite options. For example, one young adult carer commented that

“six hours [of respite] is a lot and it’s the difference between me being able to study and not” (YAC, female).

### **Care recipients**

The aim of this project was to explore in detail the experiences of young people providing support and assistance within a ‘whole-of-family’ perspective, so it was important to consider also care recipients’ views and experiences. The discussion below is largely limited to care recipients’ perspectives on their young carer(s)’ experiences and the relationship they have with them; and does not include detailed information about the care recipient’s experiences of living with a disability or long term illness. It should also be noted that in most cases we did not interview care providers and care recipients in the same caring relationship.

#### ***Relationship with young carer***

The majority of people receiving care from their child or children talked very positively about their children as carers, and reflected admiration and love for them:

“yeah they’re just incredibly responsible, they just know that if I can’t get out of bed that day, they just know what to do.” (CR, female)

“I love my girls deeply, profoundly. They’re both wonderful young women. And...and just can’t speak highly enough of that” (CR, male)

The strong relationship between care recipients and their children was also evident when they spoke about the importance of the emotional support and reciprocity of the relationship. For example,

“I can do that ad so I take...where he takes from me...I can do things too” (CR, female)

However some care recipients indicated that their relationships with their children had suffered as a result of their child’s caring role and the nature of their illness.

“They’ve found it hard to cope with the situation. I’ve always been very independent. ... and I think they’ve found that role of reversing sort of difficult” (CR, female)

“Yeah, we’re not anywhere as close as we were when she was a lot younger...’cause she was daddy’s girl” (CR, male)

#### ***Impacts on young carer and consequences***

Similar to findings from the young carer and young adult carer interviews, the care recipients acknowledged the consequences of caring on the young peoples’ lives. Some participants noted an awareness of the impacts of their caring role on the young person’s social and education experiences.

While some care recipients noted the potential negative impacts on the young person’s education, this observation was not as strongly expressed, compared with the young carers’ responses. While many young carers and young adult carers indicated that their caring role

was their priority, it is interesting to note that some care recipients indicated that their child's education was their priority.

Similarly, some care recipients responded that their children's caring role made it difficult for them to spend time with friends; while others also indicated that they made sure that their son or daughter made time for their friends and had a social life.

The most common observation about how caring impacted on the young person's life was through expressed concern that their illness or disability would take away from the young carer's childhood, and affect the normality of family life. Several care recipients talked about wanting to make sure their family had as normal a life as possible; for example,

“We decided as a family that we would do ... everything in our power to live as normal a life as we possibly could.” (CR, male)

### ***Family dynamics and caring expectations***

It is interesting to note that some care recipients expressed an expectation that all their family members would have a caring role, while others see it more as the young person's own choice. For example, one care recipient stated:

“And it's a very difficult thing to have you daughter having to help you on the toilet, and cure your wounds and ... and there is a certain amount of embarrassment, there's a certain amount of my God, you're my baby, this is just not it, but that's the role that she's chosen to do. She wants to do this.” (CR, female)

In contrast, some care recipients talked about a sense of guilt for the role their children had, indicating they did not like their children to see them in pain, or seeing their parent needing help. Some care recipients tried to hide their pain or undertake tasks such as housework when the young person is not home in an attempt to shield them from the additional responsibilities. For example, a mother said

“He doesn't like me moving anything and he'll try and do it and so I try and not do things when [Young Carer] is here because I don't want him to see that it can be hard” (CR, female).

Also, some care recipients talked about the necessity for their family to undertake caring tasks, due to a lack of services or other informal supports.

### ***Services***

There were both positive and negative acknowledgements regarding the services the care recipients' and their families received. A common response was that services were not accessible or flexible enough to assist young carers with their needs, such as tutoring for their studies, and respite to allow them to study and have time to spend on social activities. Some care recipients felt strongly about the lack of quality services and the reliability of services to attend to their basic needs. However, some indicated they were generally happy with the services they received, but still believed they should be more flexible and responsive to family needs.

## **4.4 Conclusions**

The combination of interviews with young participants (both young carers and young adult carers) and care recipients, plus valuable data from young participants' questionnaires provided a comprehensive story about the experiences of young carers from diverse

perspectives. The main areas of analysis included young people's pathways into caring, their identification with being a young carer, the relationship with their care recipient, and the impacts of caregiving on various areas of their life.

Through this analysis we were able to gain a better understanding of the positive and negative impacts of caring on these young people's lives, how these impacts have changed during their caring role, and how they perceived the potential consequences in the future. Overall, there were similarities and differences between young carers and young adult carers' experiences and perspectives. The level of divergence in the responses of the two age groups varied across the different areas of their lives. For example, young adult carers were better able to reflect on their pathway into caring, the changing nature and intensity of caring tasks, and the relationships they had with the person they cared for. Young carers were more likely to link their pathway into caring and identify with being a young carer when they attended a young carer camp or because a family member told them. In other words, their identity as a carer became apparent to them in circumstances where others "named" their responsibilities as caregiving.

Also, variation in caring tasks and responsibilities often related to whether the young person was a primary carer or the oldest sibling, and the complexity of family dynamics and the care recipient's illness or disability. With regard to the impacts of caring on the young people's education, employment, social life and health, findings from the interviews and questionnaires showed that the consequences of caring appeared to be more intense at an older age, demonstrated by young adult carers' experiences and perspectives about the negative aspects of caring and the consequences for their future aspirations. However, both age groups of participants identified various positive aspects about their caring role, most often linked to the strong relationship formed with the care recipient and their family, and also the maturity and wider sense of perspective and experience they gained from their role. There were also some identifiable differences in experiences and perspectives depending on whether the young participant was caring for a parent compared to a sibling, and whether the nature of the care recipient's illness or disability was primarily physical or related to mental health.

It is also interesting to note the care recipients' perspectives of their relationship with the young person caring for them, with respect to the impact of caring on the young person's life experiences. For example, while some care recipients acknowledged the impacts of the young person's caring role on their life they were less likely, compared with the young people themselves, to say that the young person's caring responsibility was the priority in their life. Almost all of the care recipients interviewed noted the strong relationships which they had with the young people caring for them, and most expressed strong feelings of love, admiration and respect, and a desire to maintain a normal life for the young people caring for them.

It is evident that the interviews and questionnaires generated rich and diverse findings about the experiences and perspectives of the young people. The analysis provided an opportunity to analyse the similarities and differences experienced by the younger and older participants, and the contrasting responses in many cases offered a better understanding of how their experiences and roles changed over the course of caregiving as a child and young person. These findings also identified how the challenges they experience may be addressed through improved service provision and support for young carers and the family members for whom they care.

## **5 Analysis of focus groups with policy makers and service providers**

This section presents key findings from seven focus groups involving 47 policy makers and service providers in New South Wales and South Australia. Three focus groups were held in Adelaide, two in central Sydney, one in south western Sydney and one in Dubbo. The participants included service providers in NGOs concerned with services for carers, including young carers, and government policy makers in relevant areas of policy and program development and administration. The section is organised around the topics discussed in the focus groups and, where relevant, reference is made to how these findings relate to findings from other phases of the project.

### **5.1 Issues raised by service providers and policy makers**

The strongest themes to emerge and those most prevalent in the focus group discussions about the key issues experienced by young carers reinforce and extend the findings of previous research on young carers. These include:

#### **Recognition and awareness**

Many participants noted that organisations, services and staff within them and more widely generally fail to identify a young person with caring responsibilities as a carer, or may not be aware that young carers exist, e.g. many staff in schools do not know, unless informed, that any of their students are carers. When organisations are aware of young carers, they may not necessarily have processes or programs in place to support them.

In addition, young people who provide informal care often do not themselves identify as carers. This can be due partly to their perception that caring responsibilities are a normal part of their obligations and responsibilities as family members; and/or due to fear of stigma associated with the disability, mental health or problematic drug use of the person for whom they care. Several participants noted that sometimes families are fearful of possible child protection interventions, and so prefer not to have a young person identified as a young carer. All of these dimensions of non-recognition and non-awareness mean that young carers can remain 'hidden' and do not receive the services that would benefit them and their care recipients.

#### **Engagement in education**

Many young carers were perceived by the focus group participants to be at risk of disconnecting from their education. This was seen either as a result of the young person sometimes missing school or being unable to complete schoolwork and homework assignments due to a lack of support and inflexible approaches to education practices in some schools. It was noted that young carers have lower school retention rates and difficulties transitioning to post-school tertiary education and training. Many participants felt that lower levels of educational achievement and qualifications would have long-term implications and affect the employment opportunities of young carers. Some participants in the focus groups however told of flexible educational practices in some schools that supported young people to complete their homework and to continue their education. It was clear from the focus groups that schools are a central site for assistance and support for young carers, and that many young carers see their school time as "respite" from their family caring responsibilities.

These findings from the focus groups with policy makers and service providers were consistent with findings from the qualitative research with young participants (young carers

and young adult carers). A number of young people interviewed noted that young carers were at a greater risk of becoming disengaged from education and that completion of further education at university and TAFE was most likely to be affected (See Section 4). A number of participants in the focus groups explicitly stated that flexible and individualised education options for young carers were essential to keep young carers engaged with education. Similarly, a few young carers talked about moving to new schools, which were more accommodating to their caring needs.

### **Mental health**

Young carers may be at risk of experiencing poor mental health. Focus group participants felt that young carers' mental health may be adversely affected by a number of factors, including the stress of the caring role, fatigue and social isolation from peers and friendship groups. Some raised concerns that the impact of caring on mental health might have potential long-term consequences – young carers may develop mental health problems which persist into adulthood. It is interesting to note that these findings align with concerns raised in interviews with young adult carers, where deteriorating mental health was raised as a concern by those who experienced physical and mental strain due to long durations and intense caring responsibilities.

### **Groups at greater risk or with increased need for services**

Participants in the focus groups indicated that young Indigenous carers are particularly wary of seeking support from government services due to past experiences of Indigenous children's removal from families and communities. They also noted that young caring is a particularly significant issue as care needs arise frequently due to high rates of severe chronic illness and disability among Indigenous Australians, compared with the non-Indigenous population. This is confirmed by the analysis of the ABS Census 2006 outlined in Section 3 of this report. Caregiving is perceived and supported by family and kin as part of normal family life and obligations, which may lead to reduced identification of Indigenous young people as carers.

Young carers in rural and regional areas were seen to experience geographic and social isolation, including a relative lack of support services. Participants reported a lack of transport services due to costs of fuel and long distances, young carers being unable to drive themselves into town, and poor and unreliable public transport services. They were also seen to have difficulties maintaining good health as fresh fruit and vegetables are not regularly available or are very expensive. Interviews with young participants also identified transport as a major resource and service concern.

## **5.2 Current approaches and practices in service delivery for young carers**

### **How the needs of young carers are represented and incorporated into policy development**

Participants held divergent views on the benefits of incorporating young carers into the development of high-level policy. On the one hand, some felt this was very important and suggested incorporating young carers into a range of strategic action plans. On the other hand, some felt that there are already good policy documents in place and these are largely ignored in practice. They argued that policy documents incorporating young carers would be less likely to be implemented in practice if:

- There was a lack of funding and organisational commitment; and
- The thinking, practice and culture of the organisation and staff perceived young carers as outside of the organisation's core business.

Participants mentioned several ways in which young carers are currently represented in the policy process:

- *Young carer workers*

Young carers' needs were most commonly incorporated into policy through young carer workers attending various committees within young carer-specific, and other more generic, services and agencies.

- *Young people and generic representation*

Several policy-makers spoke of representation on reference groups, cross-departmental working processes and generic youth committees. Few organisations had systems through which young carers specifically could participate in the policy-making process. Two organisations had formal processes by which young carers themselves could influence policy. Another organisation had a general process by which all young people, not just young carers, could contribute to policy. One organisation tried to ensure that young carers were represented at all levels, including the board of directors.

- *Young carers' perspectives are usually heard through regular service evaluations or those that take place after specific events.*

### **How do young carers find out about support services?**

Focus group participants reported that young carers most commonly access support services after being referred by other agencies, for example through services for the care recipient, family support services and especially through referral by schools. In response to this, service providers said they promote their work in support services, schools, departments and agencies.

It was often stated that schools, health professionals and other mainstream services for families and young people could play a stronger role in identifying and referring young carers. Some participants argued that better education about carers in general and young carers in particular was needed before a greater number of referrals would take place.

Some young carers did seek out support themselves, usually because an adult or another young carer had told them about the services. A number of participants commented that services often receive referrals from young carers in times of crisis and that media promotions were critical in raising young carers' awareness of available support. This included newsletters, newspapers, youth magazines, television programs and websites. However, some services were reluctant to use the term 'young carer' when conducting direct promotion to young carers, and wrote instead of young people 'looking after siblings' and 'supporting siblings' or looking after and supporting other family members.

During discussion about young carers' use of support services, many policy-makers and service providers often mentioned reasons why young people *do not access* support. These include:

- fear of attracting the attention of child protection authorities;

- a lack of awareness about young carers on the part of a wide range of organisations results in young carers not being referred to support services.

Some of these identified access points for referral align with the young carers' experiences regarding their access to services. A number of the young participants in the interviews indicated that their first engagement with services was young carer camps and support groups. The young carers were often referred to these camps and services through the care recipient's services, through their school counsellor or a knowledgeable teacher or because a family member sought out support for the young person.

### **5.3 Processes for coordination with other departments and organisations**

Participants felt that cooperation with other organisations facilitated the provision of many types of activities and services that could not be provided otherwise. Other benefits of interagency coordination include:

- One service cannot provide everything, so it is important to refer to other organisations; and
- Cooperation contributes to general education about young carers and the support services available to them.

Participants spoke of working with other organisations generally in two ways:

- Through local interagency processes in which a young carer worker represents young carers in a group primarily concerned with a broader issue, for example disability or young people.
- In the day-to-day coordination of various services for young people. Some participants noted that such cooperation is essential to ensure that young carers receive support, especially in rural areas.

At the same time, participants noted a number of difficulties in working collaboratively, such as:

- Establishing networks is difficult when many staff work part-time;
- Cross-agency work may create complexity in service provision;
- High staff turnover may create difficulty in knowing who to contact; and
- Some services do not take part in formal interagency processes but
- rely on informal contacts.

It should be noted that a few young carers who were interviewed had experienced some of these service coordination issues. Most notably, one young adult carer talked about the difficulty in coordinating respite, support and resources where she would have to talk to people from a number of different organisations and services, and there was little collaboration between the services. This meant that she often had to contact a number of different people in order to have some fixed or have a service provided.

## 5.4 Gaps in support and services for young carers

### Overall shortage of services for young carers

Participants noted that there were insufficient services for care recipients and that their family members had insufficient services available. They felt this was particularly true with respect to mental health services and respite services, especially emergency respite and flexible respite. Participants mentioned specific groups of young carers who they felt missed out on support services. These groups included:

- 18-25 year olds. Participants observed that it was not always appropriate for this group to access services for adults due to the different types of support they needed (in particular entering into further education and training and finding employment);
- CALD young carers;
- Indigenous young carers;
- Children of parents with problematic drug use; and
- Young carers in rural and remote areas.

### Fragmented nature of young carer service provision

Because of the observation of fragmented service provision, many participants advocated a case management model, with a case manager skilled at working with children and young people. This person would be an advocate, ensure coordinated services, engage with young people individually, consider their family context and be involved with each young carer on a long-term basis;

- *The short-term nature of service funding*

This may lead to discontinuity of staff or a reduced number of staff hours.

- *Insufficient flexibility in service delivery*
- *Lack of effective strategies to identify young carers* in a wide range of agencies and sites like schools and health services central to young people's lives.

These gaps identified by the service providers and policy makers were also identified by young carers in the interviews, and through the policy audit component of this research project (Section 6). Young people identified a lack of availability and flexibility of respite services as a primary difficulty in being able to better manage and balance their caring role with other responsibilities, notably education, employment and social activities.

In the policy audit, case management carer support is categorised as a preventative approach to supporting young carers; however these types of services are not as prevalent as other types of services.

## 5.5 Best practices and policy solutions

### Young people's involvement

For many participants in the focus groups, the involvement of young people in a service or organisation was considered best practice. However, views varied regarding the degree to which young people should be involved. Participants described how young carers were involved in their organisations, for example: completing surveys, staff selection committees,

interview panels, producing young carer resources and presenting at conferences and schools as part of a service or organisation's promotional work. Participants in the focus groups also noted that it was vital to have good policies and practices in place to support young carers gain the skills needed to contribute to the service or agency. Participants usually felt that best practice meant listening to young carers.

### **Flexible service delivery**

The other main element of best practice mentioned was flexibility in service delivery, regardless of the type of service. Flexibility was presented as crucial so that the individual needs of the young carer and their individual, personal context could be addressed, especially with respect to education. Innovation and creativity were described as the main ingredients in successful programs.

### **Case management approach**

Although participants did not always use the term 'case management', they spoke of having one contact person who would locate services and act in the young carer's interests. They noted that such a relationship needs time to develop. Regular communication, a solid relationship based on trust and long-term and consistent engagement were identified as essential elements for success.

### **Interagency work**

Participants saw cooperation and collaboration between organisations as crucial to providing responsive services for young carers. They felt that to provide the best support, they needed contact with a wide range of services, since regular liaison enabled other organisations to refer the young carer to appropriate types of support.

### **Work with families**

Some participants reported involving other members of the family as a successful method of addressing the needs of young carers. They commented that the young carer should be supported within a family context. However, they argued that the young carer should remain the central focus. A number of participants felt that communicating with the family was important to ensure parental support for a service's work with a young carer. They said this also supported the young person to be recognised as a young carer and educated the family about the young carer's needs. If parents are involved then they are in a position to support the young carer in all aspects of their lives.

### **Whole of family approach**

Both service providers and policy makers responded positively, but with caution, to the idea of a whole of family approach. Several were already undertaking this kind of work. Some noted that working with the whole of family approach was complex and time consuming, often beyond the boundaries of existing resources. Others however noted that funding already existed to support the whole family, but this approach required creativity in patching together multiple sources of support. Again, others were more wary about a whole of family approach and felt it important to provide a support service for the young carers themselves.

Respondents also noted that:

- The understanding of what constitutes “family” must be flexible and broad when working with Indigenous families;
- It is beneficial to keep parents informed about the support work being undertaken with a young carer; and
- Commonly there is a need for education within the family (both for the parents and the young carer) about the kind of work that young carers do. This allows for recognition within the family of the young caring role.

Two different interpretations of this approach were mentioned.

- Whole of family, in which the workers engage with the entire family of the young carer, while retaining a focus on the young carer as the primary client. One worker called this an ‘individual holistic’ approach.
- Engaging with parents to ensure that they understand and endorse the support being offered to the young carer. These workers were also concerned to keep the young carer at the centre of the engagement.

Some participants expressed concern that if the whole family were involved, the young carer may not express their needs strongly in comparison to other family members, including the care recipient. They therefore felt that services for young carers are best provided to the young person outside of their family context. The reasons for this position included:

- It is important for young carers to have time away from their family;
- Young carers need to spend time in an environment that focuses on them rather than the care recipient or other members of the family;
- Young carers need time to be a young person;
- Young carers need time to think about themselves; and
- Young carers will speak more freely if their family is not involved.

All of these best practices identified by the service providers and policy makers were also raised during interviews with young people providing care. Among those listed above, the importance of flexibility and meeting families’ needs and the needs of the person for whom they provide care were the most common issues raised by young people.

### **Supporting Indigenous young carers**

Only a small number of focus group participants had direct experience working with Indigenous young carers. Participants said that few Indigenous young carers use young carer services. In addition, a number of participants said they were not aware of any specific Indigenous services for young carers. Some participants felt that Indigenous young carers are more likely to remain ‘hidden’ than other young carers, because they and their families see their caring duties as a regular part of family life which is embedded in the collective responsibilities of their kin network and community. Nonetheless, those with experience working with Indigenous young carers said that good practice would include:

- whole of family support that recognises diverse family forms;

- employing Aboriginal workers to work with Aboriginal families;
- mentoring programs, which allow more flexibility;
- persistence, as this is necessary to develop trust and to make contact with people who have complex lives;
- ensuring the young carer has a relationship with a single worker who is their ‘one-stop shop’;
- engaging in interagency cooperation – especially with Aboriginal organisations;
- culturally specific programs that respect the values and characteristics of Indigenous people, e.g. understanding the role of extended family and understanding patterns of illness and disability; and
- providing a service which is part of a general Aboriginal or Aboriginal family service.

### **Supporting CALD young carers**

Few workers had direct experience working with culturally and linguistically diverse (CALD) young people. They felt that cultural and language knowledge was critical to engaging successfully with CALD young people. One worker spoke of developing ways to facilitate cultural exchange and understanding between CALD young people and other young carers. Examples of best practice included:

- recruiting young carers through organisations that provide intensive language training and other services to support CALD communities; and
- recognising issues specific to CALD communities, such as language barriers and fears about migration status, and taking these into consideration when developing resources.

### **Supporting young carers in rural and regional areas**

Several participants worked in rural and regional parts of South Australia and New South Wales. They felt that best practice in rural and regional communities included:

- providing recreational and social activities on a regular basis to address the isolation of young carers in rural and remote areas, for example camps to bring young carers together, but these should be based locally so that peer support is possible after camp;
- cross-agency collaboration between non-government agencies, sharing of resources, using local charities and generic youth services; and
- delivery of services face to face, not remotely by telephone or internet.

## **5.6 Future priorities**

### **Education**

The issue considered of highest priority for the support and wellbeing of young carers was ensuring continuation of their educational participation and levels of educational achievement. One respondent felt that by becoming a young carer, children are being denied their right to complete education to the best of their ability. While completing and achieving

in education is seen as vital, the connectedness of a young carer to the school community was also seen as important, particularly in keeping up friendships and the school-related sporting and recreational activities which school friendships usually entail. Schools are a central site for assistance and support for young carers, and many young carers see their school time as “respite” from their family responsibilities. One focus group participant noted that there needed to be guidance for young carers’ post-school options and pathways.

### **Identification and awareness**

Better identification of young carers was seen as important, so that services and parents can identify the roles and responsibilities of the young people who provide care, and so that young people themselves can start to identify their caring role and approach services for help and support. Regarding the wider community, it was suggested that there needs to be improved community awareness of young carers and their responsibilities.

### **Increased funding**

An increase in funding and staff to implement the options identified for young carer support was needed as participants argued that there was no point raising awareness about young carers unless a supportive services infrastructure is available.

Particular groups of young carers were identified as missing out on support services, namely:

- Young adult carers aged 18-25
- Children whose parents have problematic drug use, including alcohol;
- Indigenous young carers;
- Young carers in rural areas; and
- Young carers of people with mental illness.

The priorities identified by the service providers and policy makers align closely with the concerns and issues raised during interviews with young carers. As mentioned above, education was a key concern identified by young carers, especially young adult carers who strongly believed that this was a key area to prevent young carers from becoming disengaged from both education and employment. Many also indicated that increased awareness about the prevalence and importance of young carers was vital for this group to gain recognition. They believed that a better recognition of young carers would help to promote increased funding for services and programs to meet their needs. The key issues raised in these focus groups are further explored in Section 6 of this report.

## 6 The audit of carer policies and services<sup>3</sup>

### 6.1 Introduction

As outlined earlier, young people have always provided support to relatives as a customary part of family life, however, over the last two decades young carers have become a growing focus of public policy and research, particularly in the UK and Australia. Increasing awareness of young carers as a group with specific needs has been accompanied by the development of a range of supports to meet their needs. These supports, provided by government agencies and non-government organisations, include: government-provided income support, in Australia through Carer Payment and Carer Allowance, information provision and services such as respite, counselling, educational support and recreational activities for young carers as well as support services for the person being cared for.

Limited research is available that documents existing support for young carers and their families, their service needs and service providers' perspectives on best practice (Aldridge 2006; Becker and Becker, 2008a; Cass et al, 2009; Kroehn and Wheldrake, 2006). However, very little is known about the usefulness of services for young carers or their effectiveness in achieving outcomes. International research has produced some evaluations of support programs for all carers (with inconclusive results) (Eagar et al., 2007) and in Australia some government programs for carers have been reviewed (see an overview in Carers Australia, 2008). However, very few systematic evaluations of specific young carer programs have been conducted (for one example, see Hodge et al, 2008).

The aim of this Strand of the project was to conduct an audit of carer policies and current support services and program targeting young carers. However, prior to conducting the audit it became evident that there was an absence of an analytical framework to help conceptualise how services might be organised to effectively meet the needs of young people providing care. Therefore, the first step in the policy audit was to develop an analytical framework that categorised young carer policies and support services according to their overarching goals; within these categories, services are grouped according to the type of intervention. This framework was then applied to existing services to provide an overview of the service landscape but it can also serve as a basis for future evaluation planning by identifying service gaps.

### Theoretical background

The analytical framework of service goals and types of intervention was developed with reference to a number of existing conceptual frameworks outlined in detail in Section 2. These conceptual frameworks focus on:

- young carers' engagement in different **modes of care** as described by Fisher and Tronto (1990), caring about, taking care of, caregiving and care-receiving;
- the exercise of **agency** within a number of constraints such as the nature and intensity of the illness or condition, limited material resources and disrupted family networks.

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<sup>3</sup> Some of the text in this section is based on a forthcoming article: Purcal, C., Hamilton, M., Thomson, C. and Cass, B. 'From Assistance to Prevention: Categorizing Young Carer Support Services in Australia, and International Implications' *Social Policy & Administration* (in press).

Providing access to appropriate information and services is a key issue in limiting the constraints on the agency of young carers in their caring role; and

- the balance between or optimal mix of **formal and informal care** provision and how this shapes agency and modes of care. Appropriate access to and provision of formal support tailored to individual families needs in response to the nature of illness or disability, cultural expectations of intra-familial care, and family composition and structure has the potential to shift the main mode of care from ‘caregiving’ towards ‘caring about’, thereby reducing the costs of care for young carers and their families.

In order to identify appropriate points of intervention and combinations of informal and formal provision to support young carers, it is important to gain a better understanding of the pathways into care and examine the constraints shaping the entry of young carers into a caring role. The proposed analytical framework can help inform appropriate points of intervention and decisions about the optimal mix of provision in each care situation.

## 6.2 Analytical framework of service goals

As described above, young carers are usually engaged in various modes of care, act within a number of constraints and often balance some formal care provision with their informal caring relationship. Based on these conceptual approaches, a framework for categorising young carer policies and services according to their goals and types of intervention was developed. The aim of this framework was to provide a first step in assessing current service provision, and to consider which service goals and types of intervention might be desirable or achievable under which circumstances.

The framework distinguishes between three categories of service goals and types of intervention:

1. **Assistance** services aim to support young carers in their caring responsibilities. They aim to help young carers cope with their role, and encourage them to seek additional help, either for themselves or the person they care for. The services in this category are usually provided over the short-term and include support such as information, advocacy and referral, short-term counselling and peer support.
2. **Mitigation** services aim to reduce the care burden by lowering the intensity of caring, either by reducing the time spent on caring or by easing the young carer’s responsibilities. The support provided also aims to reduce the long-term negative impacts of caring on the young carer, for example in their education or social life. Mitigation-type services are usually provided over the longer term and are more intensive than assistance services. Examples of these types of services include respite services for the young carer, flexible education arrangements, financial assistance and regular provision of home care.
3. **Prevention** services aim to avoid the entrenchment of a young person’s caring role to such an extent that it adversely affects outcomes across a range of domains, including school, employment, social relationships, health and wellbeing. Arguably adequate formal support for people with a chronic illness or disability would limit the extent to which informal care by children and young people is initiated, established and routinised. This could be achieved by the provision of appropriate, accessible and affordable services for the family member with disability or severe illness, at an early stage in the onset of the condition, and also the through the removal of constraints on access to and use of services, which may include lack of information, leading to family expectations being

placed upon a young person to provide care. Preventative services may preclude negative impacts of caring responsibilities by providing adequate support to the family when a disability or chronic illness first manifests itself. Alternatively – if young caring is already established – they will help the young person move back towards the ‘taking care of’ and ‘caring about’ modes of provision. In this case young carers may still provide some support to their family member, but at a level that is manageable for them. Preventative policies and services aim for optimum combinations of formal and informal support through early intervention tailored individually to each family and personalised case-management. They encompass a whole-of-family approach, the integration of social, health and disability services (Cass et al, 2009) and a ‘no wrong door’ approach where all service entry points provide referrals to relevant services (Carers Australia, 2009).

The framework sets out three distinct categories of service goals and types of intervention but in practice there is overlap between the categories. Many services aim to achieve more than one of the above goals. For example, young carer camps are designed to provide assistance to young carers in the form of peer support and information, and simultaneously aim to mitigate the strain of caring by providing respite. Nonetheless, developing distinct categories of service goals is a useful analytical exercise that helps to clarify policy priorities.

### **6.3 Methodology**

The policy audit focused on two areas:

- carer policies – legislation, actions plans, frameworks and charters; and
- programs and services targeting young carers– education, information, support and resources including income support.

In Australia, various government-funded support programs and services exist specifically for young carers and there is also a range of carer programs that are available to carers of all ages. It should be noted that these generic services for carers of all ages, for example, Home Care in New South Wales, also provide substantial and essential services to support young carers, as noted by feedback provided by New South Wales Interagency Steering Committee. However the scope of this audit was limited to programs identifying young carers as a specific target group as the experiences and needs of young people providing support differ considerably from older carers. The audit did, nevertheless, include some generic programs and services that provide direct respite for care recipients and support to young people at risk where young carers were identified as a target group. In the audit, each program or service was assigned to the categories in the framework according to its stated aim/s and type/s of intervention/s. Often a program or service aimed to achieve multiple goals and was therefore assigned to one or more categories within the framework.

A comprehensive list of policies, programs and services designed to support young carers in each state, territory and the Commonwealth was compiled from various sources including: focus groups, service brochures, policy documents, reports and websites. The information in the Commonwealth, New South Wales and South Australian audits was sent to Research Partners and Carers Australia for their comments and feedback to:

- verify the information collected;
- identify gaps in the information collected; and

- identify any additional sources of information about policies and services in their jurisdiction.

In addition the New South Wales Interagency Steering Committee and Carers Australia provided comments on the New South Wales and Commonwealth audits respectively.

Due to a lack of resources, the policy audits of programs and services in other states and territories were not subject to the same validation process and were therefore not included in the analysis using the analytical framework. The main focus of the analysis below is therefore based on the Commonwealth, New South Wales and South Australian audits.

## **6.4 Results**

### **Policies**

Overall the audit found that the legislative frameworks are not consistent across the states and territories (see Table 6.1). The two main policy instruments are Carers Recognition Acts and Carers Action Plans, introduced at different times. The first state to introduce a Carers Recognition Act was Western Australia (2004) followed by South Australia (2005). More recently in 2010 the Carers (Recognition) Act 2010 and the Carer Recognition Act 2010 were passed by the New South Wales parliament and the Commonwealth parliament respectively. Tasmania and Victoria are the only states without carers legislation. All states and territories have developed and implemented Carers Action plans with the exception of Tasmania and the Northern Territory.

In 2011 the Commonwealth Government introduced a National Carer Strategy (Commonwealth of Australia (2011) which sets out six priority areas for action: Recognition and Respect; Information and Access; Economic Security; Services for Carers; Education and Training; Health and Wellbeing. Young carers are explicitly noted in the National Carer Recognition Framework in the Statement of core principles: “Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential” (Commonwealth of Australia, 2011:13)

**Table 6.1: Carer Recognition Acts and Charters**

State/Territory	Carer Recognition Act	Carer Action plan or charter
Commonwealth	Carers Recognition Act 2010	National Carer Strategy 2011
New South Wales	Carers Recognition Act 2010	NSW Carers Action Plan 2007-2012 NSW Carers Charter 2010
Victoria	-	Disability services Carers Action Plan 2006
Queensland	Carers Recognition Act 2008	Carer Recognition Policy 2007 Carer Action Plan 2006-2010
South Australia	Carer Recognition Act 2005	SA Carers Charter, SA Carers Policy 2006, Plan for South Australian Carers, 2009
Western Australia	Carer Recognition Act 2004	Carers Charter
Tasmania	-	-
Northern Territory	Carer Recognition Act 2006	-
Australian Capital Territory	Carers Recognition Legislation Amendment Act 2006	Caring for Carers Policy 2004-07

### Programs and Services

Tables 6.2 to 6.4 present information from the Commonwealth, New South Wales and South Australian audits respectively. The tables contain the service or program name, aims, type of intervention or support provided and analytical framework category.

**Table 6.2: National programs and Services for Young Carers in Australia**

Program name	Aims	Type of intervention/ support	Framework A-Assistance, M-Mitigation, P-Prevention
<b>YOUNG CARERS</b>			
Young Carer Respite Services ( <i>Young Carers Respite and Information Services Program</i> )	To assist young carers to better manage and balance their educational and caring responsibilities.	A mix of services, both direct and indirect respite better meets Young Carers needs, is more age appropriate and fits the family situation, thus accessing 2 types of respite:- <ul style="list-style-type: none"> <li>• Direct Respite – Young Carers can access flexible hours of in-home respite</li> <li>• Indirect Respite – that supports Young Carers, reduces their stress and meets their more immediate and short term needs.</li> <li>• Services may be provided during school vacations as well as school terms and may provided for periods longer than 12 months.</li> </ul>	M
Young Carers Information, referral and advice services ( <i>Young Carers Respite and Information Services Program</i> )	To provide accessible information and point of contact for young carers	Information (including Young Carers kit and Young booklet)	A
Supporting Young Carers Program	Provide age appropriate information and resources	Information (including Young carers booklet; Young Carers Kit) (Education/Resources, Referral/Service information)	A
TalkLink	To provide emotional support for carers	Peer Support, Counselling	A
<b>CARERS</b>			
Carer Payment	To provide financial assistance for carer.	Income support	M
Carer Allowance		Income supplement to offset costs of caring	M
Carer Supplement		Income supplement to offset costs of caring	M
Education Entry Payment	Helps pay the costs of returning to study	Financial support Education assistance	M
Pensioner Education Supplement	To help recipients undertake full-time or part-time study	Financial support Education assistance	M
National Respite for Carers Program (provides funding to 54 Commonwealth Respite and Carelink Centres nationally)	To help people find care and support to continue living independently in their homes, and to provide short-term and emergency respite services.	Information (Referral/Service information) Respite (Emergency, In-home, out-of-home, camps, flexible)	A M
National Carer Counselling Program* (NCCP)	To reduce carer stress, improve carer coping skills and facilitate continuation of the caring role	Counselling (Individual, Group)	M
Carer Advisory Service	Provides single point of contact for Carers and the broader community to access Carer specific advice; information and resources to equip carers emotionally and practically in their	Information, emotional support Includes <i>Carer Information Pack</i> Referral and assessment for Counselling	A

\*Although funded and listed separately the 2

<b>Program name</b>	<b>Aims</b>	<b>Type of intervention/ support</b>	<b>Framework</b> A-Assistance, M-Mitigation, P-Prevention
Programs (NCCP and Carers Advisory Service) are now known and operate as Carer Information Support Service	caring		
Health Institute	Practical information for finding services	Information (Education/Resources, Referral/Service information)	A
Home and Community Care (HACC ) including services such as Home Care in NSW	Program aims to support people to be more independent at home and in the community, and reduce the need for admission to a residential care facility	Respite (In-home, out-of-home) Services include: nursing care, allied health care, meals and other food services, domestic assistance, personal care, home modifications and maintenance, transport, respite, counselling, support, information and assessment	A M
<b>YOUTH AT RISK</b>			
Youth Connections Program	Aims to provide a holistic approach to servicing young people at risk of disengaging, or already disengaged from education, family and/or the community.	Education assistance Case management	M P
Australian Apprenticeships Access Program	Improve education, training and employment opportunities for young people at risk	Education Training and employment assistance Counselling (Case management)	M P
Kids in Focus – Family Drug Support program	To support children by normalizing their lives (school, support and other regular activities)	Intensive services, Advice, Referral; counselling and support	A M
National Network of Adult and Adolescent Children who have a Mentally Ill Parent/s (NNAAMI)	Provide services, work in cooperation establish links between adults and adolescents, develop networks and advocacy	Peer Support (Group activities, camps) Counselling (Individual, Group) Information (Communication channel, Advocacy)	A M

**Table 6.3: Programs and Services for Young Carers in New South Wales**

**Commonwealth Respite and Carelink Centres (CRCC) in New South Wales**

The CRCC deliver a number of Programs which include both Department of Health and Ageing (DoHA) National Respite for Carers Program (NRCP) and also FaHCSIA funding. The Young Carers Respite and Information Services Program, which is specific to Young Carers, is delivered through all CRCCs. The Commonwealth funded services aimed at all carers, including young carers, are delivered by various providers across the state and young carers are eligible for Commonwealth carer services and payments, outlined in the Commonwealth Policy Audit. The tables below (one for the Commonwealth and one for New South Wales) list programs and services specific to young carers.

HACC Region	Auspice (Location)	Type of intervention/support	Framework
Central Coast	North Sydney Central Coast Area Health Service (Wyoming)	Respite services (including access to 24 hour emergency respite) for Carers and Information services about home and community care services that assist people to stay in their homes	A M
Central West	CareWest (Orange)		A M
Cumberland/Prospect	Baptist Community Services NSW & ACT (Carlingford)		A M
Far North Coast	United Protestant Association NSW Ltd Northern Region (Alstonville)		A M
Hunter	The Hunter New England Area Health Service (Wallsend)		A M
Illawarra	Kiama Municipal Council on behalf of Southern Councils Group (Oaks Flat)		A M
Inner West	The Uniting Church in Australia Property Trust (Summer Hill)		A M
Mid North Coast	United Protestant Association NSW Ltd Northern Region (Macksville)		A M
Nepean	Sydney Anglican Mission Society trading as ANGLICARE Diocese of Sydney (Penrith)		A M
New England	Hunter New England Area Health Service (Tamworth)		A M
Northern Sydney	Northside Community Forum Inc (St Leonards)		A M
Far West	Broken Hill City Council (Broken Hill) Catholic Health Care Services Ltd (Dubbo)		A M
Riverina Murray	Interreach (Wagga Wagga)		A M
South East Sydney	The Benevolent Society (Hurstville)		A M
South West Sydney	Sydney Anglican Home Mission Society trading as ANGLICARE Diocese of Sydney (Liverpool)		A M
Southern Highlands	Queanbeyan City Council (Queanbeyan)		A M

## Programs and Services for Young Carers in New South Wales

Policy or Program Name	Aims	Type of intervention or support	Framework
<b>YOUNG CARERS</b>			
Young Carer Respite Services ( <i>Young Carers Respite and Information Services Program</i> )	To assist young carers to better manage and balance their educational and caring responsibilities.	A mix of services, both direct and indirect respite better meets young Carers needs, age appropriate and fits the family situation, 2 types of respite:- <ul style="list-style-type: none"> <li>• Direct Respite –access to flexible hours of in-home respite</li> <li>• Indirect Respite – that supports Young Carers, reduces their stress and meets their more immediate and short term needs.</li> </ul> Services may be provided during school vacations as well as school terms and may provided for periods longer than 12 mths	M
Young Carers Information, referral and advice services ( <i>Young Carers Respite and Information Services Program</i> )	To provide accessible information and point of contact for young carers	Information (including Young Carers kit and Young booklet)	A
Supporting Young Carers Program	Provide age appropriate information and resources	Information (including Young carers booklet; Young Carers Kit) (Education/Resources, Referral/Service information)	A
TalkLink	To provide emotional support for carers	Peer Support, Counselling	A
SMILES (Simplifying Mental Illness + Life Enhancement Skills)	To achieve an increased ability to cope effectively and increase in self-esteem	Information (Education about illness)  Peer Support	A
Young Carers website	To make a positive difference in the lives of young carers (to age 25) and their families, by providing	Information (Services, Referral), Advocacy,  Peer Support	A
Young Carers Newsletter	To disseminate information about programs and services for young carers	Information  Support	A
NSW Young Carer Project	To promote the issues and needs of young carers through statewide programs; Develop a young carer support network  Develop and distribute other appropriate resources; Review and evaluate existing support activities and information; and raise awareness of young carers and their needs.	Information (Education about illness, Referral/Service Information, Communication)  Individual and group telephone counselling	A  M

Policy or Program Name	Aims	Type of intervention or support	Framework
		Respite and Peer Support (Camps)	
Adventure Camps (Orange)	Group work on camp aimed at increasing self-esteem, coping skills and mental health literacy.	Peer Support; Respite (Camps) Counselling (Group activities)	A M
Connect for Kids	Provide information and support to children who have a family member living with a mental illness	Respite (Day activities) Information (Education/Resources) Peer Support (Group activities)	A M
Gaining Ground Program	Promote the mental health and well-being of children living with a parent affected by a mental health problem.	Respite; Peer Support (Camps) Counselling (Group Activities)	A M
Gaining Ground Adolescent Program	Aims to develop young people's coping skills and enhance resilience; and increase understanding of the parent's mental illness	Information (Education) Peer Support; Respite (Camps)	A M
ON FIRE!	To provide opportunities to learn, grow, and flourish.	Peer Support; Counselling (Group activities)	A M
Young Carer Social Group	Provide support for young carers	Peer support (group activities)	A
Young carer camps/ Young carer Action Group	To support young carers	Information (Communication) Peer Support (Group activities. Camps); Respite (Day activities, Camps)	A M
Camp Kookaburra	Providing camps and other activities that are fun, healthy, positive and safe	Information (Referral/Service information, Communication) Peer Support; Respite (Camps)	A M
Northern Kids Care	Support children and young people with: understanding mental illness and medication and provide them with the supports and assistance they need	Counselling (Case management) Education assistance Respite (Domestic) Financial	M P
Paying Attention to Self (PATS) -	To give young people the opportunity to learn more about mental health, explore ways of coping, and meet other teenagers who share similar experiences	Peer Support; Counselling (Group activities)	A M

Policy or Program Name	Aims	Type of intervention or support	Framework
In House Training Understanding & Supporting Carers – Young carers (free)	To raise the recognition of the role and value of carers, and to build the capacity of both government and non government service providers to support and work with carers	Information (Education/Resources)	A
Bradfield Park Wellbeing Centre Carers Program	Is tailored to meet individual needs and promotes health and wellbeing for Carers of people with a mental illness and/or drug and alcohol abuse problems	Respite (holiday camp for young carers)	M
The Children’s Program	To help children learn the facts about mental illness and drug and alcohol issues	Peer Support Information (Education)	A M
Northern Sydney Young Carers Interagency (note: this is not a direct program or service)	To identify and support young carers in Northern Sydney; raise awareness and improve access to appropriate services and resources for this target group. To facilitate cross-agency networking and partnerships	Professional development and networking of service providers in relation to the target group of young carers. Regional projects and service coordination for the target group	A
Young Carers Services in the Cooma-Monaro Region	Information	Information	A
Young ARAFMI – Kids Connecting – Central Coast	Opportunity to make new friends with other young people who share the common experience of living with a family member with mental illness	Peer support	A
Young Carers Central	Information, education,	Information, support for mental health young carers	A
Canteen NSW		Peer support, Respite (Day activities)	A M
COPMI Young Carers Initiative New England	To enhance the resilience of 14 – 24 year-olds who are the children of parents with a mental illness	Information, Peer support	A M
<b>YOUTH AT RISK</b>			
Family Referral Services	To link vulnerable children, young people in need of assistance, and their families, with the most appropriate available support services in their local areas	Information (Referral/Service information)	A
Links to Learning	To improve outcomes for young people	Education assistance	A M
Better Futures (undertaken in the context of the NSW State Plan and the NSW Youth Action Plan priorities)	To improve the effectiveness of support and services for young people aged 9 – 18 years,	Prevention and early intervention, capacity-building, improving connections with family, school and community.	P
Youth Connections	To offer support or alternative education for students who are disengaged or “at risk” of disengaging from education without	Education assistance	M

Policy or Program Name	Aims	Type of intervention or support	Framework
	achieving a year 12 or equivalent attainment		
FAMI Project (Families Affected by Mental Health Issues) (Northern Sydney Carer Support Service)	To support and promote the needs of children, young people (aged 0 – 18) and their families who have one or both parents with a mental illness, and promotes key messages of resiliency, and increases the family’s capacity to access the help and support they need	Information, Referral	A
YouthLinx – Activity Groups	To promote peer interaction and the development of self-esteem, social and life skills for young people who may be socially isolated, anxious and have difficulty making or keeping friends (aged 11 – 16 years)	Peer support, Group counselling	A
<b>Sibling specific</b>			
Sibling chat rooms and information	To reduce isolation and provide a forum for sharing feelings	Moderated forums and information resources especially for siblings, peer support	A
The Siblings Network Project	Tell your story through screen or photography.	The project is calling young people from culturally diverse backgrounds and who have a sibling with a disability to come along and express themselves at this series of exciting and fun workshops. respite	A
Sibling camps	To reduce feelings of isolation and distress	Camps which provide opportunities for activities and counselling Peer support; respite	M
Sibling camps	Learn about Cystic Fibrosis (CF), ask questions and share experiences.	Camps- peer support and respite	M
Sibling camps	To provide planned short-term and time-limited breaks for families and other unpaid carers of teenagers with an intellectual disability in order to support and maintain the primary care-giver relationship; and	Sibling camps – peer support and respite	M
Siblings program	Children learn they are not alone in their situation; and that the feelings that go with their family are OK.	Monthly, peer contact program	M A
Sibling Support Program (Sibs.org.au)	Aims to provide an opportunity for brothers and sisters (aged 0 to 25) of children and young people with a disability to enhance the development of self esteem, promote inclusiveness and a sense of belonging	Friendly, relaxed and fun activities, workshops, holiday activities, family fun days and holiday camps. Peer support and respite	M A

**Table 6.4: Programs and Services for Young Carers in South Australia  
Commonwealth Respite and Carelink Centres in South Australia**

The CRCC deliver a number of Programs which include both DoHA – NRCP and also FaHCSIA funding.

Region	Auspice Body (Project Name)	Type of intervention or support	Framework
North West Country	Uniting Care Wesley Adelaide Inc (Commonwealth Carer Respite Centre)	Respite services (including access to 24 hour emergency respite) for Carers and Information services about home and community care services that assist people to stay in their homes	M
	Seniors Information Services Inc (Commonwealth Carelink Centre)		A
North West Metro	Uniting Care Wesley Bowden Inc (Commonwealth Carer Respite Centre North West Metro Region)		M
	Seniors Information Services Inc (Commonwealth Carelink Centre)		A
South and East Country	Carers Association SA Inc (Commonwealth Carer Respite Centre)		M
	Seniors Information Services Inc (Commonwealth Carelink Centre)		A
South East Metro	Carer Support and Respite Centre Inc (Commonwealth Carer Respite Centre)	M	
	Seniors Information Services Inc (Commonwealth Carelink Centre)	A	

**Programs and Services for Youth Carers in South Australia**

Program Name	Aims	Type of intervention or support	Framework
<b>YOUNG CARERS</b>			
Young Carer Respite Services ( <i>Young Carers Respite and Information Services Program</i> )	To assist young carers to better manage and balance their educational and caring responsibilities.	A mix of services, both direct and indirect respite better meets Young Carers needs, is more age appropriate and fits the family situation, thus accessing 2 types of respite:- <ul style="list-style-type: none"> <li>• Direct Respite –access to flexible hours of in-home respite</li> <li>• Indirect Respite – that supports Young Carers, reduces their stress and meets their more immediate and short term needs.</li> </ul> Services may be provided during school vacations as well as school terms and may provided for periods longer than 12 months.	M
Young Carers Information, referral and advice services( <i>Young Carers Respite and Information Services Program</i> )	To provide accessible information and point of contact for young carers	Information (including Young Carers kit and Young booklet)	A
Supporting Young Carers Program	Provide age appropriate information and resources	Information (including Young carers booklet; Young Carers Kit) (Education/Resources, Referral/Service information)	A M
Raw Energy – South East Metro Carer Support	To provide support to young carers to manage the pressures and responsibilities of their caring role	Information (Education/Resources, Advocacy)	A

Program Name	Aims	Type of intervention or support	Framework
		Peer Support (Group activities) Respite (Domestic) Education assistance Training/Employment assistance Counselling (Case management)	M P
Western Carers (Western Metropolitan Region of Adelaide)	To provide support young carers in the Western Metropolitan Region of Adelaide	Social and peer Support (i.e. support groups, school holiday program and day activities); Information Referral Education and Training to school workers (i.e. delivery of Young Carers in Education Presentation)	A
River Murray and Mallee Carers	To provide support to young Carers in the River Murray and Mallee region	Social and peer Support (i.e. support groups, school holiday program and day activities); Information Referral Education and Training to school workers (i.e. delivery of Young Carers in Education Presentation)	A
Eyre Carers	To provide support to young Carers in the Eyre Peninsula region	Social and peer Support (i.e. support groups, school holiday program and day activities); Information Referral Education and Training to school workers (i.e. delivery of Young Carers in Education Presentation)	A

Program Name	Aims	Type of intervention or support	Framework
Northern Country Carers	To provide support to young Carers in the Northern Country region	Social and peer Support (i.e. support groups, school holiday program and day activities); Information Referral Education and Training to school workers (i.e. delivery of Young Carers in Education Presentation)	A
Young Carers respite	Access to respite to help them better manage/balance their educational and caring responsibilities.	Respite (Planned) Education assistance	M
South East Carers	To provide support to young Carers in the South East region	Social and peer Support (i.e. support groups, school holiday program and day activities); Information Referral Education and Training to school workers (i.e. delivery of Young Carers in Education Presentation)	A
BREAKTHRU Program	Supporting young carers in the northern metropolitan Adelaide region	Information (Education/Resources, Advocacy) Peer Support: Counselling (Group activities) Respite (Day activities, camps)	A M
BREAKTHRU Program	To support young carers in Nuriootpa, Eudunda, Kapunda, Lyndoch	Peer Support (Group activities) Education and training assistance Respite, Peer Support (Camps)	A M
BREAKTHRU Program	Supporting young Carers in the lower north country region	Information (Referral/Service information, Advocacy)	A M

Program Name	Aims	Type of intervention or support	Framework
		Peer Support (Group Activities) Counselling (Individual)	
South Australian Network of Services for Young Carers (SANSYC)	Bring together service providers across SA working either directly or indirectly with young carers to work together in a cooperative and positive way.	Networking and information share opportunities Collaborative projects and events	A
Recognition of Community Learners	To acknowledge of young carers (and other community learning) activities	Education	M
Special Provisions in Curriculum and Assessment	To provide alternative arrangements to students whose capacity to participate is adversely affected (i.e. caring)	Education	M
<b>YOUTH AT RISK</b>			
Youth Pathways Baptist Care (SA) Inc	To assist the most at-risk young people including young carers to make a successful transition to through to completion of year 12 (or its equivalent) and to further education, training or employment and active participation in the community	Counselling (Individual, Group activities) Peer Support	A M
Youth Connections	To offer support or alternative education for students who are disengaged or "at risk" of disengaging from education without achieving a year 12 or equivalent attainment	Education assistance	M
Youth Pathways in Rural South Australia – Yorke Peninsula Employment	To provides services to the Yorke Peninsula, Lower North and Barossa region in SA and works in partnership with community services to help the region's young people most at risk to meet their individual social, personal, educational and vocational needs	Counselling (Individual, Group activities) Peer Support Information (Education/Resources)	A M
Flexible Learning Options - SA Government, DEC's, Innovative Community Action Network, (ICAN)	Flexible Learning Options (FLO) aims to re-engage young people who have dropped out of school.	Education assistance Counselling (Case management)	M P
Alternative Learning Options (ALO) led by Department of Further Education, Employment,	To support young people at risk of disengaging from school	Education assistance	M

Program Name	Aims	Type of intervention or support	Framework
Science and Technology (DFEEST)		Counselling (Case management)	P
Reconnect Anglicare	Provides support for young people who are at risk of homelessness, or of dropping out of education.	Counselling (Individual, Group activities) Education assistance	M
Learning Unlimited programs, Mission Australia Learning Unlimited	To provide innovative and flexible learning options for young people who are currently disengaged from the education system or at risk of becoming disengaged.	Education assistance	A M
Reconnect, Mission Australia	It aims to prevent homelessness among young people, aged 12-18, and encourage family reconciliation.	Education assistance	M
The Onkaparinga Youth Services (OYS), Mission Australia. /www.missionaustralia.com.au	OYS is a Mission Australia initiative operated in partnership with the City of Onkaparinga, that delivers services to young people	Training and employment Information (Referral/Service information)	A M
Southern CAMHS Offspring group	For children who live with (or have lots of contact with) a parent or carer or brother or sister with a mental illness	Peer Support (Group activities)	A
<b>Sibling Specific</b>			
Siblings Australia Inc.	Aims to enhance the well-being of siblings of children and adults with special needs	Counselling (Individual, Case Management) Education assistance Training and employment assistance	A P
Sibling camps	To reduce feelings of isolation and distress	Camps which provide opportunities for activities and counselling Peer support and respite	M
Sibling chat rooms and information	To reduce isolation and provide a forum for sharing feelings	Moderated forums and information resources especially for siblings Peer support and information	A
Sibling groups and Sibworks Resources	To provide benefits to siblings of children with disabilities or chronic illness and raise parents' awareness of siblings' needs	Resources and information Peer support	A

Overall, services are provided directly by governments, both at federal and state/territory levels or by carer support organisations or community care providers (usually funded by governments to deliver particular services). The federal government through Centrelink funds programs that offer financial assistance to young carers who are eligible for payments, provide respite for both the young carer and the person receiving care, or support young carers' participation in education and training (see Carers Australia, 2008). Australian states and territories have put additional programs in place, and these vary across jurisdictions.

### *Service types*

Table 6.5 outlines the different types of programs and services available for young carers in New South Wales (n=56) and South Australia (n=35), detailed in Tables 6.3 and 6.4. Table 6.5 shows that the services and programs predominantly fall into 8 categories or service types. These categories include: information, peer support, counselling, respite, education assistance, training and employment assistance, and financial assistance and case management. Many services provide more than one type of assistance. Table 6.5 shows that services supporting young carers have a strong focus on education assistance in South Australia and respite in New South Wales. In terms of the analytical framework most of these service types fall into the assistance and mitigation categories.

**Table 6.5: Service/intervention types in SA and NSW**

<b>Service/intervention type</b>	<b>SA No.</b>	<b>NSW No.</b>	<b>Analytical framework</b>
Information	19*	34*	Assistance
Peer support	16	24	Assistance
Counselling	10	9	Assistance
Respite	10*	32*	Mitigation
Education assistance	12	3	Mitigation
Training and employment assistance	4	0	Mitigation
Financial support	0	1	Mitigation
Case management	4	1	Prevention
<b>Total no. specific young carer services</b>	<b>35</b>	<b>56</b>	

Notes: \*These numbers only include the main Commonwealth Respite and Carelink Centres (CRCC) in each state (4 in SA and 16 in NSW). CRCC deliver a number of programs to all carers including information and respite. The Young Carers Respite and Information Services Program which is specific to young carers is delivered through all CRCC.

### *Assistance type services*

Analysis of the information in Tables 6.3 and 6.4 shows that the majority of services and programs in New South Wales and South Australia provide assistance types of support and interventions.

Assistance is most often provided in the form of information about support services. For example, the Young Carers Information and Advice Kits produced by the South Australian Government (see in Table 6.3) are designed to be a one-stop-shop resource

for young carers, providing information, ideas and support. Young carer websites at both the federal and state/territory levels are popular with young carers. The federal and New South Wales websites together receive 3,000 hits a day (Carers Australia, n.d.). Information and advice over the telephone is available via the Commonwealth Respite and Carelink Centres established by the federal government in each state and territory.

Another example of a typical assistance-oriented program is Talk-Link. It is provided on a short-term basis and aimed at helping young carers cope with their caring. It provides counselling, access to peer support and the opportunity to share helpful information, for example on other services. In offering these types of assistance over the phone, the program responds to widely acknowledged constraints faced by young carers: concerning the difficulties attending meetings outside of their home due to caring responsibilities or transport restrictions.

### ***Mitigation***

Mitigation type services and programs address socio-economic and educational constraints faced by many young carers and, in providing support to the person with an illness or disability, also have the potential to improve the balance between formal and informal care within the family. This, in turn, may allow the young carer to move to some extent from the mode of 'caregiving' to that of 'caring about'.

Mitigation type services were the main focus of around 70 per cent of services in both South Australia and New South Wales. There was a variety of mitigation-type services, at the state and Commonwealth levels. At the Commonwealth level, for example, several programs aim to help young carers with education, training and employment. The goal of these services is to reduce the long-term negative impacts of caring on young carers' educational attainment, careers and income. As a whole, these programs cater to a range of young carers with various needs and characteristics. Youth Pathways, for example, consists of a combination of face-to-face consultations, individualised assistance and continued contact to help the young person remain at school.

As noted earlier the categories in the analytical framework are not mutually exclusive as services often provide a range of supports. This was the case in 37 per cent of services in South Australia and 55 per cent in New South Wales which provided both assistance and mitigation types of support. One example in South Australia is Raw Energy which aims to support young carers to manage the pressures and responsibilities of their caring. The program includes elements of assistance, such as information and advocacy, but also provides support aimed at mitigation, or reducing the burden of care, for example through family and one-to-one support; school support; skills development and workshops; social and recreational activities; and young carer respite including help with shopping and domestic chores.

At the Commonwealth level the emphasis is very much on assistance and mitigation with the provision of information and respite through the Commonwealth Carer Respite Centres and Carelink Centres.

### ***Prevention***

Prevention strategies encompass a combination of support services for both the young carer and the person being cared for, ideally at the onset of an illness or disability. The services required to achieve prevention differ across family situations, depending on the nature and severity of care needs and on the preferences or capacity of family members to offer informal support. In any case, prevention requires an approach that:

- strives for early identification and intervention;
- is personalised (an individual, case-based approach);
- considers the needs of all family members (a whole-of-family approach);
- provides comprehensive information on policies and services;
- is an ongoing process, i.e. not time-limited; and
- integrates service provision from different sectors such as education, health and disability (a collaborative approach).

Programs with such elements are often considered ‘best practice’. In current service provision, though, preventative strategies are quite rare and underdeveloped. In individual cases prevention may happen, where adequate services are available to avoid the entrenchment of caring at a young age or to help a young carer reduce their responsibilities to manageable levels. But at program level, preventative programs, incorporating the elements set out above as best practice in preventative services, are limited.

Support that encompassed preventative aspects as identified in the policy audit are not, in most cases comprehensive strategies. They are programs that comprise one or more elements of a prevention approach. For example, the education programs and Raw Energy mentioned above provide an individualised service. The need for collaborative relationships among service providers is emphasised in a new federal government program called Youth Connections, which aims to help young people stay connected or re-connect with education and training. It also includes early intervention for young people who are showing signs of disengagement from school.

### **Gaps in Service provision**

Overall the most commonly provided programs/services for young carers in New South Wales and South Australia were:

- **Information** about services available, illness and disability, coping strategies and other issues pertaining to the caring role
- **Peer support** through camps and other group outings and activities
- Individual and group **counselling**
- **Respite** through camps and day activities

The analysis identified a number of gaps in specific service types provided to young carers. These included:

- **Case management** approach to service provision
- **Emergency respite**
- **Education assistance** (ie aiming to help young carers balance education/ care, although the gap is less in South Australia where this assistance is better developed)
- **Employment assistance** (ie training and respite to help balance work/ care).

These results were supported by the findings from focus groups and interviews with service providers and young carers in New South Wales and South Australia. Service providers identified the following gaps or issues in service provision for young carers (Section 5):

- a shortage of services for young carers, in particular culturally appropriate services for Indigenous young carers and young carers of CALD background, and accessible services for young people in regional and remote areas
- the fragmented nature of service provision for young carers
- short-term nature of funding to service providers
- insufficient flexibility in service provision
- problems of transport.

Overall young carers identified the following gaps in support:

- more flexible arrangements for education, help with tutoring and post school education
- counselling
- case management and continuity of care
- restrictive eligibility criteria, in particular with respect to income support
- appropriate support for young carers aged 18-25 years
- transport
- financial assistance
- emergency respite
- greater support for the person they cared for, including support like counselling, home care, and medical care (ie access to specialists).

## 6.5 Summary

The application of the analytical framework to the audit of existing programs and services designed for young carers in Australia shows that most fall into the assistance and mitigation categories, while few contain preventative elements. The vast majority of services specifically designed for young carers focus on providing support and/or addressing negative outcomes for young carers rather than preventing them from occurring. Services and programs for young carers with a preventative approach emerged as a gap in services and this observation was reiterated in the information provided by service providers and young carers. This was particularly the case with respect to preventative services in education and employment, and individual case management to balance caring and other responsibilities. As noted, generic services

for carers and the people for whom they provide care, such as Home Care in New South Wales, although outside the scope of this audit, also provide considerable support to young carers. Further research is required to examine their role in supporting young carers and their relationship to the analytical framework.

The implications of these findings draw attention to the need to place greater emphasis on an early intervention and prevention approach for young carers with the provision of adequate, appropriate and affordable services to the person in need of support. This approach would facilitate the early identification of young carers, thereby reducing the likelihood of intensive young carer responsibilities becoming entrenched, which are likely to lead to negative outcomes in the short and longer-term. However, this should not be interpreted as negating or not valuing the vital support provided to young carers through assistance and mitigation type services. In some cases it is possible to effectively ameliorate negative outcomes for young carers by providing assistance and mitigation-type services. In circumstances where the young carer's role has become entrenched, assistance and mitigation may provide appropriate and effective support in the short term. Some young people may choose to provide care, and therefore need services that support them or mitigate the intensity and frequency of their responsibilities. These findings highlight the need for appropriate services, tailored to individual families' needs and preferences based on optimal combinations of formal and informal support to ease the constraints and shift the primary mode of caring by young people from 'taking care of' to 'caring about'.

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