

# YOUNG CARERS: THEIR CHARACTERISTICS AND GEOGRAPHICAL DISTRIBUTION



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**Report to the National Youth Affairs  
Research Scheme (NYARS)**

The National Youth Affairs Research Scheme (NYARS) was established in 1985 as a cooperative funding arrangement between federal, state and territory governments to facilitate nationally based research into current social, political and economic factors affecting young people. NYARS operates under the auspices of the Ministerial Council on Education, Employment, Training and Youth Affairs (MCEETYA).

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# GLOSSARY OF ABBREVIATIONS

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<b>ABS</b>	Australian Bureau of Statistics
<b>ACT</b>	Australian Capital Territory
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>CALD</b>	Culturally and Linguistically Diverse
<b>Census</b>	Australian Bureau of Statistics <i>Census of Population and Housing 2006</i>
<b>COPMI</b>	Children of Parents with a Mental Illness
<b>CSTDA</b>	Commonwealth State and Territory Disability Agreement
<b>CURF</b>	Confidentialised Unit Record File
<b>CYCLOPS</b>	Connecting Young Carers to Life Opportunities and personalised Supports
<b>DEEWR</b>	Australian Government Department of Education, Employment and Workplace Relations
<b>DFaCS</b>	Australian Government Department of Family and Community Services
<b>EDAC</b>	Ethnic Disability Advocacy Centre

<b>FaCSIA</b>	Australian Government Department of Families, Community Services and Indigenous Affairs
<b>FaHCSIA</b>	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
<b>GP</b>	General Practitioner
<b>HACC</b>	Home and Community Care
<b>HSC</b>	Higher School Certificate
<b>ICAN</b>	Innovative Community Action Networks
<b>LCP</b>	Local Community Partnerships
<b>MCEETYA</b>	Ministerial Council on Education, Employment, Training and Youth Affairs
<b>NGO</b>	Non-government organisation
<b>NILF</b>	Not in the Labour Force
<b>NNAAMI</b>	National Network of Adult and Adolescent Children who have a Mentally Ill Parent/s
<b>n.p.</b>	Not available for publication
<b>NRCP</b>	National Respite for Carers Program
<b>NYARS</b>	National Youth Affairs Research Scheme
<b>PSHE</b>	Personal, Social and Health Education
<b>SD</b>	Statistical Division
<b>SDA</b>	Survey of Disability and Ageing
<b>SDAC</b>	Survey of Disability, Ageing and Carers
<b>SPRC</b>	Social Policy Research Centre
<b>UAI</b>	Universities Admission Index

# DEFINITIONS

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**Care:** The provision of assistance and support for the activities of daily living to a person with disability, long-term chronic or mental illness, or drug and alcohol problem, or frailty due to older age.

**Young carer (Australia):** A young carer is a child or young person up to the age of 25 years who provides unpaid support for a family member with long-term disability, mental illness, other illness, drug or alcohol problem. Young carers usually have more responsibilities than other young people their age.

**Young carers (UK):** Young carers 'are children and young people (under 18 years) who provide or intend to provide a substantial amount of care on a regular basis' (*Carers Act 1995*).

**Young caregiver (USA):** 'Anyone aged 8 to 18 years who provides unpaid help or care to any person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill. In addition, to qualify as a caregiver, a parent had to report that the child helps the care receiver with one or more of the following tasks: household chores or meal preparation; dressing or feeding; taking medicine or talking to doctors and nurses; keeping him/her company, providing emotional support; shopping; paperwork, bills, or arranging outside services; moving around the house, getting around the community; bathing or using the bathroom' (Hunt et al., 2005, p.11).

**Informal care or assistance (SDAC):** ‘...unpaid help or supervision that is provided to people with one or more disabilities or people aged 60 years and over living in households. It includes only assistance that is provided for one or more of the specified tasks comprising an activity because of a person’s disability or age. Informal assistance may be provided by family, friends or neighbours. For this survey, any assistance received from family or friends living in the same household was considered to be informal assistance regardless of whether or not the provider was paid.’ (ABS 2004, p.75)

**Formal care (SDAC):** ‘...help provided to persons with one or more disabilities by organisations or individuals representing organisations (whether for profit, not for profit, government or private) or other persons (excluding family friends, or neighbours as described in informal assistance) who provide assistance on a regular paid basis, and who are not associated with any organisation.’ (ABS 2004, p. 72)

**Carer (SDAC):** ‘A person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months. Assistance to a person in a different household relates to ‘everyday types of activities’, without specific information on the activities. Where the care recipient lives in the same household, the assistance is for one or more of the following activities: cognition or emotion, communication, health care, housework, meal preparation, mobility, paperwork, property maintenance, self-care, or transport.’ (ABS 2004, p.71)

**Primary carer (SDAC):** ‘A primary carer is a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).’ (ABS 2004, p.77)

**Co-resident carer (SDAC):** Carer or primary carer who lives with their care recipient.

**Ex-resident carer (SDAC):** Carer or primary carer who does not live with their care recipient.

**Identified carer (Census):** A young person aged 15–24 years who indicated that they provide unpaid help or assistance to family members or others in the last two weeks because of disability, a long-term illness or problems relating to old age.

**Potential carer and non-identified potential carer (Census):** A child aged 12–14 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility. A *non-identified* potential carer is a young person aged 15–24 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility and did not indicate that they were a carer in the question on the Census form.

**Profound limitation (SDAC):** 'The person is unable to do, or always needs help with, a core-activity task' (communication, mobility or self-care). (ABS, 2004, p.72)

**Severe limitation (SDAC):** The person:

- sometimes needs help with a core-activity task (communication, mobility or self-care),
- has difficulty understanding or being understood by family or friends,
- can communicate more easily using sign language or other non-spoken forms of communication. (ABS, 2004, p.72)

# EXECUTIVE SUMMARY

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The 'Young Carers: Their Characteristics and Geographical Distribution' report presents the findings of a study undertaken by the Social Policy Research Centre (SPRC) for the National Youth Affairs Research Scheme (NYARS).

'Young carers' is a term used in Australia to describe children and young people who provide unpaid help, support or assistance to family members or friends with a disability, chronic illness, mental health, and drug or alcohol issues (Moore et al., 2006). Helping others and providing care are essential parts of family life, yet some young people may take on a larger share of tasks and responsibilities compared to most people their age. The caring role may affect the young person's current social and economic participation and later opportunities in life. Although supports and services exist for children and young people who provide care, many are unaware of what is available, how to access it, or even that they are eligible for support.

Research on young carers includes differing perspectives on the role of children and young people and the circumstances of families where a person has a disability. This report focuses on the experiences and circumstances of young carers, while recognising the value of research focusing on the support needs of people with disability, employing a whole-of-family approach, and recognising that formal services, including respite, are key elements of support for young carers and people with disability.

The project comprised a number of stages: a literature review of the known characteristics of young carers and strategies to identify hidden young carers; the development of a discussion paper and stakeholder consultation to determine strategies to identify and support young carers; an analysis of nationally representative data sets to identify the number and characteristics of young carers and trends over time; and an analysis of the geographical distribution of young carers.

## LITERATURE REVIEW

The review of Australian and international literature and data finds that much is known about the characteristics and circumstances of young carers in the UK, yet research on young carers (or caregivers) in the USA, Canada and NZ is still in its infancy. Definitions of 'care' and the age range of young carers make international comparisons somewhat imprecise, yet it appears that a similar proportion of young people in Australia, the USA and UK provide informal care. Among Australian young people, caring is more prevalent in the 20 to 24-year-old age group and Indigenous communities, and young women comprise a higher proportion of primary carers.

The number of young carers identified in national surveys in Australia and overseas is possibly an undercount. The reasons for this include families seeking to keep care needs private, or not recognising that assistance provided is deemed as 'caring'. Young carers are more likely than non-carers to live in low income and sole parent households. Young carers undertake a wide range of tasks, which often go beyond what children and young people would normally be expected to do in families.

UK research on the geographical distribution of young carers (defined as young people under the age of 18 years providing care) indicated that they were more likely to be found in areas with high levels of deprivation, poor health and long-term illness.

Services for young carers in Australia are provided at both federal and state government levels and through non-government organisations. The range of services available include: education support; respite support; financial support; counselling; peer support; domestic and personal assistance. Effectively identifying and supporting young carers pose many challenges for policy makers and service providers. The task is complicated by the existence of 'hidden carers'. School staff, health professionals and social workers have been identified as having a vital role to play in identifying young carers.

Recommendations for effective service delivery highlight the importance of adopting a 'whole-of-family', multi-agency approach. Service providers are also strongly encouraged to distribute information in accessible formats. The importance of a flexible approach that recognises the different needs of a diverse target population, where a 'one size fits all' policy is inappropriate, is also emphasised.

## NUMBER OF IDENTIFIED AND POTENTIAL CARERS

The *Census of Population and Housing 2006* (Census) indicates that almost 120 000 young people aged 15–24 years provide care, whereas the *Survey of Disability, Ageing and Carers* (SDAC) in 2003 estimates the number of young carers in this age group is around 240 000. The two data sources have differing methodologies, which account for the different estimates.

Key findings from the Census data on identified young carers (aged 15–24 years) are:

- The prevalence of informal caring increases with age.
- Young women are more likely to be carers than young men.
- Indigenous young people had the highest rates of informal care provision.
- Caring was also more prevalent among young people from culturally and linguistically diverse (CALD) communities than those who spoke only English at home.

Analysis of trends between 1998 and 2003 (SDAC) showed that:

- The number of young primary carers increased, due to an increase in the proportion of young women aged 20–24 years who were identified as primary carers.
- Overall, the total number of young carers (aged 10–24 years) declined, partly due to a reduction in the number of young men aged 15–19 years who were identified as carers.

Longer-term trends (1988 to 2003) for young, co-resident primary carers (aged 15–24 years) showed that the number of young men in this group remained steady but the number of young women had slightly increased.

'Potential young carers' were defined as those aged 12–14 years who lived with a person with disability or those aged 15–24 years who lived with a person with a disability and did not identify as a carer.

- Two per cent of the younger age group (aged 12–14 years) were potential carers and 0.3 per cent of the younger age group lived in households where there was no identified carer (although it is possible that the care recipient is receiving support from formal services).
- Three-and-a-half per cent, or 77 607, of young people aged 15–24 years were potential carers.
- A higher rate of potential caring was found among young people who were; aged 15–19 years, Indigenous, of CALD backgrounds, and young men.

## TRENDS IN THE CHARACTERISTICS OF YOUNG CARERS (SDAC)

Key findings of the trends between 1998 and 2003 include:

- Patterns of co-residence and the relationship with the care recipient remained stable.
- The proportion of young primary carers caring for a person with a profound limitation increased from one quarter in 1998 to one third in 2003.
- Young primary carers were generally less likely than other young people to complete Year 12 and more likely to leave school at age 16 years or less. Young people and young carers had higher levels of participation in secondary education in 2003 than 1998.

Employment rates for young people increased between 1998 and 2003, and gaps in employment participation between young primary carers and others declined. However, the composition of employment changed:

- Full-time employment rates for all young people were lower in 2003 and primary carers were less likely to be employed full-time than non-carers.
- Part-time employment rates increased for all young people in 2003, particularly for young primary carers and carers.
- The proportion of young people unemployed declined for all young people, although primary carers still had a higher proportion unemployed than other carers and non-carers.

No changes in the relative economic circumstances of young primary carers were evident. Just over 10 per cent of young primary carers (aged 10–24 years) lived in very low income households and over half lived in relatively low income households.

Longer-term trends between 1988 and 2003 for young, co-resident primary carers must be interpreted with caution due to small sample sizes and changes in the survey methods and definitions over time. Analysis of this group suggested that:

- There had been a slight decline in the proportion of young primary carers who were Australian-born.
- The types of relationships between carers and care recipients had remained relatively stable, with between 50 and 60 per cent caring for a parent in each year.

Employment patterns of young, co-resident primary carers had remained fairly consistent with around 35–45 per cent employed, one quarter unemployed and 40 per cent not in the labour force.

- Over time, significant changes in the main source of income of young, co-resident primary carers were evident. The proportion whose main source of income was government benefits doubled from 30 per cent to over 60 per cent.
- This finding may reflect changes in the eligibility criteria for government benefits to support carers, particularly the possibility of combining employment and receipt of a benefit for care.

## CHARACTERISTICS OF YOUNG CARERS (CENSUS 2006)

At the national level and for all young people, it is evident that young carers compared to non-carers are:

- less likely to be in paid employment only, or combining employment with study
- equally likely to be just studying, and
- more likely not to participate in either study or paid work.

Overall, young carers were less likely than non-carers to be employed full-time; they had similar rates of part-time employment; and a higher proportion were unemployed than non-carers.

- Indigenous young carers had only slightly lower rates of participation in employment than other groups, but substantially lower rates of combining employment and study and studying only.
- Forty-one per cent of Indigenous young carers did not participate in paid work or study, a rate that was over twice as high as CALD and other young carers.

- Young CALD carers had relatively low rates of employment, but relatively high rates of participation in study.
- Young carers were more likely to live in low income households and sole parent families than their non-carer peers.

Taking into account their lower levels of participation in education and employment, and their household circumstances of low income, it is evident that young carers may experience disadvantage and potentially be at risk of social exclusion.

## GEOGRAPHICAL DISTRIBUTION OF YOUNG CARERS

In most regions, between 3 and 6 per cent of young people provide care, although higher rates of care provision (7–8 per cent) were found in regional and off-shore Northern Territory and in Western Australia’s Kimberly region.

- There was greater regional variation in the proportion of Indigenous and CALD young people who provide care.
- Indigenous young people accounted for a larger proportion of young carers in Darwin and more remote areas.
- In major cities—particularly Sydney and Melbourne—a higher proportion of young carers were from CALD backgrounds.

Rates of non-participation in study or employment were higher:

- for young female carers than young male carers in all areas, and
- in regional areas than the cities.

High non-participation rates for young carers may reflect a general lack of opportunities for young people in these regions or specific disadvantages experienced by young carers in these regions.

- The gap in employment participation rates between carers and non-carers was highest in the remote areas of Western Australia and Queensland and was over 10 per cent in a number of other regions in all states and territories (except the Australian Capital Territory).
- Overall, young female carers were more disadvantaged than young male carers in terms of completing Year 12.
- The carer disadvantage for Year 12 completion rates was over 10 per cent in some remote and regional areas, and lower in the cities.

- A higher proportion of young carers in the 15–19 years age group lived in low-income households than the older age group.

Young carers were more likely than non-carers to live in low-income households in all regions in Australia.

- The incidence of low-income households among young carers was higher in regional areas in most states and in Hobart.
- Areas with high proportions of young carers living in sole parent families were regional areas in all states (except Australian Capital Territory and Northern Territory) and Hobart.

Overall, the remoteness of young carers' residence was generally characteristic of all young people. However, differences based on cultural background were evident.

In the Census data, identified and potential caring was prevalent in remote areas of Australia and among Indigenous communities. However, the Census data has limitations. Further research on the circumstances and experiences of young Indigenous carers in remote communities is required to gain a more detailed understanding of their situation.

## STAKEHOLDER CONSULTATIONS

Overall, the feedback from stakeholders including young-carer representatives, policy makers, advocacy groups and front-line workers related to the main issues and themes outlined in the discussion paper. In addition, they provided a number of important comments and suggestions on how best to identify and support young carers.

Stakeholders confirmed that one of the main reasons young carers remain hidden is that they do not see themselves as carers. Other suggestions included: young people do not want to be seen as different; concerns of bullying; or they are not the main carer, so their contribution goes unnoticed.

Stakeholders highlighted the need for a multifaceted approach to raise awareness of young carers through the media, internet and ongoing professional development and training of school teachers, counsellors, health professionals and social workers.

Generally stakeholders endorsed a whole-of-family approach but noted additional resources and skills were required to embrace individual needs.

## CONCLUSION

The provision of informal care clearly has economic and social value. In addition, at an individual and community level, it could be considered to contribute to building stronger social connections and enhancing the development of life skills for young people. There are, however, individual costs incurred in providing care, such as reduced opportunities for employment, education and social participation.

The findings in this research, which form the recommendations, highlight the need to further develop strategies and policies, which take account of the costs and worth of informal care, in order to promote young people's social inclusion through participation in education and employment.

## RECOMMENDATIONS

The findings from the data collected and analysed in all components of the project form the basis of the recommendations.

Key recommendations (detailed in Section eight) to assist in the identification and support of young carers were:

- increasing awareness of caring roles and the identification as a carer among all young people
- developing age-appropriate and culturally appropriate information dissemination methods for young people in urban and regional and remote areas
- supporting schools and teachers to identify and help young carers to maintain their participation in education and to contact services
- developing awareness among health professionals, social workers and service providers of young carers and the potential of a whole-of-family approach
- developing policies to help young carers participate in employment
- developing culturally appropriate supports for specific groups of carers, including young carers in regional and remote communities, and Indigenous and CALD young carers
- develop consistency in definitions of young carers in policy and data collection.

# 1. INTRODUCTION

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This report presents the findings from a study on 'Young Carers: Their Characteristics and Geographical Distribution' undertaken for the National Youth Affairs Research Scheme (NYARS). The report and recommendations are addressed to federal, state and territory governments, non-government organisations and service providers.

## 1.1 BACKGROUND

Helping others and providing care are an essential part of family life and all family members are involved to some extent in the giving and receiving of care. More often than not, parents are the main providers of care in the household, particularly when children are very young, but over time children and young people also become engaged in providing support and assistance to other family members. This may involve tasks such as watching over a younger sibling or helping with cooking or cleaning if a parent is unwell.

Sometimes, however, young people may have to take on a larger share of caring tasks and responsibilities on a regular basis compared to most young people their age. This may happen if a young person has a sibling or parent with a disability, and providing support and assistance is just something they do—a normal part of family life.

Other children and young people may have to take on caring tasks and responsibilities suddenly if a family member has an accident, is diagnosed with a serious illness or there is a change in family circumstances, such as going to live with grandparents or

a parent or sibling leaving the family home. In addition to usual household chores, those who support a family member with an illness or disability may also have to assist with showering, dressing, administering medication and they may have to provide emotional and social support.

‘Young carer’ is the term used in Australia to refer to children and young people under the age of 25 years<sup>1</sup> who provide unpaid help, support or assistance to family members or friends with a disability, chronic illness, mental health, and drug or alcohol issues (Moore et al. 2006).

The term ‘young carer’ is also used in the UK, where it refers to young people under the age of 18 years with informal caring responsibilities and the term ‘young caregiver’ is used in the USA to refer to young people with informal caring responsibilities under the age of 19 years.

Existing research on young carers shows that there is huge variation in the level of responsibility shouldered by young people who provide support and assistance to sick or disabled family members. For some, providing support and assistance has little influence on their lives and for others it can be an enriching experience that equips them with valuable skills and fosters a sense of responsibility and maturity.

Others, however, can feel overwhelmed, exhausted and stressed by the level of responsibility they have. This can lead to a range of problems, including having trouble concentrating at school, completing homework, having little or no time to socialise, and feeling different to friends (Cass et al., forthcoming).

Although supports and services exist for children and young people who provide support and assistance to family members with an illness or disability, many are unaware of what is available, how to access it or even that they are eligible for support.

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<sup>1</sup> FaHCSIA defines young carers as up to the age of 25 years. Due to data restrictions, the data analysis in this project identified young carers between the ages of 10 and 24 in the Survey of Disability Ageing and Carers (SDAC), and due to data restrictions and to maintain consistency, the age range 15–24 years was the main category employed in the analysis of the Census data. Due to data restrictions, the data analysis in this project identified young carers between the ages of 10 and 24 years inclusive in the Survey of Disability Ageing and Carers (SDAC), and due to data restrictions and to maintain consistency, the age range 15–24 years inclusive was the main category employed in the analysis of the Census data.

In Australia and elsewhere, research on informal carers, including young carers, has coincided with a policy shift away from institutional care towards care in the community. This policy shift relies on both the provision of formal care services in the community and support by informal carers. For example, in 2003, 91 per cent of younger people with disability (aged under 65 years) received help from informal carers, while one quarter received formal services (AIHW, 2005, Table 5.21: 249).

One perspective in research on young carers advocates that a child or young person assuming caring responsibilities changes family relationships and can negatively affect the experiences of childhood (e.g. Harrison and Seith, 2004; Aldridge and Becker, 1993). Research in Australia has documented that young carers are a vulnerable group with lower participation rates in education and employment than other young people without care responsibilities (Cass et al. forthcoming; Noble-Carr and DFaCS, 2002a, 2002b). Young carers, therefore, may be a group potentially at risk of social exclusion.

An alternative perspective in research on young carers is offered by proponents of the disability rights position, who have challenged community care policies and their reliance on informal carers. These researchers argue that community care policies and the notion of 'care' constructs people with disabilities as 'dependent people' and undermines their rights to choice and control in their life due to inadequate support (Morris, 1997). In addition, it is argued that focusing on the needs of carers draws attention away from the needs and resources required to adequately support people with disabilities to live independently (Morris, 1997).

Efforts to resolve the competing perspectives have argued that research, policy and the service systems should recognise and counter the needs of the whole family, including people with disability and young carers (Becker, 2005, 2007). The scope of this report, as commissioned, is to contribute to research on the experiences and circumstances of young carers, while recognising the value of research focusing on the support needs of people with disability, employing a whole-of-family approach, and recognising that formal services, including respite, are key elements of support for young carers and people with disabilities.

## 1.2 AIMS OF THE PROJECT

The aims of the project were to:

- carry out a review of Australian and international literature on the characteristics of young carers and ways to identify hidden young carers
- provide baseline, trend and current information on young carers and provide evidence of their geographical distribution based on an analysis of national data sets
- seek stakeholders' views about identifying and supporting young carers, and
- make recommendations for ways to identify young carers, especially hidden young carers, for the purpose of designing and providing age-relevant services and supports in regions where they are most required.

## 1.3 OUTLINE OF THE REPORT

The first section of the report provides an overview of the project. Section two presents the findings from a literature review that draws on both Australian and international studies to analyse what is known about the social and demographic characteristics of young carers as well as their geographic areas of residence. In addition, it provides a brief overview of services available to young carers in Australia. The review also examines the issue of 'hidden' carers and outlines a range of strategies found in the literature for identifying and supporting young carers.

Section three of the report draws upon recent data on young carers from the Australian Bureau of Statistics' (ABS) *Surveys of Disability, Ageing and Carers (SDAC)* and the ABS *Census of Population and Housing 2006*. This section provides an overview of the number of identified young carers and the proportion of young people who are identified as carers in the Census and the SDAC. Further analysis of the Census data is also undertaken to provide estimates of the number of potential young carers or 'hidden carers'—young people who share a household with a person with a disability but who do not identify as a carer.

Section four looks at demographic characteristics and trends over time in the young carers using the SDAC 1993, 1998 and 2003 and the *Survey of Disabled and Aged people (SDA 1988)*. This section examines cultural background, the care situation, participation and attainment in education, employment patterns and household and personal incomes of young primary carers and young carers compared with other young people.

The following section (Section five) presents the results of the data analysis and mapping generated using Census 2006 data. It provides evidence of the geographical distribution of young carers and 'potential carers'. It also describes the geographical distribution of a number of characteristics of young carers and areas where carers may experience greater education and employment disadvantage.

Section six contains the findings from stakeholder consultations. It describes the method of consultation, the range of stakeholders consulted (including young carer representatives, policy makers, non-government organisations and service providers) and suggestions provided by stakeholders on how best to identify young people who may be providing care to sick or disabled family members.

Section seven draws together the findings from all components of the project and discusses some of the implications. The final section of the report presents recommendations for identifying young carers for the purpose of providing assistance to this group. These recommendations are drawn from the findings of the other stages of the research.

# 2. LITERATURE REVIEW— IDENTIFYING AND SUPPORTING YOUNG CARERS

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## 2.1 INTRODUCTION

This section surveys Australian and international literature to describe what is known about the social and demographic characteristics of young carers. It then considers the limited previous international research examining the geographical distribution of young carers. The services available to support young carers in Australia are depicted and the literature on why young carers remain 'hidden' and out of touch with services and support is discussed. Strategies for identifying and supporting young carers are then outlined.

## 2.2 THE SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF YOUNG CARERS

Children and young people who provide support or assistance to family members with an illness or disability have been the subject of extensive research, advocacy and support in the UK over the last two decades where they are referred to as ‘young carers’.

Australia has also developed its own research base over the last 15 years and has examined the characteristics, needs and circumstances of young people who support or assist family members with an illness or disability. This body of research, in addition to community sector advocacy, has generated growing acknowledgment and awareness of the needs of young carers among policy makers and service providers.

Acknowledgment of ‘young caregivers’ as a special interest group has proceeded at a much slower rate in the USA compared to the UK and Australia. The first study to estimate the prevalence of young people with caregiving responsibilities in the USA was released as recently as 2005 (Hunt et al. 2005). Research and awareness of children and young people with caregiving responsibilities is still very much in its infancy in Canada and New Zealand (Baago, 2005; Gaffney, 2007).

The definition of a young carer in some of the UK research and on the Princess Royal Trust for Carers website in the UK includes reference to *inappropriate* levels of responsibility for the young person, whereas the UK government definition, provided on the definitions page of this report, refers only to the provision of a substantial amount of care.

In Australia there is also a fairly broad definition of young carers which refers to the young carer usually having more responsibility than their peers. These differences in definitions have implications for research, policy and practice aimed at supporting young carers.

### 2.2.1 Numbers

Differences in definitions and age ranges used in research on children and young people who provide support and assistance to family members make cross-country comparisons somewhat imprecise. Nonetheless, it is broadly accepted that between 2 and 4 per cent of all children up to 18 years in Australia, the UK and the USA provide support and assistance on a regular basis to family members with an illness or disability (Becker, 2007).

Data derived from the most recent, specialist *Survey of Disability, Ageing and Carers* (SDAC) undertaken by the ABS indicates that in 2003, 170 600 young people under 18 provided support and assistance to family members with an illness or disability on a regular or ongoing basis. This represents 3.6 per cent of all children and young people in Australia in this age range. A further 178 000 young adults aged 18–24 years were also providing support and assistance to a family member with an illness or disability, representing 9 per cent of young adults in this age range (ABS, 2004). Of these, around 20 000 were primary carers, that is, they provided the main support for their care recipients who needed help for self-care, communication or mobility (ABS, 2004).

While data derived from the SDAC is generally considered to provide a more accurate estimate of the prevalence of young carers than the Census, the SDAC does not provide data on Indigenous young carers. Nevertheless, 2006 Census data indicates that care responsibilities are far more common among Indigenous young people than all young people—7.6 per cent of Indigenous<sup>2</sup> young people compared to 4.4 per cent of all young people. The highest proportion of carers among young Indigenous people was in the Northern Territory where 9.4 per cent were carers (Cass et al. forthcoming).

Figures from the 2001 UK Census indicate that 175 000 children and young people under 18 years provide some level of unpaid care to other family members. This is approximately 2.1 per cent of children aged 5 to 17 years (Becker, 2007).

USA data reveals that there are approximately 1.3 to 1.4 million child caregivers aged 8 to 18 years in the US, representing 3.2 per cent of households that have a resident child aged 8 to 18 years (Hunt et al. 2005). Nevertheless, the authors warn that:

*[These figures] should be considered to be representative of households that include child caregiving and are willing to discuss this situation and not necessarily all households that contain a child caregiver. The prevalence rates should also be considered to be conservative estimates of the social phenomenon.*

*(Hunt et al., 2005: 4)*

The prevalence of young carers in Ireland is broadly comparable with Australia, UK and USA estimates. Census data reveals that there are 12 286 young carers aged 15–24 years in Ireland (Central Statistics Office, 2007), representing 1.94 per cent of all young people in this age range.

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2 Note on terminology: The authors acknowledge the diversity of Aboriginal and Torres Strait Islander peoples, who have different languages, cultures, histories and perspectives. For ease of reference, this report refers, for the most part, to Aboriginal and Torres Strait Islander people collectively as 'Indigenous' people.

Even though these survey data from Australia, the UK, the USA and Ireland show that a large number of young people provide support and assistance to family members with an illness or disability on a regular or ongoing basis, it is widely accepted that national surveys do not capture the full extent of caregiving provided by young people (Becker, 2004, 2007). Reasons for the undercounting of young carers include the fact that some people may not wish to reveal care needs and caregiving within their family, preferring to keep the matter private, while others may not recognise that the support they provide qualifies as 'caregiving'.

### 2.2.2 Gender and age

Australian and USA research evidence reveals that children and young people who provide support and assistance to family members with an illness or disability are relatively evenly split between male and female (Noble-Carr and DFACS, 2002a, 2002b; ABS, 2004; Hunt et al, 2005). In Australia, after the age of 18 years, however, more than three-quarters of young people who take on primary caring responsibilities<sup>3</sup> are female (Cass et al. forthcoming).

Both UK and Irish data, however, reflect a slightly less even split of young carers by gender. A UK report based on data collected from specialist young carer projects found that 56 per cent of the sample was female (Dearden and Becker, 2004). It is possible, however, that this may reflect a greater propensity among females to access young carer services. Similarly, Irish Census data reveals that females comprise 54 per cent of young carers aged 15–24 years (Central Statistics Office, 2007). Interestingly, young male carers comprise a larger proportion of the total number of male carers in the Republic of Ireland (9.26 per cent) compared with the corresponding figure for females (6.65 per cent). These data may suggest that the provision of care by younger males is more socially acceptable than the provision of care by older males in Ireland. Additionally, it may be indicative of the gender nature of care whereby male carers get channelled into breadwinner roles and females become more entrenched in care roles as they get older (Cass et al. forthcoming).

In terms of age distribution, a UK study of young carers under the age of 19 years has shown that the average age of young carers was 12 years and over half (57 per cent) were aged 11–15 years (Dearden and Becker, 2004). USA research has found that a third of child caregivers are aged 8–11 years, two-fifths are aged 12–15 years and a third are aged 16–18 years.

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<sup>3</sup> A 'primary carer' is defined as 'a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities'. This assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities of communication, mobility and self care (ABS, 2004: 77).

### 2.2.3 Family circumstances and characteristics

In Australia, the UK and the USA, young people with caregiving responsibilities are more likely to live in sole parent families than their non-caregiving peers. Figures from the UK indicate that 56 per cent of young carers live in sole parent families (Dearden and Becker, 2004) and USA research shows that young caregivers are less likely than non-caregivers to live in two-parent households (76 per cent compared to 85 per cent) (Hunt et al., 2005). In addition, low-income is characteristic of young people with caregiving responsibilities in all three countries (Bittman et al. 2004; Cass et al. forthcoming; Hunt et al. 2005; Noble-Carr and DFACS 2002a, 2002b; Young et al. 2005; Dearden and Becker, 2004).

A further point of comparison is the fact that parents comprise the largest share of care recipients in all three countries. UK research reveals that the majority of care recipients are mothers and this is particularly so in lone parent families where 70 per cent of care recipients are mothers (Dearden and Becker, 2004). Similarly, data from the USA indicates that almost three-quarters (72 per cent) of child caregivers are caring for a parent or grandparent, most often their mother or grandmother. The USA data also reveals that caregivers in minority households are more likely to be caring for their mother (42 per cent) than those in non-minority households (25 per cent) (Hunt et al., 2005). Australian data shows that most young people provide care for a parent, while a quarter provides care for another relative (Noble-Carr and DFACS 2002a, 2002b; Cass et al. forthcoming).

Research in Australia, the UK and the USA reveals differences in the circumstances of young carers from culturally and linguistically diverse (CALD) backgrounds. Australian research has found a higher proportion of young carers among Indigenous young people than among non-Indigenous and that twice as many young primary carers were born in non-English speaking countries as non-carers (Cass et al. forthcoming). UK research on care providers of all ages has highlighted a greater propensity of caregiving among Bangladeshi and Pakistani populations and it is possible to speculate that this greater propensity also extends to young carers (Young et al. 2006). Although the available USA data does not report on greater prevalence of caregiving among particular CALD groups, it does show that children in minority households, which have lower incomes, are also under particular stress and report receiving less help in carrying out tasks (Hunt et al. 2005).

The greater prevalence of caregiving among young people from CALD backgrounds has been attributed to a number of factors, including the cultural incompatibility of services and the perceived belief among CALD communities that caring for family members is a natural responsibility (Ethnic Disability Advocacy Centre (EDAC), 2003:

Misic, 1996). However, Young et al. (2006) attribute the greater propensity of caregiving among CALD groups to socio-economic and demographic factors rather than culture.

#### 2.2.4 Caregiving responsibilities

Tasks undertaken by young carers include a wide range of physical, household, medical, emotional and social support tasks. The caring tasks and responsibilities undertaken often go beyond what adults would normally expect of children and what most children would expect to do within the family (Warren, 2007; Becker, 2007; Early et al. 2006: 170).

Research from the UK, the USA and Australia reveals that young carers in each country undertake a similar range of tasks. USA research reveals that nearly all young caregivers help with instrumental activities of daily living, such as shopping, household tasks and meal preparation, and over half (58 per cent) help with at least one activity of daily living (including bathing, dressing, getting in and out of bed and chairs, toileting and feeding). Under a fifth (17 per cent) help their care recipient communicate with doctors or nurses.

UK research shows that two-thirds of young carers provide domestic help in the home; almost half provide general nursing-type help; four-fifths provide emotional support and supervision; a fifth provide intimate personal care and one in ten provides child care (Dearden and Becker, 2004).

There is wide variation among young carers in terms of the range of responsibilities and the level of care they provide. This is influenced by a range of factors including: the number of people being cared for; the presence of other family members to assist with care; the carer's relationship to the care recipient; the care recipient's illness; and the carer's age. The interaction of these factors influences the type and intensity of chores performed by young carers (Cass et al. forthcoming).

Both Australian and UK data indicate that, while the majority of young carers provide support and assistance to one care recipient, one in ten young carers is caring for more than one person (Dearden and Becker, 2004; Cass et al. forthcoming). Nevertheless, a quarter of young Australian *primary carers* provide care for more than one person (Cass et al. forthcoming).

The presence or absence of other family members to assist with care can influence whether a young carer takes on a sole or supportive carer role. USA data shows that at least three-quarters of child caregivers who help with any given task say that someone else also helps. However, caregivers in minority households are much less likely than

non-minorities to say that others help them with caregiving tasks (Hunt et al. 2005). This could also result from a distribution of tasks within households.

The qualitative component of the Australian study undertaken by Cass et al. (forthcoming) revealed that half of the young carers aged over 18 years were *primary carers*, with some being the *sole provider* of care. All other carers indicated that other family members also provided care either in a greater, equal or lesser capacity. Among the under 18 years cohort, many were providing care in households where a parent was the primary carer for another family member. The amount of caring support they provided varied from family to family. In some cases, the presence of an additional sibling lightened the load of caring when responsibility was shared. In other cases, however, the responsibility for caring fell predominantly onto one sibling.

Cass et al. (forthcoming) also found that the experience of caring depends to a large extent on the young carer's relationship to the care recipient. A young carer caring for a sibling where the parent or parents have primary caring responsibilities has a very different caring experience compared to a child caring for a parent, particularly if the parent is a sole parent.

UK research also shows that the nature of the illness or disability experienced by the care recipient influences the type and level of care offered by children. Care recipients with physical health problems are more likely to require intimate care, while those with mental health problems are more likely to require emotional support (Dearden and Becker, 2004). The relationship between the care recipient's illness and a young carer's responsibilities has also been identified in the Australian context by Cass et al. (forthcoming).

Age is another factor that influences the caring role and level of responsibility of a young carer. Australian qualitative data shows the onset of caring responsibilities can begin very early for some young carers—some from as young as two years—while others began caring in their twenties. Many young carers, however, had difficulty determining at what age their caring responsibilities started and simply stated: 'All my life'; 'Always'; 'Since birth'; 'I have always been a carer' (Cass et al. forthcoming).

Similarly, data from the UK indicates that a third of young carers had been caring for two years or less; 44 per cent for 3–5 years; a fifth for 6–10 years and 3 per cent had been providing care for over 10 years (Dearden and Becker, 2004) leading Dearden and Becker (2004) to state that caring 'can be a long commitment for some and begin at an early age'.

Australian data also shows that older carers undertake a broader range of tasks than young carers. Carers aged 18 years and over were significantly more likely to assist their care recipient with dressing, eating, bills and banking, attending medical appointments, giving advice and organising social activities. Tasks such as showering, cleaning the house, cooking, comforting, and listening were undertaken to a similar extent by young carers under 18 and carers aged 18 years and over (Cass et al. forthcoming). Similarly, UK research has also shown that children get more involved in caring tasks as they get older (Dearden and Becker, 2004).

Cross-national comparisons of the intensity of care provided by young carers are difficult due to differences in measurement. Nevertheless, UK research reveals that half provide care for under 10 hours per week, a third for 11 to 20 hours and one in six for over 20 hours per week. Just 2 per cent were caring for more than 50 hours per week (Dearden and Becker, 2004). UK 2001 Census data indicates that a sixth of young carers provide care for more than 20 hours per week and around 8 per cent of this group cares for 50 or more hours per week (Becker, 2007).

Figures from the Irish Census reveal that under three-quarters of young carers were caring for 1 to 14 hours per week, one in ten for 15 to 28 hours per week, 7.5 per cent for 29 to 42 hours per week and one in ten were caring for 43 or more hours per week. The intensity of care giving by young Irish carers does not differ markedly by gender with similar proportions of male and female carers providing similar hours of regular unpaid care per week (Central Statistics Office, 2007).

Australian time-use data reveals that young carers spend less time (3 hours per week) on such activities as personal care and leisure for themselves than non-carers in their age group and more time on domestic tasks (around 2.5 hours per week) (ABS, 2008).

## 2.3 YOUNG CARERS GEOGRAPHIC AREAS OF RESIDENCE

A scan of the young carer literature from the UK, the USA and Australia sheds little light on the geographic distribution of young carers. The sole publication identified—‘Who cares? Geographic variation in unpaid caregiving in England and Wales: Evidence from the 2001 Census’<sup>4</sup>—provides evidence of the geographic distribution of carers of all ages. Nevertheless, it is likely that the patterns of geographic distribution of carers of all ages also pertain to the geographic distribution of young carers.

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4 Young, H., E. Grundy & S. Kalogirou (2005), ‘Who cares? Geographic variation in unpaid caregiving in England and Wales: Evidence from the 2001 Census’, Population Trends No. 120, Newport: Office for National Statistics.

Young et al. (2005) found clear geographic variations in caregiving across England and Wales. The highest proportions of carers were found in areas with higher than average levels of deprivation and long-term illness. Carers living in those areas were also more likely to be in poor health, which is likely to reflect the general health of the area.

## 2.4 SERVICES FOR YOUNG CARERS

Services for young carers in Australia are provided at both federal and state government levels and many are also administered through non-government organisations, which often receive government funding. The range of services available include: education support; respite support; financial support; counselling; peer support; domestic and personal assistance.

### 2.4.1 Federal and state government resources

Family or community programs and services provided by the Australian Government accessible to young carers include:

- **Young Carers Respite and Information Services Program**  
This program is funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). It provides support to young carers who are at risk of not completing their secondary education or vocational equivalent due to the demands of their caring role. The program enables young carers to access age appropriate support and respite services to undertake activities such as studying for exams, to attend education, training or recreation. It also provides a range of information, advice and referral services, including referral to counselling, to support young carers in managing the challenges they face as part of their caring role. The respite services are delivered through the Commonwealth Respite and Carelink Centres and the information, advice and referral services are delivered through the Carers Australia, which subcontracts the state and territory carer associations.
- **Carer Allowance and Carer Payment**  
*Carer Payment* is an income support payment for people who are unable to support themselves through participation in the workforce while caring for someone with a disability (including a child with a profound disability who has extremely high care needs), severe medical condition or frail-aged..

*Carer Allowance* is a supplementary payment for carers who provide daily care and attention for who is frail aged or adults or children with a disability or severe medical condition at home. It may be paid in addition to the Carer Payment or other payments, such as the Age Pension. [www.centrelink.gov.au/internet/internet.nsf/payments/carers\\_allow\\_child.htm](http://www.centrelink.gov.au/internet/internet.nsf/payments/carers_allow_child.htm)[www.centrelink.gov.au/internet/internet.nsf/payments/carers\\_allow\\_adult.htm](http://www.centrelink.gov.au/internet/internet.nsf/payments/carers_allow_adult.htm)

- **National Respite for Carers Program (NRCP)**  
Commonwealth Carer Respite Centres support carers to access respite; provide information and advice about respite options; help organise emergency or planned respite; and purchase or subsidise short-term or emergency respite when needed.
- **Commonwealth Carer Resource Centres**  
The Australian Government has funded a Carer Resource Centre in the capital city of each state or territory to provide information and advice to carers. Staff can assist with referrals, counselling, support and resources on topics including carer support groups, home help, financial entitlements, support services, and arranging respite.
- **Home and Community Care (HACC)**  
This program provides community care services to frail aged and younger people with disabilities, and their carers. HACC is a joint federal, state and territory cost-shared program with the Australian Government providing 60 per cent of funds. The types of services funded through the HACC program include nursing care; allied health care; meals and other food services; domestic assistance; personal care; home modification and maintenance; transport; respite care; counselling, support, information and advocacy; and assessment.
- **Commonwealth State/Territory Disability Agreement (CSTDA)**  
CSTDA is an agreement between the federal, state and territory governments that provides a national framework for the provision, funding and monitoring of specialist disability services for people with disabilities. Through the agreement, the federal, state and territory governments aim to work collaboratively to improve the well-being of people with disabilities by supporting them to be valued and active participants in the community.
- **Carer Information Pack**  
The Carer Information Pack is produced by the Aged and Community Care Division of the Department of Health and Ageing and provides practical information to support carers in their caring role.

State governments also provide a range of supports that are accessible to young carers. Many have developed a carers' action plan that outlines government commitments to progress the objectives of carers' policy. For example, the New South Wales (NSW) Carers Action Plan 2007–12 (March, 2007) outlines a whole of government policy commitment to recognise and support carers. It identifies priority areas for action such as identifying and supporting hidden carers, as well as young carers. This includes building on non-government organisation (NGO) initiatives to reach young carers and policies, programs and resources in schools that promote and protect students' wellbeing and assist in identifying and supporting young carers.

### 2.4.2 Information services for young carers

A key focus of many service providers and organisations is the provision of information to young carers to assist them in their caring roles. For example, Carers Australia has a *Young Carers* website ([www.youngcarers.net.au](http://www.youngcarers.net.au)), which is aimed primarily at young carers, but also has sections for parents and school teachers.

Carers NSW also run a *Young Carer* project which is funded through the NSW Carers Program and administered by the Department of Ageing, Disability and Home Care. The project has its own dedicated website ([www.youngcarersnsw.asn.au](http://www.youngcarersnsw.asn.au)), which is funded by the federal Department of Families, Housing, Community Services and Indigenous Affairs, and includes information on events, programs, a Young Carers Voices section, a section for parents, and links to other relevant websites. The 'finding help' section is divided into age groups—under 12 years, 13–17 years and 18–25 years—and focuses on the different issues facing young people during these life stages.

Most of the other states and territories have information aimed at young carers on their respective Carer Association websites:

- Western Australia [www.carerswa.asn.au](http://www.carerswa.asn.au)
- Tasmania [www.carerstas.org](http://www.carerstas.org)
- Queensland [www.carersqld.asn.au](http://www.carersqld.asn.au)
- Victoria [www.carersvic.org.au/index.htm](http://www.carersvic.org.au/index.htm)
- South Australia [www.carers-sa.asn.au](http://www.carers-sa.asn.au)
- Northern Territory [www.ntcarers.asn.au](http://www.ntcarers.asn.au)
- Australian Capital Territory [www.carersact.asn.au](http://www.carersact.asn.au)

Other Australian resources for young carers include specific support groups such as:

- Children of Parents with a Mental Illness (COPMI): an online national resource centre from the Australian Infant, Child, Adolescent and Family Mental Health Association for young people with a parent with a mental illness ([www.copmi.net.au](http://www.copmi.net.au)).
- CYCLOPS ACT (Connecting Young Carers to Life Opportunities and Personalised Supports): a service provided by Anglicare Canberra-Goulburn Youth and Family Services and funded by the ACT Department of Disability, Housing and Community Services. Services provided by CYCLOPS include personal support, case management, advocacy, support groups, recreational activities such as camps, information provision, skills development, educational support and brokerage ([www.cyclopsact.org/index.html](http://www.cyclopsact.org/index.html)).
- National Network of Adult and Adolescent Children who have a Mentally Ill Parent/s (NNAAMI): established by children who have experienced life with a mentally ill parent to provide assistance for one another via self-help support, discussion groups and counselling ([home.vicnet.net.au/~nnaami/](http://home.vicnet.net.au/~nnaami/)).
- Raw Energy Young Carer Support Program: A program in South Australia that supports young people aged 5–18 years who support a family member with a disability, chronic illness or mental illness ([www.youngcarer.com.au](http://www.youngcarer.com.au)).
- Reach Out: A web-based service from the Inspire Foundation which aims to improve young people’s mental health and well-being by providing support information and referrals in a format that appeals to young people. They have a fact sheet - ‘Being a Young Carer’ ([www.reachout.com.au/default.asp?ti=282](http://www.reachout.com.au/default.asp?ti=282)).
- Siblings Australia Inc–Services for Siblings of Children with Special Needs: A national organisation committed to enhancing the wellbeing of siblings of children with disabilities and chronic illness ([www.siblingsaustralia.org.au/siblingsNEW/index.html](http://www.siblingsaustralia.org.au/siblingsNEW/index.html)).

## 2.5 WHY DO SOME YOUNG CARERS REMAIN ‘HIDDEN’ AND OUT OF TOUCH WITH SERVICES?

Much of the knowledge we have about young people with caregiving responsibilities is drawn from studies of young people who are in touch with services and supports and accordingly identify themselves as young carers. Nevertheless, it is widely acknowledged that this research does not capture the full extent of caregiving by children and young people.

Australian research has found that a key reason behind the hidden nature of young caring is the fact that many young people who provide support or assistance to family members with an illness or disability, do not see themselves as 'carers' (Cass et al. forthcoming; Moore and McArthur, 2007; Morrow, 2005). Many of these young people see themselves as sons, daughters, siblings or grandchildren who 'help out' at home. Often they do not regard their responsibilities as unusual or exceptional in any way and studies in both Australia and the UK have suggested that non-recognition of caring responsibilities is particularly common among some culturally and linguistically diverse communities (EDAC, 2003; Mistic, 1996; Halpenny and Gilligan, 2004).

Even when some children and young people with caregiving responsibilities recognise that they shoulder greater responsibility than their friends and peers, they are often reluctant to seek support. Fear of unwanted intervention from social services and fear of stigma if they speak out have been identified in Australian and UK research as a key reason behind many young people's reluctance to seek support or assistance (Moore and McArthur, 2007; Aldridge and Becker, 1994). This is particularly salient in the case of young people caring for parents or other family members with a mental illness or drug or alcohol addiction (Dawe et al. 2006; ACMD, 2003).

Other factors that discourage young people from accessing support services identified by Cass et al. (forthcoming) include:

- lack of awareness of available support
- distance from available support
- prior experience of unreliable services
- the inappropriateness of certain types of available support.

Other service barriers and community attitudes that deter young people with caregiving responsibilities from seeking and accessing support services found by Moore and McArthur (2007) include:

Service barriers:

- Services do not always acknowledge or know how to deal with young carers.
- Services do not appear to have a good understanding of the family issues of their clients—i.e. the possibility that a young carer may be providing significant support.
- Young carers are not recognised as a target group or defined as 'at risk' in programme guidelines for mainstream youth services.
- Services are not flexible enough to be accessible or to meet young carers' needs.

- Services are not affordable.
- Services that meet their specific needs are not always available.
- Young carers do not know what services are available or how to access support.
- Young carers do not have the time to access external supports.

Community attitudes:

- attitudes towards disability, illness, alcohol or other drug use and caring experienced by children and young people;
- blame and shame, particularly when caring for a sole parent;
- lack of understanding of the dynamics of caring.

## 2.6 STRATEGIES FOR IDENTIFYING AND SUPPORTING YOUNG CARERS

Too often, young people with substantial caregiving responsibilities are identified when they or their family reach a crisis point and come to the attention of social services. Much work has gone into policy and service development in the UK to try to ensure that these young people are identified *before* their problems become entrenched.

### 2.6.1 Schools

Schools have been identified as a key venue for the identification and referral of young people who support and assist family members with an illness or disability.

The Australian Government's Department of Families, Housing, Community Services and Indigenous Affairs has produced two printed resources for Australian primary and secondary school teachers. They were designed to create awareness of some of the needs of young carers and suggest how these children can be identified and supported.

The resources provide some background information on young carers, list a number of indicators that might assist a teacher to identify a young carer in their classroom, such as looking for the behaviours including: often late or misses days or even weeks of school for no apparent reason; often tired and withdrawn; has difficulties joining extra curricula activities; is isolated or is a victim of bullying; is more confident with adults than peers; does not have lunch money; or does not have parents attending school events. Information for teachers about where they can go for assistance is also included (FaCSIA, 2005; 2007).

Two UK reports also provide guidance for schools to assist them identify pupils they suspect may have caregiving responsibilities at home, while acknowledging that many may try to hide the fact (Frank, 2002; The Princess Royal Trust for Carers, 2006).

As a first step, Frank (2002) gives a number of suggestions to assist schools help young people to identify *themselves* as caregivers. These include presentations in assemblies, Personal, Social and Health Education (PSHE) sessions and displaying information on school noticeboards about support offered by the school for young carers.

Both UK guides list a number of signs that may indicate a child is caring for someone at home, although the UK Princess Royal Trust refers to young people who are taking *inappropriate* levels of responsibility. These signs included arriving late to school, inability to complete homework on time, difficulty concentrating in class, behavioural difficulties, being withdrawn or over-sensitive, untidy clothing or appearance, missing school and tiredness. Both also recommend the inclusion of a statement on school admission forms to help identify families where someone has a long-term illness or care needs. The Princess Royal Trust for Carers (2006) suggests that a school's enrolment process should attempt to establish:

- Does the pupil have parents or other family members who have disabilities or other long-term physical or mental health problem?
- Does the pupil help to look after them and what impact does this have on the pupil's education?
- Is the family in touch with support services that could reduce the pupil's caring role?

Other recommendations from these UK reports include the importance of promoting positive images of disability in schools and tackling stigma.

The Princess Royal Trust for Carers (2006) report from the UK emphasises the importance of keeping young carers in school: 'It is vital that schools balance taking a supportive, flexible approach with giving the pupil a consistent message that their education is important'.

The report provides a number of suggestions to help young carers balance their caring responsibilities with their education. It also includes an 'Exemplar School Policy' for schools to display and distribute (see Appendix A). Practical strategies offered by young people with caregiving responsibilities in the UK to better manage their school and caregiving responsibilities include: lunchtime home work clubs, lesson notes for missed classes, or access to a telephone in times of crisis (Underdown, 2002).

Young carers may also be identified and benefit from programs designed to assist in the transition from school to employment. In Australia, the Department of Education, Employment and Workplace Relations (DEEWR) has established a national network of over 130 Local Community Partnerships (LCP). The aim of the partnerships are to work collaboratively with schools, parents, businesses and community organisations within regions to support young people to improve their knowledge of their options after leaving school and to access career development advice, skills and relevant work experience. LCP has implemented three Australian Government funded career development and transition support programs including:

- the *Structured Workplace Learning program* which provides structured workplace learning opportunities (either real or simulated) to students
- the *Career and Transitions Support program* where young people are exposed to a range of career and transition support programs
- the *Adopt a School program* which facilitates businesses to work with school(s) to provide young people with in hands-on learning and develop their knowledge and skills ([www.qualitylinks.com.au/deewr.htm](http://www.qualitylinks.com.au/deewr.htm)).

Relationships between businesses and schools within regions are facilitated by Regional Industry Career Advisers so that region-relevant industry career information is provided to schools and young people in the local area. These Advisers are supported by National Industry Career Specialists who focus on identifying necessary skills, training pathways and career opportunities in each industry.

Other programs may assist young carers to remain in education. Another DEEWR program—Youth Pathways—provides individual support to assist the ‘most at-risk’ young people to make a successful transition through to the completion of Year 12 (or equivalent). More flexible education and training options in community settings are also available to young people who are disconnected from mainstream schooling through the Connections initiative. State and territory governments also have school-based support programs for young people at risk of disengagement from school, education and training.

While schools may be one of the best venues for identifying young carers, it was noted recently by Dr Jo Aldridge, Director of the Young Carers Research Group at Loughborough University in the UK, that schools are still failing to identify them. Drawing on her research with young carers, she noted that when schools do manage to identify young carers it is often as a result of persistent absenteeism or lateness (House of Commons, 2008).

Research commissioned by Barnardo's (2006) in the UK indicates that much still needs to be done to assist school staff to tackle the issue with pupils they suspect may have caregiving responsibilities. The research involved a survey of 1000 teachers (no mention of response rate) and a survey of 83 young carers. The teachers' survey found that:

- The vast majority of teachers were concerned that some young carers might be 'falling through the net' and remain unidentified and unsupported.
- Almost half were unaware whether the young carers they encountered were known to the wider teaching staff and senior management team. One quarter was not aware if the young carers they encountered had been identified by social services. Two-thirds were not aware if the young carers they encountered were being supported by local young carers' projects.

The survey also investigated teachers' opinions on the hidden nature of much of the caregiving provided by children and young people. Reasons offered included:

- *A culture of secrecy*: Teachers felt that young carers kept their caring secret because of fear of potential stigma. In this study, young carers reported that they spent, on average, four years caring for a relative or parent before they received any support and that around one third of young carers said that they did not talk to their friends about their problem.
- *Lack of awareness within families about the supports that exist for young carers*: Many teachers felt that families were unaware of available support.
- *Lack of awareness by teachers about the issues that face young carers*—More than half of the teachers recognised that they may have missed some signs that might have alerted them to the fact that they had a student who was a carer. Young carers felt that teachers were not interested in their home responsibilities and did not have an understanding of young carer issues. Two-fifths reported that their work was affected by their caring responsibilities and the same proportion reported that they were punished by teachers at times when their work was affected by their caring responsibilities.
- *Lack of knowledge among teachers about external services*—Three-fifths reported that they would not be able to advise young carers directly about any local young carer projects in their catchment area.
- *Teaching staff being unaware of procedures that exist in their school and inadequate procedures being in place*—More than half of teachers surveyed admitted they had no knowledge of a designated contact person at their school with responsibility for looking after the needs of young carers. Half thought that the mechanism in schools to identify and support young carers was not effective enough.

Teachers in this UK study felt that parents had primary responsibility for identifying young carers followed by general practitioners and schools (Barnardo's 2006).

### **2.6.2 Health professionals**

Health professionals have also been identified as having an important role to play in identifying young people with caregiving responsibilities.

The UK report from The Children's Society and The Princess Royal Trust for Carers (Frank, 2002) makes reference to the National Strategy for Carers (Dept of Health, 1999), which states that GPs and other primary care staff can provide valuable, sensitive support to young carers and their families because health is likely to be a key agency that a family turns to for help with an illness or disability. It stresses the need for health professionals to ask who is providing support and meeting care needs in the home and, if necessary, make referrals to other appropriate support services with a view to ensuring that children and young people are not forced to take on inappropriate levels of responsibility.

All of these recommendations have been compiled in an information booklet for health care professionals to assist them identify situations where young carers and their families might need support and how to offer support once a need has been identified (The Children's Society, 2007b).

### **2.6.3 Social workers**

Social work services have also been identified by a UK study as having a critical role to play as they are likely to be in contact with young people with caregiving responsibilities and their families (Thomas, et al., 2003).

### **2.6.4 Identifying and supporting young carers through services**

The importance of adopting a holistic, 'whole-of-family' approach is foremost among the guidelines for identifying and supporting young carers through services. International research indicates that the 'whole-of-family' approach places the onus on the service provider or health professional to focus on the care recipient in the context of family relationships. Such an approach addresses the needs of *all* family members rather than simply focusing solely on the care recipient, or even the care recipient and primary carer group (Baago, 2005; Frank, 2002; The Princess Royal Trust for Carers, 2005; Banks et al., 2002). The Princess Royal Trust for Carers (2005) has developed an Exemplar Protocol for Local Authority Adults' and Children's Services conducting a joint assessment and assessing support needs for young carers and their families (The Princess Royal Trust for Carers, 2005).

Research undertaken in New Zealand by the Children's Issues Centre at the University of Otago, emphasises the importance of adopting a 'whole-of-family' approach, because families rarely come to the attention of social services when there is only the single issue of children taking on a caring role. Thus many children in the role are not being identified even while the initial services to support the care recipient are put in place:

*The implication is that more of these children are likely to be identified and their needs met when the notion of client and the basis of assessment are extended to the whole family rather than an individual 'client' within the family. (Gaffney, 2007: 29)*

Given the lack of knowledge about young carers in New Zealand, a key element of the study was the development of a recording tool based on Australian and UK research for social service agencies to use to identify young carers. A copy of the tool is in Appendix B.

Four of the eight agencies approached by the NZ researchers agreed to participate. All indicated that families find the issue of children taking on a significant caring role as sensitive because it might raise care and protection concerns. A total of 21 children were identified by the four agencies as potential young carers and the percentage of their client group that could be young carers ranged between 1–15 per cent (Gaffney, 2007).

The agencies in NZ described a number of challenges they faced in identifying and supporting potential young carers using the tool:

- They did not always feel that they were in a position to talk with the child or young person or their family about this role.
- A crucial issue for agencies was: 'When would we have developed a secure enough relationship with the family to be able to ask these questions?'
- Agencies working with young people who they identified as having care responsibilities felt that their relationships with them would be compromised if they were to ask the questions.
- The tool involved assessing caring within families that could have a lot of other concerns and issues to deal with. In none of the cases where 21 children were identified as potential young carers were families or children referred to a service because of children taking on a caring role. Thus caring can remain hidden.
- In families where children take on a caring role, a lot of the stress for children can be alleviated by addressing the caring concerns for the primary carer in the family. Thus, a holistic family assessment seems most appropriate. However, families might not want a holistic family assessment.

- The amount of family privacy associated with young carers means that there is no easy approach to identifying them (Gaffney, 2007).

The importance of a collaborative, inter-agency approach is also emphasised in UK research because the needs of young carers and their families cross both adults' and children and families' services (Banks et al. 2002; Frank, 2002).

### **2.6.5 Disseminating information about services for young carers**

Distributing information about services for young carers requires consideration of the format in which it is made available and where the information should be distributed. Relevant formats include written, visual, Braille, audio and information in a range of languages. UK research indicates that locations for distributing written information include: GP surgeries; the point of hospital discharge; schools; community centres; libraries; churches; temples; mosques; synagogues; leisure centres; day centres; and youth clubs (Frank, 2002). The internet is another vital source of information for young carers as evidenced by the website links in section 2.4 aimed at young carers in particular caring situations.

### **2.6.6 Specific groups of young carers**

Australian research has found that young carers are a diverse group and has identified some specific groups that may require interventions appropriate to their particular circumstances to assist in their caring situation (Cass et al. forthcoming; Kroehn and Wheldrake, 2006). These groups include:

- young people in Aboriginal and Torres Islander communities
- young carers in rural and remote areas
- young people in families where there is a parent with mental ill health
- refugees
- young people in situations where there is drug misuse or alcohol dependency
- young people of culturally and linguistically diverse backgrounds
- young people living in areas of relatively low socio-economic status, and
- young people caring for a person with a physical disability or chronic pain.

## 2.7 CONCLUSION

Effectively identifying and supporting young people who provide support and assistance for family members with an illness or disability poses many challenges for policy makers and service providers. The task is complicated by the fact that many young people and their families feel compelled to hide their caregiving roles and also by the fact that many young people do not recognise that they are in fact in a caring role. School staff, health professionals and social workers have been identified as having a vital role to play in identifying young people who provide support and assistance for family members with an illness or disability. Recommendations for effective service delivery focus on the importance of child and family services adopting a 'whole-of-family', multi-agency approach in order to identify and support young people in caregiving roles. Service providers are also strongly encouraged to disseminate information in accessible formats about their services in locations frequented by young people and their care recipients. The importance of a flexible approach that recognises the different needs of a heterogeneous target population, where a 'one size fits all' policy is inappropriate, is also emphasised.

# 3. YOUNG CARERS— NUMBERS OF IDENTIFIED AND POTENTIAL CARERS

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## 3.1 INTRODUCTION

This section of the report estimates baseline numbers and proportions of young people who are carers in the population using the two most up-to-date nationally representative household surveys, the 2006 Census and SDAC 2003. These surveys have differing methodologies and, hence, produce different estimates. First, the analysis identifies the number and proportion of young carers aged 15–24 years identified in the 2006 Census. The estimates also show the number and proportion of young people from Indigenous and culturally and linguistically diverse backgrounds who indicated that they provide care. Numbers and trends in the numbers of carers are then estimated using the SDAC data. Finally, this section estimates the number of young people who share a household with a person with a disability but who do not identify themselves in the data as a carer. This group is described as ‘potential carers’.

## 3.2 DATA AND LIMITATIONS

### 3.2.1 2006 Census

The Australian Bureau of Statistics conducted the *Census of Population and Housing 2006* in August that year. In 2006, for the first time in the history of the Australian Census, questions about the need for assistance with self-care, mobility and communication were asked about all people in the household. In addition, questions about unpaid work, including the provision of informal care, were asked of all people in the household aged 15 years and over.

The Census question on informal care asked: '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?' Due to the nature of the data collection (self-completion rather than interviewer) and the question asked, the Census data is likely to represent an undercounting of young carers, particularly young people who provide episodic rather than continuous care (see also Appendix in ABS, 2008). The level of non-response to the Census carer question may also affect the number of reported carers, particularly among Indigenous and CALD communities. Overall, 5.9 per cent of young people aged 15–24 years, whose main language was English and were not Indigenous, did not provide a response to the carer question, compared with 7.8 per cent of young people who spoke languages other than English at home, and around 12 per cent of Indigenous young people<sup>5</sup>. These issues must be borne in mind when interpreting the results from the Census data. Nevertheless, due to the fact that the Census is a whole population survey rather than a survey of a sample of the population, it provides a unique opportunity to estimate the number and characteristics of Indigenous and CALD young carers. It also provides the only source of data on carers living in remote areas of Australia.<sup>6</sup>

### 3.2.2 Survey of Disability and Ageing 1988

The Survey of Disability and Ageing (SDA) 1988 was the first nationally representative survey in Australia to include informal carers. The SDA sample comprised approximately 67 000 people in households in both rural and urban areas of Australia. The survey identified all people who needed assistance for specific tasks, and then asked who

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5 There are a number of ways to interpret non-response to Census questions. In this report we follow the approach of the ABS (2008) and remove the non-respondents from the denominator in the calculation of rates of caring among young people. This approach assumes that non-respondents are proportionally distributed between carers and non-carers. Alternative approaches would be to assume all non-respondents are either non-carers or carers which would provide lower and upper bound estimates for the number of carers.

6 Please see section 5.2 for discussion of Census data collection in remote communities.

provided that assistance. Respondents could indicate up to five possible sources of informal or formal assistance. They were also asked to indicate the main source of assistance for each task and if the identified person lived in the same household, the person was defined in the survey as a main carer. This definition is similar to the classification of co-resident primary carers in later SDACs.

### **3.2.3 Survey of Disability, Ageing and Carers (SDAC) 1993, 1998 and 2003**

The SDAC is a nationally representative survey of households and cared accommodation which has been conducted on a five-yearly basis since 1993. Data in this analysis is taken from the household component of the survey, which is based on a random sample of private and non-private dwellings in all parts of Australia, with the exception of remote and sparsely populated areas. Data for this survey is collected through computer-assisted, face-to-face interviews.

Carers are identified by either the initial person contacted in each household, who provides general information about members of the household, or by a person with a disability or who is frail aged within the household. Carers are defined as 'a person of any age who provides an informal assistance, in terms of help and supervision, to people with disabilities or long-term conditions, or older people (aged 60 years or over). This assistance has to be ongoing, or likely to be ongoing, for at least six months'. A 'primary carer' is defined as 'a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities'. This assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities of communication, mobility and self-care (ABS 2004, p.77).

The SDAC data provides the most comprehensive data on the carer's care situation and experience of caring. For young people aged between 10 and 24 years, the SDAC in 1998 and 2003 contains basic socio-demographic information and some details on their care situation. In 1993 this information is only available for young people aged 15–24 years. In addition, for young people aged 15–24 years, the SDAC in 1993, 1998 and 2003, provides data on their personal and household income and participation in employment and study. The SDAC surveyed approximately 42 000 people in the household component in 1993, 36 951 people in 1998, and 36 241 people in 2003. Sample sizes used in the analysis are reported in the tables in Appendix E.

A number of limitations should be borne in mind when considering the information contained in these surveys. Methodological changes to the survey over this period have meant that the classification of the population of people with disability and the identification of their carers has changed. This does not affect the trend analysis between 1998 and 2003. However, trends estimated over the period 1988 to 2003 should be interpreted with some caution.

## 3.3 NUMBER OF YOUNG CARERS

### 3.3.1 2006 Census<sup>7</sup>

Table E.1 (in Appendix E) shows the number of young people who were providing care overall and distinguished by Indigenous status and language spoken at home, which in this instance is used as a proxy for CALD background. In total, 119 436 young people, aged 15–24 years, indicated that they provided care in the 2006 Census. This group was comprised of 6583 Indigenous people, 86 887 non-Indigenous people who spoke only English at home, and 23 893 young people of CALD backgrounds (and a small group of 2073 young carers whose Indigenous or cultural background could not be determined due to non-response).

Overall, young women accounted for 56 per cent of CALD carers, 59 per cent of Indigenous carers and 58 per cent of other carers. However, as shown in the previous Australia research (Cass et al.forthcoming), the gender distribution of young carers differed by age group. Young women comprised around 55 per cent of young carers in the age group aged 15–19 years, irrespective of Indigenous or CALD status. They made up a larger proportion of the older age group: 61 per cent of young Indigenous carers aged 20–24 years, 57 per cent of CALD carers and 60 per cent of carers from other backgrounds in this age group.

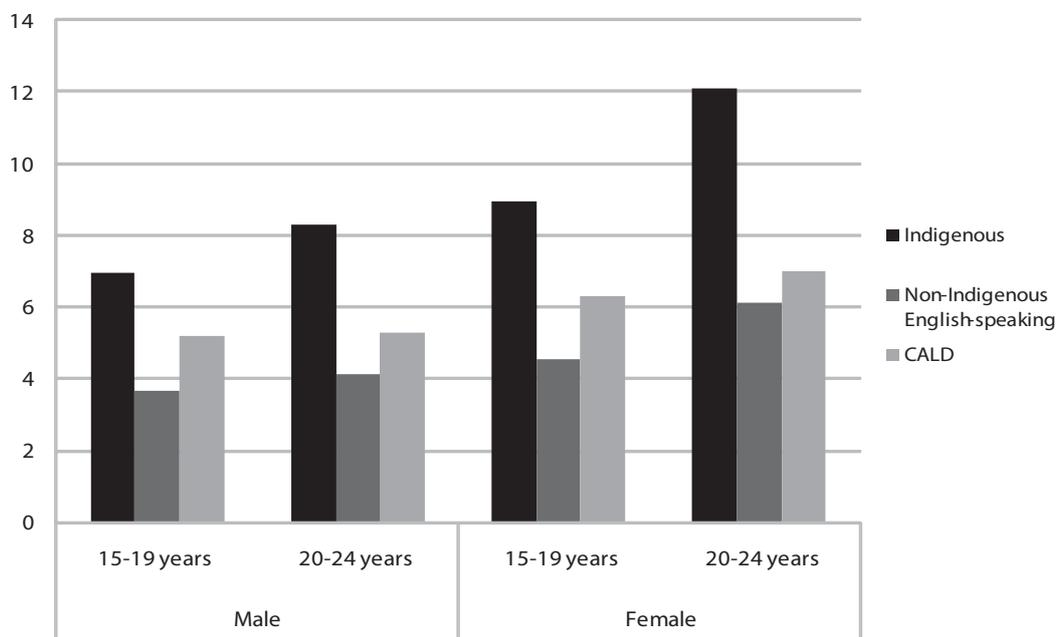
Figure 3.1 and (Table E.2 in Appendix E) shows the proportion of young people who were carers in the Census data by age, sex and cultural background. Overall, Indigenous young people were nearly twice as likely as non-Indigenous English-speaking young people to indicate that they were carers (9.0 per cent compared with 4.7 per cent respectively). This finding held irrespective of age and gender. Young men and women from CALD backgrounds were less likely than Indigenous young people, but more likely than other non-Indigenous, English-speaking young people, to be carers (6.1 per cent

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<sup>7</sup> These numbers, and all figures reported in the subsequent chapters using the Census are based on Census data tables provided at the State or Statistical Division level and the aggregate numbers may differ slightly to aggregate numbers for Australia reported on the ABS website due to confidentialising processes.

of this group). The data also indicates that young women were more likely to be carers than young men, and that young people in the age group 20–24 years were more likely to be carers than the younger age group (aged 15–19 years). Caring was most prevalent among young Indigenous women aged 20–24 years, with 12.1 per cent of this group providing informal care. The group with the lowest rates of care provision were young men who were from neither Indigenous nor CALD backgrounds.

**Figure 3.1 Proportion of young people (aged 15–24 years) who were carers by age, sex and Indigenous status and CALD status (2006 Census) (per cent)**

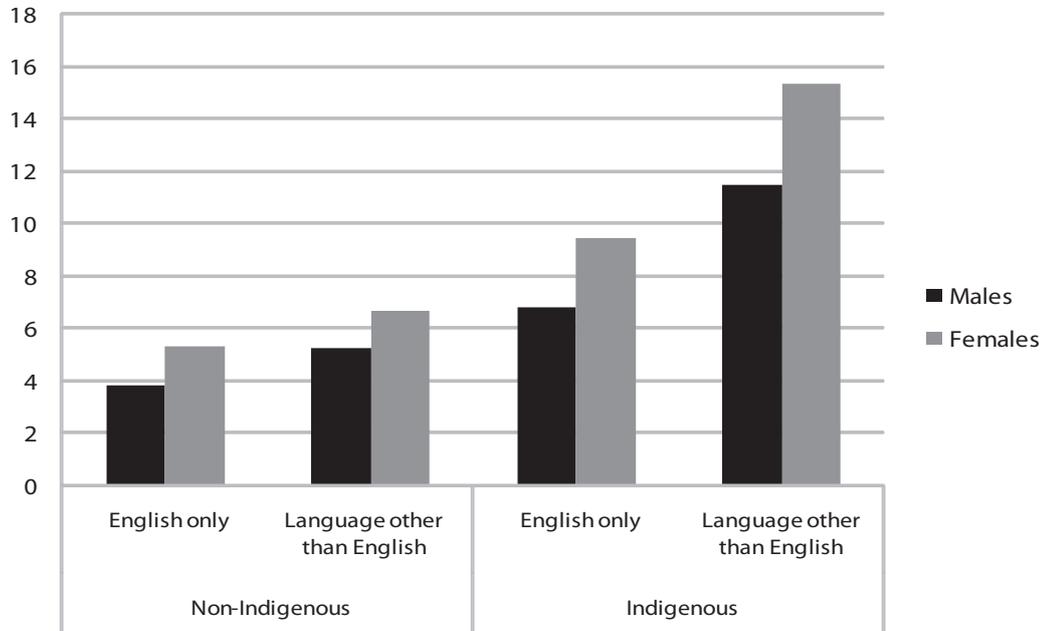


Source: ABS 2006a

Notes. Proportions are calculated by excluding non-respondents to the carer question from the denominator. Indigenous total also includes young people who identified as Indigenous and who speak languages other than English at home, which may include Indigenous languages. CALD includes young people who spoke other languages at home and did not identify as Indigenous.

Figure 3.2 examines the cultural diversity of young carers in the Census a little further by showing the proportion of all young people (aged 15–24 years) who are carers by their Indigenous status and language spoken at home. It is evident that caring is most prevalent among Indigenous young people who speak other languages at home. As will be shown in Section 5, this group of young carers tend to live in remote areas of Australia, and may speak Indigenous languages.

**Figure 3.2** Proportion of all young people (aged 15– 24 years) who were carers, by sex, Indigenous status and language spoken at home (Australia), (2006 Census) (per cent)



Source: ABS 2006a

Note: Proportions are calculated by excluding non-respondents to the carer question from the denominator, which assumes that non-response is proportionally distributed between carers and non-carers. Total excludes carers whose Indigenous status or language spoken at home was not stated.

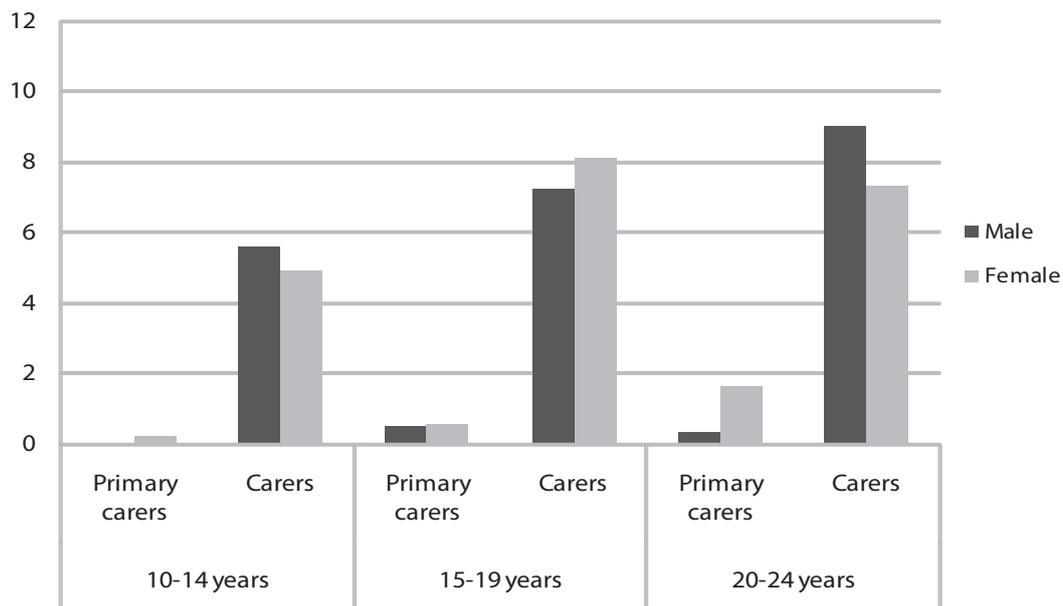
### 3.3.2 SDAC 2003

As noted before, the Census data is likely to represent an undercounting of the number of young carers. Table E.3 (in Appendix E) and Figure 3.3 show the number and proportion of young people who are primary carers and other carers aged between 10 to 24 years based on estimates from the SDAC 2003. Estimates from this survey suggest that 311 672 or 7.6 per cent of all young people aged 10 to 24 years were carers. This estimate included 240 144 young people aged between 15 and 24 years, which is approximately twice the number recorded in the 2006 Census. Reasons for the additional carers identified in this survey include the method of data collection and carer identification.

Overall, young men and women were equally likely to be carers in this survey. However, a higher proportion of young women were primary carers, or the main provider of care, compared to young men, in all age groups. In some ages (10–14 and 20–24 years)

young men were more likely to be other carers than young women. While young women comprised 49 per cent of all carers aged 10–24 years, they accounted for 74 per cent of primary carers. As indicated in the Census data, caring is most prevalent among the age group 20–24 years, and having the main responsibility for providing care, or being a primary carer, was most prevalent among young women aged 20–24 years.

**Figure 3.3** Proportion of young people who are primary carers and carers by age and sex (weighted percentages)



Source: ABS 2003.

### 3.3.3 Changes in the numbers of young carers over time (1998 to 2003)

The SDAC surveys in 1998 and 2003 had very similar methodologies for identifying young carers and so may be used to compare any changes in the population of young carers over that time.

Table 3.1 shows the proportions of young people of primary carers, other carers and all carers in 1998 and 2003 and Table E.4 (in Appendix E) shows the numbers in each of these groups over the years.

Over this five-year period, the numbers of young primary carers has increased from around 16 000 to 23 000 and from about 0.4 to 0.6 per cent of young people. This change was due to an increase in the proportion of young women aged 20–24 years who became primary carers in this period (0.8 to 1.6 per cent). The number

and proportion of young men who were primary carers did not significantly change between 1998 and 2003.

The estimate of the number of young people who were other carers significantly declined from around 318 000 to around 288 000 or from 8.1 to 7.1 per cent of young people. Although all age groups for young men and women recorded small declines, the only significant change was a decline in the proportion of young men aged 15–19 years who were carers (from 9.4 to 7.2 per cent).

These two contradictory trends have resulted in an overall decrease in the estimated proportion of young people who were identified as carers in the SDAC from 8.5 to 7.6 per cent between 1998 and 2003, although this change was also not found to be statistically significant.

**Table 3.1: Proportion of young people who are carers in 1998 and 2003 (weighted percentages)**

	Primary carers		Carers		All carers	
	1998	2003	1998	2003	1998	2003
<b>Males</b>						
10–14 years	n.p	n.p.	6.0	5.6	6.2	5.7
15–19 years	n.p	n.p	9.4#	7.2#	9.6	7.7
20–24 years	0.5	0.3	8.7	9.1	9.2	9.4
<b>Total males</b>	<b>0.3</b>	<b>0.3</b>	<b>8.0</b>	<b>7.3</b>	<b>8.3</b>	<b>7.6</b>
<b>Females</b>						
10–14 years	0.2	0.2	5.6	4.9	5.8	5.1
15–19 years	0.6	0.6	9.9	8.1	10.5	8.7
20–24 years	0.8##	1.6##	9.2	7.4	10.0	9.0
<b>Total females</b>	<b>0.5</b>	<b>0.8</b>	<b>8.2</b>	<b>6.8</b>	<b>8.7</b>	<b>7.6</b>
<b>Persons</b>						
10–14 years	0.2	0.1	5.8	5.3	6.0	5.4
15–19 years	0.4	0.6	9.6#	7.6#	10.0	8.2
20–24 years	0.6#	1.0#	8.9	8.2	9.6	9.2
<b>Total persons</b>	<b>0.4#</b>	<b>0.6#</b>	<b>8.1##</b>	<b>7.1##</b>	<b>8.5</b>	<b>7.6</b>

Source: ABS 1998, 2003.

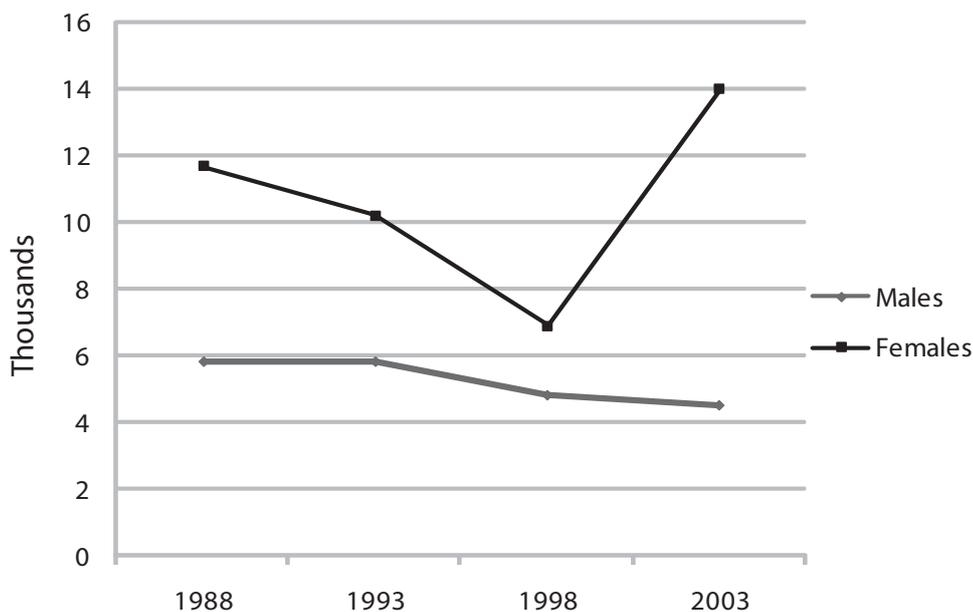
Note: # and ## denote statistically significant change between the years 1998 and 2003 (# p<0.1, ## p<0.05).

### 3.3.4 Longer-term trends in numbers of young co-resident primary carers

The ABS has collected data on primary carers who live with the person they care for since the *Survey of Disability and Ageing* in 1988, so it is possible to estimate the number of young carers in this group over that period. The data is limited due to small sample sizes. However, as young people in this group are likely to be most affected by their care responsibilities, it is important to examine the trends in their numbers and their characteristics.

Figure 3.4 describes the trends in the estimates of the number of male and female young co-resident primary carers over the period 1988 to 2003. These estimates are based on small sample sizes and must be interpreted with caution. Overall, it seems that the number of young men who are co-resident primary carers has stayed relatively stable during this time. Between 4000 and 6000 young men undertook this major caring responsibility in each of the years for which we have data. The estimates for the number of young women show greater variation—particularly between 1998 and 2003—when the estimated number of young women who were co-resident primary carers doubled from around 7000 to 14 000. In the earlier years, an estimated 10 000 to 12 000 young women had the primary responsibility to care for someone in their home. In all years, there is a consistent pattern of a greater number of young women undertaking the main caring role than young men.

**Figure 3.4: Number of co-resident primary carers aged 15–24 years by sex (1988 to 2003) (thousands)**



Source: ABS 1988, 1993, 1998 and 2003.

### 3.3.5 Hidden or potential carers

The literature outlined in Section 2 highlights a concern about the number of young people who do not identify as a carer due to non-recognition of the assistance they provide and other factors, such as stigma. While the very notion of ‘hidden carers’ suggests that it is not possible to identify this group in data sources, estimates of the number of young people who have some experience of disability, due to the fact that they share a home with a person who needs assistance, can be made. In the following tables, we use two definitions of ‘potential carers’ in the Census data to estimate the potential pool of ‘hidden’ young carers in Australia. Arguably, young people who live with a person with a need for assistance for one of the core activities are likely to provide some of that assistance. However, it should not necessarily be assumed that all young people identified by these methods are carers.

#### *Definitions of potential carers*

The 2006 Census offers the possibility of identifying the number and proportion of young people who live with a person with a disability<sup>8</sup>. For those aged 12–14 years, there is data on the number of other people with disability in the household and the number of identified older carers. Potential carers are those young people aged 12–14 years who live with a person with a disability.

For the older age group (aged 15–24 years) there is data on whether these young people identified that they were a carer and whether they live with a person with a disability. Potential carers in this age group are defined as those who live with a person with a disability but who did not identify as a carer.

#### *Young potential carers aged 12–14 years*

Table 3.2 reports on the proportion of young people aged 12–14 years by the disability status of the household members and whether there are carers in the household. The analysis showed that this group of potential carers represents about 2 per cent of boys and girls aged 12–14 years, or a total of 14 131 young people aged 12–14 years (See Table E.5 in Appendix E). A small proportion (or 2450) of this group have a disability themselves, but the majority do not. Around 0.3 per cent (or 2405) young people in this

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8 In this analysis, the term ‘disability’ will refer to a person reporting that they needed assistance for a core activity (self-care, mobility and communication) “because of a disability, long term health condition (lasting six months or more) or problems to do with old age” (ABS 2006b p.40). Due to differences in the methodology of the Census and SDAC, the Census data can provide indications of the characteristics of people with disability but is not regarded as suitable for providing a measure of the prevalence of disability like the SDAC (ABS 2006b p.19).

age group lived in a household with a person with a disability where no other identified carer was present. However, it may be that the person with a disability receives assistance from formal services.

**Table 3.2: Proportion of young people aged 12–14 years who live with a person with a disability by presence of other carers (Australia, 2006)**

	No carer present	At least 1 carer present	Total
<b>Males</b>			
No person with a disability in household	79.96	18.15	98.11
Young person has disability and other household members have disability	0.06	0.37	0.42
Other household members have disability	0.25	1.21	1.46
Potential young male carers	0.31	1.58	1.89
<b>Females</b>			
No person with a disability in household	81.12	17.10	98.22
Young person has disability and other household members have disability	0.03	0.18	0.21
Other household members have disability	0.28	1.29	1.57
Potential young female carers	0.31	1.47	1.78

Source: ABS 2006a

Table E.6 (in Appendix E) reports on the number and proportion of Indigenous and non-Indigenous young people aged 12–14 years who are potential young carers by this definition. Indigenous young people are slightly more likely than non-Indigenous young people to live in households with a person with a disability (3 per cent compared with 2 per cent). Table E.7 (in Appendix E) reports the same results for young people in this age group by language spoken at home and finds that young people from CALD backgrounds are less likely to live in households with a person with a disability than those who only speak English at home. Only 1 per cent of the CALD young people were identified as potential carers.

### ***Identified and potential carers aged 15–24 years***

Young people aged 15 years and older had the opportunity to identify as carers in the Census. Depending on who filled in the Census for each person, a positive response to the carer question indicates either a self-identified or household-identified carer. A negative response to this question may represent a young person who does not identify as a carer, particularly if they live in a household with a person with a disability. The following tables and graphs explore this question of identified and non-identified potential carers for young people in households with others (not living alone). The analysis first looks at all young people and then examines whether this issue is more prevalent among carers from different cultural backgrounds.

Table 3.3 shows the proportion of young men and women aged 15–24 years, whether they live with a person with a disability, and also whether they indicated they were a carer. (Numbers are reported in Table E.8 in Appendix E). Overall, 1.4 per cent (or 30 336) young people aged 15–24 years, were identified young carers living with a person with a disability. Also, 3.6 per cent or 79 198 identified young carers did not live with a person with a disability, indicating either they cared for someone outside their home, or they cared for someone within the home who did not indicate in the Census that they have a core activity restriction. A further 3.6 per cent or 77 607 young people lived with a person who had a disability, but did not identify as a young carer in the Census. If all these young people did provide assistance, but failed to recognise this assistance as care, this data suggests that the population of hidden carers could almost be as large as the identified carers in the Census. Young men were more likely than young women to be ‘potential carers’ (3.9 per cent of young men compared with 3.1 per cent of young women). Men and women in the younger age group (aged 15–19 years) were also more likely to be hidden carers than men and women aged 20–24 years.

**Table 3.3: Proportion of young people aged 15–24 years<sup>(a)</sup> by age, co-residence with a person with a disability, and identified carer status (Australia, 2006)**

	Lives with a person with a disability		Does not live with a person with a disability		Total
	Identified carer	Non-identified potential carer	Identified carer	Not a carer	
<b>Males</b>					
15–19 years	1.4	4.5	2.6	91.6	100.1
20–24 years	1.1	3.4	3.2	92.3	100.0
Total males	1.2	3.9	2.9	91.9	99.9
<b>Females</b>					
15–19 years	1.6	3.9	3.3	91.2	100
20–24 years	1.4	2.4	5.1	91.1	99.9
Total females	1.5	3.1	4.2	91.1	99.9
<b>Total</b>	<b>1.4</b>	<b>3.5</b>	<b>3.6</b>	<b>91.5</b>	<b>100</b>

Source: ABS 2006a.

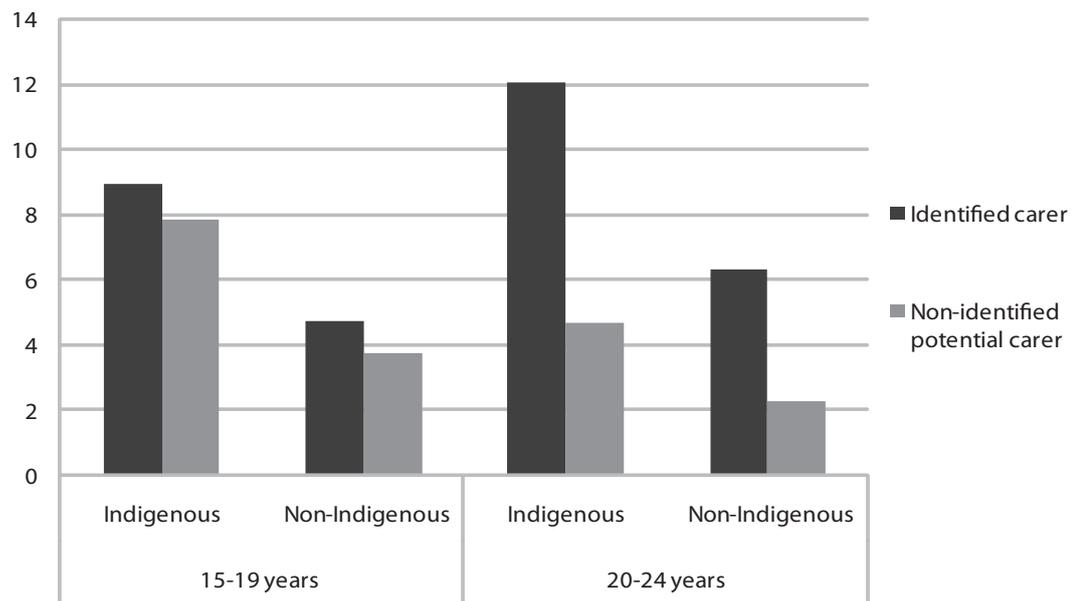
Note: (a) This sample includes young people living in households with other people only, not young people living alone.

Figure 3.5 shows the proportion of young women and Figure 3.6 shows the proportion of young men who are identified and potential carers by Indigenous status. These graphs show that Indigenous young women and men are more likely than non-Indigenous women and men to be both identified and potential carers. Eight per cent of Indigenous young women aged 15–19 years and 9 per cent of Indigenous young men in this age group were living with a person with a disability, but did not identify as a carer. This rate is double that of 4 per cent for non-Indigenous women and 4.3 per cent for non-Indigenous men in this age group. Nearly 5 per cent of Indigenous young women and 7 per cent of Indigenous men in the age group 20–24 years were non-identified potential carers compared with 2 and 3 per cent of their non-Indigenous counterparts, respectively.

A relatively equal proportion of young women aged 15–19 years were identified and potential young carers (in both the Indigenous and non-Indigenous groups). By contrast, in the older age group there were over twice as many young women who identified as carers as there were potential carers. For young men, the relationships were different. There were more potential young carers than identified carers in the younger age group and slightly fewer potential young carers than identified carers in the older age group. This finding held irrespective of Indigenous status.

All these young people are sharing households with others, so it may be the case that younger people who are still at school age may not be involved in care, or that they do household chores and assist the person with a disability but do not recognise this as care.

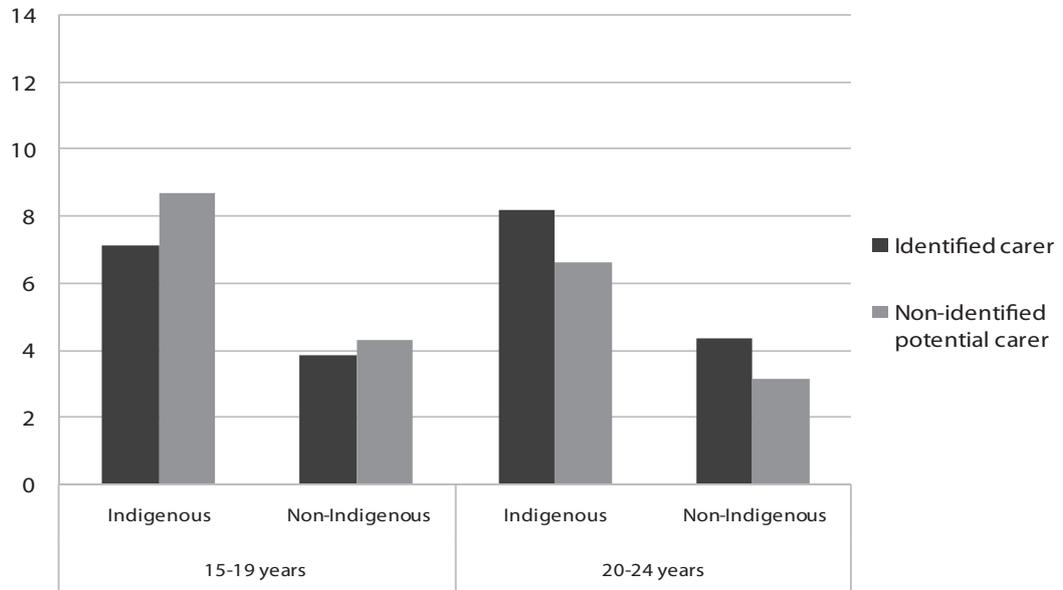
**Figure 3.5: Proportion of young women who are identified and non-identified potential carers, by age and Indigenous status (Australia, 2006)**



Source: ABS 2006a

Note: Total excludes people whose carer status was not stated and people whose Indigenous status was not stated. This sample includes young people living in households with other people only, not young people living alone.

**Figure 3.6: Proportion of young men who are identified and non-identified potential carers, by age and Indigenous status (Australia, 2006)**



Source: ABS 2006a

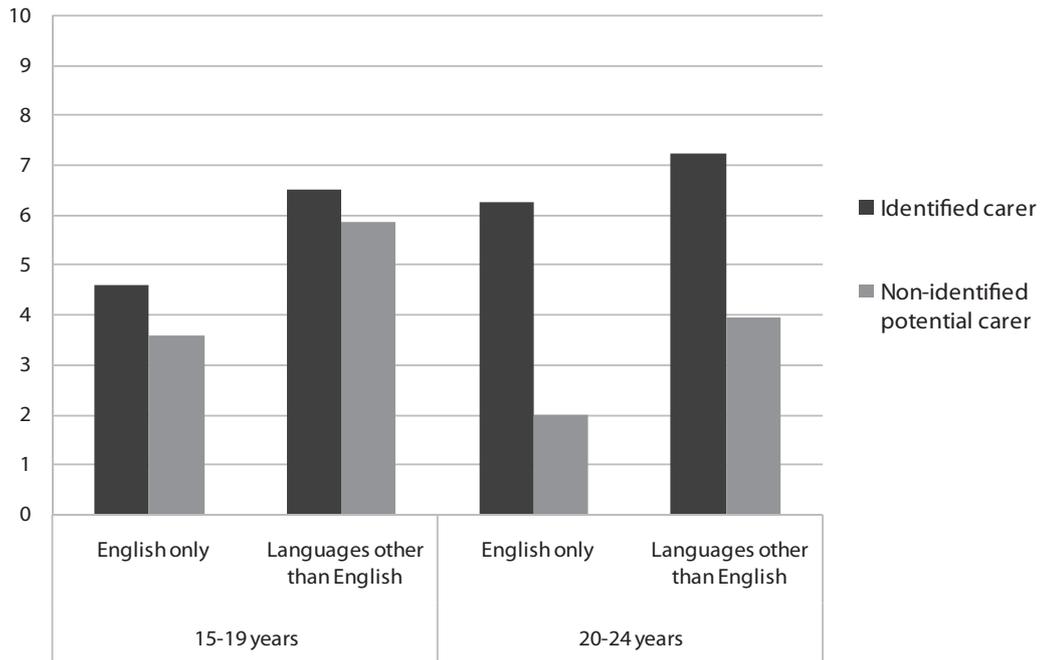
Note: Total excludes people whose carer status was not stated and people whose Indigenous status was not stated. This sample includes young people living in households with other people only, not young people living alone.

Figure 3.7 and Figure 3.8 provide the same data for young women and men respectively, distinguished by the languages they speak at home or CALD status. These graphs show that young people from CALD backgrounds are more likely than their non-CALD peers to be both identified and non-identified potential carers. Young people aged 15–19 years from CALD backgrounds had relatively high rates of potential caring (5.9 per cent for young women and 6.3 per cent for young men). Young men in this age group were also slightly more likely to be potential carers than identified carers. As in the previous graphs, among the 20–24 year age group there were more identified than potential carers, irrespective of CALD status.

These graphs suggest that there are some young people living in households where other members have a severe or profound limitation and yet these young people do not identify, or are not identified within their households, as providing assistance. It may be the case they these young people are not providing substantial or any amount of care, nevertheless this data points to two issues. First, that disability is more

prevalent among the households of Indigenous and CALD young people than other young people. Second, that there is a significant group of young people from these communities whose lives are likely to be affected by co-residence with disability and who may need additional recognition and support if they are undertaking caring roles.

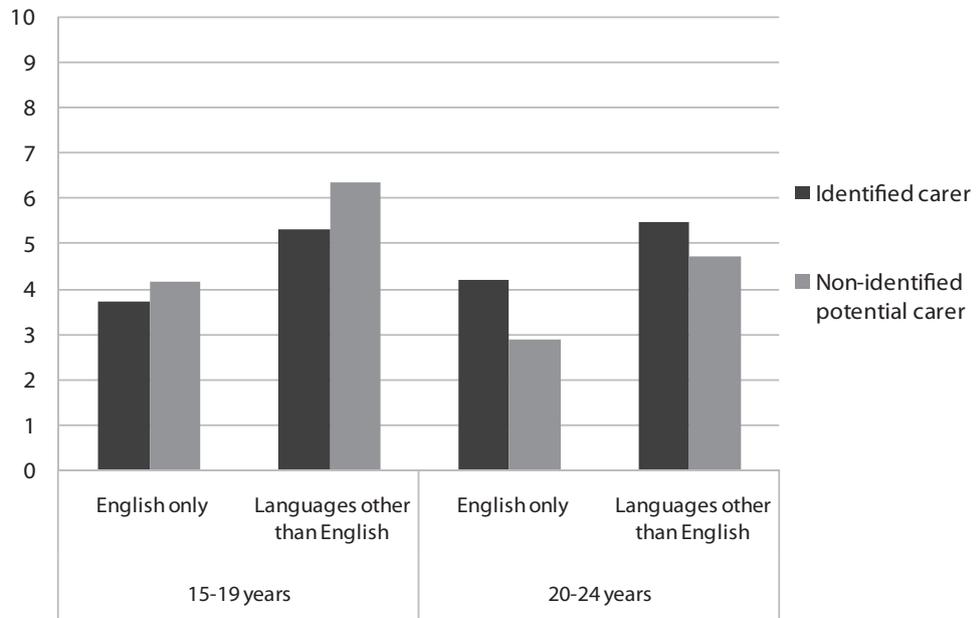
**Figure 3.7: Proportion of young women who are identified carers and non-identified potential carers, by age and languages spoken at home (Australia, 2006)**



Source: ABS 2006a

Note: Total includes people whose carer status was not stated but excludes people whose language spoken at home was not stated. Due to data restrictions, Indigenous young people who speak languages other than English at home will be included in this CALD sample. However, Indigenous young people comprise only 2–3 per cent of the population who speak languages other than English and who did not indicate that they provide care and 5–6 per cent of the population who speak languages other than English and who did identify as a carer. This sample includes young people living in households with other people only, not young people living alone.

**Figure 3.8: Proportion of young men who are identified carers and non-identified potential carers, by age and languages spoken at home (Australia 2006)**



Source: ABS 2006a

Note: Total includes people whose carer status was not stated but excludes people whose language spoken at home was not stated. Due to data restrictions, Indigenous young people who speak languages other than English at home will be included in this CALD sample. However, Indigenous young people comprise only 2–3 per cent of the population who speak languages other than English and who did not indicate that they provide care and 5–6 per cent of the population who speak languages other than English and who did identify as a carer. This sample includes young people living in households with other people only, not young people living alone.

### 3.4 SUMMARY

This section of the report provided baseline estimates of the number of young carers in Australia. The Census data indicates that in 2006 almost 120 000 young people aged 15–24 years provide care, whereas the SDAC in 2003 suggests the number of young carers in this age group is closer to 240 000. The two data sources have differing methodologies.

In the Census, young carers self-identify or are identified by the person in their family who filled in the single question on unpaid care on the form. In the SDAC, a trained interviewer asks either a person in the household or the person who needs assistance as to who provides the care for specific tasks. The latter method implies that young people who help out around the house and provide day-to-day assistance will be more readily recognised as carers in the SDAC. The SDAC, therefore, provides the best estimates of the actual number of young carers, although this too may be an undercounting of the number of young carers for other reasons, such as stigma and non-disclosure associated with specific disabilities (i.e. mental illness).

The Census and the SDAC show some consistencies and differences in the age and gender composition of young carers<sup>9</sup>. In both data sources, it is clear that the prevalence of informal caring increases with age. In the SDAC, young men and women make up an equal proportion of the young carers overall, however, young women comprise a greater proportion of primary carers. In the Census, young women account for over half of all young carers (aged 15–24 years), and around 60 per cent of the carers aged 20–24 years.

The Census, despite the warnings about non-response that must be borne in mind, is a whole population rather than sample survey, and thus, provides a unique opportunity to document the prevalence of informal caring in Indigenous and CALD communities. The Census data shows that Indigenous young people had the highest rates of informal care provision, particularly among those Indigenous young people who spoke a language other than English at home. Caring was also more prevalent among CALD young people than those who were of neither Indigenous nor CALD backgrounds.

Analysis of trends between 1998 and 2003 using the SDAC showed that the number of young primary carers increased over this period. This increase was mainly due to a higher number and proportion of young women aged 20–24 years who were identified as primary carers in 2003. However, between 1998 and 2003, the estimated total number of young carers declined from 334 316 to 311 672 young people aged 10–24 years. This represented a decline from 8.5 per cent to 7.6 per cent of young people. The overall decrease was partly due to a reduction in the number of young men aged 15–19 years who were identified as carers.

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9 For further discussion of differences in survey methodologies, and the characteristics of carers identified in the SDAC and the Census, see Appendix in ABS (2008)

The available data on longer-term trends is limited and less reliable due to small sample sizes. Analysis of longer-term trends (between 1988 and 2003) for young co-resident primary carers (aged 15–24 years) showed that the number of young men who were co-resident primary carers had remained steady during this period (between 4000 and 6000 young men) whereas the number of young women had been more variable and had slightly increased over this time (from around 10–12 000 to 14 000). A constant finding across all years was that young women made up the majority of the young co-resident primary carers.

This section also outlined a method for using the Census data to estimate the pool of potential 'hidden' young carers in Australia. 'Potential young carers' were defined as those aged 12–14 years who lived with a person with a disability and, in addition, those aged 15–24 years who lived with a person with a disability and did not identify as a carer. The data show that 14 000, or 2 per cent, of the younger age group (aged 12–14 years) lived with a person with a disability. About one-sixth of these young people lived in households where there was no identified carer. Just over 77 000, or 3.5 per cent, of young people aged 15–24 years shared a home with a person with a disability and did not identify as a carer. This latter finding suggests that, if all these young people engaged in some form of assistance, the number of potential carers is about 65 per cent of the number of identified carers.

A higher rate of potential caring was found among young people who were aged 15–19 years, Indigenous, of CALD backgrounds, and young men. The higher prevalence of 'potential carers' among Indigenous and CALD young people may reflect a higher prevalence of disability or a lack of self-identification as a carer in these communities, or both. Young people aged 15–19 years are more likely than the 20–24 year-old age group to live with their family, and thus, if they are providing assistance, it may be not be recognised as care but considered simply part of the family activity. Young men may be less likely to identify as a carer than women for reasons of stigma, or it may be the case that young men are less involved in providing assistance in households than young women.

Overall, the data on potential carers suggests that a significant number of young people in Australia live with a person with a disability and yet do not identify as carers when given the opportunity to do so in the Census. This finding implies that campaigns to promote greater awareness and recognition of caring among young people—particularly of Indigenous and CALD backgrounds—may assist these groups to access appropriate support and services.

# 4. DEMOGRAPHIC CHARACTERISTICS OF YOUNG CARERS AND TRENDS IN SDAC

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## 4.1 INTRODUCTION

Previous research in Australia has examined the number and characteristics of young carers at one point in time using the SDAC and other sources (Bittman et al. 2004; Cass et al.forthcoming; Noble-Carr and DFACS, 2002a, 2002b). The following analysis uses the SDAC and the SDA to examine trends in the characteristics of young carers and primary carers between 1998 and 2003 and for young co-resident primary carers between 1988 and 2003. The analysis considers the cultural background of young carers, their care situation, their participation in education and employment, their income levels and their geographical location.

## 4.2 CULTURAL BACKGROUND

In the SDAC it is possible to describe a person's cultural background based upon their birthplace, however, unlike the Census, there is no data on languages spoken

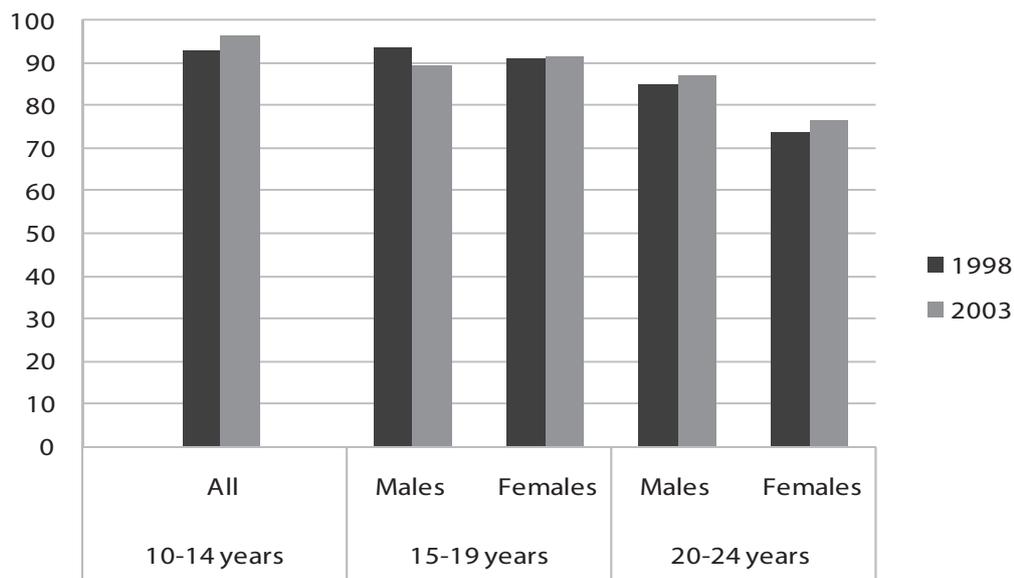
at home. Around 85 per cent of young people aged between 10 and 24 years, were born in Australia, irrespective of their carer status in both 1998 and 2003 (see Table E.9 in Appendix E). Due to the small sample sizes, estimates of the proportion of young primary carers born overseas have to be interpreted with caution. There were no significant differences in the proportions of young carers and non-carers born outside of Australia in either year. These findings differ from the Census data reported in Section Three where young people from CALD backgrounds were overrepresented in the groups of identified carers and potential carers. The different results from these two sources are possibly due to the smaller sample size in the SDAC, different definitions of caring and varying data collection methods.

### 4.3 CHARACTERISTICS OF THE CARE SITUATION

#### 4.3.1 Whether the carer lives with the care recipient

The nature and impact of caring on a young person’s life may vary depending on whether or not they live with the person for whom they provide assistance. Figure 3.3 shows that, for all age groups, the majority (85 to 90 per cent) of young carers lived with their care recipient. However, nearly a quarter of young women aged 20–24 years cared for a person living outside their home. There were no significant changes in the patterns of co-residency for young carers between 1998 and 2003.

**Figure 4.1: Proportion of young carers who are co-resident in 1998 and 2003 by age and sex (weighted percentages)**



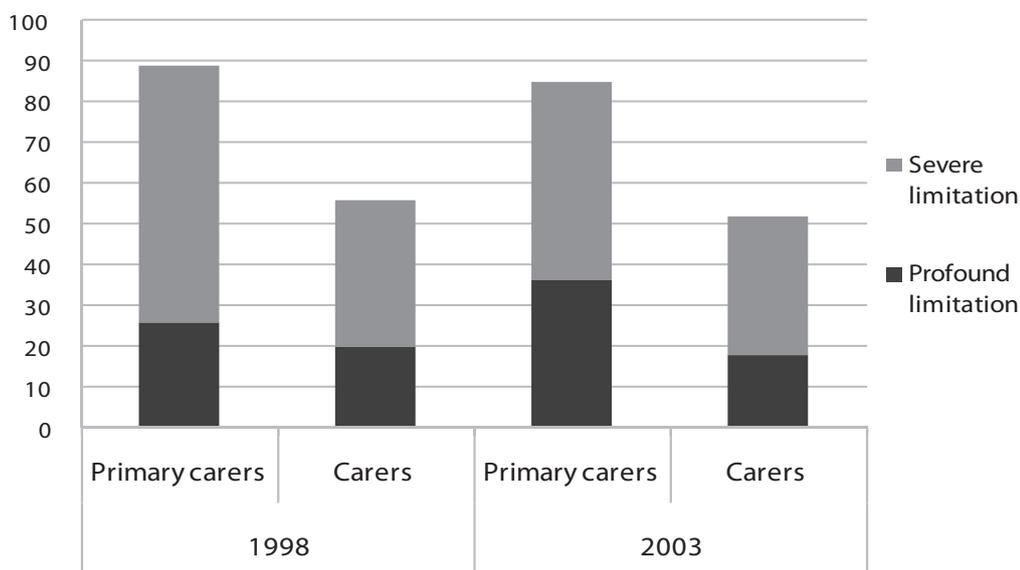
Source: ABS 1998, 2003.

### 4.3.2 For whom they provide care

Previous research shows that most young carers care for a parent. Nearly two-thirds of young primary carers and young carers are caring for a parent in both 1998 and 2003 (Table E.10 in Appendix E.) In both years, young primary carers were more likely to be caring for a partner than other young carers, who were more likely to care for another relative. There were no significant changes in the patterns of relationships to care recipients between 1998 and 2003.

Figure 4.2 shows the level of disability of care recipients (see also Table E.11 in Appendix E). In 1998, both primary carers and carers were likely to care for a person who was profoundly limited in a core activity (self-care, communication or mobility). However, by 2003 young primary carers were twice as likely to care for a person with a profound limitation (36 per cent compared to 18 per cent). In 1998 young primary carers had been more likely than young carers to care for a person with a severe limitation (63 per cent to 36 per cent) but this gap narrowed in 2003 (49 per cent to 34 per cent).

**Figure 4.2: Disability status of care recipient of young co-resident carers (aged 10–24 years) by carer status in 1998 and 2003 (weighted percentages)**



Source: ABS 1998, 2003

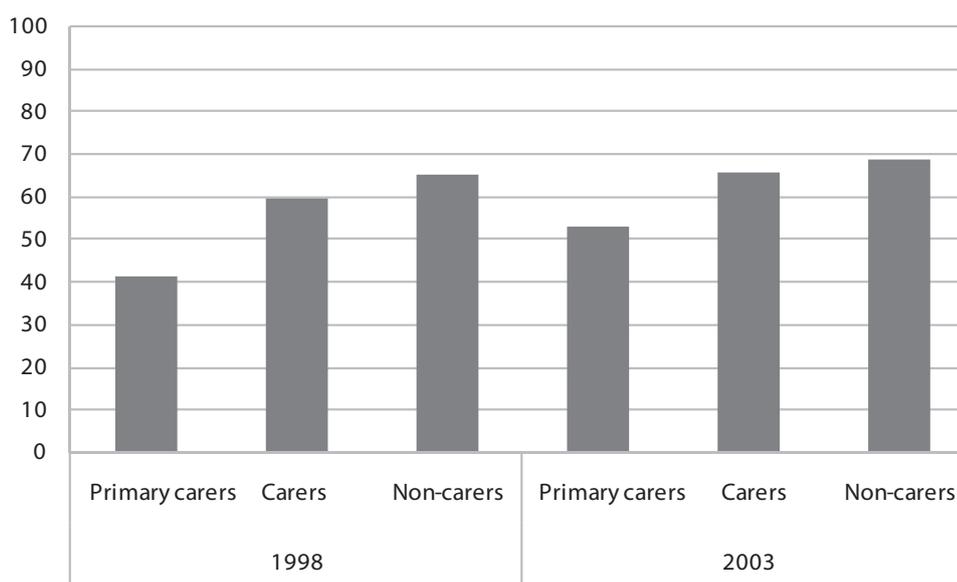
## 4.4 PARTICIPATION IN EDUCATION FOR YOUNG CARERS

Previous research, which considered the case of all carers and non-carers, found no significant differences between these groups in terms of completion of Year 12 (Cass et al.forthcoming). This study also considers the situation of primary carers, as distinct from all carers, compared with other carers and non-carers. Young primary carers (aged 15–24 years) were more likely than carers and non-carers to have left school at 16 years or younger in both 1998 and 2003 (see Appendix E, Table E.12). By 2003, young people as a group were less likely to leave school at age 16 or less and this finding held for all young carers (primary carers and carers combined) and non-carers.

Figure 4.3 (and Table E.13 in Appendix E) show the secondary school qualifications of young people aged 15–24 years who have left school. In 1998, young primary carers and young carers were less likely to have completed Year 12 than their non-carer peers. Only 41 per cent of young primary carers and 59 per cent of young carers had completed secondary school. In 2003, young primary carers were still less likely to have completed their secondary education than non-carers. But the gap in completion rates between non-carers and carers had decreased.

Between 1998 and 2003 there was a significant increase in the proportion of non-carers who completed Year 12. While there was also an increase in the completion rates for carers and primary carers, the change was not statistically significant.

**Figure 4.3: Whether completed Year 12 or equivalent (all aged 15–24 years not at school) (weighted percentages)**



Source: ABS 1998, 2003.

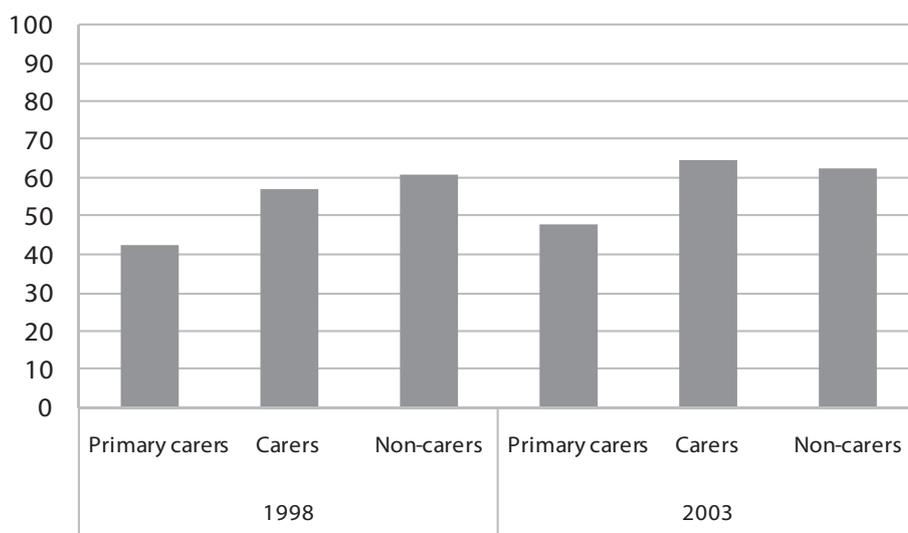
Between 20 and 30 per cent of young people who had left school were engaged in full-time study and a further 13 to 14 per cent were studying part-time (see Table E.14 in Appendix E). There were no significant differences in the rates of participation in study based on carer status and no significant changes between the two time periods.

There were no significant differences between young carers and non-carers in terms of the highest post-secondary qualifications achieved (See Table E.15 in Appendix E). Between 27 and 36 per cent of young people had some form of post-school qualification. Between 1998 and 2003, there was a decline in the proportion of young non-carers who had any post-secondary qualifications from 32 per cent to 29 per cent.

## 4.5 PARTICIPATION IN EMPLOYMENT

Figure 4.4 shows the overall employment rates of young people by their carer status over time (see also Table E.16 in Appendix E). In 1998, young primary carers were less likely to be employed than their peers—42 per cent of young primary carers compared with 57 per cent of young carers and 61 per cent of non-carers. In 2003, the employment rates for young people generally had increased slightly and there were no statistically significant differences in the employment rates of young people based on their carer status.

**Figure 4.4: Employment rates for young people (aged 15–24 years) by carer status in 1998 and 2003 (weighted percentages)**



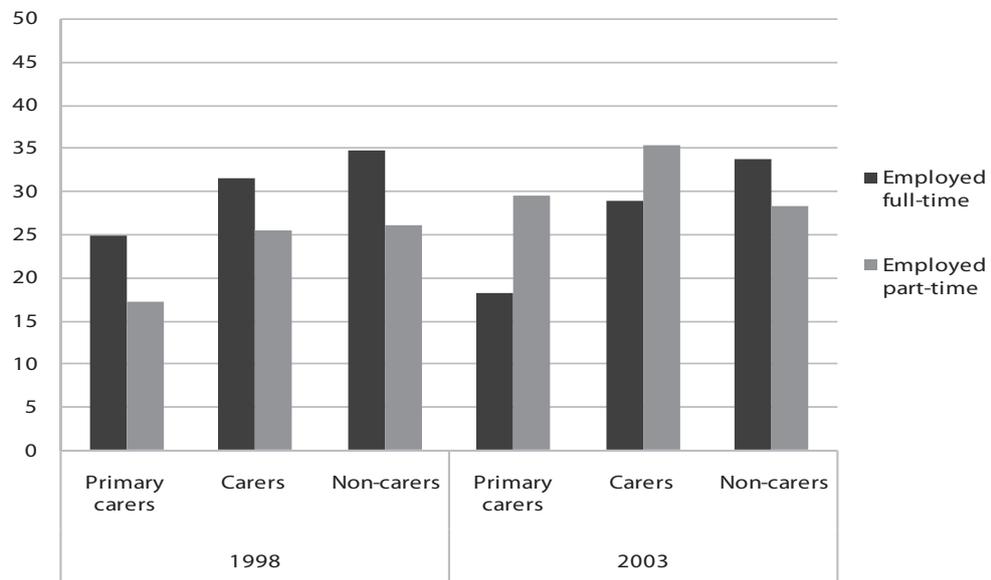
Source: ABS 1998, 2003.

Figure 4.5 and Figure 4.6 provide a more detailed picture of young people's participation in the labour force. In both 1998 and 2003, young primary carers were less likely to be employed full-time and more likely to be unemployed than their non-carer counterparts. There were no significant differences between primary carers and carers.

Figure 4.5 shows the full-time and part-time employment rates by carer status in 1998 and 2003. It is clear that, as the intensity of care provision increases, the rates of full-time employment decrease. In both years, around a third of non-carers and carers work full-time, compared with less than a quarter of primary carers. Both primary carers and carers were likely to work part-time in both years.

Between 1998 and 2003, the rates of part-time employment increased for all young people. Young carers (not primary carers) had the highest rates of part-time employment in 2003. Thirty-five per cent of this group worked part-time.

**Figure 4.5: Full-time and part-time employment rates of young people (aged 15–24 years) by carer status in 1998 and 2003 (weighted percentages)**

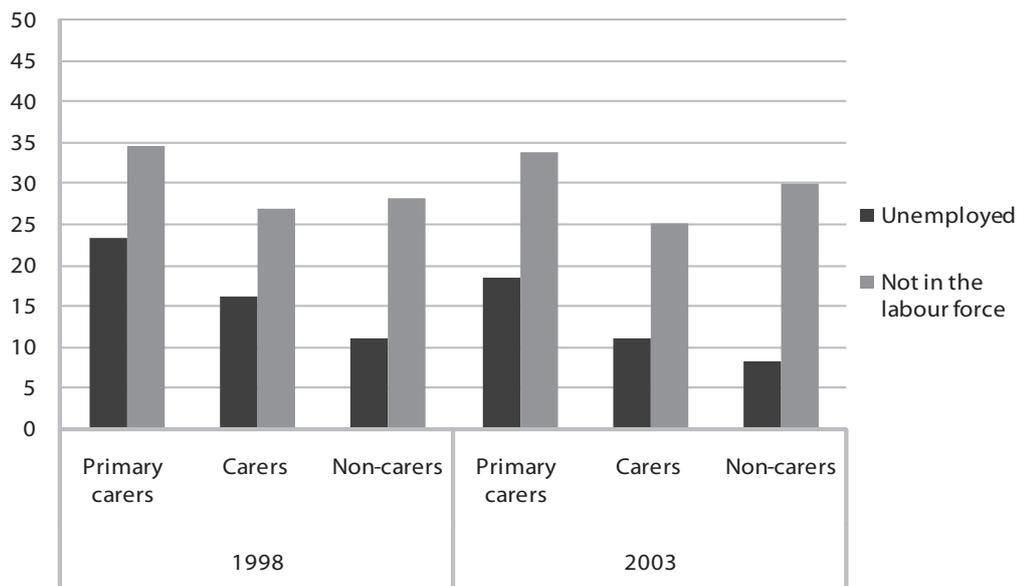


Source: ABS 1998, 2003.

Figure 4.6 shows the rates of unemployment and the proportion not in the labour force by carers' status for 1998 and 2003. In both years, primary carers have the highest rates of unemployment followed by carers and then non-carers. Between 1998 and 2003, there was an overall decline in the unemployment rate for young people. In 1998, 24 per cent of primary carers were unemployed and this decreased to 19 per cent in 2003. The unemployment rate for carers dropped from 16 per cent in 1998 to 11 per cent in 2003 and from 11 per cent to 8 per cent for non-carers.

Between 25 and 35 per cent of young people aged 15–24 years were not in the labour force in both years and no significant changes between years or significant differences between groups of young people based on carer status were identified.

**Figure 4.6: Proportion of young people (aged 15–24 years) unemployed or not in the labour force by carer status in 1998 and 2003 (weighted percentages)**



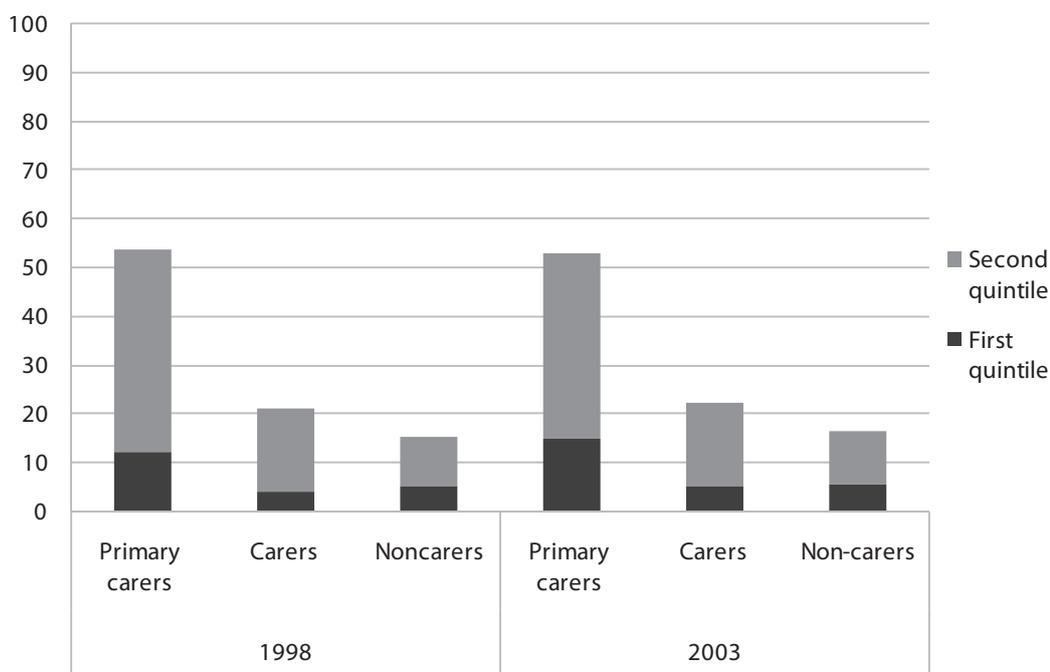
Source: ABS 1998, 2003.

## 4.6 INCOME LEVELS

Figure 4.7 reports on the proportion of young people aged 10 to 24 years living in households ranked by their gross weekly income quintile (see also Table E.18 in Appendix E). The first quintile contains households in the lowest 20 per cent of income distribution; the second quintile contains households in the next 20 per cent of income distribution and so on.

Primary carers were the group of young people most likely to live in very low income households (first quintile) in both 1998 and 2003. Primary carers and carers were more likely than non-carers to live in households in first and second quintiles. Just over 50 per cent of primary carers and around 20 per cent of young carers lived in relatively low-income households (bottom two quintiles) compared with around 15 per cent of non-carers. There were no significant changes in the income distribution for young carers between 1998 and 2003.

**Figure 4.7: Proportion of young people (aged 10–24 years) living in low income households by carer status in 1998 and 2003 (weighted percentages)**



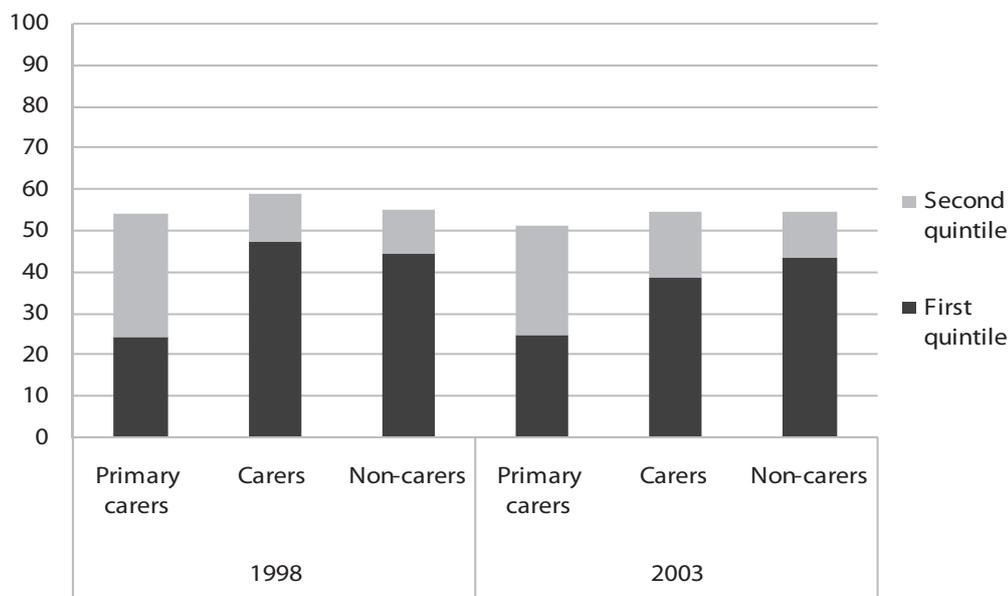
Source: ABS 1998, 2003. Quintiles are based on gross household income.

The previous figure describes the distribution of gross household income.

Table E.19 (in Appendix E) shows the distribution of young people in households ranked by their income, after adjusting for household size. This data was only available in the SDAC in 2003. The results show that, overall, more young people are likely to live in low income households after these adjustments are made. One third of primary carers lived in households in the lowest equivalised income quintile compared with 17 per cent of carers and 13 per cent of non-carers. In total, two thirds of young primary carers lived in the first and second equivalised income quintiles compared with 38 per cent of carers and 27 per cent of non-carers.

By contrast Figure 4.8 shows the distribution of young carers and other young people aged 15–24 years across the personal, rather than household, income distribution (see also Table E.20 in Appendix E). Young primary carers are less likely than young carers and non-carers to have low personal incomes (bottom quintile). This finding may be due to primary carers being more likely than their peers to be in receipt of income support. A smaller proportion of young carers (but not primary carers) had personal incomes in the lowest quintile in 2003 compared with 1998, but this difference was not statistically significant.

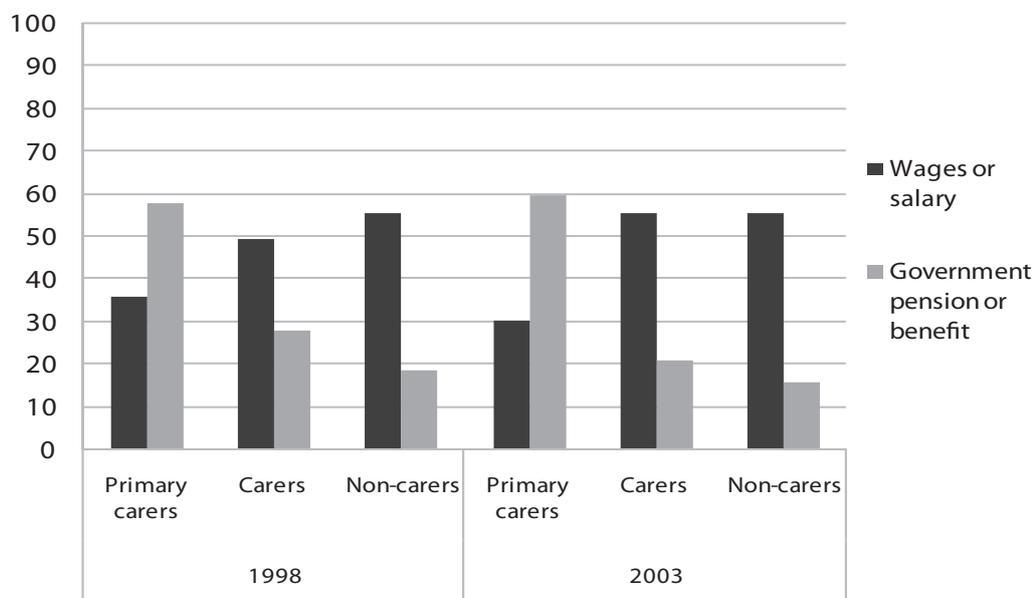
**Figure 4.8: Proportion of young people (aged 15–24 years) with personal incomes in the bottom two quintiles by carer status in 1998 and 2003 (weighted percentages)**



Source: ABS 1998, 2003.

Previous research shows that a high proportion of young primary carers rely on income support as their main source of income (Cass et al. forthcoming). Figure 4.9 shows that this finding held in 1998 and 2003. Nearly 60 per cent of young primary carers had a government pension or benefit as main income source compared with less than 20 per cent of non-carers. Young carers (not primary carers) were also more likely than non-carers to receive a government pension. In 2003, a lower proportion of carers and non-carers indicated that their main source of income was a government pension than in 1998. However, no such change occurred for primary carers. About a third of young primary carers had wages as their main source of income compared with around half the young carers and non-carers in both years.

**Figure 4.9: Primary source of income of young people (aged 15–24 years) by carer status in 1998 and 2003 (weighted percentages)**



Source: ABS 1998, 2003.

## 4.7 GEOGRAPHICAL LOCATION

Access to services and support for both the care recipient and their carer may depend upon where they live. The variables defining geographic location are not the same in the 1998 and 2003 SDAC. In 1998 the variable referred to living in capital cities, or the rest of the state. In that year, young primary carers and young carers were equally likely to be living in capital cities as other young people.

In 2003, the geography variable distinguished between major cities, inner regional areas and other areas. In 2003, primary carers were more likely than carers or non-carers to live in the other or more remote areas. Further information about the geographical distribution of carers is found in the next section examining the Census data.

**Table 4.1: Geographical location of young people (aged 10–24 years) by carer status (weighted percentages)**

	Capital city	Rest of state	Total	n	Major Cities	Inner regional	Other areas	Total	n
<b>1998</b>									
Primary carers	63.0	37.0	100.0	30					
Carers	66.9	33.1	100.0	616					
Non-carers	65.0	35.0	100.0	7103					
<b>2003</b>									
Primary carers					66.3	15.1	18.6	100.0	42
Carers					65.7	24.6	9.7	100.0	524
Non-carers					67.3	21.6	11.2	100.1	6831

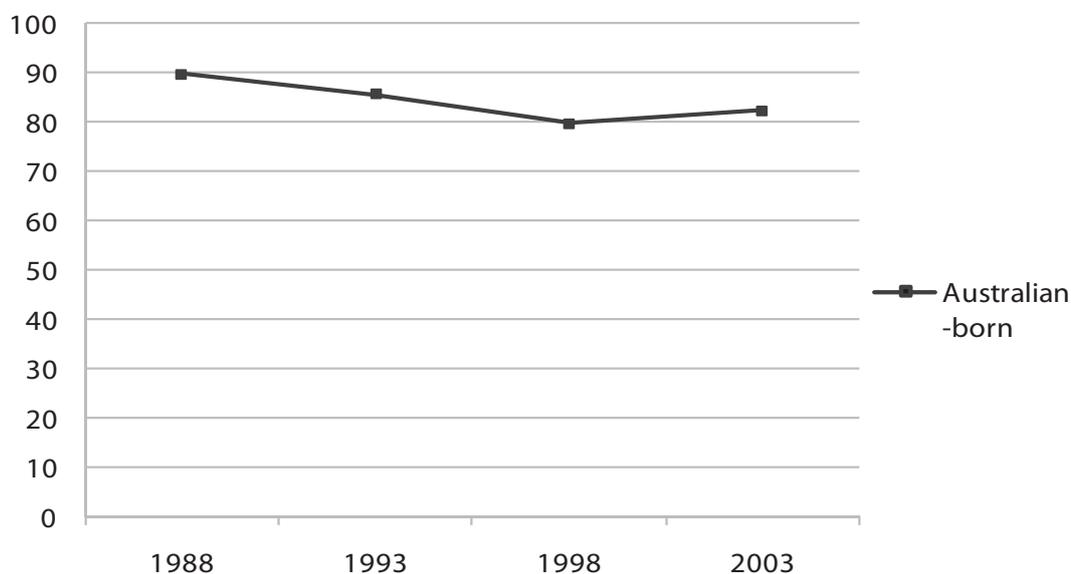
Source: ABS 1998, 2003.

## 4.8 LONGER-TERM TRENDS: CHARACTERISTICS OF YOUNG CO-RESIDENT PRIMARY CARERS BETWEEN 1988 AND 2003

As noted above, the ABS collected data on young primary carers living with their care recipient every five years since 1988. The following charts provide some information on whether the characteristics of this group have changed during this time. The sample size used in these estimations is quite small so all results must be interpreted with caution.

Figure 4.10 shows the proportion of young co-resident primary carers who were Australian-born in each year. The proportion of Australian-born primary carers has declined slightly from 90 per cent in 1988 to around 80 per cent in 1998 and 2003, which means an increasing proportion of young carers have been born overseas. Changes over time in the proportion of carers from CALD backgrounds cannot be reliably estimated due to small sample size.

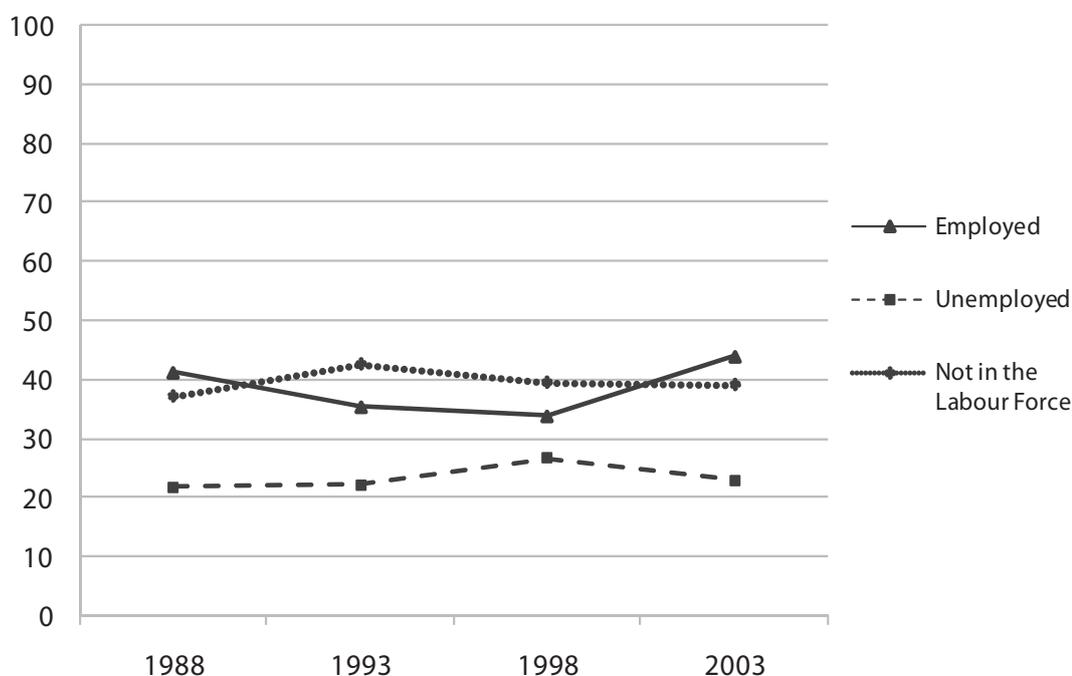
**Figure 4.10: Proportion of young co-resident primary carers (aged 15–24 years) who are Australian born 1988 to 2003 (weighted percentages)**



Source: ABS 1988, 1993, 1998 and 2003

Figure 4.11 shows the employment status of young co-resident primary carers from 1988 to 2003. Overall, the employment patterns of these young carers have remained fairly stable during this period. Between 34 and 44 per cent of young co-resident primary carers were in employment in each year, between 22 and 26 per cent were unemployed, and approximately 40 per cent were not in the labour force. The proportion of primary carers unemployed was higher than the proportion of young people unemployed.

**Figure 4.11: Employment status of young co-resident primary carers aged 15–24 years 1988 to 2003 (weighted percentages)**



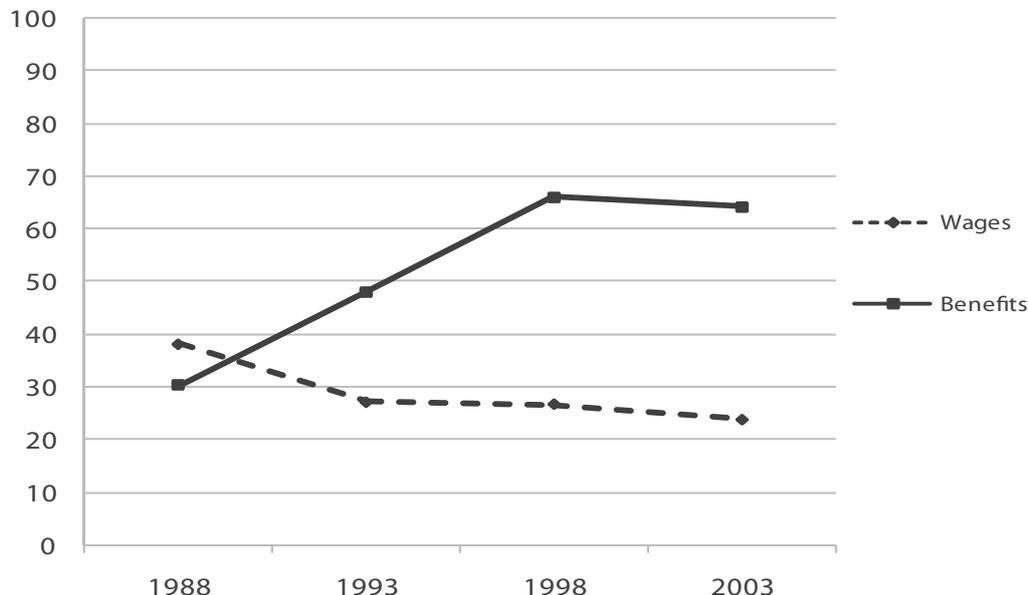
Source: ABS 1988, 1993, 1998 and 2003

Figure 4.12 reports on the main source of income of young, co-resident primary carers over time. In 1988, 38 per cent of this group obtained most of their income from wages. This figure declined to 24 per cent in 2003. The proportion, whose main source of income was government benefits, doubled from 30 per cent to 66 per cent over the period from 1988 to 1998 and remained at this level in 2003.

Although data on the type of payment received by the young carers is not available in all years, a number of changes to the income support for carers occurred between 1988 and 1998. The changes may have increased the eligibility of young people to receive carer pension or payment and combine benefit receipt with participation in employment. The changes include removing the requirement that the person cared for be in receipt of income support to one where the care recipient had 'limited means'. The eligibility criteria also changed to increase the hours that a carer was able to work, study or train and still receive the payment. The first change during this period established the threshold at 10 hours per week in 1993, and it was then changed to 20 hours per week in 1997 and in 2008 it is 25 hours per week (see Edwards et al. 2008, p.6).

In 2003, nearly 30 per cent of those, whose main source of income was government benefits, were employed, mostly on a part-time basis. A further 21 per cent reported that they were unemployed or actively looking for paid work. By contrast, in 1993 none of the young carers whose main source of income was a government benefit were employed, although 34 per cent of this group reported that they were looking for work.

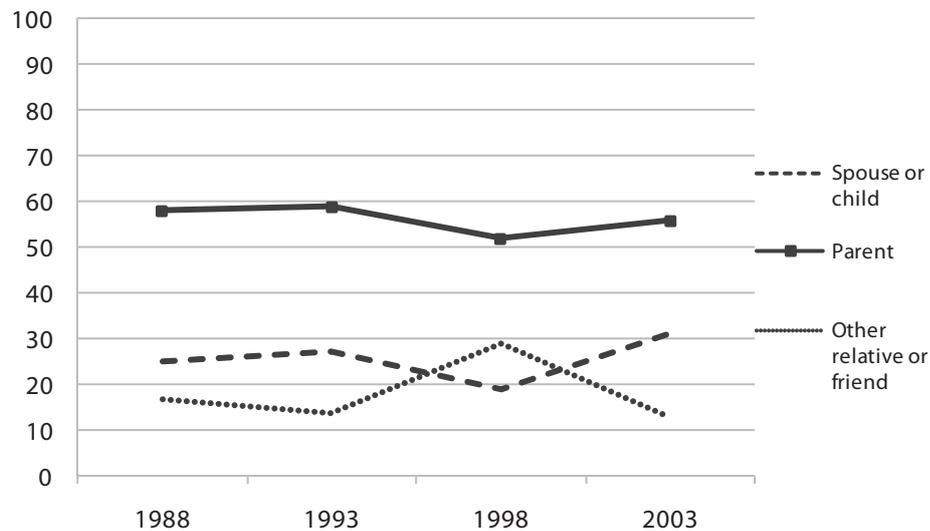
**Figure 4.12: Primary source of income for young co-resident primary carers aged 15–24 years (1988–2003) (weighted percentages)**



Source: ABS 1988, 1993, 1998, and 2003

The trend lines in Figure 4.13 show that the patterns of care relationships have stayed fairly stable for the young co-resident primary carers over the period 1988 to 2003. In all years, 50 to 60 per cent of this group cared for a parent. Between 10 and 30 per cent in each year provided care to their spouse or a child and a similar proportion provided care to another relative or friend.

**Figure 4.13: Care recipients of young carers (young co-resident primary carers aged 15–24 years) from 1988 to 2003 (weighted percentages)**



Source: ABS 1988 1993 1998 2003

## 4.9 SUMMARY

This section examined recent and longer-term trends in the characteristics of young carers using SDAC data. Basic demographic data was available for young carers aged between 10 and 24 years, and additional data on education and employment was available for young people aged 15–24 years.

Between 1998 and 2003, there were no changes in the cultural composition of the young carer group, as measured by birthplace. According to the SDAC, young carers were generally representative of the youth population in terms of birthplace. However, this finding contrasts with the more detailed data available in the Census reported

in Section Three, which suggests that young people from CALD and Indigenous backgrounds are overrepresented in the young carer population.

A number of features of the care situation of young carers were examined. Patterns of co-residence and the relationship with the recipient of care have remained stable between 1998 and 2003. Over 80 per cent of young carers lived with their care recipient, apart from young women aged 20–24 years, where one quarter of this group cared for a person outside their home. Nearly two-thirds of young carers provided care for a parent in both years. The proportion of young primary carers caring for a person with a profound limitation increased from one quarter in 1998 to one third in 2003. Thus, in 2003, primary carers were twice as likely as other carers to be caring for a person with a profound limitation, whereas no such gap had existed in 1998.

Young primary carers were generally less likely than other young people to complete Year 12 and more likely to leave school at age 16 years or less. Young people generally had higher levels of participation in education in 2003 than in 1998. Young carers followed this trend with more young carers staying on at school after age 16 years in the latter year. The gap between primary carers and non-carers in completion rates for Year 12 still remained in 2003, although the gap between other carers and non-carers decreased. No significant differences between young carers and others in terms of post-secondary education participation or attainment were identified in this data.

Overall employment rates for young people increased between 1998 and 2003, and significant differences in employment participation between young primary carers and others declined. However, the composition of employment changed. Full-time employment rates for all young people were lower in 2003 compared with 1998. The gaps in full-time employment rates between primary carers and non-carers remained in both years. Part-time employment rates increased for all young people in 2003, particularly for young primary carers and carers. Unemployment proportions declined for all young people between 1998 and 2003, although primary carers still had unemployment proportions that were nearly twice that of other carers and more than double that for non-carers. Between one quarter and about one third of young people were not in the labour force in both years, with no significant differences between carers and others or changes over the two time periods.

The lower rates of full-time employment and higher unemployment have implications for young carers' personal and household income levels. Previous Australian research has identified young primary carers as living in circumstances of low income (Cass et al.forthcoming) and this finding was reiterated in the analysis here. In both 1998 and 2003, just over 10 per cent of young primary carers (aged 10–24 years) lived in very low-income households and over half lived in relatively

low-income households, when measured by gross household income. This was more than double the proportion of young carers and other young people in low-income households. Thus, there had been no change in the relative economic circumstances of young primary carers between 1998 and 2003. The household economic situation for all young people and young carers appeared worse once income was adjusted to take account of household size (data only for 2003). Interestingly, young primary carers were less likely than other young people to have very low personal incomes in both 1998 and 2003. A future topic of analysis could be to identify the proportion of household income provided by young primary carers and the extent to which they take on a breadwinning, as well as caring, role.

Longer-term trends between 1988 and 2003 for young, co-resident primary carers showed that there had been a slight decline in the proportion of young primary carers who were Australian-born. The types of relationships between carers and care recipients had remained relatively stable, with between 50 and 60 per cent caring for a parent in each of the years. Employment patterns of this group had remained fairly consistent with around 35 to 45 per cent employed, one quarter unemployed and 40 per cent not in the labour force over this period. Despite this finding for employment, changes in the main source of income of young co-resident primary carers had been significant during this time. The proportion whose main source of income was government benefits doubled from 30 per cent to over 60 per cent in 1998 and 2003 and the proportion whose main source of income was wages declined. This finding possibly reflects changes in the eligibility criteria for government benefits to support carers, particularly the possibility of combining employment and receipt of a benefit for care. In 2003, 30 per cent of the young co-resident carers whose main source of income was government benefits were also in paid employment (mostly part-time) and a further 20 per cent were looking for work. By contrast, in 1993, none of the group who had government benefits as their main source of income were employed, although one third were looking for work. All the data for the longer-term trend analysis must be interpreted with some caution due to the small sample size.

Overall, the picture that emerges in this section is that the profile of young carers in Australia has remained fairly stable between 1998 and 2003. Young carers in 2003 remain a relatively disadvantaged group in terms of secondary education, employment and income, although increases in part-time employment rates and Year 12 completion rates for young carers are evident. These findings suggest that young carers may be a group at risk of social exclusion.

# 5. GEOGRAPHICAL DISTRIBUTION OF YOUNG CARERS

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## 5.1 INTRODUCTION

This section of the report examines the characteristics and geographical distribution of young carers based on the 2006 Census. The analysis first considers the geographical distribution of Indigenous and cultural background of identified young carers. It then describes the national levels and geographical distribution of their participation in education and employment, income levels and family composition. Data on housing mobility and access to services is also outlined. Finally, this section examines the distribution of 'hidden' or 'potential' carers across the states and territories.

## 5.2 DATA AND LIMITATIONS

Census data used in this section of the report is based upon calculations generated from specialised data tables requested from the Australian Bureau of Statistics (ABS). In regions where the cell sizes for particular statistics are small, the data will be less reliable due to confidentiality by the ABS. For some statistics, data can only be reliably analysed at a higher geographical level. As noted in Section Three, some caution should

be exercised in the interpretation of the results of the Census data, particularly for Indigenous young carers and young carers who speak languages other than English, due to the higher level of non-response to the carer question for these groups. Also, as noted in Section Three, the Census question restricts the definition of caring to that undertaken in the previous two weeks. Thus, young people who are classified as non-carers in this analysis may in fact be providing episodic care, or have cared in the recent past or anticipate caring in the future.

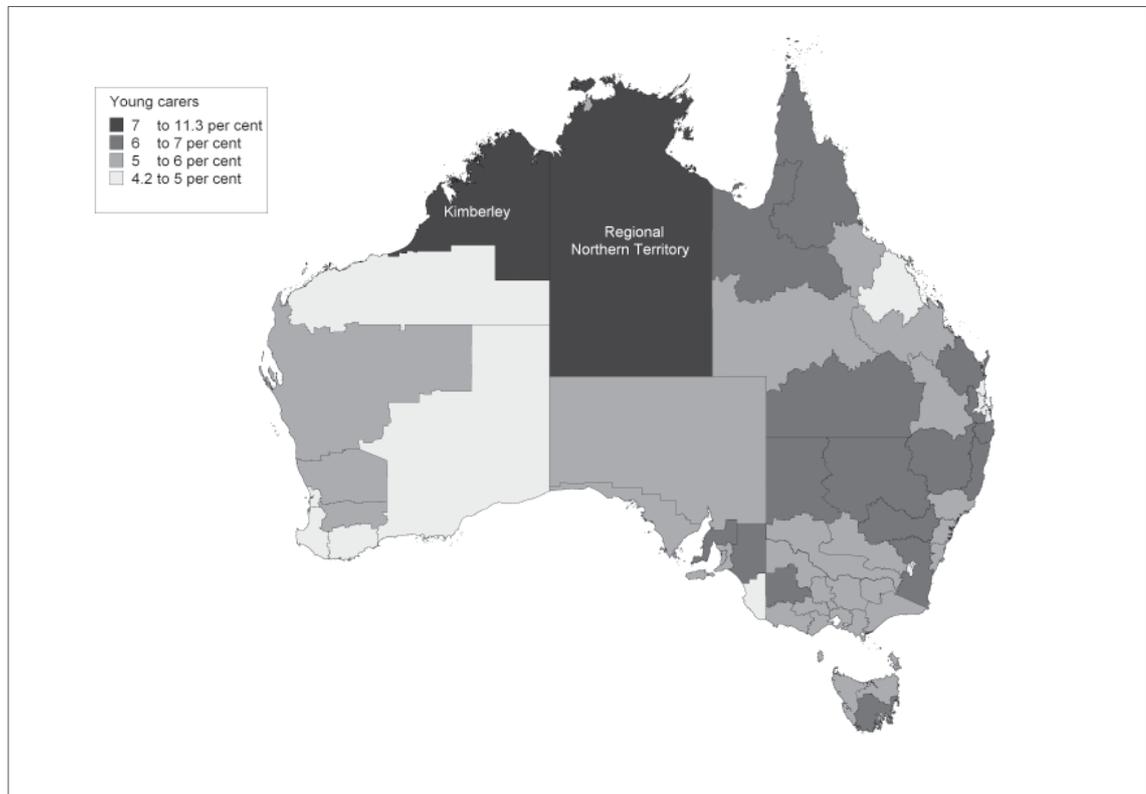
A further important point should also be made about the interpretation of Census data from remote communities. Analysts and observers of the Census processes in remote communities have emphasised the extent of undercounting of the Indigenous population (Biddle and Taylor 2008), 'the intercultural difficulties of the enumeration exercise' (Morphy 2007, p.112), and the inadequacy of the concepts used in the Census to depict the characteristics of remote Indigenous populations (Morphy, Sanders and Taylor, 2007). As Morphy (2007) notes, a number of questions relevant to this analysis should be interpreted with caution for remote communities. Difficulties also arise with the statistical concepts of 'unemployment' or 'looking for work' in remote communities (Morphy 2007, p.158). Bearing these warnings in mind, in this section we merely report the Census data for these communities as it is recorded. However, we should caution that it may not provide a full description of the characteristics of young carers in remote populations. Further knowledge about the experiences and circumstances of young Indigenous carers in remote areas is required before policy implications can be drawn from this analysis.

## 5.3 GEOGRAPHICAL DISTRIBUTION OF IDENTIFIED CARERS (AGED 15–24 YEARS)

### 5.3.1 Demographics

The following tables, graphs and maps describe the geographical distribution of identified young carers, that is, young people who indicated on the Census form that they provided help or assistance for a person with a disability. Figure 5.1 shows the proportion of young people who are identified carers in each statistical division (SD) (of which there are 66 regions in Australia).

**Figure 5.1: Proportion of young people who are carers, 2006**



Source: ABS 2006a, author's calculations

The analysis at the SD level<sup>10</sup> shows that, overall, less than 12 per cent of young people in any SD region were providing informal care and that there was relatively little regional variation in the proportion of young people (aged 15–24 years) providing care: between 4 and 7 per cent of young people in most regions indicated that they provided informal care. The regions with higher proportions of young people providing care were: regional Northern Territory (9.7 per cent) and off-shore and migratory Northern Territory and Western Australia (10.7 and 11.1 per cent respectively), and the Kimberley statistical division in Western Australia (11.2 per cent). In most regions, a higher proportion (3–14 per cent)<sup>11</sup> of Indigenous young people was identified as young carers than non-Indigenous young people (3–6 per cent). The proportion of young people

<sup>10</sup> Analysis was undertaken at this geographical level in order to preserve data quality due to small numbers of carers in particular regions. Further analysis at a smaller geographical level, such as local government area level, for the major cities could be undertaken in the future.

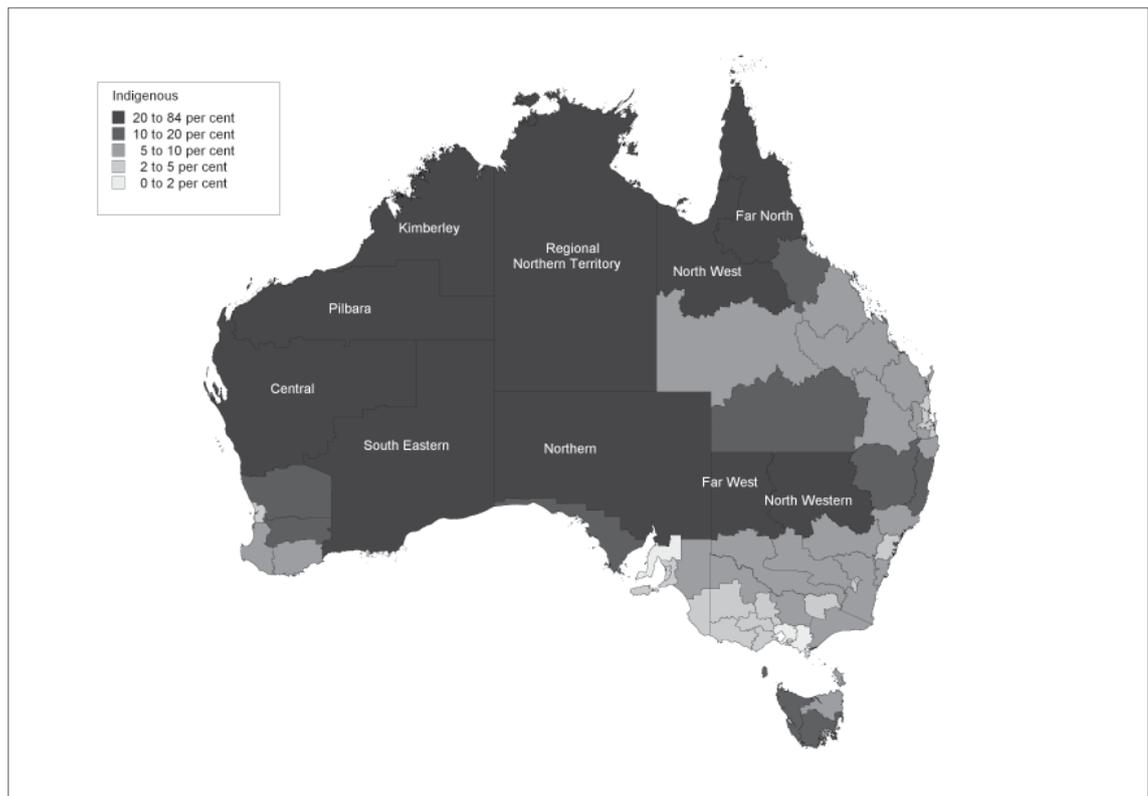
<sup>11</sup> In areas for which there were sufficient numbers for the data to be reliable.

who spoke a language other than English at home ranged from 4 to 16 per cent. (This group could also include those who spoke Indigenous languages at home.)

The following maps describe the proportion of young carers in each region who are Indigenous and who speak another language at home (Indigenous and CALD). Figure 5.2 shows the proportion of young carers who are Indigenous in each of the SD regions. In regions where there are a higher proportion of Indigenous young people in the youth population, they also make up a higher proportion of young carers. In regional Northern Territory, Indigenous young people comprise 62 per cent of young people aged 15–24 years, and they account for 84 per cent of young carers. In the Kimberly region in Western Australia, Indigenous young people make up 56 per cent of young people and 80 per cent of young carers. Indigenous young people make up 20 per cent or more of the young carers in Darwin, regional Western Australia (Pilbara, Central and South Eastern SDs), the Northern SD in South Australia, the North Western and Far West SDs in New South Wales, and the far North and North West SDs of Queensland. In the major cities, young carers are much less likely to be Indigenous, representing only 2 per cent of young carers in Sydney and 1 per cent of young carers in Melbourne. In the other cities this figure ranges from 3 per cent (Adelaide, Canberra) to 7 per cent (Hobart).

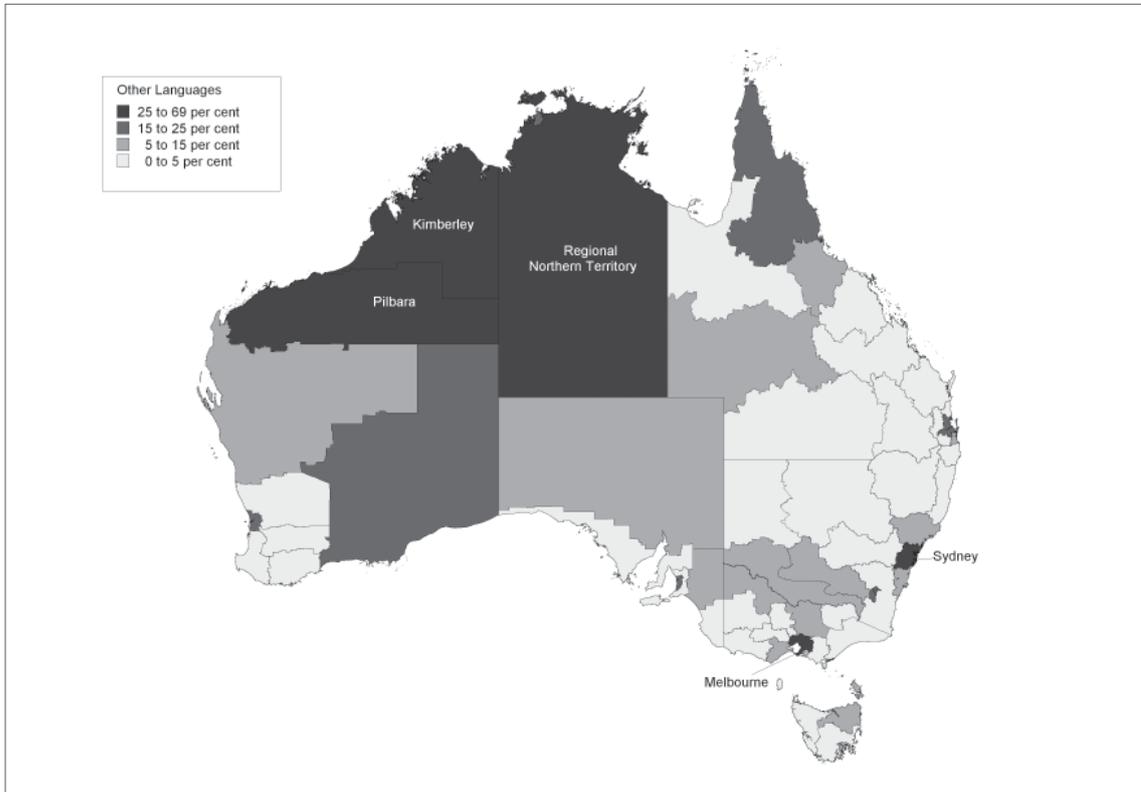
Figure 5.3 maps the proportion of young carers who speak a language other than English at home, and this may include Indigenous languages. Areas where a high proportion of young carers speak other languages are in regional Northern Territory (69 per cent) and northern Western Australia SDs (Kimberly–35 per cent, and Pilbara–29 per cent). Some of these are regions where a relatively high proportion of young people speak languages other than English at home (regional Northern Territory–44 per cent, Kimberly–18 per cent, and Pilbara–11 per cent). These areas also have a high proportion of Indigenous young carers, thus it is likely that they speak Indigenous languages. The other areas with a high proportion of young carers who speak languages other than English at home are the major cities: Sydney (39 per cent of young carers compared with 31 per cent of all young people) and in Melbourne (33 per cent of young carers compared with 27 per cent of young people).

**Figure 5.2: Proportion of young carers who are Indigenous, 2006**



Source: ABS 2006a, author's calculations.

**Figure 5.3: Proportion of young carers who speak a language other than English at home (may include Indigenous languages), 2006**



Source: ABS 2006a, author's calculations.

In other major cities, the figure were: Adelaide and Perth (18 per cent of young carers compared with 15 and 14 per cent of young people respectively), and Brisbane and Canberra (16 per cent of young carers compared with 12 and 14 per cent of young people in those cities respectively). In the major cities, given population distributions, these young carers who speak languages other than English are more likely to be from CALD than Indigenous backgrounds.

### 5.3.2 Geographical distribution of education and employment disadvantage for young carers

A key policy concern is the extent to which informal caring responsibilities affect the capacity of young people to participate in education and employment. The following tables and maps examine the rates of participation in education and employment for young people. Table E.22 (in Appendix E) shows the proportion of young people participating in various combinations of employment and education by their carer status for all of Australia. Young carers had similar rates of participation in 'education only' as non-carers, but lower rates of participation in 'employment only' and in combining employment with study. In both age groups, and for young men and women, carers were more likely than non-carers not to participate in either employment or education. The rate of non-participation for young female carers was nearly twice that of their non-carer counterparts. Just over one quarter of young female carers aged 20–24 years were not studying or employed.

Table E.23 (in Appendix E) provides a more detailed breakdown of the levels of participation in education and employment for young people. Young carers aged 20–24 years had full-time employment rates that were around 10 per cent lower than their non-carer peers but similar rates of overall part-time employment. Like their non-carer peers, many of the part-time employees were combining full-time education with part-time employment. Young carers were also more likely to be unemployed than non-carers. For young people (carers and non-carers) aged 15–19 years, about half of the unemployed were also students. However, among the older group a much smaller proportion were studying, as well as looking for paid work. Similarly, the majority of the group who were not in the labour force (NILF) and aged 15–19 years were full-time students. However, among the older age group, there were fewer students in the NILF group. Carers in the older age group were less likely than non-carers to be students while NILF.

Young Indigenous carers had only slightly lower rates of participation in employment, but not study as non-Indigenous carers (27 per cent compared with 31 per cent) (Table E.24 in Appendix E). For both Indigenous and non-Indigenous young people, the gap between carers and non-carers was 4 per cent. Young Indigenous carers were less likely to be studying or combining employment and study, than non-Indigenous carers. Young Indigenous carers also had the highest rates of non-participation in education and employment at 41 per cent. This is 10 percentage points more than Indigenous young people who were not carers and more than twice the rate of non-participation for non-Indigenous carers.

The patterns of education and employment participation for young CALD carers are very different (Table E.25 in Appendix E). Young carers from CALD backgrounds had lower participation rates in 'employment only' than those young people who spoke English at home (23 per cent compared with 33 and 35 per cent) but higher than non-carers from CALD backgrounds (22 per cent). Young people from CALD backgrounds had higher rates of 'studying only' than non-CALD young people, even when they were carers. Carers from either background were more likely than their non-carer peers not to participate in employment and education.

Young people who are not participating in either education or employment may be considered a disadvantaged group at risk of social exclusion. A lack of opportunity to participate in study or paid work at this age may lead to fewer employment opportunities and entrenched disadvantage over the life course. Table 5.1 reports on the proportion of carer and non-carers between 15–24 years who are not in education or employment in the major cities and the states and territories. In all broad regions, young carers have higher rates of non-participation than non-carers. Young female carers have higher levels of disadvantage than young male carers and the gap between carers and non-carers is generally higher for females than males. In all states and territories, carers who live outside major cities are more disadvantaged in this regard than carers living in the major cities. The broad regions with the highest level of education and employment non-participation for young male carers are regional Northern Territory, regional South Australia, regional New South Wales and regional Tasmania. For young female carers, disadvantage is more prevalent in the regional areas of the Northern Territory, Western Australia, Queensland and South Australia.

**Table 5.1: Proportion of young carers (aged 15–24 years) not in employment or education by sex and broad region (per cent)**

	Males Non-carer	Males Carer	Females Non-carer	Females Carer
Sydney	8.0	12.1	9.0	17.4
NSW rest of state	11.5	19.0	13.9	24.9
Melbourne	7.4	11.3	7.9	15.0
Victoria rest of state	9.5	14.1	12.1	21.3
Brisbane	7.4	13.4	9.5	20.0
QLD rest of state	9.3	15.3	13.4	26.4
Adelaide	8.9	15.0	9.5	18.0
SA rest of state	11.0	19.7	15.2	26.3
Perth	6.3	9.8	8.4	17.6
WA rest of state	10.3	17.8	16.7	30.6
Hobart	10.3	16.3	11.1	20.6
Tasmania rest of state	11.5	18.4	15.5	25.8
Darwin	7.8	10.3	12.3	24.8
NT rest of state	31.0	39.4	37.6	47.2
Australian Capital Territory	5.4	9.4	5.6	12.3
Australia	8.6	14.0	10.5	20.2
Australia number	98,840	7,140	117,165	13,798

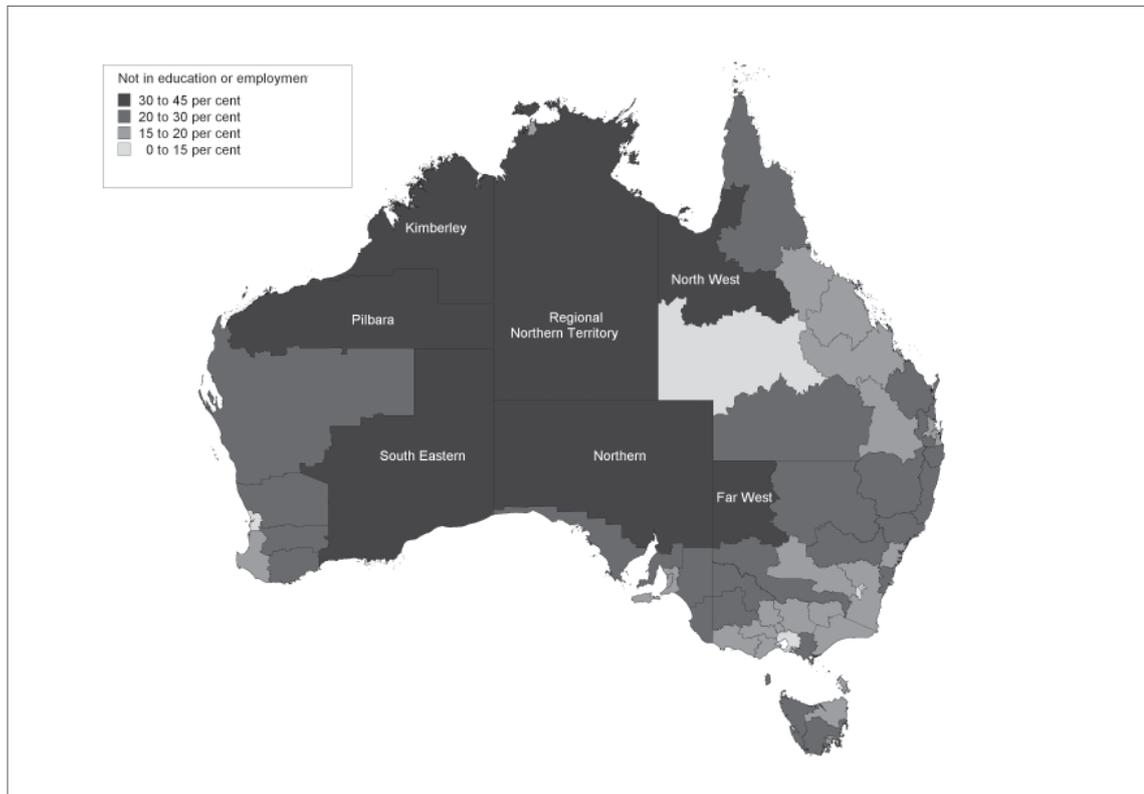
Source: ABS 2006a. Does not include individuals who did not respond to the carer question.

Figure 5.4 shows a more detailed geographical distribution of the rates of non-participation in employment and education for young carers. The regions where over 30 per cent of young carers are not participating in employment and education are: Far West New South Wales; North West Queensland; northern region of South Australia; regional Western Australia (Pilbara, Kimberly and South Eastern) and regional Northern Territory. The rates of non-participation of young carers in these regions could reflect high youth unemployment and low education participation generally in that region, or it could mean that carers are particularly disadvantaged. However, as noted in Section 5.2 the Census data collected in remote communities may not provide a full description of economic activity so some caution should be exercised in interpreting these results. The next map looks more closely at one aspect of carer disadvantage.

Figure 5.5 identifies regions that have a higher 'carer disadvantage' in terms of employment. These are regions where the gap between the employment rates of non-carers and carers is highest. Only one region (Central West Queensland) had employment rates for carers that were higher than non-carers, however, the data in this region is likely to be unreliable due to small numbers. In all other regions, young carers were less likely to be employed than non-carers. The largest gaps (ranging from 15–26 percentage points) were in North Western Queensland, South Eastern Western Australia, and the Pilbara region in Western Australia.

Comparing these two maps, it is apparent that not all regions with high rates of non-participation in paid work and study (as described by the Census data) have a large employment disadvantage for young carers.

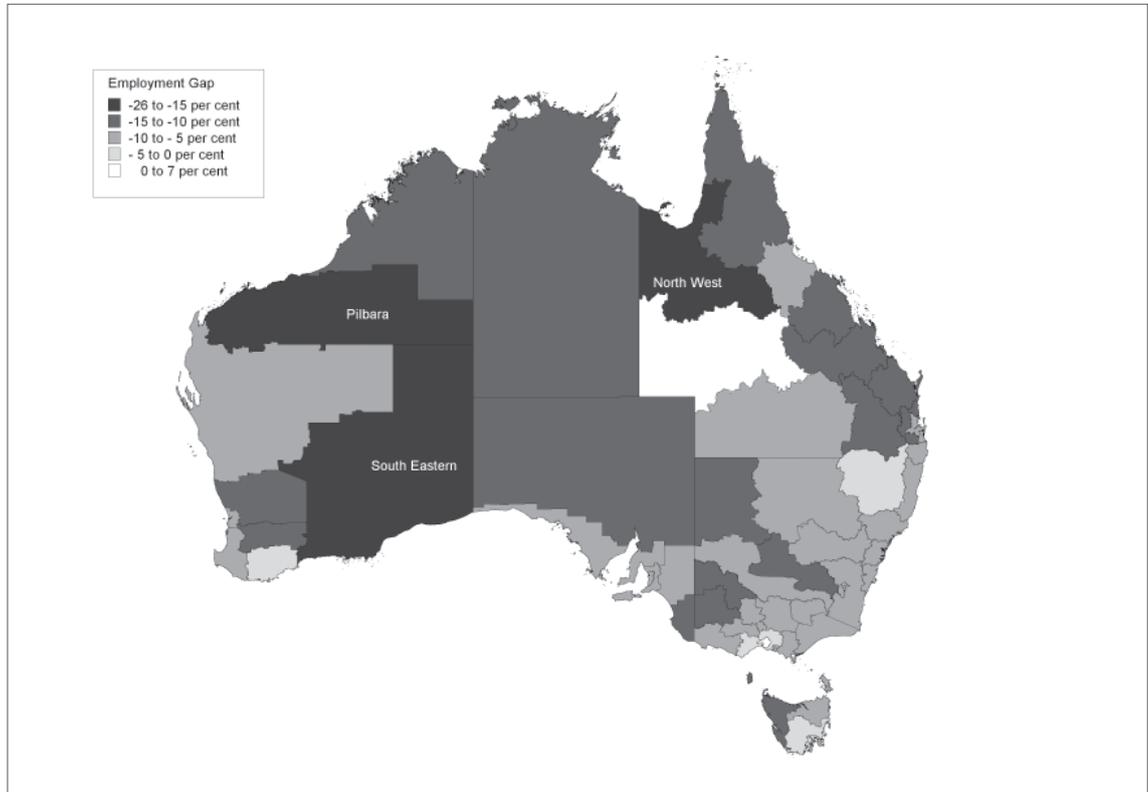
**Figure 5.4: Proportion of young carers not in employment or education, 2006**



Source: ABS 2006a, author's calculations.

Note: Data for Central West Queensland should be interpreted with caution due to small numbers.

**Figure 5.5: Employment participation gap between carers and non-carers (aged 15–24 years), 2006 (per cent)**



Source: ABS 2006a, author's calculations.

Note: Data for Central West Queensland should be interpreted with caution due to small numbers

Another indicator of disadvantage is the proportion of young people who did not complete Year 12. Table 5.2 shows the proportion of young people in the major cities and regions of each state and territory who did not finish secondary school. The differences between carers and non-carers are more pronounced among young women than young men and greater in the regional areas rather than the cities. Fewer young carers completed Year 12 in the regional areas of the Northern Territory, Western Australia, Tasmania and South Australia.

**Table 5.2: Proportion of young people (aged 15–24 years) not completing Year 12 by carer status and capital cities and balance of state (per cent)**

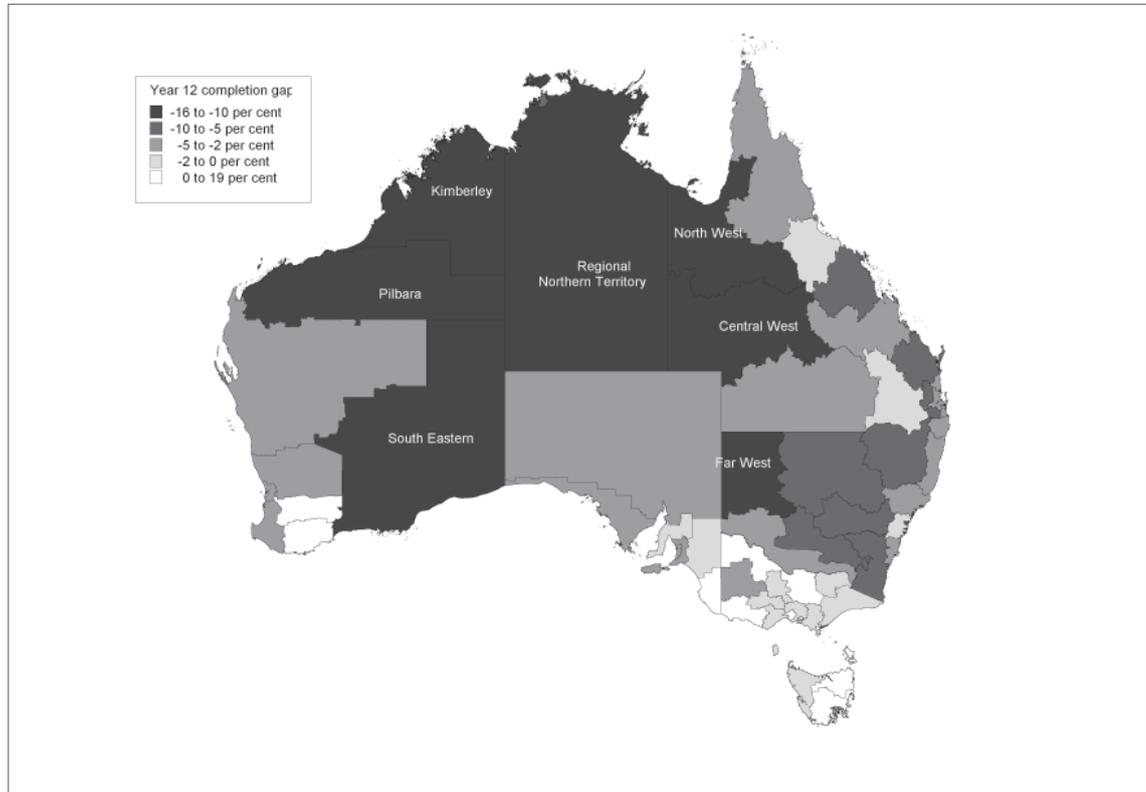
	Males Non-carer	Males Carer	Females Non-carer	Females Carer
Sydney	24.3	24.8	17.8	22.4
NSW rest of state	39.1	43.2	29.0	37.8
Melbourne	22.3	23.4	14.2	18.6
Victoria rest of state	35.4	36.5	22.8	29.6
Brisbane	21.3	24.0	15.7	22.3
QLD rest of state	32.1	33.1	23.3	32.5
Adelaide	29.5	33.4	21.0	28.6
SA rest of state	44.9	47.8	31.6	42.2
Perth	28.4	29.4	20.6	27.1
WA rest of state	46.9	52.7	37.0	49.4
Hobart	31.4	35.7	26.1	33.1
Tasmania rest of state	47.7	50.2	39.1	43.4
Darwin	38.1	39.9	30.9	41.9
NT rest of state	67.0	80.8	61.7	75.5
Australian Capital Territory	15.6	20.6	12.6	20.2
Australia	28.8	31.3	20.6	27.7
Australia number	331,648	15,954	230,634	18,972

Source: ABS 2006a.

Note: Does not include individuals who did not respond to the carer question.

The next map shows the gap in Year 12 completion rates between non-carers and carers across the regions of Australia among those aged 15–24 years who have left school. The education disadvantage for carers is most pronounced (more than 10 percentage points) in the Northern Territory, North West and Central West Queensland, Kimberly, Pilbara, South Eastern Western Australia, and North Western New South Wales. Once again, caution should be exercised in interpreting data on education from remote communities.

**Figure 5.6: Gap in Year 12 completion rates between carers and non-carers (young people aged 15–24 years who had left school), 2006**



Source: ABS 2006a, author's calculations.

## 5.4 GEOGRAPHICAL DISTRIBUTION OF ECONOMIC DISADVANTAGE

The analysis of SDAC in Section Four has shown that young carers are more likely than their peers to live in circumstances characterised by low income. The Census data offers the possibility of identifying regions where this issue is more prevalent. Table 5.3 shows the proportion of young people living in low income households in each major city and regional areas in the states and territories. In all cities and regions, carers were more likely than non-carers to live in low income households. Younger carers (aged 15–19 years) were more likely than the older group to be living in economically disadvantaged households. This finding may indicate that they are not able to contribute to the

household income to the same extent as older carers. In most states and territories, young carers in regional areas were more likely to be economically disadvantaged than those in the cities. Broad regions with the highest prevalence of low income households for young carers were: regional Northern Territory, Hobart, regional Western Australia, regional South Australia, and regional New South Wales.

**Table 5.3: Proportion of young people living in low income<sup>(a)</sup> households by age carer status and capital cities and balance of state (per cent)**

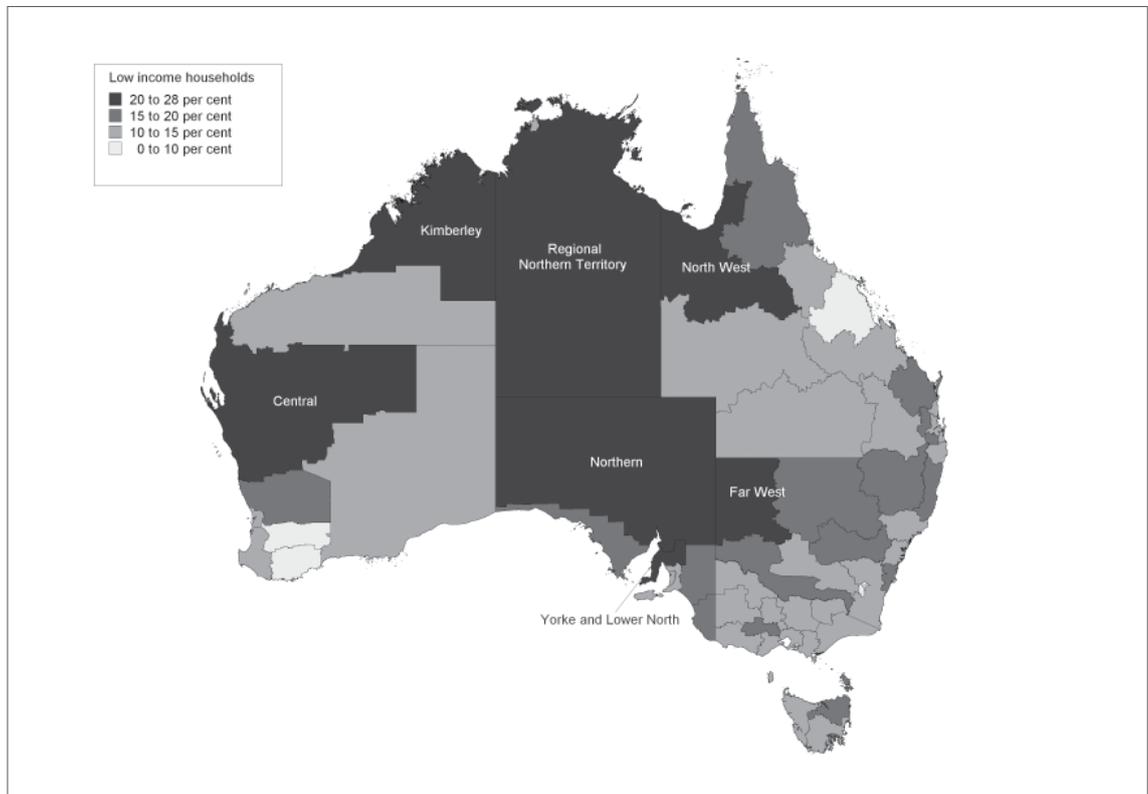
	15–19 years Non-carer	15–19 years Carer	20–24 years Non-carer	20–24 years Carer
Sydney	10.7	15.5	8.6	10.7
NSW rest of state	10.9	16.6	7.7	12.4
Melbourne	11.2	15.1	10.0	11.1
Victoria rest of state	10.4	14.9	6.7	11.6
Brisbane	7.6	12.1	6.3	8.4
QLD rest of state	8.5	14.6	5.4	9.9
Adelaide	10.4	14.8	9.0	12.1
SA rest of state	11.5	18.6	6.9	13.8
Perth	8.0	12.1	7.1	9.8
WA rest of state	9.0	16.7	6.2	14.1
Hobart	9.7	17.4	9.1	14.5
Tasmania rest of state	11.6	14.8	8.7	12.8
Darwin	6.4	11.6	3.2	8.7
NT rest of state	26.4	30.5	20.2	26.3
Australian Capital Territory	5.7	9.8	4.7	7.3
Australia	10.0	15.0	7.9	11.0
Australia number	104,246	7,257	83,629	6,736

Source: ABS 2006a.

Note: (a) Low income households are defined as those in which equivalised household income is less than \$249 per week (in 2006 dollars) and includes zero and negative incomes

The map in Figure 5.7 shows the regions where economic disadvantage among young carers is most highly concentrated. Regions where more than 20 per cent of young carers were living in low income households were: the Kimberly and Central

**Figure 5.7** Proportion of young carers who live in low income households, 2006



Source: ABS 2006a, Author's calculations.

Western Australia, regional Northern Territory, Yorke and Lower North and Northern region of South Australia, North West Queensland, and Far West New South Wales. As noted in Section 5.2, further research on the economic circumstances of Indigenous carers in remote communities is necessary to gain a full picture of their economic circumstances.

## 5.5 FAMILY COMPOSITION

Previous research has identified that young carers are more likely than other young people to live in sole parent households. The Census data confirms this finding. Table 5.4 (and Table E.26 in Appendix E) shows that 26 per cent of young carers aged 15–19 years live in sole parent households compared with 20 per cent of their peers. Nineteen per cent of young carers aged 20–24 years live in sole parent households,

compared with 13 per cent of their peers. A higher proportion of young carers live in multiple family households than non-carers. A large proportion of young carers identified in the Census live in households of couples with children.

Previous research has shown that young carers living in sole-parent households are often caring for a parent or a sibling. This group may be especially disadvantaged if the parent is unable to participate in employment due to either their own disability or the disability of a child in the family. Table 5.4 shows the proportion of young carers and non-carers living in sole parent families in the cities and regional areas of each of the states and territories.

**Table 5.4: Proportion of young people living in sole parent households (per cent)**

	15–19 years Non-carer	15–19 years Carer	20–24 years Non-carer	20–24 years Carer
Sydney	19.3	23.7	13.3	18.5
NSW rest of state	21.6	27.8	13.8	21.8
Melbourne	19.5	23.9	12.7	17.8
Victoria rest of state	20.3	25.3	13	18.8
Brisbane	20.1	25.3	11.7	18.1
QLD rest of state	21.1	26.3	12.2	19.4
Adelaide	22.6	30	14.2	21.4
SA rest of state	19.4	26.2	12.5	19.1
Perth	20	26	12.5	18.3
WA rest of state	19.1	27.9	10.8	18.3
Hobart	23.1	32.3	14.1	22.6
Tasmania rest of state	20.6	23.1	12.7	19
Darwin	22.4	25.2	11.6	16.7
NT rest of state	14.2	16.5	8.9	10.7
Australian Capital Territory	21.2	26.9	11.5	18.0
Australia	20.3	25.5	12.8	18.9
Australia number	211,944	12,352	135,225	11,581

Source: ABS 2006a

Young carers are more likely to live in sole-parent families than their non-carer peers. Areas with high proportions of young carers living in sole-parent families are Hobart, Adelaide, regional NSW and regional WA.

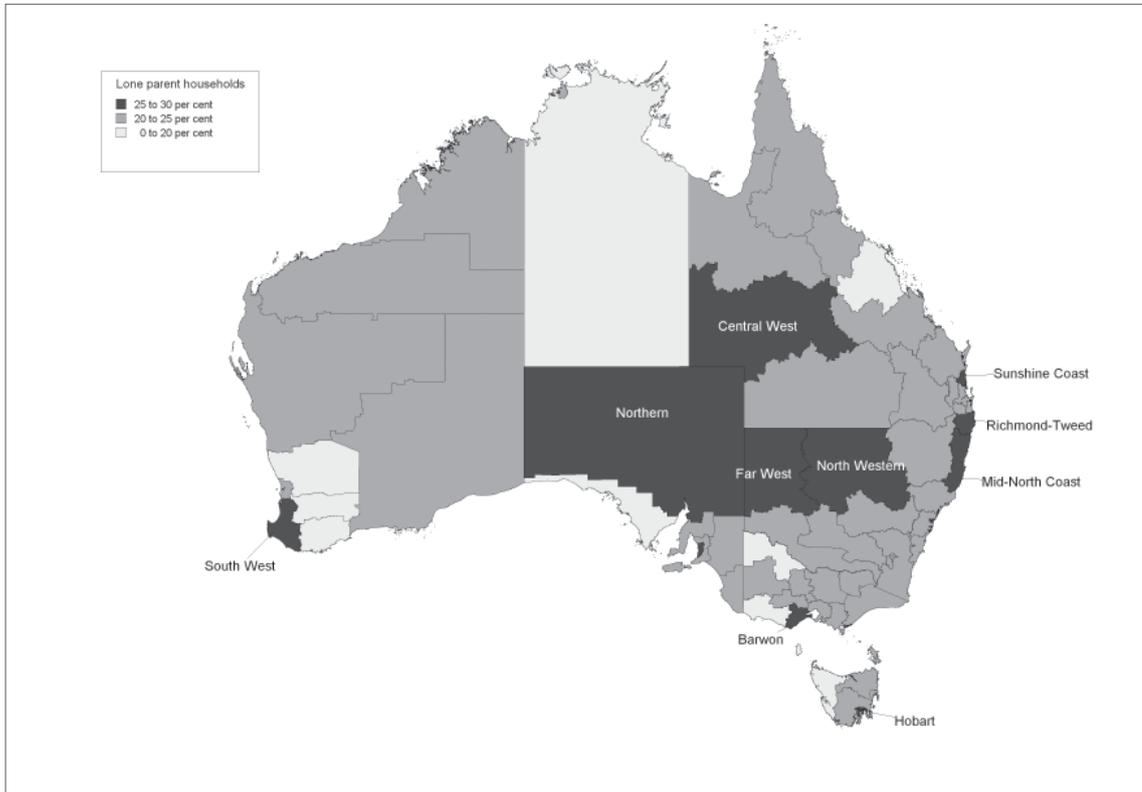
The map in Figure 5.8 shows a more detailed distribution of the proportion of young carers aged 15–24 years in sole-parent families. Regions with more than 25 per cent of young carers living in sole-parent households include: the Far West, North Western, Richmond-Tweed and the Mid-North Coast in New South Wales, Sunshine Coast and Central West in Queensland, Adelaide, and the Northern region in South Australia, the South West region of Western Australia, Barwon in Victoria, and Hobart.

## 5.6 HOUSING MOBILITY

If young carers live in more economically disadvantaged situations generally, they may be more likely to live in rental and less secure accommodation. One indicator of this is whether the young person has changed their address in the last year. Although this indicator could also imply that a person was moving into a better situation, better housing situation and may not necessarily be an indicator of disadvantage. Overall, young people aged 15–19 years were less likely than young people aged 20–24 years to have moved house in the last year. Young people from CALD backgrounds and Indigenous young people who spoke languages other than English were less likely than other young people to have moved. Young carers aged 15–19 years were usually slightly more likely to have moved house than their non-carer peers. In the older age group, young carers were less likely to have moved. English-speaking female carers and Indigenous female carers aged 20–24 years were the most highly mobile groups of young carers with between 35 to 36 per cent of these groups moving house in the last year.

The rates of mobility varied for young people across the states and territories, but there were few large differences between carers and non-carers (Figure E.1 in Appendix E). Young people in Queensland were more mobile than other regions, and young people in New South Wales and Victoria were the least mobile.

**Figure 5.8: Proportion of young carers (aged 15–24 years) in sole-parent households, 2006**



Source: ABS 2006a, author's calculations

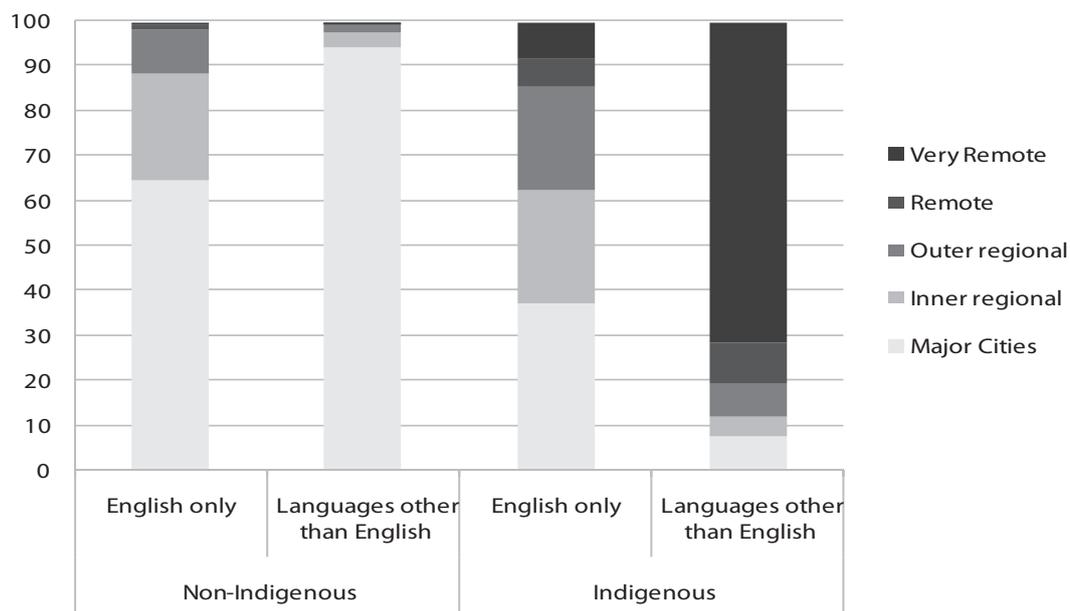
## 5.7 GEOGRAPHICAL LOCATION AND REMOTENESS

Access to services and supports depends on where young carers live. Overall, young carers are equally as likely as other young people to live in each geographical classification (Table E.27 in Appendix E). Around 70 per cent of young people in Australia live in Major Cities, irrespective of carer status, 18–19 per cent live in Inner Regional areas and about 10 per cent live in areas classified as Outer Regional to Very Remote.

Important differences in geographical location for different groups of young carers are evident. Figure 5.9 shows that the geographical location of Indigenous and CALD carers is different to other carers. The majority (94 per cent) of CALD carers live in Major Cities with only 6 per cent living in Regional areas. Just over a third (37 per cent) of young

Indigenous carers whose main language is English live in Major Cities, one quarter live in Inner Regional areas, and over a third live in Outer Regional or Remote and Very Remote areas. For Indigenous young carers who speak other languages at home, 71 per cent live in Very Remote areas and a further 17 per cent live in Remote or Outer Regional areas.

**Figure 5.9: Where young carers live: geographical location of young carers by Indigenous status and language spoken at home, 2006 (per cent)**



Source: ABS 2006a

## 5.8 HIDDEN OR POTENTIAL CARERS

Section Three outlined the number and proportion of young people who might be considered to be 'hidden' or potential carers, given that they shared a home with a person with a disability who required assistance for care activities but did not indicate on the Census form that they were carers. The data showed that young people from Indigenous and CALD backgrounds and young people aged 15–19 years were more likely to be potential or 'hidden' carers.

### **5.8.1 Geographical distribution in states and territories**

The following graphs look at the distribution of potential carers across the states and territories, first for all hidden carers by different age group, and then distinguished by Indigenous status and CALD backgrounds.

The geographical distribution of young female and male potential carers by different age groups across states and territories is shown in Figure E.2, Figure E.3 and Figure E.4 in Appendix E. In nearly all states and territories, and across all age groups, young men are slightly more likely to be potential carers than young women. The exception is the Northern Territory, where a higher proportion of young women aged 12–19 years are potential carers than young men. The distribution across states and territories differs for each age group.

For young people aged 12–14 years, there is little variation in the rates of being a potential carer. Young people aged 12–14 years are most likely to be potential carers in South Australia and Queensland (2–2.3 per cent) and least likely to be potential carers in the Northern Territory (1.2–1.5 per cent).

In the older age groups, the data describes non-identified, potential co-resident carers. Young women aged 15–19 years in the Northern Territory were the group most likely to be in this category (5.6 per cent). The Northern Territory had the highest rates of potential caring among young people aged 15–24 years. Other states with relatively high rates of potential caring were Tasmania, Queensland and New South Wales for 15–19 year olds. Tasmania, New South Wales and Victoria had high rates for the 20–24 year old age group. The Australian Capital Territory had the lowest rate of potential caring. However, the geographical variation between regions in both age groups is not large.

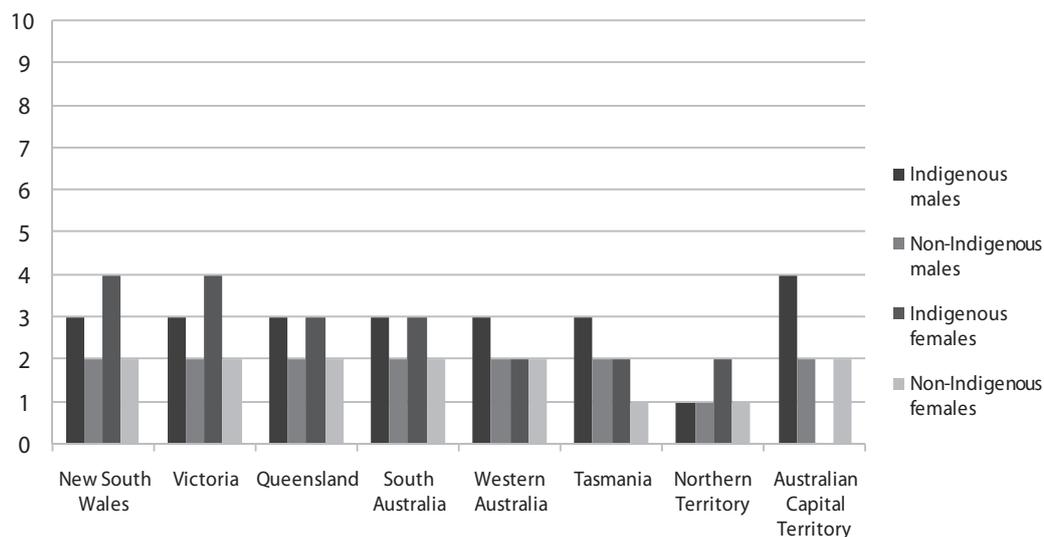
### **5.8.2 Indigenous status and language spoken at home**

Data in Section Three showed that young Indigenous people were more likely to be ‘potential carers’ than young people from non-Indigenous backgrounds. Figure 5.10 and Figure 5.11 examine this statistic by state and territory. The data in Figure 5.10 refer to young people aged 12–14 years. In most states and territories, Indigenous young people, in this age group, are more likely to be potential carers than their non-Indigenous counterparts. In New South Wales and Victoria, young Indigenous females in this age group are twice as likely as non-Indigenous young people to live in households where a person has a disability, and thus be a potential carer (4 per cent compared with 2 per cent). These two states and the Northern Territory are also the only

regions where Indigenous young women are more likely than Indigenous young men to be potential carers (in the age group 12–14 years).

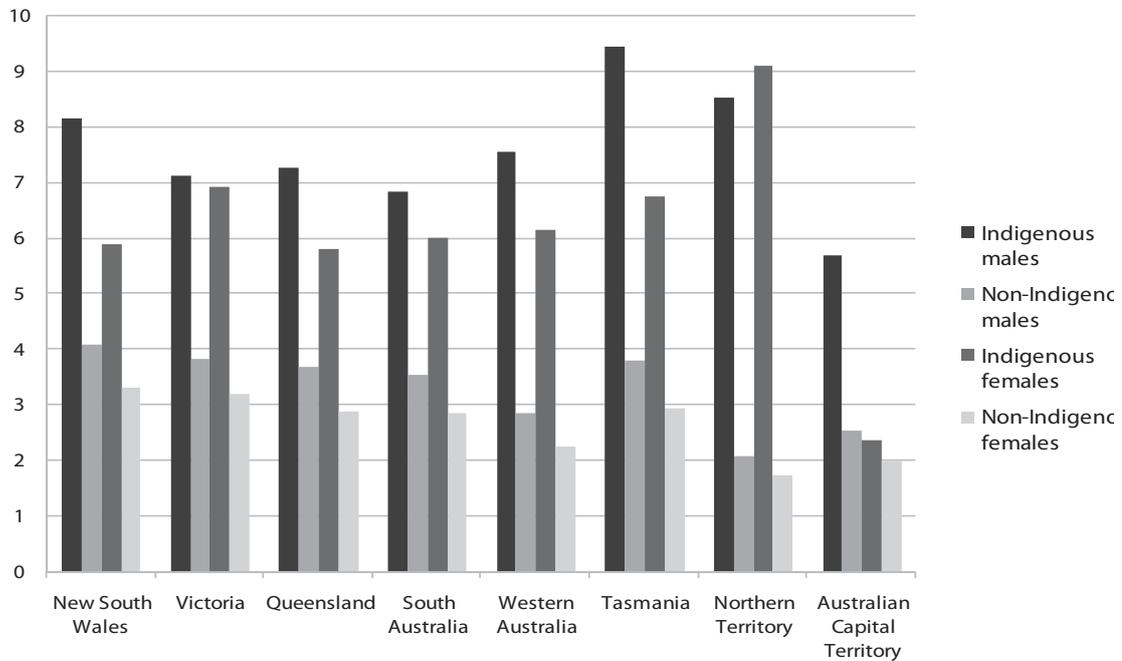
In the 15 to 24-year-old age group (Figure 5.11), there is a higher prevalence of potential caring among Indigenous young men and women than non-Indigenous young people across all states and territories. In the Northern Territory, Indigenous young people are four to five times more likely to be potential carers than non-Indigenous young people. In most other states this ratio is only double. In all states, except the Northern Territory, Indigenous young men had a higher likelihood of being a potential carer than Indigenous young women. The proportion of young Indigenous people who were potential carers ranged from 2.4 per cent of young Indigenous women in the Australian Capital Territory to 9.5 per cent of young Indigenous men in Tasmania.

**Figure 5.10: Proportion of young people aged 12–14 years who are potential carers by sex and Indigenous status and State or Territory, 2006 (per cent)**



Source: ABS 2006a

**Figure 5.11: Proportion of young people aged 15–24 years who are non-identified potential carers by sex and Indigenous status and state or territory, 2006 (per cent)**



Source: ABS 2006a

Note: A 'potential carer' is a child aged 12–14 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility. A 'non-identified potential carer' is a young person aged 15–24 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility and also did not indicate that they were a carer in the question on the Census form.

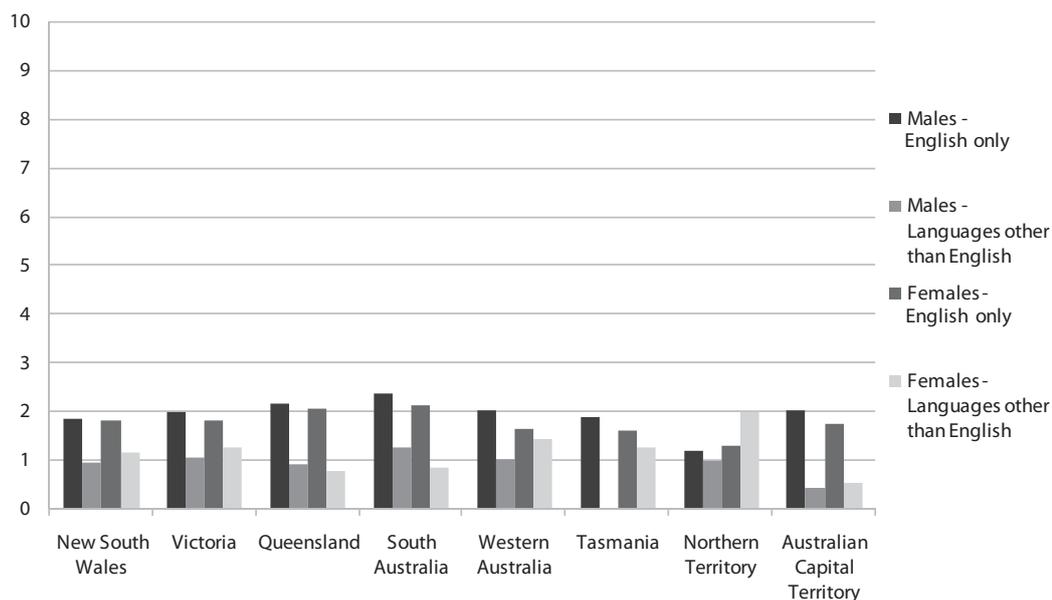
Section Three of this report also identified that young people from CALD backgrounds, or who spoke languages other than English at home<sup>12</sup>, were more likely to be non-identified potential carers than those who only spoke English at home. However, this finding only held for young people aged 15–24 years. Conversely, in the young age group (aged 12–14 years), young people were less likely to be potential carers, or live in a household with a person with disability, if they were from CALD backgrounds. The following graphs look at whether the distribution of potential carers from CALD backgrounds varies across the states and territories. For the younger age group (aged

<sup>12</sup> It should be noted that in this case, 'languages other than English' may include Indigenous languages. However, while Indigenous young people comprise only 2.6 per cent of this group in Australia, they comprise 5 per cent of this group in Western Australia and Queensland and 77 per cent of this group in the Northern Territory.

12–14 years) there is relatively little variation across these regions in the proportion from CALD backgrounds who are potential carers.

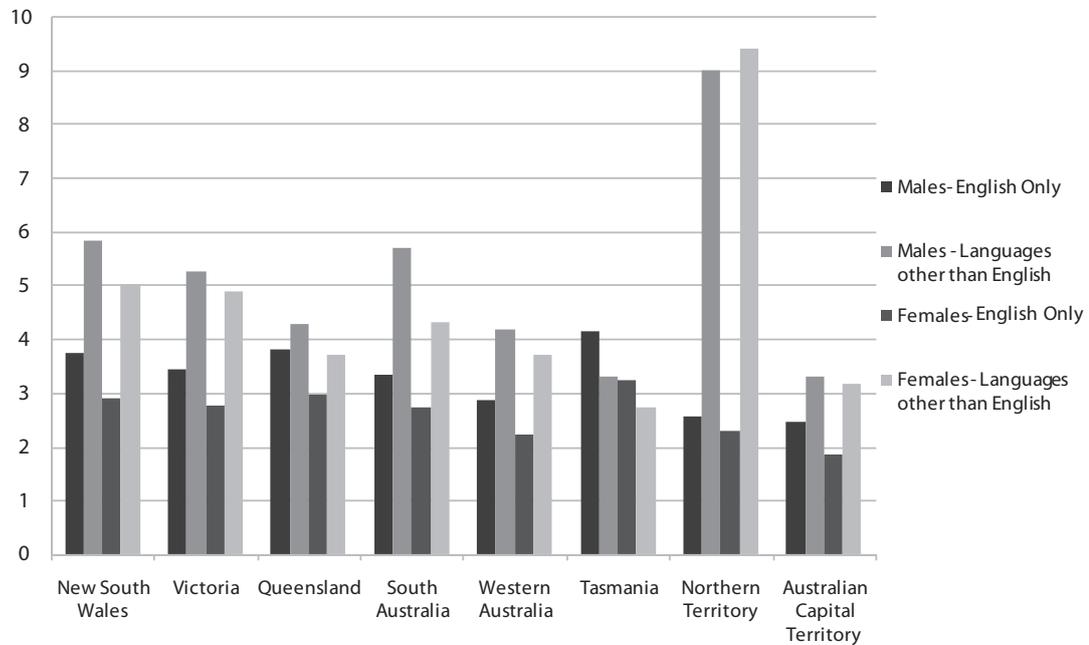
Regional variation is more pronounced for young potential carers from CALD background aged 15–24 years. The Northern Territory has the highest rates of potential caring (most likely to be Indigenous young people). In all states and territories apart from Tasmania, young people from CALD backgrounds were more likely to be potential carers than those who only spoke English at home. In all states and territories, except for the Northern Territory, young men from CALD backgrounds had higher rates of potential caring than CALD young women. Other regions with high levels were New South Wales, South Australia and Victoria, and the Australian Capital Territory once again had lower rates than all other regions.

**Figure 5.12: Proportion of young people aged 12–14 years who are potential carers by sex and language spoken at home and state or territory, 2006 (per cent)**



Source: ABS 2006a

**Figure 5.13: Proportion of young people aged 15–24 years who are non-identified, potential carers by sex and language spoken at home and state or territory, 2006**



Source: ABS 2006a

Note: 'Languages other than English' can include Indigenous languages. A higher proportion of the group who speak other languages is Indigenous in the Northern Territory than the rest of Australia.

A 'potential carer' is a child aged 12–14 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility. A 'non-identified potential carer' is a young person aged 15–24 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility and also did not indicate that they were a carer in the question on the Census form.

## 5.9 SUMMARY

This section examined the geographical distribution of identified young carers and their characteristics. The analysis was conducted at the Australian, the state and territory and the statistical division level. In most regions (statistical divisions) between 4 and 7 per cent of young people provide care, although higher rates of care provision (9–11 per cent) were found in regional and off-shore Northern Territory and the Kimberly region in Western Australia. There was greater regional variation in the proportion of Indigenous and CALD young people who provide care.

Indigenous young people accounted for a larger proportion of young carers in Darwin and the more remote areas of the Northern Territory, Western Australia, South Australia, New South Wales and Queensland. A high proportion of Indigenous young carers spoke a language other than English in the Northern Territory and the Kimberly and Pilbara regions. In the major cities, particularly Sydney and Melbourne, a higher proportion of young carers were from CALD background.

As a whole population survey, the Census data provides the opportunity to examine the ways in which young carers participate in or combine employment and study. At the national level and for all young people, it is evident that young carers are less likely to be in paid employment only, or combining employment with study, equally likely to be just studying, and more likely not to participate in either study or paid work. One quarter of the young female carers aged 20–24 years did not participate in either employment or study. Reiterating the results in Section Four from the SDAC, data from the Census showed that young carers were less likely than non-carers to be employed full-time, had similar rates of part-time employment, and higher proportion unemployed.

At the national level, Indigenous young carers had only slightly lower rates of participation in employment than other groups, but substantially lower rates of combining employment and study and study only. This led to the finding that 41 per cent of Indigenous carers did not participate in paid work or study, a rate that was over twice as high as CALD and other carers. Young CALD carers had relatively low rates of employment, but high rates of participation in study and similar rates of combining study with employment as carers from non-CALD backgrounds.

Rates of non-participation in study or employment were higher for young female carers than young male carers in all areas. Non-participation for young people and young carers was higher in the regions than the cities, particularly the more remote areas of New South Wales, Queensland, South Australia, Western Australia and the Northern Territory.

High, non-participation rates for young carers may reflect general opportunities for young people in these regions or specific disadvantages experienced by young carers. The extent of the 'carer disadvantage' in employment rates and Year 12 completion rates in these regions was explored. The gap in employment participation rates between carers and non-carers was the highest (15–26 per cent) in the remote areas of Western Australia and Queensland. However, the employment gap was over 10 per cent in

a number of other regions in all states and territories (except the ACT). The analysis of the Year 12 completion gap between carers and non-carers showed that overall young female carers were more disadvantaged than young male carers. The carer-disadvantage in education was also over 10 per cent in some remote and regional areas and generally lower in the cities.

Section Four in this report and previous research has shown that young carers are overrepresented among low-income households. The Census data confirms this fact for all broad regions in Australia. A higher proportion of young carers aged 15–19 years lived in low-income households than the older age group. The prevalence of low-income households among young carers was higher in regional areas in Western Australia, South Australia, Queensland, New South Wales and the Northern Territory, and also in the city of Hobart.

Like previous research, the Census data shows that young carers were more likely to live in sole-parent families than their non-carer peers. Areas with high proportions of young carers living in sole-parent families were regional areas in all states, except ACT and Northern Territory and Hobart.

Taking into account their lower levels of participation in education and employment, and their household circumstances of low income, it is evident that young carers may be potentially at risk of social exclusion.

Rates of housing mobility did not vary greatly by carer status. Access to services and supports may be constrained by the remoteness of place of residence. Overall, the remoteness of residence of young carers was generally representative of all young people. However, differences based on cultural background were evident. The vast majority of young carers from CALD backgrounds lived in major cities, compared with about one-third of Indigenous carers and about two-thirds of other carers. Over 70 per cent of Indigenous young carers who spoke languages other than English at home lived in very remote areas.

The geographical distribution of 'potential young carers' was examined at the state and territory level. The regional variations in the overall proportion of young people in each age group who were potential carers were not very large. Around 1–2 per cent of young people aged 12–14 years, 3–5 per cent of those aged 15–19 years and 2–4 per cent of young people aged 20–24 years were potential carers in all the states and territories. Indigenous young people were more likely to be potential carers than non-Indigenous young people, particularly in the Northern Territory. Young people

aged 12–14 years who spoke languages other than English were less likely to be potential carers in nearly all states and territories. Conversely, in the older age group (aged 15–24 years), the finding that a higher proportion of young people speaking languages other than English than English-speakers were potential carers also held for all states and territories, except Tasmania.

Overall, identified and potential caring was prevalent in remote areas of Australia and among Indigenous communities. Based on the Census data, it is also evident that many aspects of disadvantage were also prevalent in these areas. Further research on the circumstances and experiences of young Indigenous carers in remote communities is required to gain a fuller picture of their situation.

# 6. SUMMARY OF STAKEHOLDER CONSULTATIONS

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Identifying young carers and bringing them within the ambit of supports and services is a topic of immense importance to service providers and policy makers. To this end, a discussion paper was developed based on the literature reviewed in Section Two. It was distributed by email to a range of stakeholders to obtain their comments and suggestions on how best this could be achieved.

The discussion paper provided background information on:

- young carers in Australia and overseas
- services for young carers in Australia
- 'hidden' young carers, and
- strategies for identifying and supporting young carers.

It included a number of questions to which stakeholders were invited to respond (see Appendix C). Some of the questions were more relevant to certain stakeholder groups than others; therefore, stakeholders were advised to focus on those questions most

pertinent to their experience. Stakeholders were also invited to provide any additional comments and suggestions they had about how best to identify and support young carers.

Stakeholders contacted included government agencies and departments, professional organisations (social workers, teachers, school counsellors, general practitioners), non-government organisations that provide services and supports to young carers and organisations that work with children in complex family situations. The full list of stakeholders contacted is provided in Appendix D.

Themes explored in the discussion paper include:

- Why some young carers remain hidden.
- How schools might assist in the identification of young carers and the supports teachers need to achieve this.
- What information and supports health professionals and social workers need in order to identify young carers and any barriers they perceive to ascertain a young person's carer status.
- Whether service providers perceive any barriers to adopting the 'whole-of-family' and collaborative, inter-agency approaches recommended in the young carer literature.
- Additional effective strategies for distributing information to young carers and the people they care for beyond those outlined in the discussion paper.
- Culturally appropriate methods for identifying specific categories of young carers and additional categories of young carers, beyond those listed in the discussion paper, who may require targeted assistance.

## 6.1 STAKEHOLDER FEEDBACK

A total of 16 government agencies, non-government organisations (NGOs) and carer advocacy groups provided responses to the discussion paper. In addition, one carers' association organised feedback from eight young carer representatives and seven frontline workers.

Overall, the responses received endorsed the main issues raised in the discussion paper. General comments on the paper included that it was 'very comprehensive' and provided an 'extensive overview of the plight of young carers substantiated with national and international evidence'.

However, the lack of a consistent definition of young carers was raised by a number of respondents. It was noted that the definition used in this paper was not consistent with the FaHCSIA definition which includes young people up to 25 years and those supporting a family member with a drug or alcohol addiction<sup>13</sup>. It was suggested that a universal definition of the term ‘young carer’ be adopted and endorsed by government.

Another respondent highlighted the need to use a child-centred perspective, which takes account of the impact of caring responsibilities on the child or young person rather than focusing on an adult perception of the appropriateness of the caring role.

Feedback from stakeholders is divided into two sections. It begins with comments and suggestions from young carers’ representatives about how best to identify and support young carers. This is followed by a summary of the responses from representatives from government departments, NGOs, frontline workers and carer advocacy groups.

## 6.2 YOUNG CARER REPRESENTATIVE FEEDBACK

### 6.2.1 Hidden young carers

One of the key reasons outlined in the discussion paper why some young carers remain hidden is that they do not see themselves as carers. Research outlined in the discussion paper shows that they often do not regard their responsibilities as unusual, and non-recognition is particularly common among families from culturally and linguistically diverse backgrounds.

Feedback from young carer representatives reiterated these findings. They noted that the main reason young carers remain hidden was because they viewed the support they provided as nothing more than ‘just helping out the family’, which was part of normal family life. They suggested some additional reasons not mentioned in the discussion paper, including young people do not want to be treated differently due to concerns about being bullied at school; they may minimise their contribution as they are not the main carer; denial of the problem; and concerns about what others may think of their situation.

These stakeholders suggested the need for multiple mediums to identify young carers including—most importantly—schools, other young carers, families and the media, such as television advertising and the internet. Increasing awareness of young carers

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<sup>13</sup> Due to data restrictions, the data analysis in this project identified young carers between the ages of 10 and 24 years in the Survey of Disability Ageing and Carers (SDAC), and due to data restrictions and to maintain consistency, the age range 15–24 years was the main category employed in the analysis of the Census data.

within the education, health and service systems was cited as an important mechanism to assist them to access services.

When asked to comment on why young carers are reluctant to access services, young carer representatives cited many of the reasons outlined in the discussion paper, in particular: time constraints: waiting lists for support; and lack of services in rural and remote areas. Respondents also suggested a lack of confidence, or fear of being rejected if they approached someone for help, as possible deterrents to seek support.

### **6.2.2 The role of schools in the identification and support of young carers**

Research has identified schools as a key site for the identification and referral of young carers and all respondents endorsed this finding. Young carer representatives stressed the importance of ensuring young carers remain in schools by offering them understanding, information and flexibility.

Suggestions by young carer representatives to help young carers self-identify, included promoting young carer issues in schools and the broader community via the media. A number of respondents suggested that once young carers were identified schools could facilitate access to support by distributing information brochures and providing contact numbers for services.

Young carer representatives also highlighted the need for additional funding for teacher training to increase their knowledge and understanding of young carer issues. They suggested that training focus on the diversity of care situations and identification.

Suggestions of policies and practices to support young carers in schools beyond those mentioned in the discussion paper included:

- extending the special consideration policy to include young carers
- flexible deadlines for assignments and homework options when required
- mental health and disability issues to be included in health subjects, and
- young-carer workers to visit schools.

### **6.2.3 The role of health professionals and social workers in the identification and support of young carers**

As outlined in the discussion paper, health professional and social workers are key services that families with illness or disability turn to for help. Stakeholders were asked to comment on information and supports needed by them to identify young people with caring responsibilities.

A number of practices were outlined in the discussion paper, including: health professionals identifying who is providing support and meeting care needs in the home; making appropriate referrals; and maintaining confidentiality. Beyond these practices, the young carer representatives suggested that health professionals and social workers recognise young people with caring responsibilities, and recommended improved training to increase their awareness and understanding. It was suggested that training could also include relevant information about appropriate services (e.g. phone numbers of respite centres, young carer activities and flyers). Stakeholders also suggested a number of barriers for health professionals and social workers in ascertaining their patients' care needs at home, such as communication problems, privacy issues and willingness to accept help. One respondent also commented that good practice should involve young carers in the decision-making process.

### **6.2.4 'Whole-of-family' and collaborative, inter-agency approach**

Guidelines for identifying and supporting young carers through services emphasise the whole-of-family approach, which focuses on the care recipient in the context of family relationships. The majority of young carer representatives supported a whole-of-family approach. Some commented that this approach was crucial, as young carers would not accept help unless the care recipient was well looked after. One respondent stated 'yes, just helping one leaves the rest in the dark when they all suffer'. Most respondents did not identify problems with adopting a whole-of-family approach with the exception of issues around confidentiality and the increased time required.

#### ***Effective strategies for the distribution of information to young carers***

The discussion paper noted a number of formats for distributing information about services to young carers. Relevant formats included the internet, written, visual, Braille and audio information all in a range of languages. Locations for distributing written information include: GP surgeries; the point of hospital discharge; schools; community centres; libraries; churches, temples, mosques and synagogues; leisure centres; day centres; and youth clubs.

Young carer representatives were asked to nominate other effective strategies for distributing information to young carers and care recipients. These included:

- the internet via Facebook, MySpace, online schools, AnyCat
- summits and conferences
- schools, universities and TAFEs
- youth or sports clubs, newsletters
- TV advertisements
- cultural groups.

### **6.2.5 Supporting specific groups of young carers**

Australian research, noted in the discussion paper, has identified some specific groups of young carers as requiring different types of interventions to support them in their caring situation, for example, young people in Aboriginal and Torres Strait Islander communities, in rural and remote areas, and in families where a parent has a mental illness. These specific groups of young carers were listed in the discussion paper and young carer representatives were asked if this categorisation was useful. They were also asked to nominate additional groups who may need specific types of support.

Most young carer representatives indicated that the categories outlined in the discussion paper were useful as they took account of the diversity of care situations. One noted 'one size does not fit all'. However, one stakeholder suggested that young carers should be kept as a whole because it recognised the commonalities of their situations and gave them an opportunity to meet a diverse range of people. Young carers aged 10 years and under, was the only additional group identified by these young carer representatives as requiring targeted support not listed in the discussion paper.

Young carer representatives were asked to suggest culturally appropriate methods for the identification of any specific CALD and Aboriginal and Torres Strait Islander groups of young carers. Their suggestions included respect for the individual and making an effort to outreach and maintain engagement of these groups.

## 6.3 WORKERS, NGOS AND GOVERNMENTS

Feedback was also received from front-line workers and representatives from government departments and NGOs including carers advocacy groups. As noted earlier, one of the key reasons young carers remain hidden, identified in the research and echoed in the responses from young carer representatives, is that they do not see themselves as carers.

Responses from these stakeholders also confirmed these findings. Most indicated that non-recognition of the term is due to a perception that their caregiving responsibilities are no different from their peers. Respondents also noted that, once young people are connected to services, the term appears more relevant.

Apart from reasons such as fear of exposure, possible removal from the family and the stigma attached to mental illness or disability outlined in the discussion paper, stakeholders also suggested that young carers remain hidden because they do not want to be seen as different, they are reluctant to ask for help because it is perceived as failure, or they minimise their contribution because they are not the main carer.

Stakeholders were also asked if they were aware of any reasons why family members may not see a child or a young person as a carer. A number of responses reiterated those documented in the discussion paper, including cultural norms within CALD families, parents not wanting to draw attention to themselves due to fear of unwanted intervention or removal of their children, and the stigma associated with the need for care or admitting the need for help.

In addition to these reasons, stakeholders also suggested that young carers remain hidden because the traditional definition of a carer focuses on older people, they are not the main carer so their contribution is overlooked or families deny there is a problem.

Even when caring responsibilities are recognised, young carers are often averse to accessing support and the discussion paper outlined a number of barriers, including a lack of knowledge or awareness of services, time, cost, transport, and inconvenient operation time, which were also mentioned by these stakeholders.

Barriers to accessing services suggested by these respondents, in addition to those outlined in the discussion papers included:

- confusing service system
- financial strain and lack of access to services for rural and remote young carers

- literacy levels and social skills, which are important in articulating needs and accessing support
- isolation
- strict eligibility criteria of services
- information overload at assessment
- financial structure of the Medical Benefits Scheme imposes time constraints on GPs
- cultural appropriateness of services and lack of information in CALD communities.

Respondents were asked how young carers might be identified and put in touch with services. They indicated that identification of young carers required a multifaceted approach to raise awareness. They proposed an approach that included the promotion of positive images of young carers in the media, increased training of service providers (police, health and disability services), health professionals (GPs, hospitals, social workers) and department of education staff (teachers and counsellors).

They suggested that increasing awareness of young carers in schools, services and the broader community would promote self-identification and the detection of young carers at service intake for care recipients and income-support agencies. Other suggestions included mandatory reporting, expanding carer-friendly websites similar to MySpace and Facebook, online services, advertising through youth services, schools, counsellors and health services. Appropriate resources, stakeholders also noted, are required to ensure up-to-date information on services and supports are available.

### **6.3.1 Schools and the identification of young carers and supports**

The discussion paper documented research findings identifying schools as a key site for the identification and referral of young carers. All respondents confirmed this finding, particularly because young people spend a significant amount of time at school. They noted that schools have the potential to offer young carers a break from home, the opportunity to connect with other young people and a safe and protective learning environment.

However, one respondent acknowledged that teachers are under considerable pressure already and the onus of identification of young carers should not fall to them alone. Another suggestion for schools to identify young carers was through guidance or pastoral care workers.

The discussion paper outlined a number of proposals to help young people self-identify, which respondents also emphasised, including:

- promotion of young carers in schools via distribution of young carer packs or kits, DVDs, books about illness and disability and posters, organising guest speakers at assemblies and featuring articles about young carers in newsletters
- modules in personal development/health/physical education courses on young carers based on existing information packages, e.g. MindMatters, Saving Francesca by Iain Hay 'Being a carer, Being a Student and Being a Kid'
- reducing the stigma around illness, disability, mental illness, addiction and related topics via education within the curriculum
- inclusion of a statement in the enrolment form to identify families where someone has a long-term illness or care needs.

Respondents advocated a multi-level approach to policy, education and training and to increase awareness in schools and better equip staff (teachers and counsellors) with the necessary skills to identify and support young carers.

Respondents also suggested that schools provide the following to help identify young carers:

- training and education of staff as part of professional development (working together with young carers, making use of resources from carers associations and participating in carer networks)
- identification of young carers via the Carers Identification Checklist (Morrow, 2006). Other possible indicators that a student may be a young carer suggested by one respondent were:
  1. knowledge that a family member has a disability
  2. lateness or attendance issues
  3. tired, lack of concentration
  4. over-sensitivity regarding family member
  5. underachievement, homework disorganized, incomplete or lost
  6. lack of money for lunches and out-of-school activities
  7. parents not attending school events
  8. depression, anxiety and or challenging behaviour
  9. reluctance to talk about their home life.

The development and implementation of policies and procedures to provide support to young carers outlined in the discussion paper and endorsed by respondents, included:

- access to mobile phone at school
- innovative and flexible approaches to the delivery of learning outcomes; flexible timetabling, less homework and systems of support, e.g. Innovative Community Action Networks (ICAN) and flexible learning options, and
- tutoring at lunchtime.
- Other policies designed to support young carers put forward by respondents, included:
  - Youth Support Coordinator to contribute to development of supportive environments for kids at risk of not transitioning into or completing senior phase of learning
  - individual support plans for young carers, e.g. assistance with transport, financial support of disadvantaged young carers
  - information and access to support service via connections to local community workers and resources
  - anti-bullying policies and procedures incorporating young carer issues
  - young carers added to list of students at educational risk
  - recognition of carer skills and credits for out-of-school learning, HSC support, additional points for UAI, and
  - no-questions leave policy for young carers.

### ***Supports needed by school staff to assist young carers***

Respondents suggested that school staff (teacher and counsellors) had to be patient and understand young carers' situations if they were to effectively support them.

Their suggestions to facilitate this include:

- information and resources available in schools via links to carers association about young carer issues and needs, e.g. DVDs and books about illness and disability, and
- development of easy-to-follow guidelines for assisting young carers.

### **6.3.1 Health professionals and social workers and the identification and support of young carers**

The discussion paper highlighted the critical role of health professionals and social workers in the identification and support of young carers. Stakeholders were asked to comment on strategies to help them identify young carers. Similar to school staff, stakeholders suggested that increasing awareness via professional development training was a necessary precursor to effectively identifying and supporting young carers. Respondents highlighted the need for succinct training, focusing on increasing knowledge of available services and supporting staff initiatives to collaborate with other organisations e.g. carers associations. Respondents also emphasised that youth-friendly practices and a whole-of-family approach would assist health professionals and social workers to identify and support young carers. One respondent suggested that mandatory notification should be considered.

Barriers for health professionals and social workers asking about their patients' care needs at home identified by stakeholders, included lack of training and communication skills with regard to young carer issues, language barriers with CALD clients, not using a family-friendly inclusive approach, high staff turnover, high workload, lack of support from management, services not operating in a youth-friendly manner, and lack of time and resources to build trust.

### **6.3.2 'Whole-of-family' and collaborative, inter-agency approaches**

A whole-of-family approach aims to address the needs of the family and is cited in the research as principal among the guidelines for the identification and support of young carers. Most respondents indicated that a whole-of-family approach was relevant and helpful, especially for CALD families. However, respondents noted that this approach required additional resources, a greater commitment of time and a particular set of skills. Respondents also specified that good communication between services and the family was required to successfully negotiate the different needs of individuals, to maintain confidentiality and balance potential child-protection issues while continuing to support the family.

Respondents generally supported adopting a collaborative, inter-agency approach as they felt it would create positive outcomes for young carers and care recipients. It was thought that this approach offered a more supportive environment in which to share ideas. A key worker or lead agency, good communication channels and up-to-date information were regarded by respondents as necessary elements for the systems to work effectively. However, the dispersed nature of service funding and provision, different policies and procedures, limited resources, time constraints, lack of identified

communication pathways and clarity of roles and responsibilities were identified as potential barriers to working effectively together. Respondents also commented that privacy and confidentiality issues should be considered.

### **6.3.3 Additional effective strategies for the distribution of information**

Often, a family will only reach a crisis once when young people with caregiving responsibilities are identified. The implementation of effective strategies to distribute information about services and support to carers before the family reaches breaking point is an important policy priority. Respondents were asked about additional effective strategies for distributing information beyond those outlined in the discussion paper.

Their suggestions included:

- a multi-level approach (federal, state/territory, local governments) encompassing a range of options such as advertising, information and education
- dissemination through local government agencies and government and non-government organisations
- creative approaches including media campaigns in magazines, television, wiki sites and information lines, internet blogs, websites, mobile phone emails and public forums
- young carer consultants based in schools and headspace centres
- mobile workers to visit schools
- resource manuals, pamphlets and newsletters listing services and supports for young carers, and
- informal education through games and activities on topics identified by young carers.

### **6.3.4 Supporting specific groups of young carers**

The discussion paper outlined a number of specific groups of young carers requiring different types of interventions to support them in their caring situation. On the whole, respondents commented that these categories were useful and took account of the diversity of young carers. One respondent remarked that the categories should be developed in consultation with the young people. It was also noted that the categories are not mutually exclusive.

Stakeholders were asked to nominate additional categories of young carers in need of specific interventions. These included young carers who are:

- under 8 years or aged 18–25 years post secondary school
- living with grandparents
- not in education
- in poverty
- caring for a child with disability
- in single-parent families
- not employed
- caring for an elderly or frail person.

Other groups of young carers identified by stakeholders included those who have their own medical condition (e.g. an acquired brain injury), mental illness or disability, and those with family members who are victims of domestic violence or have extreme psychological trauma as a result of witnessing or experiencing violence.

### ***Culturally appropriate methods for identification of young carers***

Respondents noted that engaging with appropriate community groups and culturally specific services were important sites of information about appropriate methods for the identification of CALD young carers. One respondent noted that CALD workers from the same cultural background were necessary.

Other suggestions included:

- young carer resources in different languages available on websites and in hard copies
- consultation with CALD communities and support agencies to provide a basis for methods adopted and to develop resources within these communities
- attending CALD events and support groups
- regular networking with CALD service providers.

### ***Culturally appropriate methods for identifying and supporting Indigenous young carers***

Respondents suggested that Indigenous young carers could be identified and supported by approaching services including Aboriginal Medical Services, community and religious groups and sports clubs. Respondents also recommended approaching

trusted community leaders to help identify young carers and develop culturally appropriate support services.

Other suggestions included:

- consultation with Indigenous groups to provide a basis for methods adopted
- providing information about young carers to Indigenous carer groups and health services
- employing Indigenous young carer workers, and
- developing approaches that are sensitive to needs of different communities and recognise young carers' extended family.

## 6.4 SUMMARY

Overall the feedback from stakeholders, including young carer representatives, policy makers, advocacy groups and front-line workers, corresponded with the main issues and themes outlined in the discussion paper. In addition, they provided a number of important comments and suggestions on how best to identify and support young carers.

Stakeholders confirmed that one of the main reasons young carers remain hidden is that they do not see themselves as carers. Other suggestions included: young people do not want to be seen as different, concerns of bullying or they are not the main carer so their contribution goes unnoticed.

Stakeholders highlighted the need for a multifaceted approach to raise awareness of young carers through the media, internet and ongoing professional development and training of schoolteachers, counsellors, health professionals and social workers.

Generally stakeholders endorsed a whole-of-family approach but noted additional resources and skills were required to take account of individual needs. All stakeholders identified young carers less than 8 years of age as a specific group requiring targeted intervention.

# 7. CONCLUSION

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This project aimed to examine the social and demographic characteristics of, and ways to identify and support, young carers in Australia. The research had several components. The study reviewed the Australian and international literature on the characteristics of young carers and the issue of 'hidden or potential carers'. A discussion paper based on the literature review was disseminated to stakeholders in all Australian states and territories, including young carer representatives, policy makers and service providers. The objective of the stakeholder consultation was to seek views and information about supporting and identifying young carers in the Australian context.

The study also undertook trend analysis using the SDAC and examined a relatively new data source on young carers (2006 Census) to provide baseline information about the characteristics of young carers and their geographical distribution. The findings from the data collected and analysed in all components of the project form the basis of the recommendations made in the next section.

The literature review outlined what is known about the social and demographic characteristics of young carers, and their geographical distribution. It also reviewed the literature around the issue of hidden caring, outlined services available, and strategies for identifying and supporting young people who provide assistance to family members or friends. The review drew primarily on research from Australia, the USA and the UK, countries where policies over recent decades have emphasised care in the community over institutional care.

Previous research has noted that, at any one point in time, about 4 per cent of young people under the age of 18 years and nearly 10 per cent of young people aged 20–24 years provide regular and ongoing assistance to a friend or relative for reasons of chronic illness, disability or frailty due to older age. It found that caring is more prevalent among Indigenous communities, and young women are more likely to be primary carers—or have the main responsibilities for care—than young men. Around 20 000 young people in Australia were identified as primary carers. Existing research has also noted that these estimates of the prevalence and number of young carers are likely to be an underestimate for a number of reasons, including survey methodologies, the private nature of much caregiving, and the non-disclosure of some illnesses or conditions due to stigma. The issue of ‘hidden carers’ is further discussed below.

Two data sources with different survey methodologies were analysed in this study: the Census, in which individuals self-identify as carers in response to a single question; and the SDAC, which is a specialist survey conducted by trained interviewers, and identifies providers of care for those requiring assistance for many everyday tasks. Although these two surveys cannot be considered to document the same populations of young carers, it should be noted that the findings about the characteristics of young carers identified in the two surveys are perhaps surprisingly consistent.

The analysis undertaken in this study confirms the gender composition of caregiving, with young women comprising a higher proportion of primary carers (young people who had the main responsibility for care). Trend analysis of the SDAC, between 1998 and 2003, showed that the number of young primary carers increased over this period, although the estimated total number of all carers declined slightly.

The inclusion of a question on caring in the 2006 Census provided new data for estimating the prevalence of caring among young people in Indigenous and CALD communities in Australia. Literature from the UK and USA has indicated that caring is more prevalent in some specific ethnic communities. In this study, CALD background was defined on the basis of the person indicating that they spoke a language other than English at home. Using this definition, the Census data shows that caring is more prevalent among young people from CALD backgrounds than those from non-Indigenous, English-speaking backgrounds. The Census data also shows that the provision of informal care was most prevalent among Indigenous young people, particularly Indigenous young women.

The literature has highlighted the issue that a significant amount of care provided by children and young people may be hidden due to a number of factors. It may be that many young people do not view the assistance they provide to a family member or friend as ‘care’, rather they perceive themselves to simply be ‘helping out’ at home.

Other reasons raised in the literature for not identifying as a carer may be due to fear of unwanted intervention from services or concerns about stigma attached to some illnesses and conditions. Young people may also lack information and access to services or experience difficulties accessing services due to issues such as distance, cost and the types of services provided.

This study undertook analysis of the Census data to calculate the number and proportion of young people who may be regarded as potential carers. Potential young carers were classified in this study as those young people aged 12–14 years who lived with another person with disability, or who were aged 15–24 years, lived with another person with disability and did not identify as a carer on the Census form. The analysis suggested that there may be a significant group of young people who live with a person with disability who are not identified as carers in the Census. The number of potential carers was around two-thirds the size of the identified carers in the age group 15–24 years or nearly 80 000 young people.

There was a higher prevalence of potential caring among Indigenous young people aged 12–24 years and CALD young people aged 15–24 years. This finding may be due to higher rates of disability in these communities, or non-recognition by young people in these communities that the assistance and support they provide constitutes caring, or some combination of both these factors. Young people aged 15–19 years were more likely than those aged 20–24 years to be potential carers, irrespective of Indigenous or CALD status. This group may be young people living with parents at home who ‘help out’ other members of the family, but do not view this activity as care. Or, it may be that these young people are at an age with other priorities and are not so engaged in the task of providing care as other members of the household. Young men were also more likely to be potential carers than young women. This finding may reflect that young men provide less care in households than young women or it may be that they are providing care, but it is not recognised as such for reasons of gender perceptions about caring and stigma.

The literature also reports on the socio-demographic characteristics of young carers and the findings of previous research are confirmed in the data analysis in this study. Data in both the SDAC and the Census indicates that young carers were more likely than their non-carer peers to be living in sole-parent households. The SDAC shows that the majority of young carers live with their care recipient and are providing support and assistance to a parent. The trend analysis of SDAC revealed that these profiles of young carers had remained stable between 1998 and 2003. However, more young primary carers were caring for a person with a profound limitation in 2003 than in 1998.

The literature documents the range of tasks undertaken by young carers and the time they spend providing informal care. While young carer's circumstances and responsibilities are very diverse, their caring role may compete with other aspects of their social and economic participation as documented by previous Australian research (e.g. Cass et al. forthcoming). Data from both the SDAC and the Census indicate that young carers are less likely to complete Year 12 than their non-carer peers. The trend analysis of the SDAC suggests that more young people and young carers were participating in education in 2003 than in 1998.

Participation in employment for young carers is also likely to be affected by caring responsibilities. Young carers had lower levels of participation in employment, particularly full-time employment, than their non-carer peers in both the Census and the SDAC data. A higher proportion of young carers also reported that they were unemployed compared with non-carers. The trend analysis showed that proportionally more young people and young carers were employed and fewer unemployed in 2003 than 1998, but that the increase in employment was predominantly in part-time employment.

Census data revealed that young carers were less likely to be combining study with employment than their non-carer peers and more likely to be a non-participant in either employment or study. Census data also indicated that non-participation rates were higher among young female carers than young male carers overall, and particularly among young women aged 20–24 years. Young Indigenous carers also had high rates of non-participation in education and employment.

The lower levels of participation in employment and education have implications for young carers' immediate and long-term financial circumstances. Australian research has indicated that the circumstances of young carers are characteristic of low income (Cass et al. forthcoming). The trend analysis of the SDAC suggested that the relative economic circumstances of young carers have remained stable between 1998 and 2003. In both years, young primary carers were more likely than other carers and non-carers to live in low-income households. Young carers identified in the Census were also more likely than other young people to live in low-income households.

The regional analysis at Statistical Division level using the geographical data of the Census showed that a higher proportion of young people were carers in regional and remote areas of Australia. Young carers were also more disadvantaged compared to their peers in terms of living in low-income households, in Year 12 completion rates, and in participation in employment in regional and remote areas. The latter finding suggests a need for more research into the circumstances of young people providing support in these areas.

The stakeholder consultation undertaken in this project comprised the development of a discussion paper based on the literature review and consultation with young carer representatives, policy makers and service providers. The discussion paper raised a number of questions about strategies for identifying and supporting young carers. It sought the views of young carers and other stakeholders on a range of themes including: why young carers remained hidden; how schools, health professionals, and social workers might identify young carers and what information and support they might require in order to do so; the advantages and disadvantages of a whole-of-family approach to service provision; information dissemination strategies; and strategies for supporting specific groups of young carers.

Young carer representatives and other stakeholders confirmed that one of the main reasons that young carers did not identify as a carer and remained hidden was that they did not perceive that the tasks they undertook constituted care. They also indicated that young carers may prefer to go unnoticed at school and not regarded by their peers as different, due to concerns about stigma and bullying. The possibility that the young carer may not be the main carer, and so their contributions within the household may not be noticed was also raised.

Young carer representatives and other stakeholders endorsed the need for multifaceted information campaigns to raise awareness about young carers and for increased information to be provided to schools and health professionals in order to help young carers gain information and access to services. Young carer representatives agreed with many of the issues raised in the discussion paper as to why young carers might not wish to access services, including time constraints, waiting lists, and lack of services in rural and remote areas. The importance of schools providing flexibility, information and understanding to help keep young carers in education was highlighted by young carer representatives. Training and support for health professionals to assist them identify young carers was another theme endorsed by the stakeholders and young carer representatives. Overall, the whole-of-family approach was supported by young carer representatives and stakeholders, although young carers noted that confidentiality and time constraints may be issues to be addressed when using this approach. Stakeholders also noted that this approach required good communication between services and the family to negotiate the different needs of individuals.

In Australia, as in the USA and UK, much of the assistance required by people with disabilities or illnesses is provided by family and friends rather than formal services (AIHW, 2005). To date, no Australian research has estimated the precise value of young carers' contributions to the economy, although Access Economics estimate the value of all care provided by the informal sector to be approximately \$30 billion per year, if

it were to be replaced by formal services (Access Economics, 2005). The provision of informal care clearly has economic and social value. In addition, at an individual and community level, it could be considered to contribute to building stronger, social connections and enhancing the development of life skills for young people. There are, however, individual costs incurred in providing care, such as reduced opportunities for employment, education, and social participation.

The policy emphasis on informal care, therefore, may compete with other policy agendas, such as the objectives of increasing, labour-force participation in the context of an ageing population. The Australian Government has indicated that 'to be socially included requires opportunities for: securing a job; accessing services; connecting with others in life through family, friends, work, personal interests and local community; dealing with personal crises such as ill health, bereavement or the loss of a job; and being heard' (Gillard 2008a, in Hayes et al. 2008:9). Young carers have high levels of connection and participation in their family sphere, which may affect their social and economic participation. The findings in this research, which inform the recommendations in the following section, highlight the need to further develop strategies and policies which take account of the costs and worth of informal care, in order to promote young people's social inclusion through participation in education and employment.

# 8. RECOMMENDATIONS ON HOW TO IDENTIFY AND SUPPORT YOUNG CARERS

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## 8.1 INCREASE AWARENESS OF CARING ROLES AND IDENTIFICATION AS A CARER AMONG ALL YOUNG PEOPLE

The main issues raised in the literature review and stakeholder consultation were the lack of identification of young people as carers due to stigma, privacy issues, and non-recognition that the assistance provided constitutes 'caring'.

The data analysis identified higher rates of 'potential caring' in the following groups of young people:

- 15–19 years old
- Indigenous background
- culturally and linguistically diverse backgrounds
- young men.

Other disadvantaged groups of young carers were those living in:

- areas of lower socio-economic status
- regions with a high prevalence of sole-parent families
- remote and regional areas.

### ***Recommendations***

- Develop multifaceted campaigns using the media and internet with positive and age-relevant images of disability and caring, which aim to reduce the stigma associated with disability, illness and caring among all young people.
- Develop appropriate awareness campaigns for disadvantaged groups identified in data analysis.
- Where possible, given data restrictions, undertake further research on:
  - the distribution of potential carers at the Statistical Division level to identify regions within states and territories with higher proportions of young people whose caring role may be hidden
  - the distribution of identified, young carers and hidden or potential young carers at the Local Government Area level in major cities, particularly the distribution of CALD and Indigenous young carers.

## **8.2 DEVELOP METHODS TO DISSEMINATE AGE-APPROPRIATE, CULTURALLY APPROPRIATE AND GEOGRAPHICALLY APPROPRIATE INFORMATION**

The main methods to disseminate age-appropriate information discussed in the literature review and stakeholder consultation were to:

- Develop a multi-level approach (federal, state/territory, local governments) encompassing a range of options such as advertising, information and education
- Distribute information in a range of formats including written, visual, and in a range of languages and through electronic media including TV advertisements and on the internet, via Facebook, MySpace, online schools, conferences and seminars

- Develop resource manuals, pamphlets and newsletters listing services and supports for young carers, and distribute through GP surgeries, the point of hospital discharge, schools, universities and TAFEs, community centres, libraries; religious groups, leisure centres and youth clubs.

### ***Recommendations***

- Support all relevant stakeholders to develop age-appropriate, culturally appropriate and geographically appropriate methods of information dissemination using multiple formats and media
- Develop appropriate information dissemination methods for young people in regional and remote communities
- Conduct a policy and program audit of all policies relevant to young carers in all the states and territories and disseminate information to relevant departments and organisations.

## 8.3 SUPPORT SCHOOLS AND TEACHERS TO IDENTIFY AND HELP YOUNG CARERS TO MAINTAIN THEIR PARTICIPATION IN EDUCATION AND TO CONTACT SERVICES

The main issues discussed in the literature review and stakeholder consultation were:

- Raising awareness among staff and pupils about young carers and health issues, including in the curriculum
- Professional development for teachers and the establishment of guidelines to help identify and support young carers
- Identifying flexible ways to support all young carers to stay in school.

The data analysis showed that specific groups of young carers were more at risk of leaving school, including:

- young women
- Indigenous young people
- young people in regional and remote areas.

### ***Recommendations***

- Ongoing professional development and training of primary and secondary school teachers and counsellors on issues related to young carers, particularly about the diversity of care situations and support for young carers.
- Further develop policies to support young carers at risk of leaving school
- Where possible—given data restrictions—undertake further research on the educational participation and attainment disadvantage of young carers in local government areas in the major cities.

## 8.4 DEVELOP AWARENESS AMONG HEALTH PROFESSIONALS, SOCIAL WORKERS AND SERVICE PROVIDERS OF YOUNG CARERS AND THE POTENTIAL OF A WHOLE-OF-FAMILY APPROACH

The main issues discussed in the literature review and stakeholder consultation were:

- the need for additional information and support for health professionals, social workers and service providers in order to assist them to identify and support young carers.

### ***Recommendations***

- Ongoing professional development and training of health professionals, social workers and service providers about strategies to identify young carers and issues related to young carers
- Develop information for health professionals, social workers and service providers on a whole-of-family approach, particularly in regional and remote areas
- Develop a protocol or recording tool to assist service providers to assess support needs for young carers and their families.

## 8.5 SUPPORT YOUNG CARERS TO PARTICIPATE IN EMPLOYMENT

The data analysis showed that young carers are less likely to participate in employment than non-carers, particularly in regional and remote areas where, in some cases, there are restricted opportunities for employment.

### ***Recommendations***

- Identify flexible employment policies that assist young carers to balance their employment and caring roles
- Develop appropriate employment strategies for young carers in regional and remote areas in Australia
- Where possible, given data restrictions, undertake further research on the employment disadvantage of young carers in Local Government Areas in the major cities.

## 8.6 DEVELOP CULTURALLY APPROPRIATE SUPPORTS FOR SPECIFIC GROUPS OF CARERS

The literature review and stakeholder consultation highlighted the need to develop strategies to identify and support CALD carers, including developing young carer resources in different languages in consultation with CALD communities.

The data analysis identified a high proportion of identified and potential carers in CALD communities.

### ***Recommendations***

- Consult with CALD communities and support agencies to provide a basis for methods adopted and to develop resources within these communities.
- Where possible, given data restrictions, undertake further research on CALD young carers, particularly regional analysis in major cities.

## 8.7 DEVELOP STRATEGIES FOR IDENTIFYING AND SUPPORTING INDIGENOUS YOUNG CARERS

The literature review and stakeholder consultation highlighted the need to develop links between support services and health services, and consult with community leaders and Indigenous groups to help identify young carers and develop culturally appropriate support services. It has been noted that, due to the lower levels of participation in education, the effectiveness of schools as a site for the identification and support of young Indigenous carers school may be limited.

The data analysis identified a high prevalence of identified and potential caring among Indigenous young people, particularly in regional and remote communities.

### ***Recommendations***

- In consultation with Indigenous communities, develop approaches to identify and support young carers that are sensitive to needs of Indigenous communities, including appropriate methods for information dissemination and raising awareness about young carers.
- In consultation with Indigenous communities, develop approaches to identify appropriate policies to provide acceptable alternatives to ongoing, informal caring by young people in remote and disadvantaged regions.
- Undertake further research about the circumstances and experiences of young Indigenous carers in remote communities to gain a more detailed understanding of their situation.

## 8.8 DEVELOP CONSISTENCY IN DEFINITIONS OF YOUNG CARERS IN POLICY AND DATA COLLECTION

The stakeholder consultation noted that it would be useful to have consistent definitions of young carers where possible. It was also noted in the data analysis that difference in the objectives of surveys, methodologies used and definitions of carers make comparisons between different data sources difficult.

### ***Recommendation***

- Develop consistency in definitions of young carers in policy and data collection where possible.

# APPENDIX A— EXEMPLAR SCHOOL POLICY FROM THE PRINCESS ROYAL TRUST FOR CARERS (2006)

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## EXEMPLAR SCHOOL POLICY

At we believe that all children and young people have the right to an education, regardless of what is happening at home.

When a young person looks after someone in their family who has a serious illness, disability or substance misuse problem, he or she may need a little extra support to help him or her get the most out of school. Our Young Carers Policy says how we will help any pupil who helps to look after someone at home.

Our school:

- has a member of staff with special responsibility for young carers and lets all new pupils know who they are and what they can do to help
- runs a PSHE lesson on the challenges faced by young carers during year
- can put young carers in touch with the local Young Carers Service. We can also put families in touch with other support services
- is accessible to parents who have mobility and communication difficulties and involves them in parents' evenings
- respects your right to privacy and will only share information about you and your family with people who need to know to help you
- will consider alternatives if a young carer is unable to attend out of school activities e.g. detention, sports coaching, concerts, due to their caring role
- allows young carers to telephone home during breaks and lunchtimes
- can give parents advice about how to get their children into school where transport is a problem.

# APPENDIX B— A RECORDING TOOL FOR AGENCIES TO IDENTIFY YOUNG CARERS

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From Gaffney, M. (2007), *A research study of young carers: the development of a recording tool for agencies to identify young carers*. Wellington: Ministry of Health (in association with carers NZ)

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## CHILDREN'S CARING AND DOMESTIC ROLE AT HOME

Service Identifier:

Age and gender of children in the home (Please circle or specify)		
Age	DOB	Male/Female
Age	DOB	Male/Female
Age	DOB	Male/Female

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**Cultural Background (Please circle or specify)**

European

Maori (Please Specify Iwi)

Pacific Island (Please specify)

Other (Please specify)

**Other Household Information**

Who lives in this household? e.g. Other adults, other children, extended family. (It may be useful to draw a 'family tree' on the back to show the structure of families within the household and any variations across the week)


Generally we find that caring and domestic responsibilities change when there is a person with a disability in the household. Is there a person in your household/family with an acknowledged disability/impairment/illness?

(Please describe the disability etc. and how long it has been present or significant. What is the child's/children's relationship to this person?)


**Reason(s) for referral to agency:**


**This information has been filled in by:**


**Table 1: Role within household for family in general (rather than for specific people—see Table 2)**

- **Main role in family**—Is solely—but may be with other children—or jointly responsible for doing these things.
- **Support role in family**—care given but in support of primary caregiver or in the absence of primary caregiver

If there is more than one child involved record as for the child doing the most of the work under that task category.

Decide if the child is taking the main role or support role. See two columns in table below. Describe which tasks are done and how often they are done in the appropriate box below.

	Main role in family	Support role in family	Use (DK) when don't know	
<b>Caring Tasks</b>	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these	Who else is involved in doing these tasks?
<b>Household care or domestic tasks for household in general</b> e.g. cleaning, washing, Vacuuming, looking after pets, cooking, shopping, outdoor chores, responding to mail and phone				
<b>Childcare</b> e.g. providing care and doing specific tasks for siblings, parenting tasks				
<b>Financial</b> e.g. working so as to support the family financially, attending to finances and budgeting				

**Table 2: Care for other(s) in household**

Decide if child is taking the main role or support role. Describe tasks in the appropriate box indicating how often they are done.

	Main role in family	Support role in family	Use (DK) when don't know	
<b>Caring Tasks</b>	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these	Who else is involved in doing these tasks?
<b>Personal/Intimate Care</b> e.g. showering, dressing, assisting with eating, toileting				
<b>Emotional Support</b> e.g. comforting, listening, advising, decision making, negotiating				
<b>Medical Care</b> e.g. helping to administer medication, attending appointments, going to chemist, communicating concerns to professionals				
<b>Social Support</b> e.g. going out on outings, social activities, helping with mobility, arranging visits				
<b>Financial</b> e.g. shopping and paying for particular items, paying bills for this person				

**Table 3: Which care and domestic routines does the child (or children) do for themselves**

Decide if child is taking the main role or support role. Describe tasks in the appropriate box indicating how often they are done.

Main role in family Support role in family

	Main role in family	Support role in family	Use (DK) when don't know	
<b>Caring Tasks</b>	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these	Who else is involved in doing these tasks?
<b>Providing care and doing specific tasks for themselves</b> e.g. any of the tasks listed in the previous tables.				
Personal Care Emotional Support Medical Care Social Support Financial Support				
Who are providing the parenting for children in this household?				

**Table 4: Other care and domestic tasks not described above—this may include caring for others outside the household**

Decide if child is taking main role or support role. Describe tasks in the appropriate box indicating how often they are done.

Main role in family Support role in family

	Main role in family	Support role in family	Use (DK) when don't know	
<b>Caring Tasks</b>	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these	<b>Describe tasks</b> Note how often they are done (e.g. daily, weekly and monthly or always, often, and sometimes etc)
Please list others if any				

Please make any other comments to help us understand the general level of acceptability for this child (children) and the level of responsibility and the amount of care or work undertaken. This might include also referring to others also contributing to tasks within the household. Please note any comments or attitudes made through the interviews.

**Table 5: The advantages and disadvantages of the caring role for the child or children**

How does the domestic and caring role advantage and disadvantage the child in regards to?

COMMENTS	
<b>Physical Health</b> e.g. tired, rundown or self abuse, often unwell	
<b>Emotional and Mental Well-being</b> e.g. indecisive, anxious, depressed, negative behaviours, takes a lot of responsibility for family, feelings of guilt, anger or resentment, embarrassment, mature for age	
<b>Social Participation</b> e.g. Are they unable to participate in out of school activities such as clubs or sports	
<b>Relationship with peers</b> e.g. They may prefer the company of older people because of responsibilities, they may be embarrassed about their home life. May not have opportunities to build friendships.	
<b>Education</b> e.g. school non-attendance or truancy, unable to focus on working toward qualifications	
<b>Relationships within the household</b> e.g. strained relationships with adults or siblings or the development of dependent relationships that would not be expected for most children	
<b>Employment</b> e.g. less able to take on part-time work compared to other young people their age	
<b>Transition into Adulthood</b> e.g. denial of past, youth offending, restrictions on developing independence —in terms of finances, living arrangements, employment/tertiary study	

How does the family or family members benefit from the child taking on the domestic and caring role? Who within the household, if anyone, benefits the most?

What is the child's perspective on their role in supporting the family by taking on a domestic and caring role?

**Table 6: The current domestic needs of the family and child (or children) and the supports in place**

COMMENTS	
<p>Does the level of work and type of care being provided by children suggest that domestic support is needed?</p> <p>Yes/ No.</p> <p>If yes have others recognised the children(s) contribution to this household?</p> <p>Yes/ No.</p>	<p>If yes, who and if applicable what forms of support do they provide?</p> <p>If not mentioned already, who is providing a lot of the general care for the child or children?</p>
<p>Are all the child's/household's domestic and caring needs being met as well as might be expected in this household?</p> <p>Yes/ No</p>	<p>If no, what are the household's (or child's) current or impending unmet needs?</p>
<p>Are you in a position to see that these needs (or some of them) can be met or refer them on to those who can?</p> <p>Yes / No</p>	

Please record (turn over) any other features of this household/family that will help us understand what is happening for the child or children.

# APPENDIX C— DISCUSSION PAPER QUESTIONS FOR COMMENT

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- How do you think young carers might be identified?
- How might young carers be put in touch with services?
- Are you aware of other reasons why young people may not see themselves as ‘young carers’?
- Are you aware of any reasons why family members may not see their young family member as a ‘carer’?
- Do you know of any other barriers that prevent young carers from accessing support?

## SCHOOLS

- What responsibility do you think that schools have in identifying and supporting young carers?
- How do you think schools in Australia could help young people identify themselves as young carers?
- What policies and practices could schools in Australia develop and implement to support young carers?
- How can the various education authorities assist schools to identify and support young carers?
- What supports do school staff need to assist young carers?

## HEALTH PROFESSIONALS

- What information and support do health professionals in Australia need in order to assist them to identify and support young carers?
- Can you identify any barriers that might make it difficult for health professionals to ask their patients about care needs in the home?

## SOCIAL WORKERS

- What information and support do social workers and other welfare workers in Australia need in order to assist them to identify and support young carers?
- Can you identify any barriers that might make it difficult for social workers and other welfare workers to ask their clients about care needs in the home?

## IDENTIFYING AND SUPPORTING YOUNG CARERS THROUGH SERVICES

- Is the 'whole-of-family' approach relevant and helpful for Australian service providers?
- Can you see any difficulties with adopting a 'whole-of-family' approach?
- Can you see any difficulties with adopting a collaborative, inter-agency approach?

## PROVIDING INFORMATION ABOUT SERVICES FOR YOUNG CARERS

- Are you aware of other effective strategies for distributing information to young carers and the people they care for?

### *Targeting specific groups of young carers*

- Do you consider that these are useful categories to account for the diversity of young carers?
- Can you suggest any culturally appropriate methods for the identification of any specific culturally and linguistically diverse group of young carers?
- Can you suggest any culturally appropriate methods for identifying and supporting Aboriginal and Torres Strait Islander young carers?
- Can you think of any other groups of young carers who may need targeted support?

# APPENDIX D— LIST OF STAKEHOLDERS CONTACTED

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- Australian National Young Carers Action Team (ANYCAT)
- Carers organisations in states and territories
- Members of The Ministerial Council on Education, Employment, Training and Youth Affairs (MCEETYA) Youth Taskforce ([www.mceetya.edu.au/mceetya/](http://www.mceetya.edu.au/mceetya/)) including:
  - Tasmanian Office of Children and Youth Affairs, Department of Premier and Cabinet. ([www.dpac.tas.gov.au/divisions/cdd/ocya](http://www.dpac.tas.gov.au/divisions/cdd/ocya))
  - Youth Strategy and Participation, Communities Division, New South Wales Department of Community Services ([www.community.nsw.gov.au](http://www.community.nsw.gov.au) and [www.youth.nsw.gov.au/](http://www.youth.nsw.gov.au/))
  - Victorian Office for Youth, Department of Planning and Community Development ([www.youth.vic.gov.au](http://www.youth.vic.gov.au))
  - Victorian Office of Youth Affairs, Department for Victorian Communities, Victorian Government.
  - Queensland Office for Youth, Department of Communities, ([www.communities.qld.gov.au/youth](http://www.communities.qld.gov.au/youth))

- The South Australian Office for Youth ([www.officeforyouth.sa.gov.au](http://www.officeforyouth.sa.gov.au))
- Western Australian Office for Children and Youth, Department for Community Development, ([www.childrenandyouth.wa.gov.au](http://www.childrenandyouth.wa.gov.au))
- Northern Territory Office of Youth Affairs, Department of the Chief Minister. ([www.youth.affairs.nt.gov.au](http://www.youth.affairs.nt.gov.au))
- Office for Children, Youth and Family Support, Department of Disability, Housing and Community Services, Australian Capital Territory Government ([www.dhcs.act.gov.au/ocyfs](http://www.dhcs.act.gov.au/ocyfs))
- Youth Bureau, Australian Government Department of Education, Employment and Workplace Relations ([www.officeforyouth.deewr.gov.au](http://www.officeforyouth.deewr.gov.au))
- Australian Local Government Association representative on MCEETYA.
- Non-government sector organisations that provide services and supports to young carers e.g. The Benevolent Society, Uniting Care
- Organisations that work with children in complex family situations e.g. Children of Parents with a Mental Illness (COPMI) ([www.copmi.net.au/](http://www.copmi.net.au/)), Mirabel Foundation ([www.mirabelfoundation.com/](http://www.mirabelfoundation.com/))
- Royal Australian College of General Practice ([racgp.org.au](http://racgp.org.au))
- Australian Guidance and Counselling Association ([www.agca.com.au/](http://www.agca.com.au/))
- Australian Association of Social Workers ([www.aasw.asn.au/](http://www.aasw.asn.au/))
- NSW Commission for Children and Young People ([www.kids.nsw.gov.au/](http://www.kids.nsw.gov.au/))
- NSW Teachers Federation ([www.nswtf.org.au/](http://www.nswtf.org.au/);
- Australian Education Union (Victorian branch) ([www.aeuvic.asn.au/](http://www.aeuvic.asn.au/))
- Queensland Teachers' Union ([www.qtu.asn.au/](http://www.qtu.asn.au/))
- Australian Government Department of Families, Housing, Community Services and Indigenous Affairs ([www.fahcsia.gov.au/internet/facsinternet.nsf/](http://www.fahcsia.gov.au/internet/facsinternet.nsf/))
- Australian Government Department of Health and Ageing ([www.health.gov.au/](http://www.health.gov.au/))
- NSW Department of Health ([www.health.nsw.gov.au/](http://www.health.nsw.gov.au/))
- NSW Department of Ageing, Disability and Home Care ([www.dadhc.nsw.gov.au/DADHC.htm](http://www.dadhc.nsw.gov.au/DADHC.htm))

- South Australian Department of Further Education, Employment, Science and Technology ([www.dfeest.sa.gov.au/](http://www.dfeest.sa.gov.au/))
- South Australian Department of Premier and Cabinet ([www.premcab.sa.gov.au/](http://www.premcab.sa.gov.au/))
- South Australian Department Education and Children's Services ([www.decs.sa.gov.au/](http://www.decs.sa.gov.au/))
- South Australian Department for Families and Communities ([www.familiesandcommunities.sa.gov.au/](http://www.familiesandcommunities.sa.gov.au/))
- Children, Youth & Women's Health Service, SA ([www.cywhs.sa.gov.au/Default.aspx?p=98](http://www.cywhs.sa.gov.au/Default.aspx?p=98))

# APPENDIX E— DATA DESCRIPTIONS AND DATA TABLES

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## DATA TABLES

**Table E.1: Number of young people aged 15–24 years who provided unpaid help, care or assistance by age, sex, Indigenous status and language spoken at home (Australia, 2006)**

	Indigenous <sup>(a)</sup>	Non Indigenous		Total <sup>(b)</sup>
		Speaks English only	Speak languages other than English	
<b>Males</b>				
15–19 years	1423	17639	4302	23865
20–24 years	1308	19158	6211	27158
<b>Total males</b>	<b>2731</b>	<b>36797</b>	<b>10513</b>	<b>51023</b>

	Indigenous <sup>(a)</sup>	Non Indigenous		Total <sup>(b)</sup>
		Speaks English only	Speak languages other than English	
<b>Females</b>				
15–19 years	1783	21237	5173	28711
20–24 years	2069	28853	8207	39702
<b>Total females</b>	<b>3852</b>	<b>50090</b>	<b>13380</b>	<b>68413</b>
<b>Persons</b>				
15–19 years	3206	38876	9475	52571
20–24 years	3377	48011	14418	66870
<b>Total persons</b>	<b>6583</b>	<b>86887</b>	<b>23893</b>	<b>119436</b>

Source: ABS 2006a.

Note: (a) Indigenous total also includes young people who identified as Indigenous and who speak languages other than English at home, which may include Indigenous languages.

(b) Total also includes other young carers whose Indigenous status or language spoken was not stated. Figures are based on unpublished data provided by the ABS and may not exactly match published figures

**Table E.2: Proportion of young people aged 15–24 years who provide care by age, sex, Indigenous status and language spoken at home, (Australia, 2006) (per cent)**

	Indigenous	Non Indigenous	
		Speaks English only	Speak languages other than English
<b>Males</b>			
15–19 years	7.0	3.7	5.2
20–24 years	8.3	4.1	5.3
<b>Females</b>			
15–19 years	8.9	4.6	6.3
20–24 years	12.1	6.1	7.0
<b>Persons</b>			
15–19 years	7.9	4.1	5.8
20–24 years	10.3	5.1	6.2
<b>Total persons</b>	<b>9.0</b>	<b>4.7</b>	<b>6.1</b>

Source: ABS 2006a

Note: Proportions are calculated by excluding non-response to the carer question from the denominator. This approach assumes that the non response to this question is proportionally split between carers and non-carers. Carers who did not respond to the question on or carer status or Indigenous status are excluded.

**Table E.3: Number and proportion of young carers (aged 10–24 years) by age, sex and primary carer status (2003) (weighted estimates and percentages)**

	Number			Per cent of young people		
	Primary carers	Carers	All carers	Primary carers	Carers	All carers
<b>Males</b>						
10–14 years	n.p.	n.p.	38331	n.p.	n.p.	5.7
15–19 years	n.p.	n.p.	52499	0.5	7.2	7.7
20–24 years	2463	65246	67709	0.3	9.1	9.4
<b>Total males</b>	<b>5981</b>	<b>152107</b>	<b>158538</b>	<b>0.3</b>	<b>7.3</b>	<b>7.6</b>
<b>Females</b>						
10–14 years	1386	31812	33198	0.2	4.9	5.1
15–19 years	3854	53046	56900	0.6	8.1	8.7
20–24 years	11463	51572	63035	1.6	7.4	9.0
<b>Total females</b>	<b>16702</b>	<b>136430</b>	<b>153132</b>	<b>0.8</b>	<b>6.8</b>	<b>7.6</b>
<b>Persons</b>						
10–14 years	1836	69692	71528	0.1	5.3	5.4
15–19 years	7371	102028	109399	0.6	7.6	8.2
20–24 years	13926	116818	130745	1.0	8.2	9.2
<b>Total persons</b>	<b>23133</b>	<b>288538</b>	<b>311672</b>	<b>0.6</b>	<b>7.1</b>	<b>7.6</b>

Source: ABS 2003

Note: n.p. denotes not available for publication

**Table E.4: Number of young carers in 1998 and 2003 (weighted estimates)**

	Primary carers		Carers		All carers	
	1998	2003	1998	2003	1998	2003
<b>Males</b>						
10–14 years	n.p.	n.p.	40117	37880	41341	38331
15–19 years	n.p.	n.p.	61858	48981	63110	52499
20–24 years	3577	2463	59348	65246	62925	67709
<b>Total males</b>	<b>6053</b>	<b>5981</b>	<b>161323</b>	<b>152107</b>	<b>167376</b>	<b>158538</b>
<b>Females</b>						
10–14 years	1537	1386	35403	31812	36940	33198
15–19 years	3640	3854	61291	53046	64931	56900
20–24 years	4911	11463	60157	51572	65068	63035
<b>Total females</b>	<b>10089</b>	<b>16702</b>	<b>156851</b>	<b>136430</b>	<b>166940</b>	<b>153132</b>
<b>Persons</b>						
10–14 years	2761	1836	75520	69692	78281	71528
15–19 years	4892	7371	123149	102028	128041	109399
20–24 years	8488	13926	119506	116818	127994	130745
<b>Total persons</b>	<b>16141</b>	<b>23133</b>	<b>318175</b>	<b>288538</b>	<b>334316</b>	<b>311672</b>

Source: ABS 1998, 2003

Note: n.p. denotes not available for publication

**Table E.5: Number of young people aged 12–14 years who live with a person with disability by presence of other carers (Australia, 2006)**

	No carer present	At least 1 carer present	Total
<b>Males</b>			
No person with a disability in household	315804	71691	387495
Young person has disability and other household members have disability	228	1445	1673
Other household members have disability	1005	4779	5784
<b>Total potential carers male</b>	<b>1233</b>	<b>6224</b>	<b>7457</b>
<b>Females</b>			
No person with a disability in household	304028	64093	368121
Young person has disability and other household members have disability	114	663	777
Other household members have disability	1058	4839	5897
<b>Total potential carers female</b>	<b>1172</b>	<b>5502</b>	<b>6674</b>
<b>Total potential carers</b>	<b>2405</b>	<b>11726</b>	<b>14131</b>

Source: ABS 2006a

**Table E.6: Number and proportion of young people (aged 12–14 years) who are potential hidden carers by Indigenous status (Australia, 2006)**

	Number		Proportion	
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous
Males	470	6857	2.9	1.8
Females	450	6083	2.9	1.7
<b>Total persons</b>	<b>920</b>	<b>12940</b>	<b>2.9</b>	<b>1.8</b>

Source: ABS 2006a

**Table E.7: Number and proportion of young people (aged 12–14 years) who are potential hidden carers by language spoken at home (Australia, 2006)**

	Number		Proportion	
	English only	Languages other than English	English only	Languages other than English
Males	6865	520	2.0	1.0
Females	6038	590	1.9	1.2
<b>Total persons</b>	<b>12903</b>	<b>1110</b>	<b>2.0</b>	<b>1.1</b>

Source: ABS 2006a

**Table E.8: Number of young people aged 15–24 years<sup>(a)</sup> by age, co-residence with a person with a disability, and identified carer status, (Australia, 2006)**

	Lives with a person with a disability		Does not live with a person with a disability	
	Identified carer	Non-identified potential carer	Identified carer	Non-carer
<b>Males</b>				
15–19 years	7700	24884	14246	508551
20–24 years	6147	18077	18430	510970
<b>Total males</b>	<b>13847</b>	<b>42961</b>	<b>32676</b>	<b>1019521</b>
<b>Females</b>				
15–19 years	8783	21185	17655	490765
20–24 years	7706	13461	28867	513806
Total females	16489	34646	46522	1004571
<b>Total</b>	<b>30336</b>	<b>77607</b>	<b>79198</b>	<b>2024092</b>

Source: ABS 2006a.

Note: (a) This sample includes young people living in households with other people only, not young people living alone. Sample excludes young people who did not respond to the carer question

**Table E.9: Cultural background of young people (aged 10–24 years) by carer status (weighted percentages) (2003) (per cent)**

	Australian born	Born overseas in main English speaking country <sup>(a)</sup>	Born overseas in non-English speaking country	Total	n
<b>1998</b>					
Primary carers	85.2	n.p	n.p	100.0	30
Carers	87.4	3.6	9.1	100.1	616
Non-carers	87.4	4.4	8.2	100.0	7103
<b>2003</b>					
Primary carers	85.9	n.p.	n.p	100.0	43
Carers	86.4	4.6	9.1	100.1	525
Non-carers	87.1	3.9	9.0	100.1	6838

Source: ABS 1998, 2003

Note: n.p. denotes not available for publication

**Table E.10: For whom they provide care—young co-resident carers aged 10–24 years <sup>(a)</sup> (weighted percentages)**

	Partner	Parent	Other relative or friend	Total	n
<b>1998</b>					
Primary carers	13.2**	61.3	25.4	99.9	28
Carers	2.7**	64.0	33.3	100.0	539
All carers	3.2	63.9	32.9	100.0	567
<b>2003</b>					
Primary carers	23.4**	57.4	19.1	99.9	39
Carers	2.3**	62.6	35.1	100.0	464
All carers	3.8	62.2	34.0	100.0	503

Source: ABS 1998, 2003.

Note: Relationship with care recipient with the highest level of disability and for whom information is available.

\*\* denotes significant difference between primary carers and carers ( $p < 0.05$ ), \* denotes significant differences between primary carers and carers compared to non-carers ( $p < 0.1$ ).

**Table E.11: Disability level of care recipient (co-resident carers aged 10–24 years) (weighted percentages)**

	Has disability and is profoundly limited in core activities	Has disability and is severely limited in core activities	Other	Total	n
<b>1998</b>					
Primary carers	26.0	63.0**	11.1**	100.1	28
Carers	19.9	36.1**	43.9**	99.9	539
All carers	20.2	37.5	42.3	100.0	567
<b>2003</b>					
Primary carers	36.6**	48.6	14.8**	100.0	39
Carers	17.9**	34.2	47.9**	100.0	464
All carers	19.3	34.3	45.5	100.1	503

Source: ABS 1998, 2003

Note: Disability level is that of the care recipient with the highest level of disability if more than one recipient

\*\* denotes significant difference between primary carers and carers ( $p < 0.05$ ).

**Table E.12: Age left school by carer status (aged 15–24 years) (weighted percentages)**

	Still at school	Left school at 16 years or younger	Left school at 17 or 18 years	Total	n
<b>1998</b>					
Primary carers	n.p.	36.2*	n.p.	100.0	24
Carers	24.0	24.7*#	51.3	100.0	442
Non-carers	26.3	21.3*#	52.4	100.0	4497
<b>2003</b>					
Primary carers	17.4	34.2*	48.5	100.1	37
Carers	26.8	18.2*#	55.0	100.0	378
Non-carers	27.5	18.6*#	53.9	100.0	4278

Source: ABS 1998, 2003

Note: \*denotes statistically significant difference between primary carers and other groups ( $p < 0.1$ ).

In this case the sample size of young primary carers is too small for robust trend analysis and no significant trends were found between 1998 and 2003.

# denotes significant difference between 1998 and 2003 for that group. n.p. denotes not available for publication

**Table E.13: Whether completed Year 12 or equivalent (all aged 15–24 years who are not still at school) (weighted percentages)**

	Completed Year 12 or equivalent	Did not complete Year 12	Total	n
<b>1998</b>				
Primary carers	40.9**	59.1	100.0	23
Carers	59.3**	40.7	100.0	333
Non-carers	65.1**#	34.9	100.0	3240
<b>2003</b>				
Primary carers	52.7*	47.3	100.0	31
Carers	65.4	34.6	100.0	272
Non-carers	68.6*#	31.4	100.0	3027

Source: ABS 1998, 2003

Note: \*\* indicates significant difference between primary carers and carers compared with non-carers ( $p < 0.05$ ). \* indicates significant difference between primary carers and non-carers ( $p < 0.1$ ).

# denotes significant change between 1998 and 2003 for that group ( $p < 0.05$ )

**Table E.14: Whether studying (all aged 15–24 years who are not still at school) (weighted percentages)**

	Studying full-time	Studying part-time	Not studying	Total	n
<b>1998</b>					
Primary carers	n.p.	n.p.	68.5	100.0	23
Carers	25.7	13.3	61.0	100.0	333
Non-carers	26.3	13.4	60.3	100.0	3240
<b>2003</b>					
Primary carers	18.6	13.2	68.2	100.0	31
Carers	30.4	14.1	55.5	100.0	272
Non-carers	27.2	14.2	58.6	100.0	3027

Source: ABS 1998, 2003

Note: n.p. denotes not available for publication

**Table E.15: Highest educational qualification (all aged 15–24 years not at school) (weighted percentages)**

	Bachelors or above	Diploma or Certificate	Year 12 or equivalent	Year 11 or less	Total	n
<b>1998</b>						
Primary carers	–	36.1	32.5	31.4	100.0	23
Carers	7.8	19.7	40.2	32.3	100.0	333
Non-carers	8.6	23.7	42.5	25.2	100.0	3240
<b>2003</b>						
Primary carers	18.3	16.1	27.8	37.9	100.1	31
Carers	9.9	17.1	48.6	24.4	100.1	272
Non-carers	9.7	18.9	47.4	24.0	100.0	3027

Source: ABS 1998, 2003

Note: Between 1998 and 2003 there was a significant decline in the proportion of non-carers who had any post-secondary qualification from 32 per cent to 29 per cent ( $p < 0.05$ )

**Table E.16: Employment rates of young people (aged 15–24 years) by carer status (weighted percentages)**

	Employed	Unemployed or not in the labour force	Total	n
<b>1998</b>				
Primary carers	42.0**	58.0	100.0	24
Carers	56.9**	43.1	100.0	442
Non-carers	60.8**	39.2	100.0	4497
<b>2003</b>				
Primary carers	47.7	52.4	100.1	37
Carers	64.2	35.8	100.0	378
Non-carers	62.0	38.0	100.0	4278

Source: ABS 1998, 2003

Note: \*\* denotes significant difference between primary carers and other groups ( $p < 0.05$ ). Increase in employment for all young people between 1998 and 2003 only significant at the 10 per cent level

**Table E.17: Detailed labour force status of young people (aged 15–24 years) by carer status in 1998 and 2003 (weighted percentages)**

	Employed full-time	Employed part-time	Unemployed	Not in the labour force	Total	n
<b>1998</b>						
Primary carers	24.7**	17.2#	23.4**	34.6	99.9	24
Carers	31.4	25.5#	16.1**	27.0	100.0	442
Non-carers	34.7**	26.1#	10.9**#	28.3	100.0	4497
<b>2003</b>						
Primary carers	18.2*	29.5#	18.5**	33.9	100.1	37
Carers	28.8	35.3#	10.9*	25.0	100.0	378
Non-carers	33.7*	28.3#	8.1**#	29.9	100.0	4278

Source: ABS 1998, 2003

Note: \*\* denotes significant difference between primary carers and non-carers ( $p < 0.05$ ), \* denotes significant differences between primary carers and carers compared to non-carers ( $p < 0.1$ )

# denotes significant increase for that group between 1998 and 2003. Note that the increase in part-time work between the years 1998 and 2003 is only significant for all primary carers when grouped with carers

**Table E.18: Proportion of young people (aged 10–24 years) living in households by gross weekly household income quintiles by carer status (weighted percentages)**

	Not known	First quintile	Second quintile	Third to fifth quintile	Total	n
<b>1998</b>						
Primary carers	–	11.9**	41.5**	46.6	100.0	30
Carers	14.5	3.9	17.1**	64.6	100.1	616
Non-carers	13.9	5.0**	10.0**	71.1	100.0	7130
<b>2003</b>						
Primary carers	**11.3	14.9**	37.7**	36.1	100.0	37
Carers	23.6	5.0	17.0**	54.5	100.1	378
Non-carers	21.2	5.3**	10.8**	62.7	100.0	4278

Source: ABS 1998, 2003

Note: Variables used in SDAC are 'incwkhdc' in 2003 and 'inc100' in 1998 – approximate quintiles were constructed from the gross cash household income variables in each year

\*\* denotes significant difference between primary carers or carers and non-carers ( $p < 0.05$ )

**Table E.19: Proportion of young people (aged 10–24 years) in total weekly equivalent household cash income quintiles by carer status 2003 (weighted percentages)**

	Not known	First quintile	Second quintile	Third to fifth quintile	Total	n
<b>2003</b>						
Primary carers	11.3	35.7**	31.3**	21.7	100.0	37
Carers	23.6	16.7**	21.0**	38.7	100.0	378
Non-carers	21.2	12.6**	15.0**	51.2	100.0	4278

Source: ABS 1998, 2003. Not available for 1998

Note: \*\* denotes significant difference between primary carers or carers and non-carers ( $p < 0.05$ )

**Table E.20: Income level - gross weekly personal income quintiles (aged 15–24 years) (weighted percentages)**

	Not known	First quintile	Second quintile	Third to fifth quintile	Total	n
<b>1998</b>						
Primary carers	–	23.9**	30.0	46.1	100.0	24
Carers	8.4	47.3**	11.4	33.0	100.1	442
Non-carers	7.1	44.2*	10.7	38.0	100.0	4497
<b>2003</b>						
Primary carers	–	24.7	26.5	48.8	100.0	37
Carers	10.3	38.5	15.6	35.6	100.0	378
Non-carers	9.5	43.4	10.8	36.3	100.0	4278

Source: ABS 1998, 2003

Note: \*\* denotes significant difference between primary carers and carers ( $p < 0.05$ ), \* denotes significant differences between primary carers and non-carers ( $p < 0.1$ )

**Table E.21: Primary source of income for young people by carer status (aged 15–24 years) (weighted percentages)**

	Wages or salary	Other private income	Government pension or benefit	Not known, no income, nil negative income, other income	Total	n
<b>1998</b>						
Primary carers	n.p.	–	57.9**	n.p.	100.0	24
Carers	49.2**	2.9	27.9**#	22.9	100.0	442
Non-carers	55.2**	4.0	18.6**#	26.2	100.0	4497
<b>2003</b>						
Primary carers	30.4**	–	59.5**	10.2	100.1	37
Carers	55.2**	2.4	21.1**#	23.7	100.0	378
Non-carers	55.5**	3.7	15.7**#	28.8	100.0	4278

Source: ABS 1998, 2003

Note: n.p. denotes not available for publication

\*\* denotes significant difference between primary carers compared with carers and non-carers ( $p < 0.05$ ),

# denotes significant change for that group between 1998 and 2003 ( $p < 0.1$ ) for carers  $p < 0.05$  for non-carers

**Table E.22: Employment and education participation (broad), Australia, by age sex and carer status (per cent)**

	Males 15–19 years		Males 20–24 years		Females 15–19 years		Females 20–24 years	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Employed, not studying	15.6	18.1	45.1	52.5	13.5	14.8	36.1	46.0
Employed and studying	22.2	25.1	18.6	19.1	26.7	31.5	19.2	21.8
Studying, not employed	44.9	44	12.6	11.9	41	41.4	12.5	12.6
Not employed, not studying	11.3	7.3	16.4	9.9	12.7	6.8	25.6	13.9
Not stated	5.9	5.3	7.5	6.5	6.1	5.3	6.3	5.6
<b>Total</b>	<b>99.9</b>	<b>99.8</b>	<b>100.2</b>	<b>99.9</b>	<b>100</b>	<b>99.8</b>	<b>99.7</b>	<b>99.9</b>

Source: ABS 2006a. Does not include individuals who did not respond to the carer question. Totals may not sum to 100 due to rounding

**Table E.23: Employment and education participation (detailed), Australia, by age sex and carer status (per cent)**

	Males 15–19 years		Males 20–24 years		Females 15–19 years		Females 20–24 years	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
<b>Employed full-time</b>								
Not studying	10.4	13.2	35.5	43.8	6.4	8.2	23.0	34.0
Full-time student	0.8	0.7	1.5	1.3	0.5	0.5	1.1	1.1
Part-time student	4.0	4.9	6.0	6.5	1.5	1.7	3.7	4.5
Education status not stated	0.4	0.4	0.8	0.8	0.2	0.2	0.4	0.5
<b>Total full-time</b>	<b>15.6</b>	<b>19.2</b>	<b>43.8</b>	<b>52.4</b>	<b>8.6</b>	<b>10.6</b>	<b>28.2</b>	<b>40.1</b>
<b>Employed part-time</b>								
Not studying	5.2	4.9	9.6	8.7	7.1	6.6	13.1	12.0
Full-time student	16.2	18.4	9.3	9.7	22.8	27.8	11.6	13.7
Part-time student	1.2	1.1	1.8	1.6	1.9	1.5	2.8	2.5
Education status not stated	0.3	0.2	0.3	0.2	0.4	0.3	0.4	0.3
<b>Total part-time</b>	<b>22.9</b>	<b>24.6</b>	<b>21.0</b>	<b>20.2</b>	<b>32.2</b>	<b>36.2</b>	<b>27.9</b>	<b>28.5</b>
<b>Unemployed</b>								
Not studying	6.2	3.7	8.5	5.1	4.7	2.8	5.5	3.4
Full-time student	4.7	3.2	2.4	1.7	4.8	3.8	1.9	1.8
Part-time student	0.7	0.3	0.8	0.4	0.7	0.4	0.8	0.4
Education status not stated	0.3	0.1	0.3	0.1	0.2	0.1	0.2	0.1
<b>Total unemployed</b>	<b>11.9</b>	<b>7.3</b>	<b>12.0</b>	<b>7.3</b>	<b>10.4</b>	<b>7.1</b>	<b>8.4</b>	<b>5.7</b>
<b>Not in the labour force</b>								
Not studying	5.1	3.6	7.9	4.8	8.0	4.0	20.1	10.5
Full-time student	38.5	39.7	8.5	9.3	34.2	36.4	7.8	9.4
Part-time student	1.0	0.8	0.9	0.5	1.3	0.8	2.0	1.0
Education status not stated	0.8	0.5	0.5	0.2	0.8	0.5	0.6	0.3
<b>Total not in the labour force</b>	<b>45.4</b>	<b>44.6</b>	<b>17.8</b>	<b>14.8</b>	<b>44.3</b>	<b>41.7</b>	<b>30.5</b>	<b>21.2</b>

	Males 15–19 years		Males 20–24 years		Females 15–19 years		Females 20–24 years	
	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers	Carers	Non-carers
Labour force status or hours not stated	4.1	4.1	5.6	5.2	4.5	4.2	4.7	4.4
<b>Total</b>	<b>99.9</b>	<b>99.8</b>	<b>100.2</b>	<b>99.9</b>	<b>100.0</b>	<b>99.8</b>	<b>99.7</b>	<b>99.9</b>

Source: ABS 2006a. Does not include individuals who did not respond to the carer question. Totals may not sum to 100 due to rounding

**Table E.24: Employment and education participation (broad), Australia, by Indigenous status and carer status (per cent)**

	Indigenous		Non-Indigenous	
	Carer	Non-carer	Carer	Non-carer
Employed, not studying	27.4	31.1	31.2	35.4
Employed, studying	9.1	10.2	24.3	26.8
Studying, not employed	19.0	23.6	26.2	27.4
Not employed, not studying	40.5	31.3	16.2	8.8
Not stated	4.1	3.8	2.2	1.6
<b>Total</b>	<b>100.1</b>	<b>100</b>	<b>100.1</b>	<b>100</b>

Source: ABS 2006a. Does not include individuals who did not respond to the carer question. Totals may not sum to 100 due to rounding

**Table E.25: Employment and education participation (broad). Australia, by language spoken at home and carer status (per cent)**

	Other languages		English only	
	Carer	Non-carer	Carer	Non-carer
Employed, not studying	22.6	21.7	33.3	38.1
Employed, studying	21.5	22.2	23.9	27.2
Studying, not employed	37.7	45.1	22.5	23.6
Not employed, not studying	15.5	9.1	18.1	9.6
Not stated	2.6	1.9	2.1	1.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>99.9</b>	<b>100.0</b>

Source: ABS 2006a. Does not include individuals who did not respond to the carer question. Totals may not sum to 100 due to rounding. Language spoken at home may include Indigenous languages

**Table E.26: Household composition of young people by carer status and age (Australia) (per cent)**

	15–19 years		20–24 years	
	Non-carer	Carer	Non-carer	Carer
Couple without children	2.5	2.5	16.4	12.1
Couple with children	67.9	60.0	41.2	42.3
Sole parent household	20.3	25.5	12.8	18.9
Other one family households	2.2	2.5	4.8	4.2
Multiple family households	2.7	4.9	3.7	6.9
Lone person households	1.2	1.5	5.7	5.4
Group households	3.3	3.0	15.3	10.1
<b>Total</b>	<b>100.1</b>	<b>99.9</b>	<b>99.9</b>	<b>100.0</b>

Source: ABS 2006a.

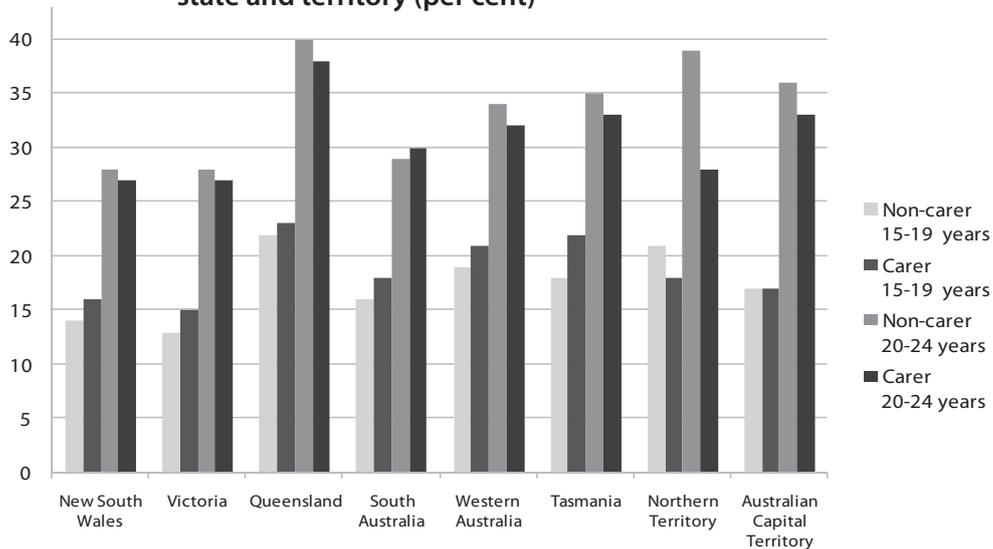
Note: 'Children' include dependent and non-dependent children and students under the age of 25 years. Most young carers in 'couple without children' households are partners in the couple, some are young people related to a member of the couple without children, e.g. cousin, sister. Other young people are unrelated to either member of the couple.

**Table E.27: Proportion of all young people aged 15–24 years by identified carer status and remoteness of usual address (Australia) (per cent)**

	Non-carers	Carers	Carer status not stated
Major cities	71.5	68.7	71.1
Inner regional	18.2	19.4	16.7
Outer regional	8.0	8.8	9.0
Remote	1.2	1.3	1.8
Very remote	0.8	1.5	1.0
Migratory	0.004	0.006	0.008
No Usual address	0.2	0.3	0.3
<b>Total</b>	<b>99.9</b>	<b>100</b>	<b>99.9</b>

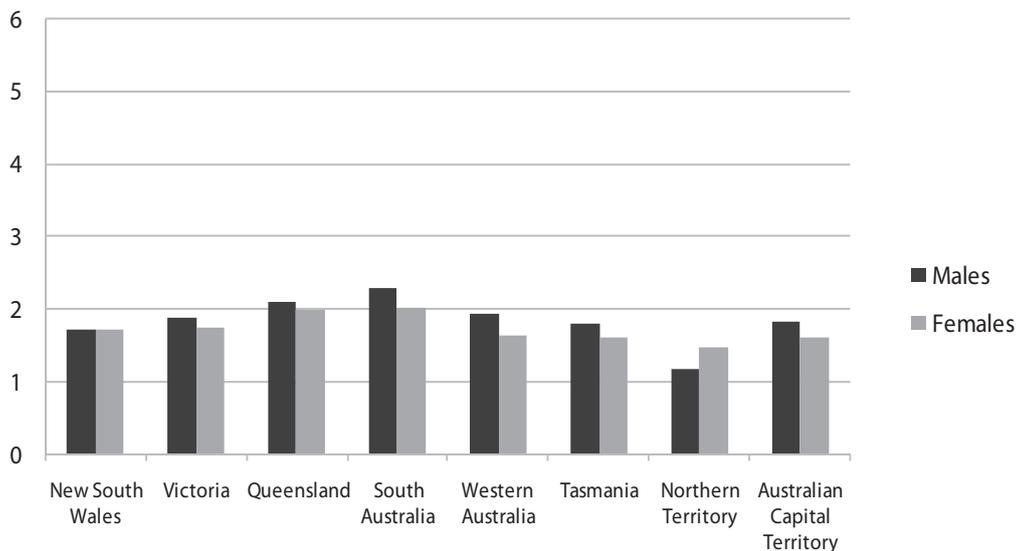
Source: ABS 2006a

**Figure E.1: Proportion of young people who had moved in the last year by state and territory (per cent)**



Source: ABS 2006a.

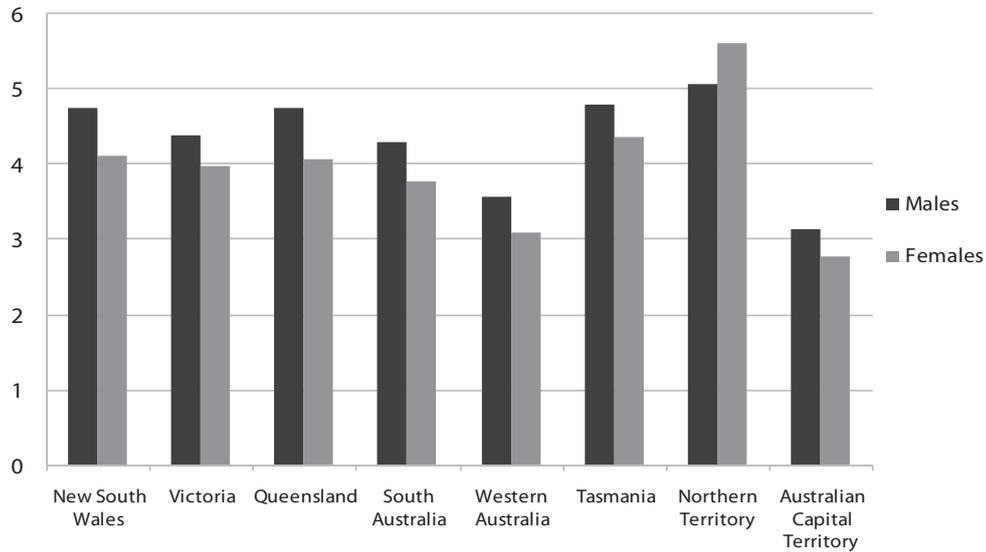
**Figure E.2: Proportion of young people aged 12–14 years who are potential carers by sex and state or territory (per cent)**



Source: ABS 2006a

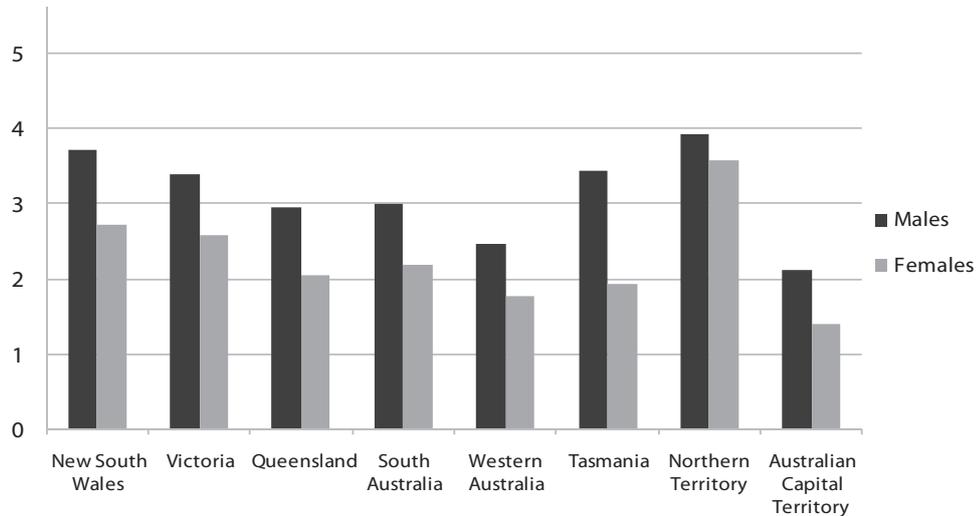
Note: A 'potential carer' is a child aged 12–14 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility. A 'non-identified potential carer' is a young person aged 15–24 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility and also did not indicate that they were a carer in the question on the Census form

**Figure E.3: Proportion of young people aged 15–19 years who are non-identified potential carers by sex and state or territory (per cent)**



Source: ABS 2006a

**Figure E.4: Proportion of young people aged 20–24 years who are non-identified potential carers by sex and state or territory (per cent)**



Source: ABS 2006a

Note: A 'potential carer' is a child aged 12–14 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility. A '*non-identified* potential carer' is a young person aged 15–24 years who shares a household with one or more people with a need for assistance for self-care, communication or mobility and also did not indicate that they were a carer in the question on the Census form

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